**Knowledge Translation: Where Should the Field Go Next?**

**StatsRRTC Reflections**

*Presenter:*

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>> SARAH BOEGE: I'm really thankful to be able to be here and present as a part of this KTER track. I'm here from the Institute on Disability at the University of New Hampshire. I’m working with the Disability Statistics and Demographics RRTC, which is a Rehabilitation Research and Training Center. I will talk more about that and I would like to give an example of how the Knowledge to Action framework can be used, and talk about the work we do, and give an introduction to another model that might be something interesting to discuss later. I will be interested to hear if anyone is using KT models in the work that they do and what's relevant for them. We will have an interesting discussion hopefully stemming from that. We will just have reflections as well on where we think the field of knowledge translation is headed next. I will be interested to hear your thoughts on that and how it can best be applied to the work that you do.

So, just an acknowledgment to our funder, NIDILRR, and a little bit of an overview. I will give a background on the StatsRRTC that I mentioned. I’ll discuss and give examples on knowledge translation, specifically with the technical assistance that we do. I think it's an interesting opportunity to talk about knowledge translation as something that can be iterative and can develop into longer-term partnerships, which I will give an example of that. Or also could be a quick exchange getting people the information and knowledge that they need. So, I will talk about a little bit of a range there. Then I will do reflecting on the StatsRRTC’s knowledge translation future, sort of what we are looking at going forward and then I will give reflections more generally on the direction of the field of knowledge translation. Hopefully we can get some thoughts from everyone about all the pieces of this.

About the StatsRRTC, one of the overarching goals, especially one of the Knowledge Translation goals of the StatsRRTC, is to be a dependable "go to" place to access the latest disability statistics and a place where you can learn about data and disability statistics, how they're collected, where you can access them and understanding what the statistics are saying, as well as what the statistics might not be able to say. So, of course, statistics are, in many cases, our best educated guess or estimate but we don't necessarily have that information about the full population. Being able to explain what statistics are saying, what they're not saying, and to really be able to inform the best use of statistics.

Sort of feeding into this more generally, our technical assistance is very broad. We just open up for anyone who has questions about disability data and statistics. This might be about methodology or anyone who is interested in finding a particular statistic and I will talk about an example of that in a moment. One thing that I appreciate about the StatsRRTC and the RRTC program in general is that it has always had an integrated approach to research and knowledge translation so there is allocated time and money that are invested in research dissemination and knowledge translation.

These efforts are integrated with the research that we are doing on, for example, measurement of people with disabilities in surveys, we have research projects on that and that sort of feeds into our knowledge translation efforts and the technical assistance we are doing with explaining those processes to people. That integrated approach allows us to be almost these knowledge brokers where we are doing research but we are also communicating with a more general audience as well.

I'm going to talk a little bit about our technical assistance as an example of the Knowledge-to-Action framework. If you were able to join us for the previous session, which was wonderful, Ann went through a thorough run-through of the process and the model. I will hit on the main points here and we can delve more into anything if we would like later.

With technical assistance, the first step, identify the problem. This is great because the requester comes to us and they have a problem, a question, something they are interested in learning more about so that piece is there right off the bat and that can be an iterative discussion as well and sometimes the requester has an idea of what they are interested in but they might not know what statistics are available out there. Or, for example, there are a lot of people interested in a specific diagnosis or disability type and a lot of the national statistics have these functional limitation questions, which get at much broader categories rather than talking about individual diagnoses, so sometimes we have to have this back and forth of okay, you're interested in this but this really is the best available statistic to get at what you're interested in. So, the identifying the problem phase is iterative as well.

Then adapting knowledge to local context and tailoring interventions, this is also an awesome area where our TA requester already has a lot of strengths in this area. Oftentimes TA requests come from researchers, maybe small nonprofits who are involved in the community that they work in, VR agencies, other government agencies or state agencies. Oftentimes the person who has this request who is coming to us already has a deep understanding of the local context and they're already set up to be able to leverage those community connections to use the knowledge in a productive and effective way. I'll give an example of that as we go forward, too.

One of the barriers to knowledge use that has emerged through this process is this background on statistics. There are a lot of complicated things that go into the creation of these statistics. I should also note that, while we're based in New Hampshire, our Center has a national focus, so we have access to statistics from all 50 states as well as Puerto Rico and D.C, when that information is collected. A lot of the statistics we are providing and synthesizing are from the Census Bureau, the CDC, and from other organizations. We are the intermediary taking that information from all these different agencies, RSA data, all that information, and putting it into one place where people can ask questions about any of this disability data or these statistics.

A lot of questions that we get are why different agencies are reporting different estimates. The CDC has an estimate that there are about 60 million people with disabilities in the U.S. The Census Bureau has a range of estimates depending on which survey you're looking at, but a recent American Community Survey estimate says there are about 20 million Americans with disabilities. You get people coming to us saying, well that's interesting, there is a difference of about 40 million people there, that has a lot of policy and practice implications. Why is that?

And oftentimes the question we get, which is very interesting, is asking which is the best estimate. Which statistic should I use? Which one really is the best? That's a tricky question, because oftentimes there really is no "best" necessarily, and that's also sort of getting back to understanding the requester's needs, what they're looking for. Sometimes data that get down to the county level is a little more limited, but if you’re really interested in county-level information, it’s worth it to use the data from that source.

Understanding the needs of the requester really play into this, and then also related to that, understanding what their comfort level is with statistics, so we have a lot of ways of breaking it down where it’s very understandable. But then we have some requesters working at a university and all they do is statistics and they want to get into the nitty-gritty so having that flexibility of more general overviews, understanding what are the basic important things to get across, and then having the iterative process that make sure the requester is understanding that and is able to use that information in an effective way.

That gets to the next piece which is monitoring knowledge use. A lot of our requests when they are a little more involved and a little more iterative, often we will send a statistic to someone, then they will integrate it into their presentation or report and then they will send us the presentation or the report before they disseminate it so we have a chance to go through and make sure they are using that information accurately and also identify an opportunity for an area where we could further support their work.

Then looking at evaluating outcomes and following up with the requester, this piece we do have a formal evaluation process and we monitor all the requests we receive and when they are attended to and the subject matter, so we have a formalized process for that, but unfortunately one thing we are finding is, with the more involved requests, people are happy to get back to us, happy to fill out the evaluation and give us more information about how we can improve the work we do, but for a lot of the smaller requests where someone is asking for the overall employment rate for people with disabilities, just a quick question, and we have a quicker response. Oftentimes when we follow up we don't hear back from that individual, so that's what we're trying to work on with evaluation when it comes to TA and how we can improve that and get better feedback.

Also related to this would be the piece of sustaining knowledge use. This is contingent on that continued contact with the requester. It's really exciting when they, you know, send us a message three months later, like, hey, this is what this statistic ended up being used for, or this was able to inform our program, or sometimes a nonprofit is applying for a grant and they will write back and say, hey, we got the grant. We're so excited, thank you for your help.

That's exciting to see where they were able to use that knowledge and then opens the door for us to say, hey, is there anything else you need? Are there any other requests we can help you with? Or sometimes they will refer someone else within their network. We did some work for the Alabama Able Program and they were happy with what we had done and they reached out to their network, and the Oregon Able Program ended up reaching out and saying hey, we would like to hear more about that, too. So really, that continued contact is how we are trying to sustain that knowledge use when it comes to technical assistance.

I think I will zip through this. This is referring to the knowledge creation funnel, if you have the sheets out, but I will go through it quickly here. As I mentioned, kind of one of the strengths of technical assistance is that it's a little bit more relationship-based, can be more informal. We can understand the exact needs of the requester. We get to have that back and forth dialogue with them and have that engagement. It's not just an online form they fill out and we can't interact with them. So that's definitely a good strength of technical assistance.

A weakness here is that communication is normally initiated by the requester, so we are trying to do more outreach and let people know that we have this service and that we're able to get disability statistics out to everyone. But, you know, if people don't know about us, they can't send a request.

The tailoring knowledge piece, normally we start with a broad inquiry, so that's the requester coming to us with their problem, question, topic that they are interested in and then we can funnel that down to a knowledge product or a tool as you can see, in that funnel on that sheet. So, this is great and iterative, too, because oftentimes on the TA requester side, they will have a product that they end up putting together like a presentation, an article or some kind of report and we will have some back and forth to collaborate with them on that and also on our side, what TA is being requested informs the products that we create.

We ended up creating this series of state-level reports with county-level data because we were having so many requests from local nonprofits, local government agencies that were interested in a state and county-specific level for statistics. So we created a series that we can refer people to. Then of course if they have a customized or specific request we can go into that for them as well.

Oftentimes statistics are available for some age range like working age, 18-64, but sometimes people are interested in a specific age range, like transition aged youth so maybe you are interested in 18-24, 18-25, so we can go to the numbers and run that estimate for people and get them that more specialized and tailored information. But we have been able to create more specific products based on what people are often requesting.

I would like to run through this example a little bit. This is the Center for Independence of the Disabled, in New York. They go by the acronym CIDNY. They are a center for independent living, which is the Administration for Community Living, or ACL. They provide a lot of services in New York City for people with disabilities, a wide range of services, creating employment opportunities and connecting people with services there, is a big piece of the work that they do. We have been working with them for the last ten years or so. This is an example of a TA request that is has blossomed more into more of a partnership. We had an initial request, they were interested in understanding the demographics of New York City better, in particular people with disabilities, and then that sort of turned into all these different reports and projects that we have been able to help support in their advocacy work.

One of the things that we helped them produce were these subway accessibility maps. So transportation, of course, is a big issue especially as you might imagine in New York City. CIDNY had gone into the field and collected data on which subway stops were accessible and which were not and we were able to send them some poverty rates by these local geographic areas, getting as specific as the five boroughs of New York City, so we were able to send really specific statistics that they overlaid, over the information they had about the subway stations. It was interesting to see which areas are struggling with people experiencing poverty and then also having inaccessible subway stations. The director of CIDNY is a lawyer and she has filed a lawsuit against the city of New York for lack of accessibility in many of the subway stations. A judge recently passed that on to the next stage, so that's sort of in the works, still in process. That's an example of how statistics can be a part of advocacy, and how one of our main goals is just to be able to support the work that people are already doing and to better understand the populations that they're serving.

These other bullet points are from the director herself and she was mentioning the work that we have done with them has helped them to plan their outreach better and their engagement and focus their resources a little more, and also to better mirror the communities that they serve. So by better understanding the demographics of the different boroughs, they were better able to hire new employees that better mirror those communities they were serving. They had found that Asian Americans were being underserved and they were able to hire more bilingual staff and translate more materials and they were able to address that and understand what was happening, and that information then turned into focus groups, and other community outreach and activities that they were able to do. So, that's also where we have this great connection where we have some statistics, and we can send those out but these organizations have the local context and the ability to interact more with the communities directly to see how that knowledge can be best used.

This is just another example of a report that they put together. It's difficult to see here but it's the five boroughs of New York City with employment rates for people with disabilities compared to employment rates for people without disabilities, to highlight the gaps there. It’s a little tough to read but for all the boroughs employment for people with disabilities is around 30 to 33% whereas for people without disabilities it's in the 75, 78% range. So just to provide that context.

So, where are we looking with the future of our knowledge translation at the StatsRRTC? We are interested in local and specific statistics, we found this to be the area where we can support advocacy aspects, and there are folks who work with specific populations or lack knowledge about populations that they serve. So that's definitely been something we found to be of great use, and that cannot always be found what we like to call "off the shelf." If you go to the Census Bureau's website, you are not often able to get level of detail with the statistics, so we think that’s a strong area where we can support work there.

We have also noticed the importance of addressing the barriers to knowledge use such as explaining statistics, being able to provide enough information about that. Oftentimes we will have people come back to us and say, hey, can you write up that explanation that you wrote or told me verbally so you can I can pass that off to my supervisor when they ask about this statistic or why this statistic is different from this other one. Trying to make sure we have those resources and we are going to develop a training program which is a different KT activity we will be doing, but that will be all around disability data, measurement of disability and surveys, and just sort of describing some of the basics of that.

We have found that it's really important to be leveraging connections and networks so we're hoping to reach out to other centers for independent living to provide local data on populations that people are working to serve, and we're hoping that that can expand to other organizations as well. So even just being here today, we're hoping to make ourselves available as a resource for VR agencies, for anyone who is interested in their county or state and the people that they're serving or, you know, if you're interested in employment rates when you are thinking about those long-term goals, this can be an interesting way to frame that or to justify the work that people are doing. I really liked it when Scott opened the first morning, or yesterday morning, saying that data is our argument for advocacy. I really love that phrase and I think there is a lot of powerful ways we can be using data and statistics.

We are also, sort of along that same line, developing a new KT plan for the grant. So just sort of going to be outlining major goals and sort of reviewing. This is the end of our first year of our five-year cycle so taking stock of where we're at, how our evaluation is working and where we can improve going forward.

Thinking about where the field of knowledge translation should go next. I'm interested to hear anyone's thoughts on this, especially if anyone in the room does knowledge translation work. I would love to hear about the models that you're using, what's working or not working or what's unclear. In a lot of the literature I'm seeing emphasis on co-creation, co-production. There has been some discussion recently about moving beyond cycles so you will notice the Knowledge-to-Action framework, which I love, is set up in cyclical way, which is a really good way to visualize and think about the process, but then there’s room for it to be iterative and to go back and forth. You might be in one step and maybe you need to look at a step before that, so I think it’s built into that, even though it’s a cycle, it's dynamic and iterative and it does have this emphasis on networks and systems thinking.

But there is an interesting model that I've seen recently just in 2018 it was introduced by Kitson and it’s the Knowledge Translation Complexity Network Model which comes out of network theory. I thought it was kind of interesting, the Knowledge-to-Action framework came more out of a health provider focus and it's interesting to see how these different disciplines are approaching knowledge translation and how people are thinking about it and talking about it. I don't know that it necessarily represents a massive shift from the Knowledge-to-Action framework, but I think it is interesting to visualize things in different ways.

The way that the model is described and visualized is a lot more amorphous. They show all the sectors that might interact, like the community sector, health, government, education, research, as overlapping spheres like Venn diagrams. Amid those, sort of on top, they have these amorphous blobs that are the process areas which look similar to the steps we see in the Knowledge-to-Action framework. There are these ideas of problem identification, implementation, knowledge creation, evaluation and knowledge synthesis and between everything there are all these different lines. So it's iterative, amorphous and I think that was an interesting way to think about it. I think some of us might be thinkers that like following the circle of the Knowledge-to-Action framework, I tend to like that, I feel guided by it and supported, but I think there’s this interesting element that brings in when thinking about just how iterative this is and how messy knowledge translation can be, it's another interesting way to think about it. It might be helpful for guiding different knowledge translation activities. I definitely would love to hear what people think about that and I think I will leave it there so we have time to discuss. Thank you all for your attention.