Launch Event Webinar: New Ethics Guidelines

Tuesday 22 October 2024 via Zoom

**SPEAKERS**

Iva Strnadová, Jonathon Kelleher, Jackie Leach Scully, Leanne Dowse, Julie Loblinzk OAM

**Jackie Leach Scully** 01:38

Good afternoon everybody, and welcome to this launch event for the Disability Innovation Institute new guidelines on ethical issues in co-production. I want to begin in the usual way by acknowledging that we are on the various unceded lands. We acknowledge the traditional custodians of those various lands from which all our online guests and presenters are joining us today, we pay our respects to elders past and present and celebrate the diversity of Aboriginal peoples and their ongoing cultures and connections to the lands and waters of New South Wales and beyond.

**Jackie Leach Scully** 02:19

I'm Professor Jackie Leach Scully. I'm Director of the Disability Innovation Institute here at UNSW Sydney. The Disability Innovation Institute (the DIIU) is a unique initiative. We focus on disability research, education and knowledge exchange, and our team members take a lot of pride in undertaking work that's radically inclusive and that crosses disciplinary boundaries. The Institute's approach is to see disability not as a problem to be solved, but an integral part of the human condition to be encountered and engaged with, rather than feared. Just a few housekeeping words here, this webinar is being recorded, and the link will be provided to you after the session with a copy of the full transcript. We welcome our Auslan interpreters. Thank you for joining us. If you have any questions for the speakers today, please enter them in the Q and A function, Closed Captions are available, and you can access these on the toolbar of your zoom screen. You can pin them to your screen by clicking the top right hand corner and select pin to pin them there.

**Jackie Leach Scully** 03:37

It now gives me a great deal of pleasure to welcome you all to this launch in the newest of our series of inclusive research guidelines, we have a number of speakers, including the members of the team who put together these guidelines. But we're going to start first of all by some words from Jonathon Kelleher, who is the Inclusion Project Officer at the Council for Intellectual Disability, and he is a trained social worker and has experience working with people with intellectual disability in the justice system, mental health and victim support settings. So over to you, Jonathon.

**Jonathon Kelleher** 04:24

Thank you, Jackie, and hi everyone. I'll just wait for my slide to come up. Thanks, Kate, so I'm here to quickly talk about easy read and how we do it at the New South Wales Council for Intellectual Disability, or we say CID for short. Thanks. Kate. So just quickly, my name is Jonathon. I've worked at CID for about two and a half years. Now I'm an Inclusion Projects Officer within the inclusion services team, and we prominently make easy read or other services and run an easy retraining and do easy read in our day to day work. So easy read is a human right, and the United Nations Convention on the Rights of Persons with Disability includes the right to accessible information such as easy read, and it says businesses and governments need to give information to people with intellectual disability in different ways. At CID, one way that we make information accessible for people with intellectual disability is easy read, and this helps people with intellectual disability get information about lots of different areas and topics. So in terms of what easy read is, at CID, we say that it's information that is easy for people to read and understand. Easy read is a type of communication that uses everyday language with images, and for lots of people with intellectual disability, it's how they choose to communicate. Easy read can be read by the person on their own, or it can be read with support from someone. So it's common for someone with an intellectual disability to get support to read. Easy read. So it's good to think of it as a conversation starter. Some easy read rules that we use at CID are to use short sentences with pictures that explain the words, focus on the key messages. At CID, our ethos is to include the need to know information rather than the nice to know information. And there's also lots of formatting and layout techniques such as having enough white space on the page, because white space is thinking space, and also to use images of real people doing real things.

**Jonathon Kelleher** 07:09

So in terms of why we do easy read, it's important because it's a way of communicating for someone who finds it hard to understand difficult language. Robert Strike, who's on the screen, who many of you, I'm sure may recognise or know, is an easy read advocate as well as a self advocate with intellectual disability, and says that "easy read means I can understand and that I'm included". Easy read isn't just beneficial for people with intellectual disability, it can also be really useful for other people or groups such as people who have trouble with reading and writing, people whose first language is not English, and anyone who wants to use it, including all of us. So just really quickly, I will go over the key steps of making something easy read.

**Jonathon Kelleher** 07:58

So the key stages of making something easy read are prepare, develop, review and test. So in terms of prepare, this will ask you to think about the purpose of your easy read, your audience, how it's going to be used, whether it is individual or with support and the key messages. Then at CID we develop, which we focus on, the language, the text, the formatting and the order and the images, and really put the easy read document together. Following that, we do a review, and we start with reviewing our own work, and then doing a peer review. As easy read is a very collaborative process. It's never just one person that starts on a job and sees it the whole way through. It's very collaborative, with lots of people looking over the resource or the document. Really importantly, after this, the fourth and final stage is to test the easy read document. There's no point making something easy read or calling something accessible or inclusive if you haven't actually tested it with your target audience. So we always test everything that we make at CID with a colleague or member with intellectual disability. So those are the key steps of making something easy read, and this has been a really quick summary of easy read. So if you have any questions about easy read or what it all means, or if you're interested in getting training or assistance from CID in terms of easy read services, translation as well, we have the details on the screen and call us on 1800 424 065, or email us at info@cid.org.au. Thank you everyone.

**Jackie Leach Scully** 09:45

Thank you very much, Jonathon. And just to clarify for people, we started out with that introduction from Jonathon, because our guidelines are also going to be available in easy read, and we make sure that all of our guidelines are available in that format as well. So we have a few minutes here before Jonathon, sadly has to leave and we move on to the rest of our presentation about the production of those guidelines. So if you have any questions for Jonathon, we can take them now, and I actually do have one already, which is "thank you for your presentation. Can you please elaborate on easy read versus easy English? Are they both the same? Can they be used interchangeably? And are there any recommendations in regard to which term to use?"

**Jonathon Kelleher** 10:42

That's a really interesting question. I think there is still some kind of debate and discourse going on at the moment in relation to easy read versus easy English. At CID, we use easy read, which is the - each sentence having an image directly next to it. I think easy English is a further step to that, perhaps having just maybe one very short sentence next to an image within the page. But at CID, our expertise is certainly within easy read rather than easy English as a standard formatting for people with intellectual disability.

**Jackie Leach Scully** 11:29

Okay, thank you. Here is a second question for you, "do you find that some people have difficulty deciphering images?"

**Jonathon Kelleher** 11:43

It depends, sometimes. So we use photos of real people doing real things at CID, and we test all of our documents. And so if we go to testing and we show an image that perhaps is confusing or doesn't relate to the message, then that's where we would pick that up and then change it and ask them for ideas about, okay, that picture maybe isn't making sense or connecting to the words enough. Do you have any suggestions, ideas about how we could find a better image to represent the words on the page?

**Jackie Leach Scully** 12:20

Okay, thank you for that. And a final question, I think, before we have to let you go, is, "if you could just say a few more words to elaborate on the testing process, what kind of changes might happen as part of that in the testing for producing easy read?"

**Jonathon Kelleher** 12:37

Yeah sure thing. So testing is really critical part of the process of making something easy read. And so at CID, we will sit down with a colleague with intellectual disability and generally ask them to read out the document so that we can kind of observe if they trip up or have difficulty on reading or pronouncing any of the terms or sentences, and then asking them about what they think might be difficult concepts or words to understand for themselves or other people with intellectual disability, checking in understanding, asking open ended questions about the images and whether the images match the words and help connect the meaning. And then there are many changes that can happen as part of the feedback that we get from people with intellectual disability, we'll incorporate those changes after the testing. So then improve the document and make sure that it's in line with with our guidelines, and also what they have just told us about, perhaps potentially confusing words, language and images. And I know Rachel Spencer is an expert on the topic of easy read and Easy English, so I'm really glad that she has just jumped into the chat there.

**Jackie Leach Scully** 13:53

Okay, thank you. We do have to move on now in the chat, people can find contact details for the CID phone and email address, and I would just like to put on the record how much the DIIU appreciates our collaborations with the Council for Intellectual Disability in the past and hopefully in the future. So thank you, Jonathan, for taking part this afternoon.

**Jonathon Kelleher** 14:19

You're very welcome. Thank you.

**Jackie Leach Scully** 14:23

And now we're going to move on to presentations by the team who were involved in the research, and then production of our guidance on ethical issues in co-production research. They are Iva Strnadová, Leanne Dowse and Julie Loblinzk OAM, they will introduce themselves when they come to speak, so I'm going to hand over now, thank you.

**Iva Strnadová** 14:47

Thank you, Kate. Thank you everyone for joining us in this wonderful event. We are so proud of the work that we can share with you, and which you will hopefully find very useful. I would like to start before I pass on also to my colleagues with a beautiful acknowledgement that was developed by Council for Intellectual Disability. So we thought it's really important to include it here. We know that we are on First Nations land, and we respect the First Nations people from this land. And on this land we live, work, play, swim and dream. First Nations people have lived on this land for many years, and now we live on this land together. We respect all First Nations, people and elders, and we learn a lot from their stories, and we can also learn from each other in this webinar today. So thank you very much to CID for this beautiful acknowledgement. In this presentation or in this webinar we are using, as you will notice, easy read principles, and so we would also like to acknowledge the use of photo symbols that we do pay subscription, so we are very proper in using them. I would like to at the beginning of this webinar also hugely thank the National Disability Research Partnership because they gave us the funding to make, to develop this guidance and to really make this was always a little dream of ours, so to make it happen. I would also love to very much acknowledge the colleague authors, besides those that are present here for all their work on the guidance, specifically Ben Garcia- Lee, Sarah Hayes, Michelle Tso and our Director, Jackie Leach Scully, and very, very big thank you to all the researchers, academic researchers and co researchers with disability who talked with us, as well as the chairs of ethics committees who spoke to us, because, based on what they told us, besides also reviewing literature, this guidance could have come to see the light of the world. So now, introducing, very shortly, the three of us. My name is Iva Strnadová and I work at the University of New South Wales as a professor of special and inclusive education at school of education. Importantly, I am leading the research agenda at the Disability Innovation Institute, and I'm a very proud board member of Self Advocacy Sydney, which is an organisation run by and for people with intellectual disability. And I'll pass on to Leanne.

**Leanne Dowse** 17:52

Hello, everyone. My name is Leanne Dowse. I'm a professor emerita at UNSW, and I've been involved with the Institute sort of from its inception, so it's fantastic to still be involved in some of its work.

**Julie Loblinzk OAM** 18:09

Hi everyone. My name is Julie Loblinzk. I work alongside Professor Iva. I'm a research fellow adjunct lecturer and a board member of Self Advocacy Sydney.

**Iva Strnadová** 18:23

Thank you Julie. So this important guidance on ethical issues relevant to inclusive research is something that has been called for by many people who engaged with our previous guidance and just to give a little context for those of you who might not have it, inclusive, research is really important because it explores the issues that are relevant to people with disability and their lives, and importantly, it recognises the expertise that people with disability have about their lives and their knowledge of issues that are important to them. It also recognises the contributions that people with disability make in research, and it also can provide information that then people with disability can use to advocate or self advocate for changes to happen, and we move to next slide. Co-production, then is really the way to make inclusive research happen. And it is about working together, doing research together, and together, we mean academic researchers, co researchers with disability and of course, any other involved parties. And I would like to highlight here that our guidance is really focused primarily on ethical issues connected to research led by university researchers. So it's a very specific context. I also would like to acknowledge that we are using the term 'co researchers', and we use it because the co for us highlights the collaboration and the equally a different contribution. However, we also know that this is such a rapidly developing field, and there are so many other equally important terms that people use, such as lived experience researchers. Some people talk about advisors. We will talk about it a bit later. So of course, we acknowledge that people might have different names.

**Leanne Dowse** 20:47

First question really to talk to you about is, why do we feel we need this guidance? So aside from the fact that almost since its inception, members of the UNSW research community and other colleagues have always identified ethics and ethical issues in co-production research as a really complex issue, that that where guidance is needed. What we do know is that in our review, that the National Statement, which you can see, that the National Statement on Ethical Conduct of Human Research, when you have a look carefully, only talks about people with disability with certain kind of diagnoses, so people with cognitive impairment, disability or mental illness are picked out. But generally, there's not much guidance within that, guidance around research that concerns disability, and where that guidance does exist in the document, it talks only about people with disability as research participants and not as co researchers. Likewise, the National Statement currently does not mention co-production at all. So what that really meant is that, what it means is that researchers, basically who are undertaking co-production have to work out for themselves how to describe it and how to do it ethically. And for ethics committees, it means that ethics committees also have to work out for themselves how to check that co-productions done ethically. And so it sort of means that our sense of it was, everyone's just making it up as we go. And so that was really the motivation for doing this piece of work. Next slide, please.

**Iva Strnadová** 22:24

And so how I will just very briefly say how we made this guidance. So we have looked at national and international peer reviewed literature about this topic. We also looked at the gray literature, such as websites or things that are not necessarily peer reviewed. We have also looked at similar guidances from other countries, and we definitely, very gratefully, talked to 18 academic researchers who are engaged in the inclusive research, six co researchers and three chairs of Australian University ethics committees. So based on all of this richness of information, we developed a guidance.

**Leanne Dowse** 23:11

So one thing that I wanted to quickly do before we go into any too much detail, is that in reviewing all of that material, we really could see that there was some really kind of foundational or fundamental things that are obvious in the literature and have been obvious from what people have told us, which we wanted to sort of set out in the guidance that is not really related to specific strategies or issues themselves, but just general things we understand, and they include things like that co-production really makes research better, that it enhances the integrity of research, that it highlights, also, as Iva's already said, the lived experience perspective in all of research. We also know that the ethics application process itself is extremely inaccessible for people, for co researchers, and that means there's often any of the academics, particularly joining us today, will know that the complex technical and format and language that's required in an ethics application can really marginalise co researchers, and what we see that effectively, it can really exclude them from decision making about the research itself. We also know that people who are co researchers can actually experience harm in the ethics application process, and these are for a few reasons that were identified to us, particularly things around that ethics committees who are not familiar with disability studies, as in it as a general kind of discipline, can assume a medical model or take a deficit view of understanding disability. And this can mean that they, they tend to take, or may tend to take a more sort of protectionist approach when they're reviewing applications, and particularly also that there's actually written, as we've said already in the National Statement, some assumptions about people identifying vulnerability and lacking capacity in particular groups. And what we know, of course, is that these words, particularly in these concepts, and these assumptions can be very harmful to co researchers. We also know that there can be counterproductive sort of assumptions. So researchers can sometimes assume that committees, ethics committees, can actually understand what co-production is, and so that as researchers, they don't always clearly explain it in their applications. And sometimes ethics committees assume that having co-production is a kind of red flag that you know this is going to be complicated, ethically complex research, and it can be, you know, researchers can often kind of feel like it's a bit too hard. So we also see that there's often sort of conflicting ethical principles. As we said, there's very limited information about how to make judgments, about whether a co-production project is abides by ethical principles, and so committee members can often make personal judgments that can be influenced particularly by their experience of disability or their knowledge of disability. Next slide please, Kate.

**Leanne Dowse** 26:33

We also know that researchers often come to co- production research for all sorts of different reasons and from different disciplines, and so people may not know what is required in terms of actually describing the co-production process. So it can kind of often leave everyone in the dark about how to make decisions. We also know that there's variability in that, in researchers experience. So we see this kind of now emergence of co-production as a really important thing, particularly in our funders. Many funders are requiring co-production, but researchers can have sort of different levels of confidence in actually articulating what co-production is in their applications. And also we know that sometimes the research, the actual application and assessment process, people can experience it as sort of a bit combative, and that human committees are often mostly concerned with risk and with litigation. And so we really see that a direct relationship and a kind of relationship exchange is something really important. Next slide, please, Kate.

**Leanne Dowse** 27:51

So after we've covered those big picture issues in our guidance, we've in our analysis of all of the materials that Iva mentioned, we've picked out six key issues that we see as really kind of pulling together the kind of key issues that we see people really need to understand and work with in ethical co-production. So what the guidance does is it, first of all, picks out each of those issues. It provides a sort of definition and some discussion and description of what that issue is, and provides some more context to what the issue is, to make sure we sort of have these understood in kind of nuanced ways, I guess. And then next slide please, Kate. For each of those areas, we've provided strategies for research teams and strategies for ethics committee. So the issues that we identified are relationships in co-production, processes in co-production, roles in co-production, benefit and risk in co-production, vulnerability and capacity in co-production and quality in co-production. So for each of those, there's a three or four page section in the guidance which hopefully will increase people's understanding and include strategies about how we go about things. So Iva and Julie are now going to talk about each of those issues briefly. So jump two slides. Please. Kate.

**Iva Strnadová** 29:18

Perfect. Thank you so much, Kate. So the first issue in co-production is really about understanding and what we will be now talking Julie, Leanne and I about is very relevant to both researchers who do co-production and apply for ethics as well as for ethics committees. It's important to understand the co-production is relationship, and it is about relationships that are built on respect, relationships where people share power, and relationships where all decisions are made together. So it's not just about focusing on one person who is co-researcher, it's the relationships within the team, and I'll pass on to Julie.

**Julie Loblinzk OAM** 30:07

Thank you, Iva. It's also about being able to have time, to be able to build the relationships, and that can take hard work and being able to build strength in being able to work together, being able to look at what are the strengths to people being involved and playing to that, being able to work out things in what's being done so that there's agreement with everyone that's involved, being able to communicate information with each Other, listen to each other, have teamwork and collaborate with doing person centered planning.

**Iva Strnadová** 31:08

Thank you so much. Julie, and it's really important for the for the ethics, for the people who write the ethics applications to communicate this story, because that can be very reassuring for ethics committees that those relationships are there, and equally, for the ethics committees to look maybe for an evidence in the application. Another important issue. Next slide, thank you. Are really what processes take place in co-production. So I think it's important to understand that co- production is different from usual research. And Julie, if you provide maybe a few examples.

**Julie Loblinzk OAM** 31:55

So it's really important to be able to work within a team, provide feedback to people with intellectual disability on information and being able to get their feedback so that it can be taken away, looked at, changed, and then go back to them in another workshop to let them know what's actually happening, to give them that feedback and to give them information that they can take away and use.

**Iva Strnadová** 32:38

I think that is a great example where the researchers, as well as ethics committees, need to realise that there is very likely not a crystal clear plan from the beginning to the end for the research study, or that maybe Stage 2, 3, 4, are really just more flexibly and more vaguely described, because at every stage in co-production, the co researchers, the academic researchers and other involved parties keep on coming back together and seeing, is this working or not? Do we need to change some approach? Is this research method working? Is it safe? Maybe we didn't have a good appreciation before, and so, so it's really important to have that flexibility, to have that continuing process almost of the application, when you can apply for the ethics, but also flag with the committee that the future phases will be applied for in the next in the next round, when they when we have a really clear vision of what is going to happen, if that makes sense. And if we can move to next slide, we really like this, this ethics committee chair inside, when they beautifully said that it's not just filling the form, which sometimes we tend to do as academics, but it's about setting up a whole story about the research we are going to undertake, because that can help the ethics committees to understand

**Julie Loblinzk OAM** 34:29

And sometimes co researchers join from the beginning, and sometimes they come in at a later stage, and it's looked at what they're involved in.

**Iva Strnadová** 34:42

So the story can change absolutely thank you so much Julie.

**Iva Strnadová** 34:47

The next slide is about next issue, and this next issue are the actual roles in co- production. And so here, what is really important to mention is that co researchers with disability are different from participants, and this sometimes gets lost, either in the way that we as applicants, people who do research, write the application, or in the way it's understood. So being a co researcher is really human resources matter. It's person who is employed in the research project, while participant really then falls under, under ethics, ethics scrutiny, if you wish. Another really important thing is that the names of the for the role for the co researchers are really very different. We have picked up here some that the lovely people that we interviewed shared with us that their teams used, and so we can absolutely understand, or I can definitely understand, that it can be very confusing for the Ethics Committee to see these diverse terms and not really understand what does it mean, what is the role of the person? So one of the things that we would highlight in our guidance is be very clear. It's fine if you have a preferred name of the role, and that's that's good, but explain it. Explain exactly how the involvement will look like across the different stages of the study. Next slide, please.

**Iva Strnadová** 36:40

Leanne, beautifully mentioned already the benefits and risks in a co- production, and that's something that national statement asks ethics committees and researchers, of course, both parties, to consider. And really the research that can go ahead is a research where benefits, so the things that can go well and can improve, things are outweigh the risks. So the things that can go wrong, and we know from literature that there are so many benefits to including co researchers in in research teams, and literature tells us about skills development, but skills development from everybody, I need to highlight, not just for co researchers. It also means giving voice to people with disability training and job opportunities, very importantly, and it really allows for the real world impact, because the research can make a real change in people's lives. Julie, did you want to add anything? No. Now in so this is just what I've mentioned, one of the insights of ethics committees chair, that the committees do tend to have that culture of ethics when they more look at the risks than benefits and think more about the concerns about vulnerability and harm, rather than how this co-production research can make things better, you can move to the next slide. I think big, big topic for us is the and it was mentioned in the chat already, which I'm very happy, thank you Caroline, is the vulnerability and so, and we know that this is coming originally from good intention. There have been some really bad experience in the past when it comes to research and people with disability, but unfortunately, we have now moved to being overprotective, and so the National Statement as it is actually assumes that three groups are inherently vulnerable, automatically vulnerable. People with intellectual disability, cognitive impairment and mental illness, and therefore the ethics committees tend to be more protective and assume the vulnerability, but people with disability see it as taking their rights away from being part of research and contribute feed. Feel that it is unfair and disheartening, and I'll pass on to Julie.

**Julie Loblinzk OAM** 39:30

Thank you. So when we're talking about vulnerability, we're talking about that people with disabilities, it can be triggering when you're talking about vulnerability. People with intellectual disabilities and other disabilities can feel that they can get upset or have hurt feelings. Things when people are trying to be protective of people with disabilities and people with an intellectual disability or disability want to be able to show that they have the skills to be involved, be included, and show that it can be done in a positive way and not negative.

**Iva Strnadová** 40:29

Thank you, Julie. I could not say it better. Thank you, if you can move the slide, the very connected topic is, of course, capacity. And so we really wanted to highlight in our guidance that United Nations Convention on the Rights of Persons with Disabilities assumes capacity. It really talks about people with disability having legal capacity on equal basis to others. So this is really important. However, the National Statement asks researchers, and you know, ethics committees, to check that when it comes to people with intellectual disability, cognitive impairment and mental illness. I'm quoting the names of the three conditions, that researchers have to ask for consent. And this can be really difficult and confusing for the ethics committees, and it adds to the confusion also with when it comes to the different role, if person is a co researcher or participant. Julie, did you want to add something to this?

**Julie Loblinzk OAM** 41:41

Yeah, so I just want to mention that I work with Iva and her team, even on ethics applications, and it can be even emotional on how language can be upsetting when you're describing the processes and the stages and understanding consent for even people with an intellectual disability to be able to take part, and it's ridiculous that people with an intellectual disability can get married, have children, go through a divorce, and we're still looking at trying to prove capacity.

**Iva Strnadová** 42:36

Thank you so much, Julie. I think another thing that I would like to mention here is, as we talked, Julie rightly mentioned, we work together also on ethics application. And I would really like to encourage the ethics committees, and I understand that very rarely, there would be a member on ethics committees either who have disability or have some experience or knowledge about this area. But the language you use, even in responses to researchers, can be very hurtful. So we such as, if there is a how will you know that is an intellectually disabled person that is very hurtful. So if you can move to next slide, this is a slide that from one of the studies Julie and I have done in which these are some of the labels that people had. And you know, these words are still use about people, abnormalities, deletion, retardation, insufficiency and so on. And of course, if the ethics committees don't have a disability awareness training, they might still know the terms that very used to be common in I don't know earlier years, or would they hear in the news, which offer also is not very, very community approved and so it's really important to be very mindful of the language we can move the slide.

**Julie Loblinzk OAM** 44:19

So this is about being able to make sure that the right language is used because it's very hard for a person with a disability to hear negative words. They don't want to be able to take part. They want to be able to have clear information, and it's easy read was talked about in the beginning, and it's about being positive for people with intellectual disabilities to be involved. So it is strengths based. For everyone and not negative or people feeling sad.

**Iva Strnadová** 45:06

Thank you so much, Julie and So, moving on over to Leanne,

**Leanne Dowse** 45:12

One of the other, the final issue actually, that we go into a great detail in the guidance is about quality and co-production. So many researchers mentioned this to us, particularly, what we know broadly is that co-production does, you know, have had the capacity to increase enhance the integrity of research? It's all great, but we don't know anything about how to actually measure there's no guidance. There's nothing in the literature about how to make judgments about the quality of a project. And so we've sort of had a little bit of a go, very early stages of a go. In fact, we feel it's very under done, but it's a whole other project. We think about what, what sorts of issues and things will be important in making an assessment of co-production and its quality. We've got some of the points around that there are really two things going on in the ethics application, particularly that a committee must have a look at, which is the quality of the collaboration between researchers and co researchers, and also the quality of the outcomes of the study. And they're two quite different things that people often don't, sort of make a an issue. And coming back to Shane's question, which I'll answer now, Shane, but of course, the other thing, of course, around quality, is the concern that many people raised about the quality of ethics committees themselves and their their adequacy in looking at co-production and disability research. You know, are ethics committees generally fit for purpose. And you know, we use the analogy in the work in terms of First Nations research that actually we now require that if research is done around First Nations people, that there needs to be First Nations people making assessments of its ethical qualities. We don't have any of those luxuries in the disability field at all. And so we are really in our guidance, really pushing the idea that we must, we must do something about helping to understand how to express, measure and assess quality and research. Next slide, please, Kate.

**Leanne Dowse** 47:24

And then the last thing that we included in our guidance is some of those big picture and systemic issues. So we know that co-production and research doesn't happen in a vacuum, and so we really wanted to just raise some of these issues. They're not necessarily directly impacting the individual researcher or the individual institution. But these are very big, broad brush stroke things that we think are really important to look to for the future. The first one we've called ethical governance, and this expressly, sort of looks at the ideas of capacity and vulnerability and the ways that these actually, as Carolyn also points out in the chat, they do convene the UN CRPD, and we really feel as though that's an area of really importance for us to to tackle as we go forward, and also this issue around the under representation of people with disabilities on ethics committees, which is, again, you know, just a longer term issue that maybe, maybe sits with the National Research the Council, NH and MRC, who creates the guidelines. The second thing we talk we have identified is something which we call research cultures. So as we know, co-production is now really increasingly in many disciplines, not just in disability, but in lots of other disciplines where researchers are working with people with lived experience. And in fact, it's increasingly encouraged funders are incentivising researchers to use co-production, and we can see within our own institution, but certainly across the institutions of people we talk to that there's a lot of lone people trying to work it out for themselves. So we really wanted to make a call for the recognition of building of, you know, democratic research cultures within universities themselves. The third one which most people who spoke to us spent lots of time talking about this, which is around institutional infrastructure and how that people experience that as a very common barrier to co-production work. So that is around things like HR processes about having to absolutely argue every time you want to put in an application that wants to hire someone. A co researcher with the disability administrative policies around salaries. You know, it is a kind of previously understood thing that, of course, you don't pay people properly. So there's a whole set of things people mentioned, finance systems, also inaccessible HR systems, salary systems, all of the processes that a university uses are incredibly inaccessible, often for co researchers. So there's a whole area of institutional infrastructure which really is important. And then the last thing I wanted to mention was research funding and commissioning. So we know that this sort of growing recognition of the right of people with disability to be involved in research about themselves, you know, hallelujah, means that funding schemes really are increasingly requiring the use of of co-production or co-design, or whatever we but funders often put it in and don't tell us what it is. And so there's a real challenge there around if funding bodies, particularly are requiring co-production or co-design as part of their tender processes, there's a real need to understand how to articulate what's required in the first place. And I think part of the problem we see here is that people put it in their tenders, and then as researchers and co researchers, we sit down and say, right, so how do we do it? It means that the project expands beyond the resources and the time available to actually do the project itself. So there's a real issue there around understanding why co- production is needed at what part of the process it's needed, and also recognising the resources that are needed to actually do co-production well. So that's our kind of final stuff about having a go at everybody else beyond the university. I think we might have one last slide.

**Iva Strnadová** 51:45

So we would like to just really share, we wanted to finish on very positive note. And so we would like to just share how we see co-production, in our experiences, in doing it. So I will pass on to Julie.

**Julie Loblinzk OAM** 52:01

Thank you Iva. So experiences with co-production is that people should feel valued being able to be involved in decision making together in stages, that people feel comfortable working, planning so we get it right. Capacity is assumed and should not be and sometimes reasonable adjustments need to be made, working out who does what in a group, making sure that people do have a chance to be able to have a say in getting feedback from people in co-production, being able to talk within a team and being able to give positive feedback, making sure that everyone gets information, and it's easier to read things when it's in easy read or plain English, being able to get minutes and actions so that people know what's happening and what they've got to be able to do, and within a team taking time so that things can be reviewed, because we need to look at what's working, what's not working, and finally, just it's really positive for people with disabilities, to be able to present and do things at conferences, and being able to talk about co-production and working within a team in projects and getting everyone involved.

**Iva Strnadová** 53:56

Thank you so much Julie and thank you everybody for your attention. Now we will move to questions.

**Leanne Dowse** 54:04

Perhaps I can jump in and just answer a couple that are kind of lurking around there. Carolyn asked very early on why we using the term co-production. I think Patsie, you've come in and and also asked the question. So Carolyn's question was about what's the difference, or why we're using co-production versus co-design. And then Patsie come in with a similar question, which is about why we're using co-production instead of inclusive research. So we've opted to use the term co-production for, I think, a range of reasons. One is to bring into alignment what it is that we're doing in inclusive research with other disciplines. As co-production is recognised as a process, it doesn't just happen in disability research. it's common in other lots of other marginalised groups, but and so we are using the umbrella term inclusive research, but we've often felt that there just isn't enough meat on the bones of what inclusive research really means. And so we use in all of our guidance documents, that the idea that co-production is the way to do inclusive research. So it's about the application of the principles of inclusive research to actually the practice of research in terms of the difference between co-design and co-production. And I know Carolyn has pointed out that the Australian government uses co-design, but to us, co-design is only one part of the process. So a design process might be everybody giving their ideas about what a project should investigate, what it should look at, and how we do it, whereas co-production looks at every possible stage of the research process. So anyone interested in that, we already have two other previous guidance documents which set out in detail those different actual processes. The research process is design, implementation and then dissemination, then reflection. So we see co-design as being only the first part of the whole process of there's not really an umbrella term that works, but we've opted for co-production because we feel it goes beyond co-design. Okay, I don't know if that's answered any questions, but any other questions.

**Jackie Leach Scully** 56:21

We have a couple more. We've got about three minutes before we end, but we have several comments and questions, and I'm running through them, looking through them as quickly as I can, because I know that you've answered a couple. There is one question from Jody, which is asking about the key differences between the new resources in comparison to the original. And I think that might mean you're referring to the first guidance that was produced from the DIIU about four years ago. Is that correct? Because if that's the case, these are are not and relaunch of those that their new set of guidelines around ethical issues in co-production, in particular, if I've misinterpreted that, maybe you can pop a question in the chat again.

**Leanne Dowse** 57:19

If you're Interested in finding them, the DIIU website has a resources tab, and you can just go straight there, and they're all now listed and available. And we've designed this third one assuming that you've already kind of looked at the previous two. We do refer to them in the guidance. The other thing I think we didn't mention also is that in terms of sort of detail about how we developed, the actual guidance, the literature and the methodologies we've also we will also have a background paper which talks about how we actually did develop this one. So they are quite distinctive but interrelated.

**Jackie Leach Scully** 57:59

Okay, thank you. There's a link to those guidelines in the chat for that everybody can see. And I think there was a final slide right at the end of this webinar that has a QR code, which means you can also link to that, to the those resources through that tech route, Carolyn, right at the end, has a question here, asking very quickly, if these resources will be used by the NDRP, I would hope so, since they commissioned them and paid for them in the first place, and they'll be used in the sense that the applications and projects and so on will be evaluated in accordance with these guidelines, and of course, they'll also be distributed beyond the NDRP and to other places that will be ethically evaluating co- production type applications in the future as well. Can I just thank everybody for attending on what, at least in Sydney, is a really lovely, sunny day when you could well be outside doing other things. And to our speakers, of course, and for all their work in the past couple of years in undertaking this project, as I said, you can learn more about guidelines on the website, and the website also will obviously include more information about the DIIU itself. So thank you, everybody. Iva, Julie Leanne, our Auslan interpreters, and also to people who've been in the background supporting this webinar, Kate and Michelle, thank you.