

2021 Online KT Conference: Research Results for Policy Outcomes

Translating Research into Disability Policy: Insights of a Former Congressional Staffer

Bobby Silverstein

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JOANN STARKS: OK, welcome back, everyone. We're now in the homestretch, and we're very much looking forward to hearing from Bobby Silverstein, Principal with Powers Pyles Sutter & Verville. He has over 45 years of public policy experience in the disability policy arena. Bobby is well-known for his many years working as staff director and chief counsel for the US Senate Subcommittee on Disability Policy when it was chaired by Senator Tom Harkin.

This afternoon, Bobby will share his insights and experience on translating research into disability policy. So, Bobby, will you say a few words to introduce and describe yourself? And thanks so much for being here today.

BOBBY SILVERSTEIN: Thanks. Good afternoon, all. My name is Bobby Silverstein. I use his/him pronouns. I'm a 72-year-old white male with definitely gray hair, and I wear glasses. And it's great to be with all of you today.

This is obviously, from my perspective, a very critical topic. Having spent over a decade on Capitol Hill, hearing and seeing and experiencing researchers on virtually every bill that we worked on, I know how absolutely important it is to learn some of the skills that are necessary to make sure that your research is translated to public policy. Next slide, please.

So today, I really want to talk about two main topics. The first one is how research informs the policymaking process. And secondly, some tips on how to present your research in a way that maximizes the likelihood that it will be used, considered by policymakers and their staff. Let's make sure we're all on the same page here. And so, let's start with a definition and understanding of what is public policy.

It really comes down to a simple notion of trying to come up with solutions for problems that are of general concern, general applicability to the public. And that can be in the form of establishing civil rights for people with disabilities and standards that define what we mean by civil rights. In

other words, how do we proscribe inappropriate behavior, like discrimination. And also, public policy involves the solutions that result in outcomes of appropriate behavior.

For example, affirmative action. That is management by objectives that ends up with the outcome of equal opportunity. Another purpose of public policy is to provide resources, whether it's federal or state, to address a particular issue, and resulting in possibly the provision of services or supports to people with disabilities to enhance a policy objective like independent living, economic self-sufficiency. And sometimes, public policy results in the provision of benefits, cash benefits and assistance to people that also enable them to live independent lives.

So, when we talk about disability policy, it really has two different aspects, disability-specific legislation, as well as generic legislation that addresses the interests of people with disabilities. So, in the first category, we have laws like the Americans with Disabilities Act, the Individuals with Disabilities Education Act, the Rehabilitation Act, the Developmental Disabilities Assistance and Bill of Rights Act. And in the second category, those in terms of generic policy, we're talking about legislation like the Affordable Care Act, Medicaid, particularly, for example, home and community-based services, and the Workforce Innovation and Opportunity Act, which funds American job centers to make sure, again, that people with disabilities are effectively treated and receive services from our American job centers.

So, what is the role of research in advancing disability policy? To me, it comes down to a simple notion-- we need research to explain why change is necessary, the nature and scope of the change, and also implementation strategies. So first, research is always used to document the nature and severity of the problem so that policymakers and their staff can understand the historical and policy context.

This is a critical issue. When we were doing the Workforce Innovation Act in Congress and then WIOA, the Workforce Innovation and Opportunity Act, there was a provision that said all people are entitled to the services provided by American job centers. So, the number of staffers said, all. Why do we need to specifically say anything about people with disabilities? All means all.

So, we gave them research documenting the failure of American job centers to provide services and supports to people with disabilities. Oftentimes, they would say it's not my job to serve people with disabilities. Go to voc rehab or someplace else. And it was that research which demonstrated that the failure to provide services and supports which set up, now we get it. And if you look at the legislation now, you will see it says all, comma, including people with

disabilities, and those with significant disabilities. So, it was the research that allowed us to make sure that people with disabilities were served.

The second purpose of research is to identify the policy options. Oftentimes, people, policymakers do not know how to address the needs of people with disabilities. And so, we need to be able to have the research of the best promising and emerging practices, which then can be included in the legislation.

We need to do research to justify policy options. Oftentimes, the best ideas go absolutely nowhere because we can't demonstrate the benefit of the service or support for policy vis-a-vis the cost. And these economic analyses sometimes are make-or-break policy initiatives.

The next category is developing and advancing implementation methodologies. Enacting legislation is fine, but implementation, implementation is what we really should be concerned with. And we have to use the research to develop the appropriate finance systems, the reimbursement rates, the evaluation criteria, because sometimes, these what we call methods of administration can actually impede, rather than facilitate, public policy initiatives. And the last one is to measure compliance. We need help in establishing success criteria that works for people with disabilities.

Now, one of the things that folks ask me to do is to share some of my experience on what role NIDILRR has played over the years, and other federal agencies, in advancing disability policy. And all of you know-- hopefully, those from other countries also know NIDILRR, the National Institute on Disability, Independent Living, and Rehabilitation Research. Well, because of NIDILRR's focus on investing in applied and action research, oftentimes, NIDILRR's research truly facilitates achievement of our national goals for disability policy of equal opportunity, full participation, independent living and economic self-sufficiency. So let me just share with you some of the examples.

You folks may or may not know that NIDILRR-supported research directly led to the development of the World Wide Web Consortium, W3C, international standards used for ensuring accessibility and usability of websites, online systems, mobile apps, and other forms of information and communication technology. These WCAG Web Content Accessibility Guidelines are used and included now in section 508 of the Rehabilitation Act, which ensures accessibility by federal agencies.

If you look at state laws that deal with ICT accessibility, you will see that many of them make specific reference to WCAG. And again, we can thank NIDILRR-supported research for this. Some of you may be familiar with the Technology-Related Assistance for Individuals with Disabilities Act. That was passed a number of years ago, and now is still in existence, providing resources for pretty much every state to advance the use of assistive technology for people with disabilities. A big deal. Well, this legislation, again, was based in large part on research performed by NIDILRR grantees.

Now, you folks know how critically important personal assistance services is to some people with very significant disabilities. They need assistance if they're going to work in toileting, in eating, in getting their clothes on and off. But when we passed the ADA, one of the provisions is you have to provide reasonable accommodations, but reasonable accommodations was never interpreted as requiring the provision of PAS.

But because of the work of NIDILRR grantees, we laid a foundation for when the administration, the Obama administration was updating the section 501 regulations dealing with affirmative action by federal agencies, that research was critical in the decision by the administration, the Equal Employment Opportunity Commission to include and require PAS as a form of affirmative action. And when we look at implementation of the ADA and state civil rights laws and 503 affirmative action by government contractors and 501 federal agencies, we see the incredible advances to opportunity for people with disabilities because of technology. And so many of the technological advances are the direct result of research conducted by NIDILRR.

Now, we're all hopefully returning to the workplace, but have spent more than a year dealing with the COVID-19 pandemic. And a group that I work with, the Disability and Rehabilitation Research Coalition, DRRC, has used research conducted and supported by NIDILRR to advocate for the inclusion of people with disabilities in the data collection efforts, because if you don't collect the data and you don't disaggregate the data, there's a good chance that people with disabilities will be left behind in terms of testing and delivery of different strategies for addressing the pandemic.

And because of the research used in the advocacy, CDC is including disability status in case reporting forms. And when I did these slides, there were interim recommendations by what's called the COVID-19 Health Equity Task Force that was established pursuant to a executive order by President Biden. Well, next slide, but yesterday, the task force announced its set of recommendations.

And that will be presented more officially in the next couple of days. But in the outline, there were at least 12 different references to disability, ranging from recognition of long COVID, again, because of research, what services that people with disabilities may need. And the disaggregation of data has been absolutely critical. So again, the research was used as the basis for the advocacy, which we now see in a critical task force report.

Now, we always talk about the ADA, and the advocacy efforts were absolutely critical in making the ADA a reality, the grassroots efforts by the disability community, working with those in the business community who were interested, with our friends in Congress. But the research efforts are not always recognized, but they were critical.

And I can tell you that for a fact because I was, as a staff director working on the ADA, was the one who relied on this research, whether it was from the National Council on Disability finding that the severity and pervasiveness of discrimination is well-documented, well, it was that documentation towards independence and on the threshold of independence that made the difference. Statements by the US Commission on Civil Rights that discrimination persists, President's Commission on HIV Epidemic that discrimination against individuals with AIDS/HIV infection is widespread and has serious repercussions for both the individual and the nation, it was the research that helped make sure that people with HIV/AIDS were included in the ADA.

Now, research is also essential for justifying key provisions. Reasonable accommodations. We had data from key economists and Job Accommodation Network showing that, in general, there were no costs for any accommodations. When there were costs, often it was less than \$500. And there were situations where it might be more costly, but we had the data. The standards for making facilities accessible, there was extensive data showing the potential cost, and refuting folks who were saying that the cost would be astronomical, particularly with respect to new construction.

Every piece of legislation in Congress considers must have a cost/benefit analysis. And again, it was the economists, the researchers that help us show that the benefits far outweigh the costs. And most recently, you may have read that, in the midst of COVID, a number of hospitals and states were developing or using critical standards of care that resulted in the exclusion of people with significant disabilities. But we used data and analysis to show that this was not only not necessary, but inappropriate, and that science should be the basis for who gets served, not perceptions about quality of life.

Now, the next discussion here of the early intervention for infants and toddlers with disabilities is one of my favorite topics for discussion. This, I worked on the early intervention program when I was working in the House of Representatives on the Subcommittee on Select Education. And a lot of policymakers were not interested in developing a new program, or even on of a topic like infants and toddlers with disabilities. No, we don't want to do that.

But there was a critical report to Congress, and it was presented by Madeline Will as part of a Republican administration. And let me read part of what the report said. Quote, "Studies, research of the effectiveness of preschool education for children with disabilities demonstrated beyond doubt the economic and educational benefit of programs for young children with disabilities. In addition, the studies have been shown that early intervention is started, the greater is the ultimate dollar savings and the higher the rate of educational attainment."

The committee report accompanying the House bill cited two research to indicate the early intervention can accomplish and help enhance intelligence in some children, substantial gains in development, reduces family stress, saves substantial costs to society and school. Again, research laid the foundation for this. And again, the report said the legislation is based on research in child development and early childhood education.

Now, here's the part that was most interesting to me. The legislation includes what's called a minimum standards for what needs to be in an early intervention program if a state wanted to receive aid. And it's described as comprehensive, coordinated, multi-discipline, interagency programs for not only infants, but also their families. And there are nine components that must be included in the state plan.

Well, I was invited to a NIDILRR research convening, and folks were there to talk about early intervention program and the new legislation. And a number of folks said, isn't it amazing the coincidence between the best practices that we identified through research and what's in the legislation? And I just had the biggest grin on my face, because yes, we stole from the research, and it wasn't a coincidence. It was the research that allowed us to reach a consensus and have minimum standards.

So, let's jump now. Here are a slew of examples of the critical role that NIDILRR has played in advancing disability policy, and the critical role that research has played. Now, the last part of my presentation, I want to share with you some tips, some of the things that I learned by watching folks testify, by talking to folks, by just basically being able to pull together the lessons learned. And I'd like to share some of them with you now.

The first thing is-- and we learned this from Madison Avenue-- you've got to have a title. You have to figure out how you're going to frame your testimony if you're giving written testimony. People don't say I'm going to talk about disaggregation of data in the midst of the COVID-19 pandemic. That is what you may want to be talking about, but it does not grab the attention of the policymakers. You've got to figure out something that is reflective, that is going to make them think and feel. I want to hear what this person has to say. People with disabilities count. We know what gets measured and what gets reported gets done. Something with intensity that may grab their attention.

You want to introduce yourself after the present of the title. And think about how you do it because what you're doing is trying to convince folks. And you have to have credibility to be convincing. Your gravitas. So, you've got to figure out who your audience is, and frame your background in a way that piques their interest.

Next is framing the issue in personal terms, even and especially for research. You need to get to their heart and soul before you get to their head. They have to understand why they should listen to you, why what you're saying is going to make a difference. And particularly for researchers because what you find can be very, very dry, but important. But if they understand the context on how it affects people-- in this case, people with disabilities-- you're again going to grab them in.

And then you define the problem. You deal with some of the themes and principles and approaches, and then you explain your research. So often, those who started with their research, you know what the result was? The members of Congress, at least in my experience, would get so bored that their head would go down and they'd start doing something else, probably signing letters to constituents. But if you can grab their attention and explain how it affects people, what the issues are, and then share your research, you have a better chance of making the difference.

So, you're now describing your findings, conclusions, and recommendations, but do it in a language that they can understand. If you use acronyms or jargon, you're going to lose your audience. And here's the other part that may be a little difficult, but it's critical. If you're testifying about a bill, you need to know the critical parts of the bill. You need to talk to other advocates. You're part of a team. You're part of a coalition. Don't just do this. You've got to learn the right words, the right phrases, the key purpose that your research can perform for moving the policymaking process forward.

And then last is, if there is research that may come up with a different conclusion or a different nuance, you may want to share that, because again, that gives credibility. And then explain how

your research may be different, and why. Maybe it has a little different orientation. But take into consideration the existence of other research, as well, even if it reaches a different conclusion and may result in policies that you may not support or agree with.

Now, here are some different tips for oral testimony. And it may be official. It may be at a hearing. It could be at an open meeting by the member of Congress. Or it could be just one on one in their office. Or same at the state level or the local level.

The first is to follow the guidelines for written testimony. They all still apply. Introduce the topic in a sexy way that gets their attention. Tell personal stories that are tied to the policy that you're trying to achieve. Then, provide the specifics from your research.

The next key thing is stay in role. Some of you are advocates as well as researchers, but if you're in the research role, stay in that role. You don't have to do the advocacy. You'll have others testifying there. You're there with the gravitas. You're there to lay the foundation to justify the legislation, to explain why a policy is necessary. Let others do the advocacy. Stay in role.

The next is, again, keep the message simple. Only make a few points. So, you're highlighting the key findings, conclusions, and recommendations. And here's the next thing. If you read your testimony, you can guarantee that 80% to 90% of it will never be heard.

You have to have eye contact. You have to engage the policymakers. Otherwise, they will lose interest. And try to use examples, anecdotes from real life, from your research to make your research come alive.

So let me try to summarize some of the key points that I've included in the presentation. In this day and age, with politics being as ugly sometimes as it is, we can lose sight of the importance of research. You think things are just done because a Democrat or a Republican proposes it, or one person says it's good, or one group, and nobody cares about the research, the basis for it. Research is necessary. It may not be sufficient to get legislation enacted, but it is necessary to document the problem, identify options, justify the options, develop methods of administration for ensuring or maximize implementation of the programs, and for measuring compliance.

And the second part of the presentation is to recognize that how you present your research is often the difference of whether or not it is used. You need to have a title and a topic that grabs their attention. Get to their heart and soul before you get to their head. Explain how the research

is going to impact the policy, whether it's to justify it or explain that the benefits outweigh the costs.

You can make a difference, even in this political world. Thank you for the time. And we'll open it up now to some of the respondents.

JOANN STARKS: Thank you so much, Bobby. That was excellent as usual excuse me. And we're running a couple of minutes ahead of time, which is great. That means we'll have more time to answer. We've had a few questions that have come in for you. So, I'm going to go ahead and hand this off again to Kathleen, ask our reactors to get back on camera and I see they are. So, without further delay, Kathleen, please take it away.

KATHLEEN MURPHY: Sure. So, I have harvested the questions in the chat and I think we will have time to get to them. So, thank you for posting those. We are going to turn first to our lined-up reactors to see what else they might have to say and I'm sure they've been reading those comments in the chat as well. So, this time around, we're going to start with Piper and then move to Marcia and Dahlia Shaewitz. As a reminder, Piper is joining us from the University of Illinois, Chicago. Piper?

PIPER HANSEN: Kathleen and thank you for your presentation. I find it reassuring that the role of research really does play a big role of shaping what policy looks like. I think as you've mentioned and alluded to it can get a little bit lost and everything else that happens at a governmental level. So, thank you for sharing that perspective.

I think one of the things that I wanted to talk to you a little bit more about was the impact of either current priorities within administrations or what's happening in the world. For example, there are so many policy changes that happened as a result of COVID. So, I'm curious to hear your perspective on how you think that knowledge of lawmakers and policymakers has maybe changed because of the impact that COVID has had on the disability community and obviously globally as well and even more broadly, what the impacts of different priorities or experiences of individual policymakers might have and the impact that we potentially could have by presenting research.

BOBBY SILVERSTEIN: Did you want me to respond now or wait for the others?

KATHLEEN MURPHY: Please, Bobby.

BOBBY SILVERSTEIN: What's that?

KATHLEEN MURPHY: Yes, please.

BOBBY SILVERSTEIN: To me, COVID has certainly presented not only incredible burdens but some opportunities. We know, for example, that a lot of folks' companies are using hybrid models now or returning to the workplace. Well, for years and years, people, some people with disabilities, not all, please, wanted to telework and they tried to say this is a reasonable accommodation and it's necessary and there were all kinds of excuses and explanations for why it was not possible.

Well, with everybody teleworking, there is a new understanding of what is possible. Researchers need to document this what can be done? What are some of the best and promising practices? That's a role for research to do. Policy makers are also again in large part because of the priorities of the Biden administration with its executive orders, which are stressing diversity, equity, inclusion, and accessibility, we are finding that people with disabilities are no longer an afterthought in public policy and our principle of universal design.

And not only I'm talking buildings, I'm talking about the development of programs and initiatives are beginning to take disability into consideration at the initial design stages. And that is true in terms of COVID guidance, where CDC research, OSHA based research and EEOC, Equal Employment Opportunity Commission statements of policy in terms of ADA requirements for access and equal opportunity are all coming together.

And so instead of having words like balancing the rights of people with disabilities and the need to keep workplaces safe and healthy, we're pulling them together. And the research and statements of health care from the HCR including as part of their presentations the notion of equal opportunity for people with disabilities. So, I see a new understanding by policy makers of the need to disaggregate data so we know the impact of policy on the full community of folks.

KATHLEEN MURPHY: OK, thank you Bobby. I mean there's definitely a lot of attention to disaggregation, right? How else are we going to address intersectionality? We're going to turn next to Marsha.

MARSHA ELLISON: Sure, thank you. And Bobby, I want to thank you for making researchers like me feel like we actually are doing something valuable. So, I really appreciate that. And just to sort of reiterate some of the things that hit home to me in your discussion, things like having a catchy title that gets people's attention and speaking to people's hearts before you speak to their

heads and personalizing with anecdotes. Those are things that I've learned also along the way about speaking to policymakers.

But what I wanted to ask you was for me, it seems like there is research that's on one side and there's the policymakers on the other side and there's like this middle place where people like you and advocacy organizations and I don't know what, but I think that there are many other parties and avenues that bring that research to policy in addition to that are important, besides researchers actually giving personal testimony.

So, I wanted to ask you about that and it coincides with the question that Jennifer Solecki posed in the chat. What advice do you have for identifying the right people or communities to bring one's research findings to?

BOBBY SILVERSTEIN: Two related but distinct issues. To me, the first thing is researchers-- well, let me put it this way. Effective advocacy efforts require a coalition of folks that follow strategic plans. That coalition needs the input and participation by researchers. Research is a key component of a coalition effort to foster and further public policy.

The second question that was in the chat is who do you bring your research to? And that requires research to know who the champions are. But it's more than the policy. We love to talk to the policymakers. But it's often staff, staff, staff, staff. I'll never forget working on one piece of legislation, the technology assistance program for people with disabilities. We had passed it originally and some of you on the phone may know Rud Turnbull, know that name. He was a Kennedy fellow of that year. He's the guy who took the NIDILRR research and put it together into a piece of legislation.

But after a number of years, a number of folks in Congress wanted to wipe it out. They said it's over. Six years, it's done all its work. And the community said, no. We've got plenty more we need to do. And they found one staffer from Missouri and the-- Senator Bond I believe was the chair at that point, a conservative Republican. But that staffer because of advocates back at home in the state loved this program and she, because of folks back home-- and I can't say it was researchers as well-- but one person, one staffer made the difference. It was then the researchers who came to show how to document the difference to this person who can then use it with her Republican colleagues to save this legislation which still exists today.

MARSHA ELLISON: Great story, Bobby. Thank you.

KATHLEEN MURPHY: Yeah, thank you, Bobby. And thanks for engaging with people in the chat and pulling in their questions as well. And we're going to turn to Dahlia now.

DAHLIA SHAEWITZ: Sure. Hi, Bobby. It really resonated with me how you outlined a framework to advocate through written or oral testimony. So many people, general public think that their voice doesn't matter or they don't have a voice in policy-making. But in fact, people with disabilities are bringing expertise and that expertise is their lived experience. And I had a bunch of questions written for you but I actually want to ask you this.

I recall the story that the former Senate leader back at the final couple of years of Obama this is when ABLE Act was coming out, that he had a staff person who had a child with a disability who helped him understand the value of the ABLE Act. It is literally that personal. How can we get more people with disabilities into those staffers, right to get them-- and not just on Capitol Hill but state and local policy. How do we get people with disabilities into those circles to influence policy?

BOBBY SILVERSTEIN: Well, part of it is-- two ways the pipeline of universities, graduate programs to make sure more people with disabilities are learning about the policy making process, working in advocacy organizations because frequently folks from advocacy organizations then move to staff at executive and legislative branches. But we also need to get more people with disabilities running for office. Because that's just one example that you just had of somebody with a personal experience.

I can tell you the ADA wouldn't have happened if Orrin Hatch, who was the ranking member on the committee of jurisdiction, did not have personal experiences, I think it was with the nephew. Bob Dole's personal experiences and Senator McCain's experiences working with folks in the deaf community and Senator Domenici's I believe his father was visually impaired or blind. And I can go on and on. And Senator Harkin understood disability discrimination because his brother was deaf. He lived it.

And when folks in the office were expressing concern to him about, don't go too far with this ADA stuff before when it was being considered, I'll never forget. With his finger just turning red and said, don't you ever, ever bring up politics with respect to the ADA. My brother was deaf. I understand discrimination firsthand. We will do whatever is necessary to make this law happen. It was that personal experience that so energized Senator Harkin and others to make sure that policy occurred.

So, I would like also more people with disabilities to be running for office. And when you're at the table, that's when you can make a difference. And that's the thing that is just so critical. But you can't make a difference without the research with justifying what it is you're doing.

DAHLIA SHAEWITZ: Great. Thank you, Bobby.

KATHLEEN MURPHY: So, there are some helpful comments in the chat just about that promoting the pipeline of people with disabilities running for office. And Anjali Forber-Pratt, who those of you who missed on Monday or may not be aware, she's the new incoming director of the National Institute on Disability, Independent Living, and Rehabilitation Research. Thanks for saying hi there, Anjali, and feel free to join us in this discussion if you have anything that you'd like to add. We do have a little more time and we're delighted that you're back with us.

So, Anjali did notice that the National Council on Independent Living has is tracking candidates with disabilities who are running for office and also offers a training to promote that. There was another question in the chat, or an observation about how often do researchers actually end up not necessarily running for office but being involved in policy making worlds. And I know it does happen. Like I can think of certain individuals. Like Michael Gamel McCormick-- I know not everybody knows him, but some of you do-- has I think gone back and forth between policy and the research world. Also, isn't there a fellowship or something, Bobby, for researchers that he had and others could have?

BOBBY SILVERSTEIN: It's not just for researchers but a lot of them are. The person now I believe who is that the Domestic Policy Council for President Biden, Kim, was a former Kennedy fellow and also an academic. The Kennedy fellowship is what I think you're referring to.

KATHLEEN MURPHY: I am, mm-hmm.

BOBBY SILVERSTEIN: And every year, the Kennedy foundation folks-- I'm on the panel off-- interview folks and a lot of them are folks from academia. As I said, both Ann and Rud Turnbull were Kennedy Fellows. Rud worked with me and Ann worked with other policy makers when she was here.

KATHLEEN MURPHY: Yeah, thanks. It's Kimberly next, Ed, so I'll put her name in the chat. Because my involvement in NRTC, which is the Professional Association of NIDILRR Grantees, I was able to talk to some of her colleagues at one point. And we also do have-- everybody who

registered, we gave them the opportunity to ask some questions. And there was one that I thought was really good that we haven't really exactly covered.

We've talked a lot about content of a message and who should deliver the message and how to deliver that message. But especially right now with so many people, including Congress, working sometimes from home, what are good channels to use to embed this content into?

BOBBY SILVERSTEIN: Well again, working with coalitions. There are folks who will know who the right people are and how to get their emails.

KATHLEEN MURPHY: Mm-hmm. So, email.

BOBBY SILVERSTEIN: Some emails are oftentimes that is worth gold if you can do that. And if I can kind of go off of that question with another nuance--

KATHLEEN MURPHY: Absolutely.

BOBBY SILVERSTEIN: There's different kinds of advocacy. Some organizations have a position. They go forward with that position and that's it. But if you ask me who are the best advocates? They are people that provide critical, legitimate, accurate information to the staff. And sometimes that research presented as research, not as advocacy information but as research, will be the difference between including a provision or a bill being enacted.

Again, stay and roll. You can be an advocate because if you're doing research in this field, I'm sorry. You care about people with disabilities. You may be objective and hopefully you are and use scientific rigor but you're trying to advance an agenda but stay in your lane.

KATHLEEN MURPHY: Which is interesting because sometimes people are in the researcher role in this field because they also drive in a different lane and have that personal ties so it's an interesting point that you're making.

BOBBY SILVERSTEIN: You can also, if you're a parent or a person with a disability, you may be in a different lane. You may be in terms of advocacy. But don't then do the research. If you've got research that is going to be critical to secure enactment of a bill, a provision stay in that lane. People just so often don't understand that. It's just again, when I'm the recipient as a staffer of that information, I don't want that researcher's credibility undermined by using polemics or rhetoric. I want them to use not jargon but I want them to be true to their research domain, their background.

KATHLEEN MURPHY: Sure. A real data driven message.

BOBBY SILVERSTEIN: But you can still do it in a personal way. But again, if we're looking for evidence based, data driven solutions, hello. The research community has got the answers.

KATHLEEN MURPHY: Mm-hmm. Because Nat Dean was pointing out-- Ken, I think you mentioned this as well. It can be really helpful to do some research on the background of the member of Congress or even the staff and figure out why they might care. So, I could imagine you could preface and say, well I'm aware you have a nephew with this issue. I'm a parent and this is why I care about my research. Let's talk about the research.

BOBBY SILVERSTEIN: But then you've got to be careful because then you're in the role of advocate, parent, and researcher. And again, if you're presenting the research, for me personally-- let me tell you a quick story. I see I've got one minute. But let's see if I could talk a little bit--

KATHLEEN MURPHY: You're fine. You're fine. You're five minutes, actually. We're going and I don't have that much to say to wrap up the conference, so don't worry about it.

BOBBY SILVERSTEIN: When we were doing the reauthorization of the Individuals with Disabilities Education Act a number of years ago, it was a very, very controversial reauthorization. There were efforts to totally gut IDEA, particularly with respect to disruptive and dangerous children and they wanted to expel and exclude folks and we were able to resist that. But one of the things that we had to do this was a board of education person from Pittsburgh, Pennsylvania and she stayed in her lane as a member of the Board of Education.

And she said, these other folks from Board of Education who are saying all these things, they're wrong. We figured out how to do this in Pittsburgh without excluding and suspending and expelling kids with disabilities. And we did it by having functional assessment, behavioral intervention plans. We trained our staff and our suspension rate went from x down to almost nil. And her gravitas made a tremendous impact on members of the Senate.

She happened to also be a parent. But she was not playing that parent role. She was staying in the lane of Board of Education. Because the National School Boards Association wanted to make dramatic negative changes to the law. So, she was saying, I'm one of you and we can do it if you use best practices.

KATHLEEN MURPHY: So, Jessica Lukefahr, I mean, that was a great example. So, she asked, if you're a researcher and advocate how do you make a decision between the two? So, you

obviously think that person made the right choice. But is there a time when you should be the parent at a time when you're not?

BOBBY SILVERSTEIN: Sure. But that's where you can't-- advocacy systems change does not occur in isolation with one person trying to do something or research. It usually succeeds when there's an organized coalition with a strategic plan and through that coalition, you will be figuring out what's your role.

KATHLEEN MURPHY: So, I know Dahlia, you've been pretty active in the chat here. Is there anything that you wanted to share with the whole group while you're on?

DAHLIA SHAEWITZ: I can't stop chatting. No, but Bobby, as you were talking, it reminded me of when I worked-- and I know Cindy Kai is on the line and Pimjai is here so it correct me if I get my facts wrong. But a number of years ago, we had information about traumatic brain injury research. And so, we went to the hill person. I forget if it was a Senator or Congress congressperson. I think it was congressional caucus on TBI. And we went and presented him with information from the model systems, we met with his chief of staff and the chief of staff, when we were done speaking, said, and what do you want?

We didn't want anything. We just wanted to share information and tell them there was this thing, this group of researchers who know all about traumatic brain injury. And that sort of disarmed the staff person and she invited us to talk more. And they ended up inviting her to a model systems traumatic brain injury researcher meeting to have further conversations and what that resulted in, I don't know but it was really interesting because it wasn't about pushing an agenda. It was educating, informing and they were able to receive it because there wasn't a hidden agenda. It was all very open. So, I just want to share that story because I thought it was a positive experience.

BOBBY SILVERSTEIN: That's perfect because what that shows is, again, you you've reached the promised land of advocacy when the staffer or the member calls you. The purpose of this meeting was to just say, hello. We're experts. We're here if you need us. We don't have any particular action item on our agenda. We're here as an expert. And because of that, 50 times a day, they're asked to do something by somebody. And here you're there and you show your gravitas. You show your credibility. You show your knowledge.

When the brain injury legislation is up for reauthorization, who are they going to go to talk to? When there are issues about essential benefits and how cognitive therapy may be an important

rehabilitation, who are they going to go to? They're going to go to this group who had established this credibility as somebody to get expert advice from.

KATHLEEN MURPHY: So, we do have a surprise guest this afternoon in this discussion. Doctor Anjali Forber-Pratt is NIDILRR director and has joined us and I think has some pearls of wisdom to share.

ANJALI FORBER-PRATT: Yeah, so I just wanted to say thank you so much and Jessica, I really love the question that you're asking. And I think there's also a way to really bring together both your identity as a researcher and as an advocate. Some of these terms and research, we're seeing participatory action research, community-based research and at NIDILRR, it's something that we're very proud of where we require that funded projects have involvement of either people with disabilities or organizations representing people with disabilities as part of whatever work is being proposed.

And in that way, we're trying to do multiple things. Unfortunately, there is not yet enough investigators with disabilities who are engaged in doing this type of research. And so that's one way that we're really trying to intentionally bridge that gap. And then secondly, I also put in the chat space some of our ADA centers on disability. There's actually an upcoming participatory action research consortium coming up and I put the link there in the chat, which could be a way to learn a little bit more about really how to bring together each of those identities. But I do want to echo something that Bobby said which is also important.

It's knowing what hat it is you're wearing and in what setting. Because if someone's expecting you to be wearing that research hat and you come on too much with the personal story, it has the potential to be misleading and vice versa. If they really want to hear the personal activism story but you're coming in with all of the statistics and all of the latest findings-- part of it is about making sure that those expectations are clear up front.

And those of you who have heard me speak, oftentimes I say, hey, I'm both. I'm the researcher and the activist. And so, I try to set that expectation up ahead of time of saying, hey, I am a person with a disability but I'm also the disability researcher and wearing this hat as the director of NIDILRR. So, I think setting those expectations for whatever engagements are that you're having is really important.

BOBBY SILVERSTEIN: Totally, totally agree.

KATHLEEN MURPHY: Yeah, that's interesting too because the parent doesn't have to say, I'm a parent. But obviously, Anjali, when you're in the room, people know that you might care about the issue in a particular way. Yeah.

BOBBY SILVERSTEIN: But here's a reality. If Anjali is going in front of a group that doesn't know her, what's the potential for stereotyping her as just another advocate in doctor clothing? So, she may need to show even more gravitas in terms of data and science speak that's still clear to be able to say, whoops. This person's got something on the merits not just in the heart, but in the merits to support what we're doing here. So, part of the issue is recognizing the audience and if you can get a sense that they may be stereotyping you, you've got to figure out a way of breaking that stereotype as well.

KATHLEEN MURPHY: That's really fascinating, so trying to manage implicit bias.

BOBBY SILVERSTEIN: Yup.

KATHLEEN MURPHY: So, we are getting close to the top of the hour. We are going to keep the room open for 10 minutes past so that people who want to do the evaluation will have time to do that.