

What is Neurodiversity The history, current research and the positive impacts of inclusive science

CARLO CAPONECCHIA:

Good morning, everyone. Welcome to this, our second inclusivity seminar. I'm sorry, I'm getting quite a bit of feedback at the moment, so we may need to turn some of our microphones down. Thank you so much. Good morning and welcome. My name is Dr Carlo Caponecchia, I am the Associate Dean Equity, Diversity and Inclusion in the Faculty of Science along with Professor Sarah Brough. And I'd really like to welcome you to our seminar this morning on neurodiversity. Before we start, I'd like to acknowledge the Traditional Owners of the land on which we meet. I know we're all on different country at the moment, so I'm coming to you here from Gadigal land and I'd like to pay my respects to the Traditional Owners of Gadigal land and thank them for their care of this place and extend that respect to their Elders past, present, and emerging, and welcome any Aboriginal and Torres Strait Islanders who may be with us this morning. And if you'd like to, I encourage you to just recognise which country you're joining our meeting from this morning perhaps in the chat.

We have a great panel today to talk about neurodiversity and I'm very keen to introduce them to you. Just a quick note before we do get started, that the session is being recorded, so if you need to leave the presentation early for whatever reason, or you miss something, you can always come back and watch again, and we'll be sending you a link to that recording to everyone who's registered for the session when the session is done. We also really encourage participation. This is a conversation more than a presentation. So, do post your questions in the chat and we will come to those questions during the course of the seminar.

Today's topic is neurodiversity, and I'm really happy to be hosting this topic. It's an extremely important topic and one that I don't think we really speak about enough in this space of Equity, Diversity, and Inclusion. I'd now like to introduce our great panel that's gonna be talking with us this morning. So, firstly, Lehan Zhang is a data science student who's currently in our faculty, in Faculty of Science. She's currently completing an internship full-time as well while she finishes off her studies. Lehan is the student rep on the Faculty of Science Equity, Diversity and Inclusion Working Group, or SEDIWG. Hi, Lehan, thanks for being here.

LEHAN ZHANG:

Hi, thanks for having me here.

CARLO CAPONECCHIA:

It's great to have you here, Lehan, and it's really important to have a student perspective on these topics, so we really appreciate that. We also have with us today Professor Julian Trollor. Julian is a professor of neuropsychiatry and heads the department of Developmental Disability and Neuropsychiatry in the Faculty of Medicine. Welcome, Julian, thanks for being here.

JULIAN TROLLOR:

It's a pleasure. It's great to be with you all.

CARLO CAPONECCHIA:

And also with us is Dr Jane Hwang. Jane has a background in psychology and is a researcher in the Kirby Institute, and she works in intellectual disability, autism, and ageing. Welcome, Jane.

JANE HWANG:

Hello, it's great to be here. Just to make a small correction, we have now moved to the school of population health.

CARLO CAPONECCHIA:

Thank you for correcting that for us, very good. I know we're all gonna be very interested to hear about your research on autism spectrum disorder across the lifespan as well, which I think is really important, rather than only talking about children, so we're looking forward to that.

So, where I think that we need to start this morning is at the very beginning, as they say, which is to clarify the concept of neurodiversity. It's a broad umbrella term, and we may all have slightly different understandings of what's included in that term. And so, I might throw this one to you, Julian, first up to help us understand what do we mean by this term, neurodiversity, and what does it relate to.

JULIAN TROLLOR:

Thanks, Carlo, and welcome, everyone, to this important topic. Essentially, neurodiversity is a relatively recent concept and it refers to our ability to understand that there is variation in the human brain and its functioning in all sorts of domains, including the social domain, our social skills, learning capacity, our basic cognitive functions like attention, but also things like our mood and other mental functions. It's a term that was first coined, it's thought, in the late 1990s by Judy Singer, who is an Australian sociologist, and she helped popularise this concept. And in its essence it represents, I think, a shift from a medical model viewing particularly developmental disorders and other differences as conditions and disorders to be treated under a medical concept, through to a social construct. So, viewing those with neurodiversity as a part of the breadth of human experience and not something to receive a medical cure, but, I guess, there are limitations of the construct. Not sure if we want to discuss those now or leave those to later. Progressively, the term has also widened. So, although it began as a construct particularly around autism, it's been broadened to encompass other developmental disorders, intellectual disability, and things like attention-deficit hyperactivity disorder. And even in some spheres, people with core mental health conditions, such as schizophrenia, bipolar disorder, mood disorders, have really developed an affinity to this construct of neurodiversity.

CARLO CAPONECCHIA:

Wow. So, that's a really broad range there. It really is a wide term with a lot of potential inclusions. So, how do we manage that? I guess that means we need to always say what we mean when we're using that term because we could be referring to intellectual disability at some times, and other times to mental health issues, and at other times to autism spectrum disorder, for example. Is that right?

JULIAN TROLLOR:

Right, but I do think at the fundamental level we just need to appreciate that the human brain and its functioning varies from person to person. And so, essentially, we're dealing with a person first, and I think having a person at the centre and not necessarily a focus on a disorder or dysfunction is the important point.

CARLO CAPONECCHIA:

Sure. We might use that to talk then a little bit about some of the language issues, cause you're talking about putting the person first. So, as I understand, there are some controversies and some different preferences regarding the language that people wish to be used. And this is summarised as the person-first language, as opposed to identity-first language. Can you tell us a bit about that?

JULIAN TROLLOR:

Yes, this is really interesting, in that people who are neurodiverse vary in their preference in terms of language. So, for example, I deal a lot with people with intellectual disability and people with intellectual disability prefer people-first language. So, always the preference is people with, or a person with, intellectual disability as the lived experience. But the preferences of those on the autism spectrum vary. Often people who are higher functioning would prefer identity-first language. So, I'm an autistic person, is an example of identity-first language. But some people, and particularly parents of children with more severe autism, prefer the language to be different and to be person-centred. So, I think there's no one-fits-all here. We probably need to ask the person what their preferences are in terms of language and how they'd like to be addressed and how they view their own neurodiverse experience.

CARLO CAPONECCHIA:

Sure. So, Jane and Lehan, do you have any views on this language issue?

LEHAN ZHANG:

I definitely think it's a personal preference issue. So, I think the most important thing is just to respect who you're talking to and if they prefer identity-first or person-first language, to respect what they choose, yeah.

CARLO CAPONECCHIA:

Great.

(CROSSTALK) Go ahead.

JANE HWANG:

I was trying to say, I have nothing to add. I think it's been summarised very beautifully by both of you.

CARLO CAPONECCHIA:

I thought while we were talking about just getting familiar with this concept, Julian, you also touched on some of the controversies that exist in this area. So, I wondered if we could explore those a little bit more because it really helps to understand what the controversies might be. Yeah.

JULIAN TROLLOR:

Thanks, Carlos. Look, I think some of the issues that strike me as problematic, particularly when the

neurodiverse aspect is promoted as relevant to people with more severe forms of disability. And I think this is particularly apparent in, say, people with intellectual disability and autism where the concept of variation as part of the human condition is still relevant but it may trivialise, or minimise, the functional impact of the particular condition for the person. But also when we are initially assessing a person and their functioning, we run at risk if we just run with a social model of underplaying the potential medical, or contributing factors to the neurodiversity and functioning differences. A simple example would be, there are some conditions associated with the experience of autism spectrum symptoms that have core medical, or even genetic causes. And if we start with the social construct first without providing adequate medical or detailed assessment, we might miss some really important contributing causes to that functioning difference.

CARLO CAPONECCHIA:

So, it's really about getting the right balance, tailoring that to the individual.

JULIAN TROLLOR:

That's right, and I think both can coexist. And because we know that people who are neurodiverse often experience health and mental health issues, we need to understand that having a wholistic framework that's not particularly biased or dominated by either the social or medical model, but has the person at the centre and has a holistic approach to supporting the person where they need that to optimise their functioning is an important principle. And also just thinking about how the more social models, and this is where neurodiversity comes in, informs how we as a society should be changing to ensure that neurodiversity is valued within our society. And that those who are neurodiverse are supported to participate fully in every aspect of life, including education, which, of course, is one of our key focuses here at UNSW.

CARLO CAPONECCHIA:

OK, do you think that, given we've talked about the inclusion...

(COUGHS) Excuse me, the inclusions of neurodiversity being so, for want of a better term, diverse, do you think that there's sometimes a desire in the lay community to try and say, oh, someone's on the spectrum, where on the spectrum do they sit?

I get a sense that people are trying to do that and it may not be necessarily the best strategy.

JULIAN TROLLOR:

I think it's perhaps a mistake to view anyone who is different to yourself as having some issue or having some neurodiversity. I think it's almost a subtle form of labelling. We're noticing difference, we don't relate to it, we're searching for an understanding, and so we might raise the issue of whether the person is somehow on the spectrum. And I think that's an unfortunate thing. I think we should be valuing difference, not seeking to label it, and we should be relying on the person and what they tell us about their own experience and whether or not they choose to disclose that they're neurodiverse or not, I think is not really relevant. I don't think we should be second-guessing.

CARLO CAPONECCHIA:

Sure. That's great. I think that's also a really nice segue to where I wanted to move next, which is to actually hear about some lived experience. So, just so everyone knows, we've done a lot of planning

for this session and we've talked to Lehan earlier, and, Lehan, I'm gonna come to you now. I understand that you're willing to share some of your lived experience in this area. I acknowledge that sometimes that creates a burden for people with lived experience to have to stand up and be their own champion. But I do understand you're willing to share some of that experience with us, and so, I know we'd all be interested to have the benefit of that. Lehan.

LEHAN ZHANG:

Yeah. Sure, definitely. I really agree with Julian about what he said earlier about the differences because I actually went through 13 years of education having no idea that neurodiversity was a thing, or that I potentially was struggling with a lot of the related mental health issues. So, it wasn't until at the end of the first year of university that I actually went to my GP and went to a psychiatrist and said, look, I struggle with all these issues of burnout, with anxiety. And so, I actually got a diagnosis of ADHD and anxiety at the end of first year of university, which led to my psychiatrist and I having discussions about autism spectrum disorder, which I actually had no clue about until then. And so, after doing a lot of my own research, that's how I came find that I identified with a lot of the points of being on the spectrum. And that's what I identify with, although I haven't gotten an actual formal diagnosis, because in Australia, once you pass the age of 18, you don't actually have the Medicare supports to get a fee-reduced diagnosis. So, if I was to get a diagnosis, that would cost me thousands of dollars out of pocket, which, as a student, isn't affordable.

CARLO CAPONECCHIA:

Wow. I had no idea about that issue of diagnosis costing so much money after a certain age. That's fascinating, I had no idea. Thank you so much for sharing that.

It is really important, I think, in seminars like this to hear about real stories and experiences. So, thank you. And I wonder, while we're still talking, if you could reflect on the language issue. So, if we try and demonstrate some of the things that we're talking about, what's the language that you prefer, Lehan?

LEHAN ZHANG:

Yeah. So, personally I prefer that I acknowledge as an autistic person, but in regards to my ADHD and my anxiety, for that I don't consider myself as an ADHD person, I just consider myself as a person with ADHD and anxiety.

CARLO CAPONECCHIA:

OK, so it's different depending on which experience we're talking about, even?

LEHAN ZHANG:

Yeah, definitely.

CARLO CAPONECCHIA:

That's great. OK, do remember to keep putting your questions into the chat and we'll come to those and feed them through our discussion But where I'd like to move to now is to start talking about research and to find out a little bit about the research that some of the members of our panel have been doing, especially in relation to ageing. So, we might move to you now, Jane, to talk a little bit

about that research. You've been doing research on autism spectrum disorder, and particularly with adults. So, typically, most of the research, as I understand it, is done with children. And I think a lot of people are probably familiar with that kind of research and activity that there are, for want of a better term, strategies or treatment programs to help children develop cognitive and social skills. But you're doing research with adults. So, perhaps you can tell us a little bit about the kinds of research that you do, the kinds of main findings that you've had, and the methods that you use.

JANE HWANG:

Yeah, absolutely. So, yeah, the focus of my research has been on understanding the needs and the circumstances that surround middle-aged and older adults on the spectrum, Carlo, as you put it. You know, traditionally people tend to associate autism with childhood and as a childhood condition, and you'll see it portrayed, you know, not only in research but also in popular media and things as well. It's much more associated nowadays with younger adults and things as well.

Autism doesn't go away, it is a lifelong condition. And in the same way that there isn't a dedicated research agenda to ageing and lifespan issues in the general population, I've been trying to spend some time filling those gaps in our understanding of how ageing might affect autistic adults. Sorry, I'm just going to decline a call. Yeah, so I think, first and foremost, it's very important for you to know that there is very, very little known about autism in older age, particularly 50 plus, even 40 plus. The literature is growing, I think, especially in recent years, as people begin to realise that there's a need, but there are still major gaps. So, especially in ageing specific issues, things like retirement, independent living, dementia, social needs, and health care needs as people get older. Things that are quite well-researched and understood for the general population, unfortunately, the understanding just sort of lags behind a lot. So, in terms of my work, I might share with you one particular study that might be of interest to you and relevant today.

CARLO CAPONECCHIA:

Yeah, please.

JANE HWANG:

So, that's some qualitative research that I did with older autistic adults and carers, where I asked them what it means to them to age well as an autistic adult. And I think what the findings unveiled was something very much aligned to this concept of neurodiversity. So, the idea for the work actually came from looking at this theory or model of ageing well, which was becoming very popular in the general population. And it was a model that was quite aligned to a medical model of disability and it basically said, OK, if you want to age well, you need to tick off A, B, and C, criteria. And the criteria were things like, you know, maintaining good social connectedness and being free of disease, etc. But the important thing was, it said that if you have any disability or condition, that in and of itself detracts from your ability to age well. So, obviously, being researchers in our field, we take a bit of offence to that. They're basically saying if you have a disability then you can't age well. And so, we sought to reconceptualize ageing well in a way that's more relevant for autistic adults. And what I found was that when we thought about this concept, no adults actually said in any way, or hinted in any way, that their neurodiversity, or their condition, was a hindrance to their ageing well. So, rather, their criteria for ageing well is much the same as non-autistic adults. You know, they want to stay fit and healthy, they want to maintain healthy relationships with people, have financial stability.

It's quite the same, what they desire, and how they would conceptualise it. But the only difference is that each areas of these lives are, in a sense, coloured by their neurodiversity. So, they display difference. They also want to maintain healthy relationships, but the specifics of what they consider a healthy relationship might look a little bit different. So, I guess this leans more towards a social model of disability, where it's not necessarily the condition itself, but the circumstances that surround the person living with a disability that determines their level of disablement, or in this case ageing well. Yeah, so, I guess, an implication of that finding is obviously to focus less on what they can or can't do, or what autism, you know, how it affects their ageing. But it's more, how can we support autistic adults to go about their daily activities with the same amount of comfort, same amount of confidence, as your typical adults by attending to those disabling things in their environment? Yeah, so, I think that was quite an interesting finding that aligns well with sort of what we're talking about today.

CARLO CAPONECCHIA:

It's really interesting that the whole model, the concept of ageing well, basically cut people with disabilities out. That, in itself, is really highlighting a big problem in some of the ways that we approach our theory making. That if our theory can't apply to a whole segment of the population, then our theory probably needs revision. So, that's really interesting, reflecting the idea that you have to talk to the people who are ageing to ask them about what it means to age well, I think that's kind of a summary of what you're saying there. I imagine that there are some challenges in doing this work, and probably ethical challenges, practical challenges. So, I wonder, Jane, and maybe Julian, you can jump in here as well, if you can tell us a bit about how you have sought to have people with disability as partners in your research and how you've worked with them to create this research.

JULIAN TROLLOR:

Thanks, Carlo. Perhaps, Jane, feel free to jump in. It's very important when considering research within the field of disability to engage in inclusive research practices. Often there are various terms used to describe inclusion, or participation, of people with disability in research itself. But right from the get-go, it's very important that the research is conceptualised with input from people with neurodiversity. And it's key that the research questions being asked are relevant to people who experience neurodiversity. It's important that the conduct of research engages and involves people with neurodiversity. And that the outputs and products and translational capacity of the research is informed by the wishes of those who are neurodiverse. So, you can see that the whole research cycle, in fact, should be very much with the person, or people, with neurodiversity or disability at the centre. And so, I think we've moved quite remarkably in this way from seeing people with disabilities or neurodiversity as people to be studied, to be embedding those on the spectrum, neurodiversity, and people with disability as core partners in the research. But for me as a medical practitioner and medical researcher, this has been an incredible shift. I come from a neuroscience background. We're used to conducting studies by cognitive neuroscience, neuroimaging, etc, research being done to participants. And it's been a big journey personally, and that's been informed by disability colleagues here at UNSW, disability researchers and their practices. But it's been encouraged too by groups like the Autism Cooperative Research Centre that funds Australian longitudinal study, Autism in Adulthood. And the autism CRC has been very much set up upon the basis of inclusive research

practices. And so, it's been a delightful journey, and one which is very enriching, I think, in both directions.

CARLO CAPONECCHIA:

Jane, would you like to add anything there? I was also wondering about whether the methods that you used led to change. I mean, you were talking about doing really qualitative work. Do you have any reflections on that?

JANE HWANG:

Yeah, I think, obviously, qualitative work, proceeding a lot of the areas where we don't have, you know, robust understanding. So, first consulting with autistic adults and the actual autism community about, is this research, is this topic important? What aspects of it are important? And really coming in with a mindset where we don't assume anything. I've been, I think, extremely lucky to have built a network of autistic adults and family members who have been extremely generous with their time in helping me to design and conduct research. And they tend to be, you know, very, very, extremely generous and happy to share their lived experiences for research. And for that, I'm very grateful. I do tend to think of it, I guess, when I come into a research project, you know, really considering inclusivity at four different stages. In conceptualising it, in conducting it, so, you know, the materials, recruitment materials, questionnaires, any sort of writing or instructions that's prepared for autistic people, is it autism-friendly? Because it can impact findings, also in our interpretation of the findings. That's a step where once we've collected all the information, we then write a discussion in our papers. But is that really the correct way for us to interpret those findings? And also, how they're disseminated. So, the research findings need to go back, obviously, to researchers and practitioners, but also to the autism community so they can also learn more about autism and about the research that's being done. Yeah, I think one of the biggest challenges is definitely always trying to avoid being tokenistic in the way that you include autistic people in your research. So, it's not just about ticking a box. OK, I've had someone say that this research is meaningful, it's really about having them drive the research and it can mean that sometimes things take a bit longer. Yeah, it's embracing the fact that having those processes really means that you come out with research that is meaningful and impactful.

CARLO CAPONECCHIA:

That concept you said about making the materials, the recruitment materials autism-friendly, I wonder if we can drill down into that a little bit to give a bit of an example. I sit on one of the ethics committees, and their materials, they're not friendly, I would argue, to anyone. I'm probably not supposed to say that, but they're quite dense.

Can you tell us a little bit about what you mean by making the documentation autism-friendly?

JANE HWANG:

Yeah, definitely. I mean, ethics materials is always a challenge because there are set templates that you have to use. Autistic people can struggle with ambiguous language, different types of words, areas in the text as well. Sometimes things like contrast between the visually, the text and the background, and things like that. So, there's a lot of different things that you need to consider. Yeah,

so there is that struggle of trying to work with existing set processes and trying to make them better suit the people that you want to approach. Yeah.

CARLO CAPONECCHIA:

But, I guess, you also have people there to consult with, to check whether those materials are going to be easier to interpret and how they can potentially change. And that's the idea of working together in sort of co-design, I guess, yeah?

JANE HWANG:

Yeah, definitely. With the questionnaires for the longitudinal study that Julian mentioned as well, we had several autistic adults go through them and pilot them and give us a bunch of feedback about what they liked about it, what they didn't. And they're very honest. I love that about, you know, you just continuously learn about how you can make the research better suited.

JULIAN TROLLOR:

I think, could I just jump in there and add to that? One of the surprising things for me was to discover that many of our standardised writing instruments that we would apply to the general population asking about health, or mental health and wellbeing, are inherently biased and have assumptions about the person's wishes, functioning, social participation, etc. And it wasn't until we, in fact, engaged with autistic people in the design that we were informed about this. Now, sometimes you can change things and sometimes you can't because you're using a standardised measure, you can't readily adapt that, maintain its validity. So, there are limitations to that. But, I guess, as we get more cluey, perhaps things can be designed in a more holistic manner.

CARLO CAPONECCHIA:

OK. We might move now to talking a little bit about education and students, because for most of us we're in an environment at university where a lot of what we're doing is interacting with a whole bunch of people who are learning and many of us are teaching. And so, I thought it would be a really good lens to place on this discussion as well.

And, in fact, one of the reasons I was keen to have a seminar like this on neurodiversity was because of some of the statistics that I came across from Equitable Learning Services, ELS. And I'll admit, I was... I guess I just didn't know that, but what I found in those data is that about half of the students that go to ELS requesting assistance are requesting assistance for mental health experiences. And the next most common thing that students are asking for assistance with is neurodiversity. And it's about a quarter. So, after mental health being 50%, the next quarter is neurodiversity, including autism spectrum disorder, ADHD, and Asperger's syndrome, and also, I believe that includes Tourette's syndrome. I thought this was really interesting because it's never been presented to me in that way before. And while that is an underestimate of what's going on in our student population, it still shows us that the relative proportions of what our students are experiencing. And I think justifies us talking about this issue more. So, I wanted to come back to Lehan now as well to talk to us as a student and to talk a little more about maybe some of the experiences you've had, Lehan. I wondered if there might be one or two sort of experiences you've had in studying that have been difficult or challenging or interesting that are related to this topic that you could share with us.

LEHAN ZHANG:

Yeah, definitely. So, as Jane mentioned before, everyone on the spectrum experiences difficulty related to their neurodiversity in very different ways. Me personally, I struggle sometimes with interpreting ambiguous language and, in particular, in a uni setting, interpreting assignment topics and questions. So, one particular experience, in first year I took a psychology course where we had to write an essay based off a very ambiguous topic that was given to us. And so, I wasn't sure if I was interpreting the question right, so I brought a draft with my main points and my main understanding to my tutor. And I just asked her for clarification on if I was interpreting the topic correctly. And my tutor actually told me that she wasn't allowed to clarify my understanding due to unfairness. And so, to me, that was uncomfortable, because I then went on to write a whole essay and spent a lot of time doing something that was actually unrelated to the topic and I got marked down for it. So, if I had just gotten the opportunity to clarify my understanding initially, that wouldn't have happened.

CARLO CAPONECCHIA:

Wow, that's interesting, and, I guess, a little disappointing. Although, I know that that's sometimes a common kind of justification that teaching staff give, that they feel conflicted about providing too much information. So, what do you think that could have been done there? What do you think could've been done differently in that scenario to provide clarification for you, but also maintain, for the tutor, that sense of not giving the game away, so to speak, a sense of integrity around the assessment? Is there anything that you think could've been done differently that would have achieved both of those things?

LEHAN ZHANG:

I think it's hard, because as a student in that position, like, if you were to get that extra support, like you would kind of have to disclose the issues you're suffering with. So, you would have to say, I'm autistic, I have trouble interpreting this, and for a lot of people that's really uncomfortable. And for myself at that point, I didn't even realise that I was on the spectrum. And my strategy at that point was, I think, like, this is around the time that I actually was starting to get my diagnosis and I got told about ELS, so, Equity Learning Services, so I actually went straight to them. And through them I was able to get access for future courses to tutoring services, where they would have an external tutor, like, help me clarify the questions. But I think just like being in class in those situations, I think tutors need to be more aware of, I think, being able to identify the difference between clarifying the question where someone has clearly attempted to like, work towards a solution compared to someone who isn't putting in the effort to learn because people, a lot of people are often, like, very interested in the topic, and like, very keen to work on their assignments. But, like, when you get pushed back like that, it's quite a discouragement for you to continue to like, pursue the subject.

CARLO CAPONECCHIA:

Sure. I guess, in some ways, you know, in learning and teaching, we talk a lot about feedback. Maybe the shift is to view what you did as feedback to us. Not feedback at the end of the semester, but real-time live feedback to say, there's something that's not clear here and maybe you can find a way to help. And, I dunno, it strikes me that for a teacher to take an example from a student and say, well, maybe you could think about it in this way, or you could think about this example, or you could go and do some reading from this paper, is actually something you could do to provide support that you actually don't need to know anyone's diagnosis or difference. That kind of action and help

everybody without needing to know that this person, this student has a difference, in these terms. So, I think there are some real challenges there. We have some questions from our audience, and I encourage our audience to keep putting in some new questions, but we have some questions about educational support. So, I'll give these up to the panel, as well as you, Lehan. One of our audience members is asking, What are the implications for educational support for those who are autistic in higher education, especially if you're not able to get a diagnosis due to costs?"

JULIAN TROLLOR:

Carlo, perhaps I could jump in as a clinician and help here. So, I think there are various levels of diagnostic assessment that can be performed. So, a clinical diagnosis can be given after a detailed assessment by an appropriately qualified professional. Often that's a clinical psychologist or a psychiatrist. Now, there are significant costs often associated with that, but it may not extend to the couple of thousands of dollars required for a much more detailed and formalised diagnostic assessment using a standardised measure. There are many screening questionnaires that can be administered that are free of charge within that clinical diagnostic context without the need to necessarily undertake the very detailed assessments that are part of a standardised diagnostic assessment. There's some really good guidance on this with the Autism Cooperative Research Centre releasing guidelines on diagnosis. And I think it would be helpful for those interested in knowing what the recommendations are about diagnosis to look at that website to get a sense. Because, clearly, I think in order to go to ELS and ask for specific adjustments, it's important to have things clearly documented. My sense is a clinical diagnosis is adequate for that purpose, that's a less expensive prospect.

CARLO CAPONECCHIA:

OK. That's really important information. What we might try to do is to ensure that, that link is put into the resources that we're going to send out to people after this seminar. So, we'll find that one, and make sure that everyone who's registered will get access to that. So, thank you, Julian, for that. We also have another question here about practical changes in relation to education. So, the question is, What are practical things that UNSW staff can do to create a supportive environment for staff and students who identify as neurodiverse? So, maybe this is something that we could get each of our panel members just to give us a bit of a reflection on. So, maybe we'll come to you, Jane, first.

JANE HWANG:

I don't know if it's necessarily practical, but really raising an awareness and capability among teaching staff is very, very important. The university does have the FULT course, which is the Fundamentals in University Learning and Teaching that we all have to do. So, building in something into that course that allows staff to recognise and sensitively deal with. Obviously, we don't want to be handing out labels to students while we're teaching, but just to know that it's a possibility. And, you know, I've definitely come across neurodiverse students in my teaching and they've felt comfortable enough to speak to me about it because of the nature of the research that I do, but I can imagine it's not that easy for other students. So, sensitively dealing with it, also offering flexibility in the way that they teach and then the way that they assess, I think, would be beneficial. Relatedly, I think, some of the administrative processes could be made better. Cause really the only option to students at the moment is, you know, if they're having certain issues to approach ELS, or to put through special consideration to get a doctor's certificate and request an extension. And, you

know, sometimes that's not a reasonable ask, especially if there's something happening on the day of an assignment, or something, you know, there's a meltdown, a burnout, or if there's, you know, it's really the nature of the actual task that they're struggling with. And, obviously, if they're in the process of figuring out what they're experiencing for the first time, while they're in higher education, it's a bit silly to say, OK, just get a doctor's certificate and that'll deal with it. So, yeah, I can definitely say I've bent, not broken, bent certain rules for certain assignments for class participation. The purpose of course activities is to assess how well a student is engaging with, and grasping information given to them. And as long as the teacher feels that the student is doing that to a satisfactory extent they shouldn't be tied down with processes. So, I think that's... Yeah.

CARLO CAPONECCHIA:

No, that's great. Thank you. What about you, Lehan? What kinds of practical things do you think university staff can do to support neurodiverse people better?

LEHAN ZHANG:

Yeah, I definitely agree with the point that Jane made, and especially because I think a lot of issues that neurodiverse people will suffer from, and especially such as those on the spectrum, easily burn out or suffer with social anxiety and anxiety-related issues, which impact assessment. And, in terms of special considerations, especially with things that you're suffering which may not have physical symptoms, it's really hard to kind of go to a doctor, especially if you're feeling burnt out, and then have to explain yourself, especially if you don't know what you're going through. And so, dealing with the bureaucracy around the administration, that like, a lot of people just end up dropping out of courses or not being able to continue because they feel like they aren't able to scale back and kind of sort out their mental health-related issues, like, with support from the university. And I know it's difficult, especially in more STEM quantitative courses to allow for different ways of showing your understanding of the material. But I think that allowing more scope and different ways of assessment would benefit people who learn in different styles. Especially, I found in a lot of my STEM courses, like, with online learning now, a lot of the assessment tasks are just like Moodle quizzes where you don't get marked on your answer. And especially for people with ADHD who are prone to making mistakes, you can easily lose entire 20% of your grade because you aren't allowed to show your understanding of the course materials. So, I think it's important to allow different ways for people to demonstrate their understanding.

CARLO CAPONECCHIA:

Sure. So, would that be in doing assessments through different formats, like allowing people to create websites or make videos or diagrams or those kinds of things? Is that the kind of thing that you mean, Lehan?

LEHAN ZHANG:

Yeah, obviously that's hard to implement in a lot of courses, but having more flexibility with that and even in the chase-up process. So, for example, if you get marked badly for an assessment, like having the staff have some understanding of allowing people to then showcase their understanding of the material in a different way. For example, coming in for like, a one-to-one meeting, for example, being like, this is how I interpreted it, this is my understanding, let me show you what my assignment wasn't able to.

CARLO CAPONECCHIA:

They're really good suggestions. Maybe also giving opportunities for people to make choices in assessment, to choose a format that might work best for them, or to ensure that across the assessments there's some different kinds of tasks that you can do. OK, and Julian, practical things that university staff can do?

JULIAN TROLLOR:

Thanks, Carlo. Look, I think one of the most important things to recognise in this concept of neurodiversity is strengths. So, many who are neurodiverse have incredible strengths in particular areas. And those can be really relevant to specific courses, to creativity in certain areas. So, recognising the strengths of the person, valuing diversity in the way we approach every aspect within our UNSW community. Having the opportunity for leaders within the university community to identify as neurodiverse is very valuable, because it instantly enables students to relate to people and see that those who are neurodiverse can be successful and thrive within the environment. And, I think, ultimately ensuring that we're flexible enough in the way we're teaching and supporting so that when we do have a comment, such as the one Lehan took to her teacher, that we prepare to stop and think, hmm, clearly there's an issue here. Perhaps we've designed this assessment in an unhelpful way and we could do a better job. Often when we are challenged by a student, defensiveness kicks in because we're short of time or resources, and so the easiest thing to do is just to say, put the hand up saying, no, sorry, we can't do that because, rather than just take step back and say, hey, I think we need to adjust things here.

CARLO CAPONECCHIA:

Sure. I really think that idea of focusing on strengths is a really nice way to round out our seminar today. So, thank you for that. We're approaching the end of our time, and so, what I'd like to do now, given there's no more questions from the audience, is really thank our panel for their time and their expertise today. So, thank you, Jane, Julian, and Lehan. It's been great to have you with us. We really do appreciate this, and, I guess, we see this as the start of a conversation. I don't think we were necessarily having the conversation yet. And so, I hope that this can be a real start to this and I look forward to more discussion and more action, in relation to neurodiversity in the future.

I just want to make a couple of notes that remember that the presentation today has been recorded, so you can check back with it and we will be sending out, as we mentioned, a short survey for all our audience members. So, it'd be great to have your feedback on that survey and we'll send out some resources with that email as well. So, do look out for that one. I also want to mention that if any of the things that we've been talking about today have raised challenging issues for people, please know that there are several sources of support that you can access. And those include a counselling service through the university and, of course, for staff members, the university's employee assistance program. If you need to know where to access those, you can just look for the wellbeing websites on the university's home page. They're very easy to find, and if you can't find them, come and hit me up and I'll help you find them, as will our EDI team. Lastly, a reminder, this is the second in our series of inclusive science seminars, and our next one is on next Tuesday where professor Sarah Brough will be hosting a session on gender and artificial intelligence. And that promises to be a really interesting session as well. And so, we hope to see all of you there for that session also next

week. I think that's all from us. I'd also like to thank our EDI team and everyone who's helped to put our event together. So, a big shout out to Andrew Addie, Mikaela Viray, Sarah Brough, Morgan Sutton, and, of course, the support of our Dean, Professor Emma Johnson, who's a really great supporter of Equity, Diversity, and Inclusion work across the faculty and the university.

That's where we'll leave it this morning, everyone. Thank you so much for being here and for participating, and enjoy the rest of your day.