UNSW Disability Innovation Institute

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*Doing Research Inclusively: Co-Production in Action* Launch 2022

Transcript

## Karen Fisher

I'm Karen Fisher. Welcome to everyone here today. It's really exciting to be able to launch the University of New South Wales Disability Innovation Institutes Institute's new production, Doing Research Inclusively: Co-Production in Action. I'm a professor at the Social Policy Research Center and I'm chairing today. I'd like to start by Acknowledging Country. I'm at Carraginn, Kings Cross in Sydney, and I understand that many of you are from all around the country on many lands of the First Nations peoples. I'm on Gadigal land. One of the exciting things about doing co-production for me has been learning from First Nations peoples across my years of research. And today I'm sure that we'll learn from you too, and any First Nations people who are here today. So before we start, I'd just like to say a little bit about the Institute.

The UNSW Disability Innovation Institute is a world first initiative. We focus on disability research, education and knowledge exchange. And its team is very proud to undertake work that is radically inclusive and crosses disciplinary boundaries across the whole of the university. Their approach is to see disability not as a problem to be solved, but as an integral part of the human condition that's encountered and engaged with rather than feared. And in this light, I'm delighted to be here to open this event. At the heart of the Institute's work is the idea of inclusion. And so the Institute today will be launching new guidelines on how to actually do that.

So now I'm going to introduce the two speakers today. The first is Professor Iva Strnadová. She's the Academic Lead Research for the Institute and a Professor in Special Education and Disability Studies at the UNSW School of Education. Her research aims to contribute to better understanding of and improvement in the life experience of people with disabilities. She has a particular research interest in the wellbeing of people with developmental disabilities, that's intellectual disability and autism, and their families over the life span, diverse transitions in the lives of people with disabilities, and girls and women with intellectual disabilities, and parents with intellectual disabilities and inclusive research.

The second speaker is Professor Leanne Dowse, who's an Emeritus Professor with the Institute. Her research and publications applying models of critical inquiry to the study of disability, in particular intellectual and cognitive disability. Her work utilizes multidisciplinary approach to investigate social justice issues for people with complex needs. In particular her work addresses the intersections of disability with mental illness, acquired brain injury, homelessness, social isolation, early life disadvantage, experience of out-of-home care, substance use and violence.

Our third speaker today, unfortunately, is sick but I'm still going to introduce her because she's such an important part of this work. And that's Julie Loblinzk, who's a researcher and advocate with intellectual disability. She's been involved in disability advocacy for the last 27 years and currently works with Self Advocacy Sydney as the organization's self advocacy coordinator. She was recently awarded the 2022 J. Moss Award for Self Advocacy Sydney in recognition of her outstanding work in the field of intellectual disability.

So I'll hand over now to Iva and Leanne.

## Iva Strnadová

Hello, everybody. It's such a pleasure to be here at this occasion to introduce the new set of guidelines that will hopefully help many, many colleagues in academia and belong to undertake inclusive research co-production. Before we start about what really let us the development of these guidelines. I would like to also give a big shout, shout out, I think is the correct English term, to Ben Garcia-Lee, who is the coauthor, of this guide, of these guidelines and is here with us, which is absolutely great. Hi, Ben. And you will meet Ben later in the year where Ben, he will be talking about how he uses the co-production guidelines in, in, in the real life in his in his research. So that will be very exciting. So watch out for that.

So how did how did we come to these guidelines? As Karen rightly said at the heart of the Institute is to conduct inclusive research, to really co-produce research in a way that people with disability are engaged in every single step of anything we do. And we know that co-production is absolutely critical because it promotes inclusion of people with disability. It helps us to explore issues that very often would not be even thought about if we didn't collaborate. It recognizes the contribution of all people present in the, or being part of this journey. And provides information that can really make a difference. And it reminds me of today's meeting, we've had today even on Impact that was held in my faculty where we were talking about how so many researchers at the university have really focused on solving world problems.

And we can see how much how much value can be added if we do research and co-production with people with disability and their organizations. As as many of you know, we have developed the first guidelines three years ago, and we had such a positive feedback from people. However, we kept on being contacted by our academic colleagues who really genuinely wanted to do a do a co-production in their research, but we're not sure how to do it. And they kept them calling for really practical, almost a step by step guide in how how to approach co-production and how to do it really well with integrity. And that's that's why these guidelines happen. So these guidelines are actually intended for academics, people working in academia and guiding them on how to be inclusive in every step of the way, and I will pass now on to my beautiful colleague, Leanne, who will walk you through the structure and our thinking behind it.

## Leanne Dowse

Thanks very much, Iva. And hi, everybody. It's absolutely great to see so many people with us today. I'd also like to add my thanks to Ben Garcia-Lee, the research assistant extraordinaire who's really contributed very significantly to the content of the guidelines and very much drawing also on his own research experience in the field of his Ph.D. work. So what I want to quickly just run you through is how we've structured the guidelines and in really thinking through and trying to conceptualize what we thought should be in these guidelines, really in response to what Iva identified as people saying, okay, they're all great.

The principles that we identified in the first materials are great, but what how do we actually do it? And so the way we've approach the guidelines is to structure them around the stages of the research process. And so, many of you who are familiar with research, the research process will note, well, we'll see that these are certainly things that you're aware of, but we've particularly given some emphasis to the beginning point and the end point here, which and I just want to try to explain what each of these areas are.

So the first area that we've identified is really important in co-production is this point of initiating research. And so this is really where the research ideas sort of comes to life. And here we're talking about things like how do we arrive at a joint understanding of a research topic? We run through some of the questions and issues that get posed at this time.

But really our main message here is ways of thinking of ways that research can be agreed to be of benefit to people with disability. We're here responding to a long tradition of disability research not being particularly beneficial for people or not really speaking to people's lived experience. So we've set out in the guidelines ways of thinking about how to how to even think before you begin how to embed co-production from the very word go when you first start to talk about a particular topic and how in a sense to take some steps to ensure that the topic itself emerges from the lived experience of people with disability and and the sort of joint interest of researchers and people with disability themselves. So the next stage is the planning stage of research. And most of you will understand that that's around research design in the technical sense and here we have identified two sort of key sets of decisions which we think are important. So the first decision is the the thing that all researchers do work out what the research is going to look like, what sort of questions are going to be asked, generally speaking, what the design will be, who will you talk to?

All those sorts of things but importantly for this document, we also talk about how decisions about co-production will happen. So it's making sure that there's a thread of paying attention to co-production from the very word go and in the planning phase. So not only does research need planning, but we're acknowledging that what's also crucially important is that a research team always needs to actually set aside time to plan for co-production.

And so you'll find some information and guidance in how to do that with the research team as you go. So the third area is actually the doing of research and this generally speaking in the in the research area would be known as all of the things that have to be done applying for ethics, for instance, recruiting participants, creating your fieldwork instruments, and then going out into the field and collecting your data.

But also we importantly identified in this area specifically the sorts of co-production activities that really need to be paid pay attention to. So it's really working with co-researchers to identify who are the right people to talk to, how to engage them, how to appropriately recruit or invite people to be part of the research, how to ask the right sorts of questions, what sorts of questions should they be and how to ask them, and also how to work together to collect data.

So we've got some really useful tips and tricks in terms of thinking through how that might happen, particularly things around safety for all of the members of the research team and also the benefits of doing that. The next section that we talk about is about making sense or sense making, and this is, for researchers, the area of analysis, interpretation of data.

So again, here it's about how do we do data analysis, where do we do something descriptive or analytical, or whether we're doing something statistical and how do we develop our insights from that? How do we work out what the data is telling us and what does that mean for answering our research questions? And we see this particularly as a very, very important collaborative process in co-production.

And so we provide some guidance and questions around how that can be done in a team with some academic and community researchers. The next section, the next step in the process of research is about sharing our research. And so again, this is in research, it's called dissemination. But here we talk about when the findings go public and what we need to plan for and think about.

So what we see here is that co-production can broaden the kinds of places that and the kinds of ways that research is shared. So that might be developing different sorts of outputs to identifying the diverse audiences that we might want to communicate, the outcomes or the findings of the research and talking about the best ways and the best formats to use to be able to communicate those findings.

And here we're really thinking broadly podcasts, theatre pieces, traditional reports, plain English, a whole range of suggestions. And then the final area, the final step of research, which we're particularly proud of having really thought through, is and we feel is really particularly important. It often gets left off. The process is what we call reflecting. And in reflecting, we're talking about what's been learned in the co-production process particularly. So not so much reflecting on the research process, although that's quite important. We're really highlighting here that as we tried together to build a strong body of co-production research and information and knowledge about the process of co-production we we want to talk about what worked well in the co-production process and also identify where we could have done better or what we could have done differently.

And we really emphasize this needs to be a pretty open and honest conversation about how we think the co-production process has gone. So I'll just finish my little bit by just showing you a little bit or explaining in some way for each of those sections of those steps of the research process we provided a standardized format, if you like.

First of all, we provided some key questions that can be asked. You and your research team can use those questions to work through the issues that need to be addressed in that phase. And it gives you a kind of rationale for thinking why you might do co-production in this way at this point in each of the phases then we also answer the question, what can co-production look like? So we've provided some examples and what the benefits of co-production of those things at those key points will be. Finally, we talk about what co-production can produce so we're really output focused in this area. What sorts of things will be you can expect to achieve if co-production runs well in this phase of the research? And then we've provided what we think is a co-production outcome for each of the different phases of the research. As you as you have a look at yourselves through the document, you'll see that we've tried to maintain the same approach. So we've got a lot of guidance for you in terms of the sorts of questions to ask, the sorts of things that that co-production can bring and the sorts of things you should expect to see, if you will, if co-production is working for your team. Iva.

## Iva Strnadová

Thank you so much, Leanne. I will finish off describing the guidelines by also talking about some of the tools that that we have developed and again, a big shout out here to Ben, which we found that usually a research team might struggle in this area. So creating the co-production agreement from the really very beginning or creating accessible dissemination plan that that is solid. So as we go through every stage of the research, but also the training for the whole team on how how to really work effectively together. So there are some really useful tools that you will you will explore at your own pace. I will pass on to Karen.

## Karen Fisher

Great. Thank you very much, Leanne and Iva. And Iva's going to come back and talk a bit more later, about how she and Julie have have used this sort of process, what I think is so helpful for all of us in seeing the this publication is that it just puts down in very simple steps how how to do this or questions that you might ask of yourself.

And when I think back about my own practice where I use disability inclusive processes in virtually all my research now. But one of the things I notice when reading this guide is it makes it sound like it starts at the start and finishes at the end. And of course, it's never like that. But what's so good about this guide is it helps you think, well, if you if you lived in that perfect world, that none of us lived in, these are all the things you would do.

However, most of us don't live in that world. We we start somewhere else. And I think of my own practice. I probably started at the end, and I think that's a good thing to remember for any of you where this is new, you don't need to start at the beginning. You can start wherever you like. So if I take my example, we started by inviting disabled persons organizations to come to the university to either host or facilitate a session or a workshop that reflected on the research that we had done to show us how to do it better or to show us how to do it differently next time. And so that was a very simple way for us to start to build those relationships with people. So we chose not intentionally because I didn't have this guide 20 years ago, but we started at the other end and have gradually worked our way back to the beginning I think the advantage of the guide is you'll be able to start at the beginning and work your way forward, or some of you might choose to start in the middle.

I'll hand back to Iva to give us an example of how you might use it.

## Iva Strnadová

Thank you so much, Karen. It was really useful reminder about, about, yeah, you don't have to start in the beginning and, and you can just pick it up at whatever stage you are at. So I'll start. I will start this presentation by just saying that this presentation was prepared by Julie Loblinzk, Skie Sarfaraz, and myself and unfortunately neither Julie or Skie could have been here. So I will need to present by myself, but I'll give a little bit of a context to this work. So I think it's fair to first start, oh, I went too far. So to start with the work that Julie Loblinzk, who was introduced by Karen, a lifelong self-advocate and advocate for others and, and myself have been doing.

So we have been doing inclusive research for almost a decade now and we have been working on numerous projects. We as we went as we have been learning together. That would go back to your point just then Karen. We have really initially learned how to, how to engage in co-production throughout the whole research process of our first research projects were definitely not as thought through, I would say and based on our experiences as the ones we are working now. And I'm sure we will keep on learning and discovering new things because we are really very much focused on on co-production in every step we do. We have also developed Disability and Me blog in which we share our opinions or outcomes of our research in Easy Read English. So it is really accessible to everybody and not not just for academics. And Julie also comes to my classes and lectures to undergraduate and postgraduate students who absolutely love her. So the context of what I will be talking about and why Julie and I were the key speakers for this part is, is a lot of work that we have been doing doing together over the years.

As you might have noticed, our Guidelines, Co-Production in Action, are not only written in standard English, including the attachments, but also in Easy Read. They are also translated to Easy Read English and including the materials that can be useful to the teams. And so thanks to the fantastic work of New South Wales Council for Intellectual Disability and again big shout out to to their team.

We have now six booklets, six separate individual booklets which was also part of their feedback, not to keep it as a one document but keep it separately. So people as Karen indicated very well can pick it up where they are and where they need to. And of course all the resources what I need to admit from the beginning and I would like to remind everybody who's listening that these, the Co-Production in Action, the guidelines are meant from the very beginning for academics, for colleagues in academia, research, university researchers who who want to genuinely want to engage in co-production and don't know how.

So initially we still felt that it's very important to translate everything we do into Easy Read English. But as as in this process of translating, we have actually found out that this is a, these Easy Read booklets are a fantastic tool for for mentoring new colleagues who might have disability or disability organizations in inclusive research. And so some of the, while they were not yet published but we had the advantage of having the draft versions of the Easy Read, Julie and I started to use these guidelines when working with our new colleague, Skie, who is also a self advocate from Self Advocacy Sydney, fantastic young lady who is very engaged in research.

And so as we are working together on a research project, we found these booklets really useful to answer any questions that Skie has had over the course of the project. And again, coming back to Karen's point, we couldn't start with the first one because we already had the project when she joined us. So yes, we picked it in the middle and started from there. So that's, that's another example. And the points that are covered here are from our discussions when we were doing these slides when we were discussing and particularly Skie and Julie what they really like about these guidelines. So they did like the that it is really step by step guide that can be nicely used that it brings great clarity about roles of all partners in the co-production and that that shows that all team members have equal opportunity in co-production.

And I think that's something we sometimes forget to highlight and provides practical tools that we often don't know how to how to approach. And so we have been using these guidelines within our project GeneEQUAL. GeneEQUAL is a project funded by the Department of Health, New South Wales, that is aimed on making a genetic health care being more inclusive of and accessible for people with intellectual disability. And it's a first, first world initiative where everything that is done in this project is done in co-production with people with intellectual disability. And so it is within this project that we have been using together the Easy Read guidelines to, to inform every stage of our work. So some of the things on reflection that that we have found useful.

I have a quote from Skie who talked about how it really helped her to put together a picture of what research is, and that was really lovely to hear. For Julie and I, on reflection, this is kind of self, self-assessment as well, of our work, it was an important reminder of best practice in research, and I particularly mean it now in terms of risk assessment. In one part, in one of our booklets, we talk about how it is really important to consider how to make research field work.

So for example, going out and talking to people, how it's really important to make it safe for everybody, for the researchers, for the participants, for the co-researchers, for everybody involved. And, and, and part of these practices can be also debriefing after the after the interviews that are conducted. But sometimes people can hear really maybe traumatic experiences of others and might need the researchers might need psychological counseling themselves after what they have heard.

And so it's really important to prepare the risk assessment and plan how to act in these situations. And Julie and I reflected that because we both had been involved in in talking to people with very traumatic experiences for literally decades and also because we do have automatic practice of debriefing after the interviews. We really do not plan for don't do risk assessment or not really formally sit down and prepare the plan.

And we both have our coping strategies and so we don't really, yeah we, just then the two of our work together, we actually were not doing this, and now having a team of three, we understood, you know, this is really important and responsible thing to do. And so so yeah, it was a good reminder for us of what is the best practice in co-production and how, why is it important.

So that's a bit of a sharing from our learning, advice. Some of the other things that Julie and Skie picked up about the Easy Read guidelines were how it can really assist people to start thinking about a new project and enacting it. And for example, how to build advisory committees, and Skie particularly highlighted the excellent choice of NSW CID of the pictures that are used throughout the guidelines, which really showed diversity of people as well, which which is something we really appreciated. So these are just some reflections or examples of using the Easy Read guidelines for mentoring and research.

## Karen Fisher

Great, thank you very much, Iva. So, now we're up to the part where you can add into the discussion and and ask any questions about the guidelines or reflect on your own practice in doing disability inclusive research and co-production.

## Iva Strnadová

And can I just start with answering the first two questions that came through to you and I, all of these guidelines, so the standard English and the Easy Read English, but also Word versions, not just PDF, so everything is really accessible, are on our website. We, we have uploaded them last night managed and so they are there and for you to download and use and give us feedback which will be absolutely amazing.

We are not pretending we have covered everything, that it is a perfect and unchangeable piece of work, so any feedback of course is always very welcome.

## Karen Fisher

And the link to the guidelines is now in the chat. So if you'd like to pick it up there or, or you can go to the website for the Disability Innovation Institute. So we have a question that was posted when people were registering and so this is a question for Iva and Leanne, how does your work differ from the similar sounding work from the Research for Development Impact Network in 2021, Making Research Inclusive of People with Disabilities?

## Leanne Dowse

I can pick that one up, Karen, thanks very much and thank you to the person who sent that question in and reminded us of the importance of sort of diverse sources for co-production. I was actually involved in an advisory capacity on the development of the Research for Development Impact Network's, I really highly recommend it to people to go and have a look at. It is a very specific set of guidance for co-production and research in the development context. And in a sense one of the things that we've very much tried to do with our work at the Institute is to make our guidance sort of general enough to be applicable to a whole range of fields. And so we're very pleased to be for our work to form part of a really a growing I mean, I certainly think many of you can Google there is some very good production resources for the agency that developed by the Agency for Clinical Innovation—I think Tracy's online today or hopefully—in New South Wales, which also addresses co-production. I think the important thing to say is I think you'll find that there are there are there's nothing in competition about any of these resources, but in fact they're often developed in the context of different types of research. And in a sense, you know, medical and health research might be quite different to other research that people might be might be looking to undertake.

So I feel as though, ours, we have really thought to be as generic as possible, so we haven't sort of landed in a particular topic area. And we feel that our work also applies to mixed methods research, to statistical related research, as well as qualitative research that more uses a people to people focus. And so they are similar.

Of course, all guidance on co-production is similar. And as you know, co-production is not something that's unique to disability research, that very much we've seen co-production emerge in a whole range of areas. I think what is really heartening and fantastic to see is that many of the funders in the European context and in the UK particularly are now requiring co-production, evidence of co-production and as part of their funding, factors that will be taken into account in terms of criteria for success.

And so we feel as though any kind of guidance, which I generally feel is pretty consistent across, we checked our guidelines against lots of others available. I think the ways that different things are written in different levels of detail will speak to different researchers in different contexts. So while we certainly encourage you to look at ours and use them to the extent that you can, it may be that you'll find that there are other resources around co-production that are just as useful for you, so no competition.

I think the more we see in terms of resources for co-production, for researchers in in the disability context, the better off we'll all be.

## Karen Fisher

Thank you. We have a question here in the chat for from Georgia van Toorn. Thanks so much, Iva and Leanne for this great resource and the event. My question is around the practical constraints people with disability and DPOs are currently facing with COVID and more generally in terms of their time and resource constraints. In my recent experience, I've found DPOs seem to want to be involved and co-produce research, but are not always in a position to commit sustained in-depth engagement. And so there are some ethical questions around asking too much of people adding to their already very large workload and compensating them for their time and expertise. Do you have any suggestions on how to approach this issue with consideration and respect?

## Iva Strnadová

I can start and Leanne please jump in at any point. I think this is an absolutely fantastic point and thank you for raising this up, and I think you... I do agree that the organisations genuinely want to be engaged in co-production but might have constraints that they are you know, that are limiting their engagement in co-production.

So I, I think first of all it's to me it's about relationships. And that's one thing that, that we keep on highlighting throughout the guidelines and we talk about that co-production takes time and it is grounded in building relationships and, and so even developing the relationship with partners that that I know when when I can approach them and when what kind of work they would be comfortable with that I can discuss with them and what is too much for them.

I think it's it's really important. And and when you develop those relationships, you can have a much more honest conversation also about what you could do from your side to make it possible for the organization. And and you know, very often we get requests in the Disability Innovation Institute. Hi. I want to do co-production Can you link me up with organization doing X, Y, Z, the disability organization. And it just doesn't work like that. You do need to develop those. It's not the quick dating service you do need to commit. And it is that initial process. You are absolutely right that there needs to be proper compensation for time and expertise. And this is where where we always try to get creative and apply wherever we can so we can also fund the co-production part of the research.

And I think what is encouraging from what Leanne said that more and more funders are calling for co-production actually understand the building in costs for, for, for doing the co-production properly, but yet there is not... absolutely need to be need to be compensated for the time and expertise, there are no two ways about it. Leanne, I'm sure.

## Leanne Dowse

Yeah I will add a couple of things that again, thanks Georgia, it's a fantastic question. I think it's not a new problem, but it's certainly something that we, we have had at the back of our minds that we all have as we've gone through research. One of the things that we've really tried to make fairly clear, particularly through the processes of research, is that not every, every part of the research needs to be.

So our document in a sense is, is to help people with decision making about the the process and engagement level of co-production. And one of the things that we provided is, of course, some context around the importance of research, of making agreements, what is it that everybody agrees to do. And it's at that point, as we've said, I think in one of our appendices, where people need to be honest about what their capacity to commit is, sometimes, as you say, it's really not about whether there's money available. It's actually just about sheer person hours. And the, you know, the, the always, you know, the ever present too much work to do and not enough people to do it. And so, certainly in my experience and the way we've tried to build that into the guidelines is to really understand how that can be negotiated and renegotiated as you move forward.

So organizations, just because an organization can't give lots of time, it may be that they can provide something more than just advice, but not turn people up to go and collect data. But I think the most important thing there is to be honest and upfront about it and to actually create an agreement about it.

And one of the other things that we've also highlighted in here is the importance of really thinking at that point about how you will resolve conflicts of interest, because I think that's one of the things that your question really talks to Georgia is everybody agrees it's a really great idea at the beginning. And then suddenly as we get along, suddenly something happens. You think, hang on, we're not. No, we're not on the same page. And so in our experience, we've, we very much have recommended in the guidance that teams need to talk about these things or partners need to talk about these things from the very word go, and that there's a written agreement that when a conflict of interest or a conflict of opinion or a difference of opinion arises actually identifying how it will be resolved is actually really crucial.

And we see that is really a really important sort of safeguard in this process where even though people can't be in the field or give a lot of time to doing some of those practical activities in their research, that there's an agreement on the expectation. And I think our, I think as Iva and I were working through the text particularly, and in the Easy Read particularly, we spent many hours. And do we say this way, do we stay that way? It's really about the importance of honesty, openness and being very explicit about what the agreement is. And I feel like just with that at the start, it gives a really good guide for you know, A, that a project can claim co-production because I think we're sort of at that point where there are quite a lot of projects that are claiming to be co-produced and I don't think we, any of us have a really clear criteria of what actually constitutes co-production or whether a project is co-produced. We sort of know when it's not, if that makes sense. I'm sure that will make sense to people we know. We know it when we see it and we know what it's not. And so again, that's one of the important things that we talked about in this reflecting process of really trying to build up a body of knowledge about how we negotiate all of these things, which Karen so rightly said at the very beginning, we've set out in our dreams the perfect process, but how we negotiate, how that actually happens in practice. And I feel like being honest and open and recording agreements and recording the way that we anticipate co-production will work is really a really important first step.

## Karen Fisher

Thank you. We've got quite a practical question here, Have you addressed the issue of getting ethics approval for co-production work?

## Iva Strnadová

We do talk about ethics in in the guidelines and as part of the process. We are, our next piece of work that we are going to undertake following these guidelines will be specifically targeting the issue of ethics for co-production. And I know there are very mixed experiences of the researchers and I and there are many, many questions in stake from the perspective of ethics committees, but also researchers and how to go about applying for for the approval, but also for the ethics committee, how to understand how co-production works. And that experience is diverse. And I have to say that you know, my experience with UNSW Ethics Committee has been fantastic and they really understand. But of course, that's more than decades of applying for co-produced research. And so there is that mutual learning from each other but we definitely know that this piece of work is needed. And that's the next plan for the DIIU. So keep eyes on this space.

## Leanne Dowse

Yeah. Thank you again for the question that gives us a sense that really we are on the right track with the next thing we do have planned. I mean, one thing I would probably add just to the whole kind of ethics question is I mean, we do expect a lot of ethics committees in that they need to be on top of new approaches. And the issue I think many of us who've been doing research in disability for quite some time have come upon is that ethics committees just have a natural tendency because they need to follow a set of legislation and guidance on how they assess ethics applications, they almost always or they actually do always equate the presence of disability with vulnerability in the research process. And I feel like that's been our very most difficult sort of understanding to shift because that's how ethics committees often come to a research project that has disability in the label. When you have to tick a box that says people with disability are involved, I think that's one of our biggest, biggest issues to really tackle is is to really have ethics committees understand that people with disability have a right to be part of research about themselves, rather than just being deemed sort of vulnerable to exploitation. That's a little bit shifting, that sort of dialogue. I think the other the other kind of issues, and I know I'm probably speaking on behalf of Ben Garcia-Lee here, but Ben and another research colleague of mine, Michael Baker, who's doing an honors in criminology and Simone Rowe, who's also probably on today, have really had to tackle this kind of issue of what is to shift the perception that people with disability, particularly people with intellectual cognitive, can only be participants in research. I think that's really at the heart of what we want to try and achieve with our next set of outputs is that people are part of the research process. They're co-researchers and they have multiple potential roles. Some people can be participants and we don't want to get bogged down in the how do you pay people? But that's often what we find ourselves doing in those and how we recruit people so that they're not coerced, et cetera, et cetera. I think if we can get ethics committees to really understand the importance of co-production, I think a lot of those other fears can also be allayed because what we're arguing in these guidelines is that people with, having people with disability on your team means that your approach to the field is much safer. It's much more well informed by the lived experience of disability so that it's a bit less than 'us and them', you know, that researchers might potentially do all these terrible things that make people vulnerable or coerce them into things. And in fact, I think the goal is to really shift the idea, I think we'll be aided in that by the fact that co-production is really becoming a very much more common approach in other disciplines beyond disability studies with other so-called vulnerable groups in social research particularly.

And so I'm pretty confident that ethics committees have their ears open to this because in my experience, they're always very much willing to learn. It's really about us having the time or taking the time to actually clarify issues for them. And so that's certainly what our next process will do. And I feel like we've got lots of experience and lots of ideas over time about I think we understand what needs to shift.

## Karen Fisher

Thank you. The next question is whether you have any advice for working with research commissioners, particularly government who typically want research faster and cheaper than good practice would suggest, how to describe the value of inclusive research and its value to the findings.

## Iva Strnadová

It's a fantastic question because we get so, so often approached by governments with timelines that are simply not realistic for this work that want co-production, I think once once you collaborate in in a co-produced way with with the government body though, they get the understanding of of of the value and why is it so important. We recently have been collaborating in partnership with Leanne, Julie, myself and a big beautiful team of other colleagues with New South Wales Department of Education and we were in collaboration developing an alternative to 'Tell Them From Me' survey which is completed by all, can be completed by all students in New South Wales about their education experiences. To us, I have to say, unsurprisingly, it wasn't accessible to students with disabilities and so in co-production with 24 schools, in co-production with their students, we have developed an alternative called 'My Say My Way', which is which is accessible even to students with moderate and high support needs. So and I think the we've argued well the timeline and the Department understood, but I think also being in partnership with us throughout the process, I think they would much better understanding what it actually takes to co-produce something that has a chance to last, last and to make changes in people's lives.

## Leanne Dowse

Can I just make an additional comment there that I mean, given that most government commissioned research work is actually applied research, it's actually research that's meant to make things better for somebody in a government that a government delivers a service to. I don't think it will take very much more time for governments to really come to the realization that co-produced research is just much better. It's just much better at achieving real, relevant, real world research that actually is shaped not just by policy pressures or but it's actually about what people want and need. And so I feel as though we're on a bit of a journey there. And I think the other thing that's really in our favour is that we're beginning to see the outcomes and outputs of co-produced work.

So it can be co-produced program design, and that's very much where the sort of co-production and research impetus came from. If you think about it, it's actually emerged from this process of co-design for programs. And so we've we've literally taken as our starting point some of the research around service and government program co-design and applied it to the research context ourselves. And so I feel like just being able to clearly make that argument that actually it is just better, it is just more effective, it's a more effective way to spend money because the outputs and the application of any research will be much, much more close to what governments want and also that it is actually the right thing to do.

That's the other thing I think for researchers in universities, it becomes a challenge as well. You know, many of us are used to just charging off and doing our literature reviews and our consultations and all of those sorts of things. What I think we're showing with co-produced research and the more we do it and the better the outcomes, is that moving beyond simple consultation into co-production of both programs and research and evaluations.

I mean, there's a whole range of things that that co-production is applied to. I think we will just see a much stronger and better out set of outcomes for government. And I think in a way, we just have to watch that shift occur over time. We're seeing really good examples now of how people are using it. That's one of the things we'd love to hear.

If you do yourselves, use the guidelines in your own work just to let us know about it so that we can also help to use the evidence of really good co-production and to to show that as an argument for ethics committees and for commissioning bodies. That co-production actually works and it works so much better than some of our old approaches.

## Karen Fisher

So we've got time for one more question. I know that there's lots more questions in both the Q&A and the chat and I'll ask the speakers to answer those after this session. So we've got your emails and they can get back to you. So the last question is how can we ensure that these excellent guidelines are used by researchers who have not previously thought about the need to be inclusive of people with disability, and as a result, implicitly exclude many people from their research?

## Iva Strnadová

Thank you very much for this question. And hello. I think that this is something that you can help us with. We will, of course, they are accessible on our website, and the role of the Disability Innovation Institute continues to be to really help researchers to understand the importance and value of co-production. So we keep on collaborating with colleagues who are learning about co-produced research. But please do share widely because we need people to know and learn so you can be our biggest allies in this in this adventure.

## Karen Fisher

So very, very sorry. There's some really interesting questions there that I'd love to hear the answers to, but hopefully we'll get them posted out. I think one of the big things that I've taken from this that we haven't spoken a lot about today, but really reflects the interest that we've seen in the questions and discussions is how much co-production is about relationships.

It is about time about getting to know each other to about reaching out and one of the things that I would implore is that those of you who are people with disability and representing disabled persons organizations is for you to use these guidelines too, to hold university researchers to account. Basically, as Iva said, these guidelines reflect good practice in research, irrespective of what sort of research you're doing. If research is going to be ethical and if it's going to be useful, they should be following these guidelines. So make sure that we use them. Thank you. And I'll hand Iva to just close us for today.

## Iva Strnadová

Absolutely. So thank you so much, everybody, for joining us. And if you want to find out more about this work or any other work the Disability Innovation Institute is doing, please visit our website, all lower letters, disabilityinnovation.unsw.edu.au. And of course, there will be a recording of this event available, including the subtitles. So please watch this space and feel free to reach out and ask many other questions. We are ready. Have a great day. Thank you.