**Everything You Wanted to Know about Advisory Boards**

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>> ANN OUTLAW: Good afternoon and welcome to today’s webinar – Everything you wanted to know about advisory boards. I’m you host, Ann Outlaw.

This webinar is brought to you by the Center on Knowledge Translation for Disability and Rehabilitation Research, which is funded by NIDILRR or the National Institute on Disability, Independent Living and Rehabilitation Research.

A bit of housekeeping before we get started. The link to CART will be put in the chat window in just a second. You’re welcome to ask your questions via the Q&A window located at the bottom of your screen. If you have any technical difficulties, please ask your questions there as well.

Advisory boards, or bodies that provide expert advice and guidance to an entity, particularly from stakeholders and consumer stakeholders, are crucial to achieving a projects’ success. We know that stakeholders are in integral component of all knowledge translation activities. So how we solicit this input is gets a little bit murkier. Today’s webinar will host two NIDILRR project directors and members of their advisory boards. We’ll hear from them how they’ve connected, how they sustain their relationships. One dyad has been friends and colleagues for over 30 years and how they continuously improve the boards to inform their research activities.

First off, we have Dr. Allen Brown who directs the Mayo Clinic Traumatic Brain Injury Model System. And with him is Geoffrey Lauer who is the chief executive officer of the Brain Injury Alliance of Iowa and has served in many capacities to improve policy issues to help those with brain injury.

Also joining us is Dr. Kathy Paez who directs the NIDILRR project, Improving Assessment of Opioid Use Disorder in People With Disabilities Related to Chronic Musculoskeletal Pain. Lynnae Ruttledge serves on the board of this project. She’s spent her career on advocating for disability public policy in the US and abroad.

Welcome to you all.

Let’s go ahead and get started. So first off, how and when do you engage your advisory board members in your project? Allen, I’ll pose this question to you first.

>>ALLEN BROWN: Our advisory board members, you know as you already stated, and our advisory council has been together for upwards of 25 years now and-the reason we initially engaged was to know more about what was happening in our community relating to specifically acquired brain injuries and traumatic brain injury so that we could better serve them and get a greater understanding of their needs medically and otherwise. So, we engaged them by basically inviting them to come and meet with us on a regular basis with our clinical practice. That started off a meaningful relationship that as I said we’ve sustained over the years. It has really grown into collaborating in the design and the implementation of our research programs. I think one of the reasons that our group has stayed engages over the years is because we have developed these common interests in designing research that is addressing needs and unmet needs in our community. And that we are involved in them together. So, we basically have common interests that we address and out comes that are meaningful to us both. I know Jeff can also give his sort of angle on this as well but we really do-it is very much a partnership and once the relationship was initiated it naturally grew and became more interrelated.

>>ANN OUTLAW: Thank you so much for that Allen. Kathy, would you like to talk about how you have engaged your board member?

>> KATHY PAEZ: Good afternoon, our board members consist of approximately 12 people that represent a variety of perspectives and as Amy said, our project is on opioid use disabilities due to chronic musculoskeletal pain and a lot of people in this situation have been on opioids for quite a while. Given the opioid epidemic there is a lot of issues around prescribing appropriate, how do you diagnose opioid use disorder for someone who has been on opioids a long time, just a number of issues. We engage a number of people from the medical community as well as the disability community. We have a diverse set of feet of panel members some are physicians, one is an occupational therapist, a woman with a disability, a disability researcher on our group, and then people with policy background, advocacy background, addiction specialists. It's a very robust group of people that are really engaged in the work we're doing. We first contacted them when we wrote the proposal and so in some ways they were engaged right from the beginning but we first formally met about 6 months after our project started this past March so this was a newly formed group and we've engaged them pretty much every step of the way in their project. We have four major tasks. One with a systemic, systematic literature review which we completed. The others are a set of interviews with approximately 60 people both people with disabilities as well as medical providers and the third is the modification of a screening instrument that assesses for opioid use disorder and lastly the development and dissemination of materials to share our research findings. And so the advisory panel was engaged right from the point that we were developing the research questions for the systematic review and for an interview guide to do our interviews. They also helped us with identifying experts in the medical community that we could interview. Once we had assembled findings from our literature review and the interview findings we presented those to the advisory panel and they provided feedback to help us understand how those findings fit into the real world and what were the issues that people with disabilities and medical providers were most concerned about. We've had two meetings thus far and we have a third meeting planned in one month and at that point we'll be discussing what topics we should select from our findings that we should be developing materials on and the materials will be assembled into a tool kit, and so they review all the documents we create and provide feedback. For instance, two issue briefs have been released and in both cases we sent them back to our panel and they provided feedback on those as they will for the material we develop in the future and then lastly, they will help us identify the channels where we should disseminate the material and also help provide us with connections to various groups of people that can help as well with making the public aware of materials that we've developed.

>> ANN OUTLAW: Excellent, thank you, Kathy. It sounds like your project hit the ground running and your Advisory Board members have been key in helping you get there. Next slide, please, Arianna.

So I'll pass this question on to Lynnae and to Geoff first. As an Advisory Board member what has helped to keep you engaged? Geoff, would you like to take a stab at this question?

>> GEOFFREY LAUER: Sure. Lots of things. But the core piece is I think the project or the leadership at Mayo in this case the team leadership willingness to do two things. One is to take a risk to get into the communities, in terms of a medical, potentially a medical model looking at how to do community‑based I think it's called, Allen, community‑based randomized clinical trials so clinical trials are messy to begin with but then when you add a bunch of advocates and family members and individuals, it can get a lot messier and they in this case have been willing to come down into the communities that surround the project hub in Rochester Minnesota, and think regionally so they'll pulled in advocates from Wisconsin, from North Dakota, from Iowa, from the contiguous states.

So there's a sense we have skin in the game, there's something locally. It impacts our mission both as individuals who show up as advocates. My day job is with the Brain Injury Alliance of Iowa, and so we learn how to better provide rapid, reliable and relevant information when we meet regularly with our colleagues not just Mayo colleagues but the folks around the table who come from the State Agencies in the various states from the Departments of Public Health, from the VA systems, from Departments of Human Services and Vocational Rehabilitation. Sometimes these are people that we might be able to see locally but we don't see except around the table where there's a facilitated discussion so we all learn around research that frankly just excites us.

>> ANN OUTLAW: Excellent, so there's that intrinsic value that helps keep you engaged. Lynnae, would you like to jump in here?

>> LYNNAE RUTTLEDGE: I think a couple things in addition to what Geoff just said. I think if you step back a moment it's about participatory research that we as people with disabilities who are impacted by the research that's going to be done are actively and intrinsically involved in that research. And I think it just leads to better engagement and better outcomes.

I think what sets the panel apart from others that I've been involved in with the work that we're doing is really about respect, and it's about really wanting and engaging with us in a way that is respectful in terms of the language that's used, in terms of the approach that's used, in terms of the overall essence of why it is that we're at the table as colleagues and peers, with the medical community and the research community.

So I think those are some of the ways that it really helps keep our members engaged, because we really feel valued, and we see the value of our investment of time, and we also are invested in better outcomes as a result.

>> GEOFFREY LAUER: one more thing I'd like to add, Ann.

>> ANN OUTLAW: Sure.

>> GEOFFREY LAUER: There's a specific member of our group as long serving as any of us who has brought a spectacular brownie recipe so most of us come back hoping the brownies will come on each time and if he's not on the phone, Craig, they better be there next time.

>> ANN OUTLAW: That's a warning, Craig. I think you're online, so bring those brownies. So to Lynnae's point that meaningful engagement is what a lot of people wanted to talk about today, they felt the value of this webinar was about was having meaningful engagements where you feel like you're making a difference and you are an equal partner to the project staff, so thank you so much for sharing, both of you.

>> LYNNAE RUTTLEDGE: Can I just jump in one more second? I really think that one of the things that has set our panel apart is that I was asked first to be on the advisory panel and asked to be what's considered to be a peer leader or the chair of the panel but it's really resulted in a collaboration between the project staff and the advisory members and myself individually who's really viewed as co‑participants in this process. It's not them versus us. It's not them doing something for us. It really is a collective "we," and I think that's how you keep people engaged.

>> ANN OUTLAW: Thank you so much, Lynn fly. Can you describe the role of the peer leader a little bit more in‑depth, please?

>> LYNNAE RUTTLEDGE: Sure. It really is to serve as that voice of a person with a disability who is on the advisory panel and respected for the voice that I bring, and so I serve as a focal point for engagement for people with disabilities and I can lend my voice as a person with a disability who understands chronic pain, but also as a person who has been involved in disability‑related advocacy both here in the United States and internationally.

So I think it's really being viewed as a leader within the disability community as well as a leader on the panel.

>> GEOFFREY LAUER: in terms of the Mayo group, and sorry, Al, I do need to say that the Mayo team, the research team, embraces and has at the table with strong participation people with lived experience both individuals with brain injury and I have a daughter who's had a brain injury, the capacity of people like Lynnae and others to bring kind of the brass tacks of how things are going to affect us and is this an interesting question to us that we're going to look at, or work worth doing?

The respect of having them come and say we could do a lot of different things but what's going to make a difference? And how can you help us make that difference? That is huge.

>> ALLEN BROWN: Real briefly if I may, so from what Lynnae and Geoff were saying and talking about skin in the game and things like that, so Geoff alluded to sort of the kind of community‑based research that we have been doing over the last 10 years or so, community‑based pragmatic clinical trials and literally those are not only the research question is developed within our advisory group, the methodology is developed together, driven by the literature and of course sort of our expertise and then actually it's a collaborative implementation part is collaborative with members of the team, the clinical trial we're currently involved with is together with the brain injury alliance of Minnesota and in past years, it's been with brain injury alliances of Minnesota and Iowa and Wisconsin so ‑‑ and they're essentially designed for implementation which means that we also, we want to make certain that it's meaningful and that if the findings are found to be effective in the community, then we can just immediately use them to improve outcome right away. Sorry, I just wanted to ‑‑

>> ANN OUTLAW: No, excellent point. I'm glad you brought that up, Allen. It's wonderful to hear how you've ‑‑ for both of the projects that we have, that we're hosting today, that you've included folks with lived experience on ‑‑ throughout all parts of your research project, not just the dissemination channels and maybe after your research has been done but really getting them involved in the very beginning to form your research questions, to form your proposal and keeping those folks engaged and listening to their voices throughout the Advisory Board meetings.

So this gets, the next question, gets into the nitty gritty of how you keep the Advisory Board going. Arianna, can you progress the slide, please? So to Kathy first, do you define explicit expectations guiding your Board members, including time commitments, what the Board goals are, duties, perhaps payment for their time? Do you have these expectations aligned as you were reaching out?

>> KATHY PAEZ: Yes, we did. So we recruited our advisory panel members when we were writing our proposal so you can imagine it's always a hectic time when you're trying to get a proposal done and we identified them basically by networking so what we did was we generally reached out by email and asked if they were interested, and then we gave kind of an overview of what we would be expecting them to do and then we'd set up a meeting by phone so we could go into more detail about the purpose of the project, what their role would be, how much time it would take for them to be on the Board and to help us and if they agreed to do it then the next step us was we followed the phone call up with a letter where we provided more detailed information, and including how they would be compensated. And we have a yearly stipend that we send out to our Board members at the end of each year.

And then we have bi‑yearly meetings so twice a year we come together and we meet, and generally what we do at those meetings is we review the contributions of the Board from the previous 6 months, and then we go over what our steps are going to be in the project in the upcoming 6 months, and where we need their involvement and feedback, and so we do that so that they can know what to expect, when we'll be contacting them. A lot of times we're sending them emails in between meetings asking for feedback and so they can expect that email will be coming.

And so that's our approach as far as how we try to be very clear as to what they will be involved in doing and what time commitment it is for them.

>> ANN OUTLAW: Right, thank you so much. Allen, would you like to discuss this question?

>> ALLEN BROWN: Oh, sure. This group has our Advisory Council has been established for so long that there were never any sort of specific definitions or explicit expectations of the individuals that were involved in the Council. People are identified basically like Kathy were saying by sort of networking and talking with others with common interests, and just the guts of it are that we meet twice a year, I believe it's twice a year, Geoff, and individuals ‑‑ and the number of people on our Council I think is boy, probably in the 20s, I would say, something like that?

>> GEOFFREY LAUER: Yeah, yeah.

>> ALLEN BROWN: And as Geoff previously said from ‑‑ there are clinicians and Public Health and members of the community, individuals that receive medical services and their families related to acquired brain disorders in general and other community members, and basically, there isn't any financial ‑‑ specific financial ‑‑ we don't really ‑‑ there's no paying ‑‑ we don't pay them anything, but we do pay for travel to Rochester and back, and overnight, and meal and stuff during the day.

But really, the expectations are that you come and participate, and even without anything more specific we've had no problems with people meeting and exceeding expectations every single time we meet so it wasn't specific, as Kathy was saying it wasn't specific for a specific grant. It's evolved such that there is a very high level of guidance and direction for all the grants that we write, because that's always one of the sort of standing agenda items for our meetings but it's essentially naturally evolved over time so that as I said we sort of have a standing agenda that sort of starts with generally speaking, us reviewing sort of what's happening with current grants and those are usually dominated by NIDILRR grants and result from the previous trial, what's coming up next, what research questions we want to engage in, and then as it gets closer and closer to the application deadline, we become more specific about this, and then the second half of the meeting is basically going around the table usually by state and getting feedback on what's happening in each state, and, you know, basically local concerns and progress and sort of what's happening in everyone's community.

So we don't have real specific guidance and outline for what the expectations are, but despite that, the expectations are always way exceeded.

>> ANN OUTLAW: It sounds like despite the two projects doing this very differently, the outcome is the same. People are exceeding the expectations that you have, whether it's explicit or just understood amongst the members. So that's fantastic to here. Arianna let's move two questions on. I'd like to skip the next one and go to how you foster meaningful engagement.

One back.

There we go. I'm skipping that other question just because I understand we're about halfway through this webinar, and this is where a lot of folks wanted to focus in on the conversation. Having said that, I also wanted to remind participants that you're welcome to ask your questions in the Q&A window at the bottom middle of your screen, of the Zoom screen, so please type in your questions, and I will relay those to the participants.

So let's really dive in deep here about how you all foster this meaningful engagement amongst your Advisory Board members. It sounds like both of you are doing it. You're doing it in different ways but I'd like to hear, Kathy, would you let us know what are some of the steps that you've taken to do this? And then perhaps Lynnae, you can then chime in and talk about how this has worked for you.

>> KATHY PAEZ: Yeah, I think the first thing we did was we just honestly got lucky, and we have a very diverse group of members with different perspectives, and who are open to listening to each other, it's actually kind of exciting to hear people from the medical community and the disability community coming together and talking about the issues around our topic area. And there are a lot of issues and so we have a face‑to‑face meeting about, oh, I guess that was in March. I guess our second meeting was in March.

And it was just interesting to see how avidly the members listen to each other and we kind of try to set that up because generally what we do is, our meetings with our Board revolve around discussion, and so we really work to present a pretty concise amount of information that is kind of the send‑off point for the Board to discuss the issues around our project, either issues that are just challenging for us to deal with in terms of trying to do the research on a topic, or issues that are of concern on the ground, and often those are the topics that do get the most robust discussion, is: What are you facing every day as you're taking care of people that are in chronic pain and you're trying to manage opioids in an environment where there's a lot of pressure to stop prescribing? And then as a person with disability who feel like opioids benefit you, what are the challenges that you're experiencing as you go to these physicians and they're concerned about prescribing and you're having trouble getting pain meds through your insurance yet you've been using them in a way that's been beneficial to you for a number of years.

And so there's a lot of discussion around the issues there, and so I think that again has helped. Having the right members, having a topic that's of interest to the people that are participating, and laying the groundwork so that there can be a robust discussion.

So I think that's one set of kind of things that we did. The other just, you know, I think Lynnae being our chair has been a really great thing for our project because first of all, she's very experienced in this kind of thing. She has really tremendous skills, and she's really helped to guide those meetings to make sure that everyone is heard. She'll ask some really great probing questions if the group suddenly gets silent and we're kind of thinking, well, somebody will speak up or not, she'll kind of nudge people and come up with a probing question, or weigh in and then ask other people for their opinion.

So that's really helps the meetings keep going. And then I think the last thing is just we have a process to monitor our accountability to make sure we follow through on those recommendations so during the meeting we take minutes and we record the meeting and so we have detailed notes and then we take action items from those notes, put them in a spreadsheet so that we can track them and make sure that we really do follow up on all the great ideas we hear. And then we review that tracking sheet periodically because as we move from phase to phase in the project something that maybe had been said 12 months ago, all of a sudden it's really relevant and we want to pay attention to it so members see the results that what their input is actually acted on.

>> ANN OUTLAW: You, Kathy. Lynnae, does that ring true to you? Is that how you've been able ‑‑

>> LYNNAE RUTTLEDGE: Definitely. Let me just quickly say two anecdotes of prior experiences that I've had that are nothing like the positive experience I'm having now. I can remember being at a State legislative hearing and having a local advocate who talked about the lack of value of the State Rehabilitation Council that she was on and she said well, it's always a free lunch. I don't feel that that's the way AIR treats us or expects us to be engaged, and I think that we are really valued as partners in this process.

The other experience is one that I have personal experience with, and that's that I get often asked to write letters of support, and to serve on advisory panels, and there are so many instances where I will be named in a project, and they will get funded, and then I'm never engaged, and I think that that's really something that happens with people with disabilities, and that we aren't necessarily valued for the perspective that we have or the role that we can play. We are just there to add window dressing so that an organization can get funding, and that's just not been the case in the panels that I'm involved in.

I think there's a real high level of respect between the staff and the panel members. There's a single point of contact on the staff so that we know that when we get an email from Amy Lynn, that that's going to give us valued information. It's not a barrage of people. It's one person. And we know we can go to her and she responds and she responds quickly, so I think it's a matter of an organizational strength that AIR brings to our project, but it's also a level of respect for the people that are investing their time and their energy.

I'm a person with a visual impairment, and I have the opportunity to lead the discussion in our meetings. The assistive technology that's used is really very low‑tech, it's that someone literally sits next to me. Other people are around the room and as they raise their hand, I don't see them, and the staff will just gently nudge me and say: This person has a question, or this person has their hand up. And it's done in a respectful way that allows everyone to be engaged, and really has helped me be a better peer leader and co‑facilitator, because it is something that I value.

I want to have more engagement with the people that are around the table, and I don't see them, and so it becomes a real part of functioning better as a result. So I just wanted to share that.

>> ANN OUTLAW: I'm so happy to hear that the steps that Kathy's project has taken to keep you as a major component of the process is working. That's exactly what we wanted to hear.

And you highlighted one of the questions that have come up from the audience, which is assistive technologies. Before we move on to hear more about how the Mayo Clinic's TBI project has engaged meaningful engagement, I wanted to hear from back at Kathy if you use any other assistive technologies to help engage your advisory members.

>> KATHY PAEZ: Well, what we did at the beginning was we reached out to each of our members to see if they needed anything to assist them to fully participate in the meetings, and we found that they didn't. However, we did recognize ‑‑ we have one person with a spinal cord injury, and so it's very difficult for him to travel, and so we're very sensitive to the fact that in‑person meetings for some people are hard, and so we limited those to one meeting, just so the members could see each other face‑to‑face, but recognize that, you know, it's ‑‑ in some ways there's also a down side to it in terms of accessibility.

>> ANN OUTLAW: Right, right. And that definitely understanding the needs of anyone in your group is part of that, allowing them to have the most active voice they can based on either the logistics of meeting in person or creating opportunities to meet remotely.

Allen, how would you say that you've been able to foster this meaningful engagement amongst your Advisory Board members for so long?

>> ALLEN BROWN: As we've been talking about for previous questions, a lot of it has been because we have so much common interests, and then over time have evolved such a, sort of an intimate relationship related to actually designing and implementing research projects, as Geoff said, these are ‑‑ everyone has skin in the game, and not just skin in the game as it relates to being involved in the research and its design, but also we are involved with each other in each other's communities, in each other's ‑‑ in other ‑‑ at the State level, at the national level in various organizations and that's really what's let us not only maintain the engagement, but actually grow the science actually.

I mean, of course, as you know, NIDILRR in particular has a big interest in community‑based everything, but certainly community‑based clinical trials, and it's really helped us sort of use the science and ‑‑ to engage others so that as I said so that if we spend all this money and time designing these clinical interventions for implementation, if you will, then as I said before, you don't have to do a bunch more, if you find something that's effective in the community, then you can just use it, because the evidence supported it.

And we have also gone with greater collaborations with Departments of Health here to also then look at the expense and cost effectiveness, because of our all peers claims data set in Minnesota so that we cannot only see whether or not the clinical intervention is effective in the community but also to study the costs related to it.

And all these people that are involved in doing that are on our Advisory Board and so as Geoff said earlier, you know, everybody has skin in the game. That just one example. We've been involved with the BIAs in all of the states with curriculum based interventions and things like that.

I don't know, Geoff, maybe your perspective would be far meaningful.

>> GEOFFREY LAUER: You know, Al, I think you hit it. The meetings that we go to, as we sit around the table, there is a degree of collaboration that is state to state, because the State Agency folks are there and they're learning from each other and they're often times being able to take promising practices back or they're able to share what they're stuck with, professional to professional around the table, there are folks from a variety of different kinds of disciplines that are picking each other's brains during breaks and at lunch and then questions that come up and then person to person and I can't speak and I won't speak for Audrey Alison and Tom Tadlock two members who I think are on the call today but I think both of them would share that there's a lot of opportunity for individual advocacy, whether you're a person who has lived experience with a brain injury, caregiver, individual, there's information from our peers, people's lived experience, the professionals that are in the room, to better understand how to either for ourselves or for others increase accessibility, availability, appropriateness and acceptability of services and supports from the medical realm all the way to the community and that is reinforced when Al comes and speaks at one of the Brain Injury Alliance conferences or when one of the Mayo staff comes down and helps with a workshop on a specific topic, or we're asked to brainstorm with staff on any other number of topics.

So we get included ‑‑ individuals get included in a range of brain injury research and practice that would be much broader, and there's also that chance then to bring other people up. I tend to bring young professionals up to sit at the table so that they can be encouraged to learn, and these are folks in their Ph.D., Master's level work so they can look around and go oh, this is what we can do if we bring people with disabilities to the table and if we treat everybody around the table as if they have value and worth, and recognize that they do.

So it's pretty exciting.

>> ALLEN BROWN: And very much a synergy over the years, and really evolutionary synergy that the energy sort of feeds on itself.

>> ANN OUTLAW: Definitely, building the pipeline of inclusive and belonging communities with all of us, and listening to the voices at the table. Excellent.

Let's go on to the next question, Arianna. This leads into one of the questions that we've gotten in the chat box, is: Are there any KPIs, or I believe that stands for key performance indicators, that you collect related to your Advisory Boards? Or what other method of continuous quality improvement do you do?

Kathy, would you like to chime in here?

>> KATHY PAEZ: Sure. So that's a really interesting question because I think we don't have a formal continuous improvement process, but I think we do do it informally, and as Lynnae mentioned, we have one person, Amy Lynn, who's responsible for the Advisory Board, so she helps to serve as the liaison to the Board, and is the one that communicates, that does some of the coordination, and makes things get done.

And I think the other thing that she does is she's very in tune to both sides. She's aware of what's going on with the Board members and the research team, so she makes sure that if there's something that comes up that we could do better, that the team knows about it, so let's say if she hears something back from one of our Board members that kind of indicates, hey, this is an opportunity to do things a little bit better, she'll be sure to bring that up.

I think we have a fairly flat team structure. There's really ‑‑ there's myself and then another kind of a Project Manager, Project Director kind of person, and then the team that's doing the work, and so as a team, we're kind of all into it together, and the team really values the advisory group, and so we're just really in tune to ways that we can interact more effectively with them, and at what point we could really use the feedback from them, and so we discuss it. It's part of our team meetings. We don't set aside time to talk about what we're going to do at a Board meeting. If we're doing the work, we're continuously thinking about, okay, is this something we should engage our Board to weigh in on?

And so it just keeps us in that mindset of using them to the fullest, and as Lynnae said, I think there's a lot of respect back and forth because we fully recognize we can't do this work very well without their help, because they're really part of the team.

So I think ‑‑ and then I think the other thing is Lynnae has been really great. She's provided us with tips and some guidance to help us be more effective in how we work with the Board, and so periodically she'll bring something up and we'll think oh, yeah, that's a good idea. We need to do that, so we're open to feedback as we go. And again, like I said, we act on it. When we get feedback, we track it, we act on it and we make sure we follow through.

>> ANN OUTLAW: Definitely. It seems like that tracking sheet that you mentioned in the previous question helps keep you accountable and may build avenues for the Board members to relay information about how to improve the work that you're all doing.

Allen, may I pose this question to you? Do you have any key performance indicators or methods for improving the work that you do?

>> ALLEN BROWN: So because this Council within this institution is basically solely sort of monitored and ‑‑ we don't have ‑‑ there are no ‑‑ we don't have to report to anyone related to its activity, so we sort of report to ourselves, but as Kathy was saying, our Board members, our Council members, are all very ‑‑ provide lots of very highly valuable feedback and are free to do so, and we get plenty of it and we value it all.

And ‑‑ but there isn't any specific ‑‑ for example, during a meeting, there isn't a specific agenda item or time that we get it, but there's plenty of, as Geoff was saying, plenty of time outside of the agenda including social activities afterwards and things like that where we get plenty of feedback about what we might want to change or how we might want to improve what we're doing. Specifically as it related to performance indicators for the members of the Council that are involved in our research, by the nature of the methodology that we use for our clinical trials, it is one of sort of continuous improvement and iterative review of the effectiveness of our interventions, and then modifying them and refining them as we go forward, because that is part of this process of design for implementation, because it parallels or it's quite similar to what we do in clinical practice.

So we want to test these interventions as we would use them naturally, so that if they work, well, then, we can naturally just incorporate them into our practice. The current trial is a little bit novel in that we are combining a medical and sort of social model of disease in that using this program resource facilitation which many of you are probably familiar with that was developed in Minnesota and Iowa around here with the brain injury alliances, and as part of that, we have iterative or sequential reviews of how this is going for everyone involved and we refine this intervention over time so in a way that's more formalized specifically related to the granted components of the Council.

>> ANN OUTLAW: Thank you so much. We have about 11 minutes left so I wanted to request again that if anyone has questions from our group of participants, please feel free chat them in either in the Q&A window or the chat box. Either one works just fine.

Let's move on to the last question, Arianna. What are qualities of an Advisory Board that you feel effectively encourages participation among its Board members? Lynnae, would you like to chime in here?

>> LYNNAE RUTTLEDGE: Sure. I think first of all we should go back to the comment that was made earlier about the value of brownies. I think that when you think about how people contribute, often it's in terms of do they show up? Do they talk? Do they follow up? But it's also: Are they engaged in a way that shows you respect and how much they're enjoying what they're doing?

And I don't know that that's a ‑‑ that's never going to be a continuous improvement indicator, but I think that if you look around the table and you look at the interactions between people, you're going to see whether or not people feel valued and I think the brownie indicator is one that we should all be advocating for.

I think that for our panel, it's really a matter of feel that there's a shared commitment to the project focus, so it is shared between people with disabilities with lived experiences. It's shared with researchers. It's shared with the medical community, and it's all focused on: What could we collectively do better to get better outcomes?

And I think that we collectively are responsible for that so I think that's one way that we really encourage participation is keeping us all focused on expecting better outcomes and what can we all bring to the table to have that happen.

I think that the diversity of participants really adds value and makes us more effective as a result, and I think it's because we have people from across the country. We have people across lived experiences. We have people with networks and connections, so they're so much more broad than what any of us individually bring. I think there's a real respect and value in our panel as a result, and something that Kathy mentioned was really about how we communicate, and do we have respectful and open lines of communication.

I tend to always read documents that are being developed from the eye of a person with a disability, and do I see evidence that we're being respected? There was at least one time where we started out using language related to people with disabilities as "patients," and that was so clearly not appropriate, and when I brought it to people's attention, it was like: Oh, of course you're right.

And we changed the focus of that particular issue brief so that it reflected that lived experience, and not used those terms of being a patient. So I think that as we've worked together, we effectively are communicating better, and I think that that really encourages participation across all of our Board members, and I think that everyone comes to the table with a sense of equal value, and equal participation, and I think that's really resulted in a really good project, and I think better outcomes.

>> ANN OUTLAW: Thank you, Lynnae. Very important points there.

Geoff, would you like to have the last, the last word on this?

>> GEOFFREY LAUER: Always. So thank you. It's very rare that I would deny that.

So working with Mayo, in our neck of the woods in the upper Midwest, for generations, it's been known as the WFMC, the world famous Mayo Clinic and many folks who work at Mayo and frankly many folks in health care do for many reasons, they distance themselves from patients at some level, and they categorize people in ways as diagnoses. I would give Mayo a cultural and historical nod that this has happened before Al Brown came to work there but he certainly inherited that in terms of engaging people around the table. He and his colleagues, they police each other. They have a culture of looking for the strengths in each other, and then also identifying where the challenges might be, and helping beyond a prescription pad obviously.

So that's broad, but something that's very simple that I think Al as project Director and his colleagues do well is they have an agenda during the meetings and so there is a clear piece of time in which Mayo, this project, the Mayo TBM model systems project reserves to dig into their issues, and we all know when we come, that's one of the goals we have, is to offer feedback, to try to brainstorm options.

Sometimes somebody comes up with the idea maybe if you use a different color paper you'll get better survey response. Somebody scratches their head and says really? Yeah, go look at the literature.

Another place is that there's a part of the agenda that's just reserved to go around the table, and from the Ph.D. epidemiologists to the physicians in the room, to people who don't have anything behind their name, and don't need to have any, because they do have probably the grassroots perspective, they're all equally respected and they have time to ask questions, to share if they have personal stories, if they have questions about policy at the State level, if they have ‑‑ there's kind of a vertical integration about where you can ask at any level.

So I think the agenda makes a difference. Nobody walks away feeling like there wasn't time for them to be heard.

>> ANN OUTLAW: Thank you. Thank you so much, Geoff. We have about 4 minutes to go, so I have a few closing slides that I'd like to do. Next slide, please, Arianna.

I know this is small. The slides are on our website at KTDRR.org but first I just wanted to thank all the panelists for sharing your experiences today. It's important to take away that though your Boards are structured differently, they've been created and tailored to fit the needs of your project and the members of the Board project staff should consider how and when they reach out to the Advisory Board members whether it be as you're forming your research project, collecting your data, tailored your dissemination activities to the appropriate channels or sustaining your project after it's closed out.

We spent a lot of time talking about meaningful engagement and it's crucial to have on an active Board. It creates processes that ensure accessibility and foster active listening of all the voices at the table.

If the members are from a disadvantaged group or there may be power differentials amongst the members, take the extra time to engage these members through private conversations or in other ways that are preferred by those Board members.

You've invited your Board members there for a reason, so make sure that you're hearing what they have to say.

And then regarding continuous improvement, if something isn't working on the Board, solicit input from the Board members to see what needs to change and improve the time together.

And finally, budgeting. Let's go on to the next slide. There's some budget resources. So here's some additional resources that I thought I'd share today. I was fortunate enough to attend a recent presentation on effective stakeholder engagement at KT Canada back in May, so they talk about patient engagement which I know isn't quite the right wording for our group here, but they're coming from a health care focus so that's why they've used "patient."

But these resources are from the George and Fay Yee Centre for Healthcare Innovation and they provided these resources and were open to me sharing them with our group today.

So first is a budgeting spreadsheet, and they have 15 budget considerations for building an active Board and on the right side of this page there's a downloadable budget tool which I have found very handy.

The second bullet here is an interactive mapping tall to help your project decide which participatory approach is appropriate for your engagement strategy and finally this blog series, it focuses on many factors. I think there was 20 or 30 different blog entries on factors to consider when engaging stakeholders, so next slide, please.

So thank you all for attending. We'll fill out ‑‑ we'll pass out an evaluation, or we'll direct you to an evaluation at the end of this webinar. The evaluation link will also be on our website shortly.

And if you have any questions that weren't answered during today's presentation be sure to include them in the evaluation and we'll be sure to respond to those. And the last slide please. Thank you all to the panelists who were able to participate, and to all the people who have signed in, as well. We appreciate the time you took to share your experiences with our Board ‑‑ with your Boards.

I'd also like to thank NIDILRR for providing funding for this webinar, and all of our KTDRR activities. Thank you, and have a great afternoon. Bye‑bye.

>> ALLEN BROWN: Thank you.

>> GEOFFREY LAUER: Thank you all.