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Community Engagement Initiative Knowledge Translation (KT) Project. Presenters -- Researchers: Charles Drum, PhD, Sara Rainer, BS, and Tom Seekins, PhD. Participant in the research project: Carol Conforti-Adams. Scientific and Consumer Advisory Panel Member: Gwen Gillenwater

Charles Drum: What I am going to tell you about is the Community Engagement Initiative Knowledge Translation research project. Now, we wrote it up as a KT research project. Inadvertently, the knowledge "transfer" language got adopted in some documents. This is really a knowledge "translation" research project.

I'm the principal investigator on this project. Sara does all the work.Tom Seekins is a research partner in this particular project but he will continue in his role as kind of the meta-reflector at the end of our presentation.

Tom has had the most difficult task. He's had to sound intelligent all day long. I'm required to do that for one hour. I think that's fair.

Gwen is part of the scientific advisory panel and will be doing kind of a project reflector – reflection, and Carol is one of our research collaborators, actually implemented the intervention that I'm going to describe to you.

So, the Community Engagement Initiative, or CEI, is an evidence-based technique to identify and resolve local barriers to accessing healthcare and recreational opportunities. I think it's well established that there are significant disparities in accessing healthcare for people with disabilities, and of the importance of recreation opportunities -- not just around physical activity and health and wellness, but also the social participation value of recreation opportunities.

Quite some time ago we got funding from NIDILLR to develop this particular methodology that is reflected in the figure on the screen right now, consisting of four different phases. We also got CDC money to actually implement it. We collaborated with Glen and did an embedded case study to establish the initial evidentiary basis for this technique.

And now we're in this stage where we're doing a more advanced pilot study of this technique. The four phases are not rocket science, but they're extremely important. They consist of, first the town hall meeting in a local community where people with disabilities across disability populations and their families are invited to come to a town

hall meeting in which we ask them to identify assets around healthcare and recreation, and to identify barriers to accessing healthcare and recreation.

Through a facilitated process, the barriers are prioritized and then they go forward and are presented in phase two, which is a community collaboration meeting. Representatives from the town hall meeting participate, and the community's infrastructure -- whether it's transportation, or healthcare managers, are invited to participate in the community collaboration.

Together, they enter into phase three, which is a mobilization process to address prioritized barriers. Then finally, evaluation is always important to determine, did you have an impact? Were the barriers solved or not?

Now, we've been focusing on local level barriers. That's extremely important on this research project. We also have a social ecological framework that guides the facilitation, the examination of the barriers. So we purposefully look at transportation barriers, community design barriers, attitudes in communication and other. Largely this is a non-adversarial approach.

So, what we wanted to do in this particular research study is to figure out how much help do communities need to successfully implement this technique, the CEI technique.

How many identified barriers will be resolved in the nine months in our communities of interest and in previous iterations? We've had about a 70 percent resolution percentage, meaning that about 70 percent of the barriers were resolved during the nine-month time period – a very high degree of success.

We wanted to know whether that continued on or not. We also wanted to absolutely fundamentally recognize that when you do KT, when things go from the bench to the community, people change the protocols. And so we wanted to purposely measure the kind of changes communities were making through this process.

Our method is to implement a pilot project using a cluster randomized controlled trial with equivalent materials design in eight communities, four in New Hampshire and four in Montana.

So what does that mean, right, in the interest of KT? What it means is, that we took all of the communities in Montana and New Hampshire between the population size of 2,500 to 10,000, and we randomly selected eight of those communities.

We reached out to those communities and we tried to identify local partners. Our order of selection was first to go to a disability organization, second, to go to a social service organization, and third, to go to a governmental agency or unit, to partner with us in putting on CEI.

So, equivalent materials design -- what does that mean? Well in this case, it means that we had three levels of knowledge translation support. Our four minimal KT assistance sites received $4,000 and a number of materials on how to do, and how to put on CEI.

Our moderate sites received the cash, the resources and they attended a training on how to do CEI.

And then our intensive sites received the cash, the materials, the training and then we worked with them to provide technical assistance during the process. To some extent also helping them co-facilitate the sessions at the town hall meetings, etc.

So that's what a cluster randomized controlled trial with equivalent materials design means.

We also had a number of outcome measures that were collected at the sites. We identified the number of barriers that were initially identified – always there are way more barriers than we have time and resources to address.

So, we've identified the number of prioritized barriers by site. And as we go along, we're tracking the number of remediated or resolved barriers. We also have each site keep action logs to describe to us the steps that they are taking with regard to, like, committee meetings or other community mobilization efforts.

We're, as I mentioned earlier, tracking the degree to which the communities are changing the CEI process. And then finally, like some of the other projects, we were relying on a modified measure that David Gray and his team at Washington University developed, and that's the survey of participation and receptivity in communities.

We're using two elements of that: the healthcare portion and recreation or PARTS portion of it. So on a pre-, post- nine-month basis for the people that attend the town hall meetings, we're seeing whether or not they feel like their community is more receptive to them when they access healthcare or recreation, and whether or not their participation rates have gone up as well. So that's the pre-post-outcome measure that we are collecting for this project.

Sara is going to switch and talk about progress to date. Let me back it up one more for you and hand this off. I do want to emphasize that these are preliminary results. So we have eight communities and you are going to be seeing the results from four communities that have gone through all four phases. We have four other communities that are in phase three, and we should have those completed in 18 months.

Sara Rainer: Thank you. Again I'm Sara. I'm a graduate student at the University of New Hampshire studying public health. I started on this project helping to produce materials, the how to guide, the web page, and I've served as a primary contact for the facilitators within each of the eight communities.

So, to date, we have two minimal KT assistance sites that have completed all four phases. We call those the phase four communities. We have one moderate KT assistance site that has completed all four phases, and then we had one minimal KT assistance site that withdrew from the study. So we are going to look at the results of each of those.

Community 1 is a phase four community; they received the minimal level of KT assistance from us. They had a how-to guide, funding, it was up to them on how they were going to implement this process. The invitation to this community was sent to a local governmental agency and that invitation was passed down to an individual who is really interested in this process.

The community was randomly selected, so we worked with what existed there and who could be our partner. The process was changed quite a bit, as we anticipated, in this minimal KT assistance community. Rather than host a town hall meeting and a community collaboration meeting, this group brought everybody to the table right from the get-go and actually formed a committee.

This committee met on a monthly basis and they used CEI to sustain their activities to look at barriers in the community and how we could resolve those.

You can see that three of the barriers fell under the transportation category that were prioritized; two related to healthcare and one to recreation. I would like to note that in most communities, transportation barriers were the same for both of those: healthcare and recreation. One fell under community design, and one for attitudes and communication.

In this community, all five of the prioritized barriers were resolved. This picture here is an example of one of the barriers that was resolved. The committee decided to really push their local community center to prioritize the purchase of an accessible van that could be used in the community. This was something they had considered in the past and this project and the committee was able to really push this and get that moved forward.

Community 2 is a phase four community as well that received the minimal dose of KT assistance. This community, the process was led by a CIL and a CIL member, two CIL staff members facilitated the process. There were 11 barriers that were prioritized in this community.

Three of them were under transportation, four community design, which were all related to recreation, two related to attitudes and communication, and two related to other. And eight of the 11 barriers in the community were resolved.

The example that you can see here, it’s a screenshot of a mailer that went out. One of the issues that was prioritized is that snow is piled in access aisles and curb cuts and this is a community that gets slammed in the winter with snow. So, they decided to send out a reminder to people to shovel their sidewalks. And this went out in the town water bill, so it went out to everybody in the community.

Community 3 is phase four community that completed all four phases. They received the moderate level of KT assistance. So we trained the facilitators on how to implement this process. This was led by staff from an area agency that provides community-based services to individuals with developmental disorders and acquired brain disorders.

Those who attended the town hall meeting felt that transportation issues were too large in the community to address with such a small amount of funding and with this CEI project.

They decided that what was important to them was that more recreation opportunities needed to be available in the community. So, they prioritized one barrier -- they wanted to create more opportunities to engage in recreation. And they had a really interesting interpretation of what recreation is in their community.

They decided to start a cribbage club and they also held a series of community dances. You can see this photo is actually from one of the dances. It sold out. It was a hit. There were 130 people at this dance, and they held a few others.

Right now they are still trying to have a supper club at their town hall, but that was something they weren't able to start in the short time frame that they had.

Community 4 is listed at the bottom here. Community 4 received minimal KT assistance, and they, this effort was led by a CIL member.

What happened in this community was that she decided, the facilitator decided, to reach out to community members and go straight to the town hall personnel to see if there were any other community engagement efforts going on, anything that would dovetail with the CEI project. And also to get their buy in on this project. 'Is it okay if we do this in the community?'

A few concerns were raised by community members. One being if issues are brought and there's not enough funding to address them, we don't want to have people's spirits coming up, 'Oh we're identifying all these barriers, but maybe they won't be able to be addressed.'

And another question came up, 'Can we merge the first meeting and the second meeting into one?' Being a minimal KT assistance site, this was totally up to the facilitator to decide. Can we have two meetings? Or is it okay to merge them into one?

She decided that we needed to have two separate meetings. Some people weren't happy about that. I mean, volunteering their time, and time is limited. Recruitment efforts maybe fell short, but what happened in this community was that one person showed up to the town hall meeting and we decided to end the effort there. The individual was from the community next door, but they were still able to talk about her community and things they could do to improve access.

Charles: So the slide says it's a moderate site and you've been describing it as minimal. Which was it?

Sara: Oh, I apologize. It was a moderate KT assistance site. They did receive training from us.

Charles: But they didn't receive technical assistance. So in the interest of science, we did not answer the questions. We did not answer the emails. 'Can I do it this way? Can I make these changes?' We simply didn't respond. And I think that contributed to, in the end, this thing not working at all.

Sara: So, a summary of our preliminary findings with these four communities -- actually all of the sites, all eight communities – we've had 178 participants. In the phase four communities, which involves three communities, 14 of 17 prioritized barriers were remediated.

In the phase three communities, there are four communities still working to resolve local barriers. There are 24 barriers that were prioritized, so we're waiting to see which ones will have been remediated in the time frame.

I handed out a summary of everything that we have from all the communities to date. I wanted to give you more information. I'm pretty sure, on the handout, it has a cover page that just goes over the four phases just in case this gets lost in the materials that you get today, so you know what project this was affiliated with.

So on the second page you can see a summary of the percent of barriers that fell under transportation, community design, attitudes and communication, and other. And the following pages tell you more detail about the actions taken around each issue that was identified.

Charles: So I think it is really important to be aware that many of these are not high ticket items. Communities are really focusing on what's doable. They know best within their communities -- how big to dream, how far to go.

And so, as a consequence, there's a range of actions that have been taken. But overall, we see how a very high level, about 75 percent of the barriers to date, have been remediated during the nine-month process of the CEI.

Based on our preliminary findings, and again, things are going to change, we anticipate, once we get our four additional communities. But what we did find in these four sites is that, you know, they can be very successful – the minimal KT. Or they can fail completely. We did have a complete failure.

We have examples of where communities have changed the process. We have anticipated that, and I think that's an interesting finding in and of itself, that communities do want to do that.

Examples that Sara gave were the combining phase one and two activities, forming a committee to sustain CEI activities outside of the mobilization. We anticipated and then focusing sole on recreation. These are all choices that the communities made.

Sara: We've also seen that depending on the level of technical assistance that they received from our research team, there might be a difference in the number of barriers

that are prioritized and those that were remediated. We're going to keep an eye on that from the other four communities.

Charles: Our sense is that with some technical assistance communities might be taking on more complex or difficult barriers, and left at their own devices, they'll go for the low-hanging fruit. That's not always the case, though, which you'll hear later.

Sara: Also, there's a difference among implementers. So we have folks from CILS, other disability organizations, local government agencies, so there are a lot of factors that influence the success of these communities. And we are wondering how much the organization has to do with that.

We've seen some communities that have had staff turnover, it's happened time and time again, and how that affects the time frame, and who's leading the process and that connection with the community that's engaging in this process. So, that's been a major factor that we've seen influence the success of the community. Additionally, the personal characteristics of the facilitator who's leading the process plays a big role in the success of the community.

Charles: You say that because you co-facilitated.

Sara: Absolutely.

Charles: Energy and passion make a difference.

So, you know, in looking at these communities, we've often billed this as a non-adversarial approach to access barriers. That still holds true, by and large. I think that's an important element of the CEI process. It's also increased awareness and endorsement of the importance of disability issues in communities that haven't addressed those in the past.

I think some of what we heard earlier about looking at cost-effectiveness or cost, needs to be examined and we do not do that outside of the costs of putting on CEIs. But we have not looked at, you know, are there preventive measures that are now that you are gaining as a result of this process, that saves money in the downstream.

All of those I think are important and a valuable area for us to examine in the future. Certainly, replication on a larger scale is extremely important. So, I acknowledge David's earlier comments about the possibility of differential funding tracks on the replication side and going to scale, that would be a really important area.

I think another important area is to hear from Carol who is one of the implementers of the CEI process and had the minimal level of assistance in hearing your reflections on the process.

Carol Conforti-Adams: Hi, I'm Carol Conforti-Adams, and I'm from New Hampshire, and I was Community 1. They first said this was a random selection, and it really was. I think the stars were all in line because my town that I just got a new job in, I don't live in

that town, I'm a welfare case worker. It's a community of 5,000 people. I had been working there maybe three months before this letter that came to one of the communities through the town hall to a community volunteer, who said 'I can't do this project. You are new in town, maybe you can.' Alright! I looked at it, and it just so happens that I'm a 6-7 quadriplegic spinal cord injury working this job, so I have an investment in disability awareness and what's going on community wise.

Actually, prior to being in a chair, in the 80s and 90s, I worked clinically in a hospital, bedside teaching. I was doing health promotion wellness in the 80s and 90s. So, I was highly invested in personal responsibility and health and wellness, and the doctors didn't control it, you did. Then I had a family and ended up with a spinal cord injury. But - so, I accidentally ended up in this case worker job; I took this position. And even better, I didn't have to be monitored very much – which is always my M.O.

So Sara called me, and I said I knew research projects, I'm very invested in research but I'm more interested in doing.

And so she said, 'Well, we got all these materials and, but we're not going to really help you, you just have to report to us.' And I was like, 'okay.' So, we had just started this advisory council and I proposed it to them.

They looked at all the paperwork, and it was a little overwhelming to them, saying 'We're supposed to do this in nine months?' I said, if we put it on our agenda every month and we look at how we do the process, we'll get through it.

And so we had some very interested committee people and my focus really was we had a welfare director that gave out checks. Mine was really to help people. Instead of giving a hand out, giving a hand up. I was very much into self-improvement and behavioral change of people.

So, we met and we prioritized. We happened to have some, we had a young man who was, had an intellectual disability and he had a transportation problem. This project looked at transportation with healthcare and recreation and, so, he volunteered and he did a Facebook survey.

And we also have a Facebook for the town that we're in that anyone in the community can Facebook into. So we did that. We got a very soft study of where the issues were.

And then we proceeded to know that transportation is the issue in New Hampshire, and we don't have a doctor in town, we don't have a health center. Most of the athletic things were through school, not for adults. There was college in town, but -- so, we got this transportation study, we ended up getting a community action that was a countywide community action and had services in the next town, but really didn't have services in our town.

But they had a bus that would pick people up and bring them to the senior meal site. So we said, well you've got this bus and you are doing these things, and as you go to

Concord, you can go through the highway or come through our town and get to Concord. So we got them to come into town twice a week. Once was to bring them into Concord, which is the capital, the biggest city to us, for a two-hour stint wherever they needed to go. And that was on Tuesdays. On Fridays, they come into town and they bring people to the bigger grocery stores than the little market that we had in town so they could get more quantity for their dollar.

And the other piece that it opened up, this bus was really for seniors, but the community action program was really looking at discrepancies of other people that might have disabilities that weren't physical for one, but they couldn't drive.

So, we were able to open up this bus ride because they had room, not just for people over 62, not just people with physical disabilities, but a range of people. And they made three different bus stops in the town to come in.

So that was one of the real benefits. And I got to tell you, if it wasn't for this young man who had the issue sitting in our group of providers, we wouldn't have come up with that solution that quickly. Because I would have never thought of a Facebook survey.

So, that was one of the things that came out. And we also, we had the local community center who was going through a strategic plan and this was perfect for them because now we had data for them for their board to vote on upgrading their little vans to an accessible bus. That bus is now used for their activities, but then there is opportunity for others in the community as need be. Hopefully for recreational opportunities.

The other piece we did was, you know there was, there was a town newsletter that was on the website. And then it sort of got dropped because of staff change overs and job descriptions and people's priorities.

And our advisory group said, 'This is a great mode of communication, maybe this is a way, if we can get this newsletter out, that had all the town meetings and activities and some of the things going on, but also to make a disability awareness piece of that newsletter.'

We were, you know, this was a not-in-your-face type activity. We just wanted to passively bring people's awareness us up, so we started with just doing a little thing on person-first language. What does that mean? Why should we think about that? And so bringing up the sensitivity of non-disabled individuals of what some of the simple soft things that happen that can actually really depress somebody, you know, make a barrier emotionally for them to reach out and get out into the community, just like we heard this morning about the difference when you had home modification that made life simpler, then people were ready to step out and do something else.

So, we had that initiative. We also had two projects in town that actually not many people around our table, because we were helping human service people, knew about, but there were two environmental studies going on, one was for a traffic rotary and one was for safe schools. So the school people knew that.

But we had the opportunity to say, ‘Hey, you’ve got these, you have these design plans, we'd like to see them. Bring in your blueprints.’

So we had a meeting or two where we actually went over the blueprints. Who knows when that will actually be implemented but we have put it on our long-term checklist to really check and make sure when they get to the implementation stage and they start cutting prices, next thing you know, that curb cut’s off [the list], or you know, that sign’s gone or whatever.

So those were the projects. So we looked at the community, and those two projects were happening at the town level. And then we also looked at more of a universal design in saying ‘Where are some of these barriers starting from?’

And here again, we're not doing this right now because nine months was a short period of time, but we're focusing on, with the local college trying to put data an ADA Title 2 and 3 project, with a Power Point, and then I'd like to go out and educate my peers in chairs and things to actually go to the local planning board and say, ‘This is what a barrier looks like. This is what the ADA says.’ You know, this is how you are in an important role because people have to bring their plans to you, now you know what the barriers are. Now you know what to look for. Now you know what the ADA says you need to.

Many times in rural New Hampshire I see changes in structures and they never address access issues. So, those were the things that we found.

I think it was instrumental to have these folks bring it to our community because we wouldn't have thought of it before, before that at all. And it was just one element of the other things the advisory council was doing, but now it is part of our general agenda each month.

The other piece of it, we got the tools and the framework, but it was nice that we were able to massage it, to what we needed in our community. Right away, our people didn't want to have two meetings. We were meeting once a month any way. So they didn’t want to have another meeting. But what we wanted to do, because we are such a small community, and most of our service providers were outside of the community, we wanted to bring them in because they were also providing services to our clients.

And we wanted to have, again, just like the young man we had that did the traffic study, if he wasn't sitting at our provider group, we wouldn't have gotten that input. So we really wanted to bring all parties together. We didn't want to separate them. We were able to use the same survey tools. I probably should have talked to Sara before I massaged them a little bit, ‘cause some of the demographic things like, ‘What was your income?’ would be different from a provider than a client.

But, we were able to do that. And it was successful. And my recommendation would be that, and especially hearing some of the other projects, the community engagement

piece is sort of the foundation that you sort of need to move forward with a lot of other projects.

And I know people, you know, sat down and did needs assessments and things like that, but it's really nice to get everybody in the room at the same time and make it small enough like a community. So I would hope that your community engagement project could be something that you could train, or do a workshop or do part of a larger statewide workshop. People could go -- you can train them to go and do the community engagement initiative, or modify it, but at least give them the toolkits that they can work with in their community how to do it.

So, as I said, I'm really pleased to have been involved in it. I'm pleased to be here. I like to promote myself to a lot of new people out there. I do a lot with train-the-trainer and health promotion and disability.

And the big thing I saw is the whole integration piece of it. It's really important pieces that you have presented today. And community awareness, advocacy, leadership all come with that integration.

And then you guys want to do the research, do the research so we can get more funding. You know, but I really stay away from the money. It isn't the issue of making a change, it's really the motivation and the self-advocacy and the leadership out of that, that will make the change, with our growing population of people with multiple abilities, that we can get universal design more and break down barriers in communities.

Charles: Thank you, Carol, that's really helpful. Gwen, you've been around this project for a while, you've seen us doing this work for some time.

Gwen Gillenwater: I want to start out by thanking Glen [White]. I have been with this project since day one, I guess. I have to say I was truly amazed today as I listened to all of the presentations and how far we've come.

I remember when there were rocky roads, I wasn't sure we were going to make it there, you know. And so, everyone, I'm just really, really impressed and amazed, and this is the kind of evidence I wish I had had when I was up on the Hill for NCIL, trying to get policy changes, because really and truly Tom was right. That's ultimately what we have to do to get any changes, is to get some policy changes.

And not only do you need the hard evidence, you do, with the numbers and everything else, but you also, and I thank Amelia for this, you have to look at the economy of it all. If it is not cost-effective -- I learned that one the hard way two years sitting on the Medicaid commission and trying to convince governors and others that there was reason that we had to look at some of these cuts and everything else they wanted to do because of the of the costs.

And so, that, that has to be in the forefront. I think probably more so now than it used to be. I'm a child of the 60s. I was an idealist. I did my early marching and all in civil rights,

you know. The better world, that's what I was working toward. Forget the money, Carol, and I agree with everything Carol had said, but I do think we have to look at the money. We can't avoid it in any way.

I think that really the points that Carol, I told her, I said you can take as long as want, you speak as long as you want today. Because Tom is going to follow-up with his meta-reflection, I think I'm the mini reflection or something, but I think Carol did a lot of reflecting too, you know. And I agree with everything -- except the money. Okay? We gotta look at the money.

There has to be, I think the coming together, that's the whole key. And one of the things that I respected, I mentioned to Charles and the work he's done, is that it really is about community. That's the bottom line. I was a community organizer, you know. Barack and I had some things in common, except I was a generation ahead of him.

But there has to be a sense of community in making those changes that we're talking about. I think one of the most disturbing things that I've seen -- and I'll be 70 my next birthday, I've been around. I know I don't look my age, but hey. I'm almost 70, okay, and one of the things that I've really seen, I grew up in a coal camp. My daddy was a coal miner, killed in the coal mines actually. There was a sense of community.

My grandmother told me one time that notices from the company that came out had to be in 12 languages because that was the diversity we had in the coal camp, and it was very bare minimal survival, truly, but there was a sense of community.

When the whistle went off, and we knew there had been an accident in the mines, everybody came out in the yards. Everybody helped each other. And then I went on to grow up even later in a small town.

That sense of community is the thing that concerns me most right now. I think the CIL community and the disability movement overall, we have that sense of community, but we've got to reach out beyond that if we're going to make true change.

It's always been an uphill fight. We know that. In Congress. In our State legislatures and everything. But we've got to do more now to bring that together. The kind of evidence that, and I think this is the platform, we've got to start with the foundation, the kind of evidence that that this project and some of the others have shown is definitely, have to, it's needed.

But we've got to pull in the other partners. We've got to put out enough, you know, bait, whatever we want to call it to bring them to the table with us. Because it's the only way that we are going to bring about true change within that community.

And I found, even in South Carolina, oh I have to thank Glen's people for keeping up with me, I moved around quite a bit in 10 years or so. And I spent some time in South Carolina. You think of South Carolina -- I was directing a CIL there -- as a place you

would think there was real community. And there are, but the communities do not necessarily come to the table.

I'm out in Colorado now and I haven't been out there long but I'm finding that people don't know who lives next door, you know. All these housing projects are going off, left and right, you don't even know what your community is. I've been very concerned about some of the things I see out there. They are building institutions out there like crazy.

Right across the street from me there's going to be a new memory care facility. Guys, that's nothing more than what we were looking at as nursing homes for many years. You know, that's what it comes down to. I've been in one of them and found out.

So we've got to come together as a community doing more cross-section. I think that idea that you had about bringing other people to that table, it just opens up so much, you know, to consider and think about and innovate and all the rest of that. We've got to get on to Tom's ecological approach here, you know. I had him defining that for me at lunch time. I'm going to have to learn more about how we can pull that one off.

And the other point I would make is in developing. Carol is a good example of a true community leader who's got the energy and the passion and all to really be able to get the fire going. We've got to develop more of that, especially in our younger generations. I can't preach that enough, I've practiced it as Glen knows when I was a CIL director, even at the national level. But we've got to do more and more to develop those and to find the ones and help them learn more, be trained to be able to become the community leaders because that's where it's got to start.

I appreciated what Charles said about learning hard lessons. We don't always win. You got to be able to take that and pick up the pieces and move on, because the next day, those same struggles will be out there and you still got to be able to approach it.

And I think that, basically – oh, less control. We have to do what's doable, you know. Keep on -- start there but move on, you know. Keep getting -- change is going to happen. I know that everybody's talking. There's always going to be change. I lived in Washington, D.C. for 25 years. There was never a year that there wasn't change at some time or another, okay.

Change is going to happen. The question, and I think in the next few months we'll see even more change coming about. What we've got to do is be able to adapt to that. It's one thing I think our community is pretty good at: adapting.

We've got to be able to adapt to that change and make it positive change. What scares the heck out of me sometimes, is that I see some of this change going backwards. And I didn't live through the '60s and '70s and all to see some of this, okay?

Diversity. That's the other thing we've got to reach out for. We have got to make an affirmative action in pulling in people, you know, from other origins, nationalities,

languages, you name it, into our -- at our table. That's got to be our main priority I think in reaching out.

Tom Seekins: One of the other things I want to note is that -- I think Gwen really sparked this thought in my mind -- much of the time when we talk about environment or community, we tend to focus on the physical, and not necessarily the organizational, social or emotional aspects of community.

And, I think many of the people in this country in particular and around the world are searching for a sense of community, and belonging and participation. And I think that the disability field has an opportunity in a very unique way -- the ways that it's contributed to other areas -- to make substantial contributions to the creation of community through the focus on participation.

I'd also like to note, just a little more strategically or technically, one of the decisions that we made was to focus on small communities. And I want to highlight, because Gwen pointed out the issues around Denver and large communities, it used to be that the Federal Government or national leaders talked about the states as the laboratory for the nation.

But I think conditions are now such that communities are the laboratory for the nation. And there are, Lillie may help me out, I may get some of these numbers wrong, somewhere around 40,000 or 45,000 communities in the country, a little lower than that, but there are a lot. And they vary in size and structure. And the smaller the community gets, the less resources they have to achieve the same kinds of requirements of large communities. So, that an outside entity can become a catalyst for change and the creation of capacity for self-determination within a community. And I think that's another contribution that this kind of approach can make. Thank you.

Charles: We have targeted larger cities. And their overall success rate is about the 70 percent. If you look at the smaller communities, I think there's a higher success rate in resolving the barriers. That's really helpful, Tom.

Andrew Myers: Hi, Andrew from Montana. You reached out to the planning board, and talked to them about the ADA and what that meant.The comment is, how receptive were they? Because if they're positive, it could be a good opportunity to include this in a chapter in the master plan, which is a binding document.

Carol: We're putting a presentation together -- actually I'm still trying to get students together to help me. If I had a little funding I could try to do it myself with peers. But that is an excellent idea. The biggest thing with community is bringing up the awareness. If you have the diversity of people in the audience then you are multiplying your consciousness. If you have white people in the room you only have those white people raising consciousness, so that's why we wanted to go out to the planning boards because in New Hampshire, these are volunteers. They meet twice a month. They deal with people being angry because they can't get what they want, and they don't know

what the barriers might be unless they actually have a disability themselves, visible or hidden disability. So,I think that's an excellent idea. That would be a building block if we could get this going and do it one-by-one and the whole idea is to actually train people in that community that have disabilities to be able to get the resources and technical assistance from the Power Point so they feel empowered that they know something. And they can go, instead of going and saying, “I'm here to complain about my issue,” this is more of a universal issue in the community. And this is why, why we're addressing it now. So, I think that is just one piece of, an integral piece of integrating diversity in the community and educating people on the barriers, both physical and emotional.

Christina Holt: Thank you so much for the work that you all are doing. I think that it's great the community engagement and the high rate of ability to ameliorate some of those barriers is really impressive. I did note that a couple of the communities have combined some of the meetings or asked if they could, and I wondered if you all have thought about wiggle room on that nine-month time period, or anything that you've learned for the future implementation.

Charles: Those are very good observations and questions. And we have looked at extending out to at least a 12-month time period for the collection of data. I think we need to look at our final results before we determine the flexibility, you know, that's given directly or indirectly. I think there's a tremendous amount of value of having the two phases done separately. It may not work in every community. But in the vast majority of communities where this has been done, it's like 35 or 40 communities who have implemented this technique, there is so much value to having the disability community come together, right, and their families and then to go together to that next phase and to work with the community infrastructure. It does seem to result in breaking down more barriers, increasing more awareness and having a beneficial impact, based on earlier research and preliminary results. If it could be done by a single one-off, that might be a possibility. What we've found in other research is that the community infrastructure folks will often dominate at the town hall meeting, and they will tell the disability community **these** are the barriers you are experiencing or they will reject the barriers that people with disabilities want to have prioritized. And so those are some of the values and the reasons why we've tried to keep that separate. We'll look at the results with this round and see if that’s going to hold or not. I also like Carol’s suggestion and we thought about are we going to get to this place where we can do a training of the trainers kind of approach and have that to be our next stage.

Carol: I'd like to piggy back on that. I think there is a value to bringing people with disabilities and their support families and friends whatever together to talk, I think when you do bring both groups together, it really is a facilitator issue of how to not let that dominance happen. So, yeah, you have to be really sensitive respecting the voice that's talking at the time and people with disabilities have a tendency to get more emotional and more involved, and the professionals seem to stay very subjective -- I mean

objective about it and they'll say these are the numbers, you know. So, yeah, I think that piece is a facilitator piece. And I think because our provider group was meeting already, we had some of those and they really wanted to hear some of the specifics. And we also wanted to know that we couldn't get the outside providers in without, you know, we were very conscious of their time restraints and bringing them in to get them to share with us. It was more of the time – we have nine months and we have to do this. So, community has to massage that differently. But it's nice to have the resources available so you can massage something instead of recreating something because then if you recreate the chances of getting it done are really minimal. So and it gave an initiative.

I would like to see project be able to say, "Where have you gone a year from now?" To really see the long term pieces of it. And I really strongly believe integrating this community engagement project into a standing type of organization or committee or group so it is always on your agenda. We don't want to lose it. That's the one thing I've always thought. There's research out there and then does it get dropped? And so I think for the benefit of the positive outcomes we have to look the at the longitudinal view of it a little bit more.

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