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

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
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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

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...

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.

about that research. You've been doing research on autism spectrum disorder, and particularly with

It's quite the same, what they desire, and how they would conceptualise it. But the only difference is

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 admeeng ( )-5.5 (w)ef1.2 (e):

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

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,

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 reley4.1 (me)-5.5 (d)-C(e)0.7(c)2.2 (a)-1.9.7(y4.1l7(e)0.7((e)0.81-0.7(e Tc 0 Tw 9. (e)0.81-(

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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.