

MAULISHA CHAWLA:

Good afternoon, everyone, and welcome. I'm Maulisha Chawla, and part of the equity, diversity and inclusion team at the School of Biotechnology and Biomolecular Sciences Student Society. We've been working with the science, equity, diversity and inclusion team at the UNSW to bring today's seminar on Neurodiversity Movement in Science. I would like to start our discussion today by acknowledging the Darug people, who are the Traditional Custodians of the land from which I'm speaking today. And I would also like to pay my respects to the Elders past and present and to extend that respect to other Aboriginal and Torres Strait Islander people who are here with us this afternoon. If you would like to, I would encourage you to recognise which land you are joining from in the chat. Today's session will be recorded, so if you need to leave early or miss any part, you can watch this again at your convenience, as the link to the recording will be emailed to everyone who has registered. We encourage active audience participation, as this is a discussion, more than a presentation. Please use the live Q&A chat function for any questions you may have and we will address as many as possible. OK, so I'm very pleased to be hosting today's discussion topic on neurodiversity, which is an important concept in terms of equity, diversity and inclusion. To begin our session today, I'd like to introduce you to our panellists. We'll start off with Isabelle Vertucci, who is an Equity Program Coordinator. Isabelle.

ISABELLE VERTUCCI:

Hi, everyone. Thanks so much for having me on your panel today. My name is Isabelle. I work in the Central Peer Connections team here at UNSW, which essentially looks after all things, peer mentoring and peer support, specifically for new students coming into the uni. I was once a student of UNSW myself as well, and I have a physical disability, which is probably the reason why I have so much passion in the area of disability advocacy. After leaving uni, I went and worked in the disability space for about five years. And now I've come to the university and wanna do as much as I can to change our conversation around disability, include a bit more disability pride and really change the visibility of disability at UNSW as well, which is why I started as a disability champion from April. And I'm really passionate about making sure that we have a really great community of disability, especially amongst students at UNSW.

MAULISHA:

Thank you. We have Dr Samuel Arnold, as well, on the panel today.

SAMUEL ARNOLD:

Thank you. I'd like to acknowledge the Gadigal clan of the Darug nation. So, thanks for the opportunity to speak today. I'm a psychologist. I only do a little bit of clinical work. I work mostly as a lecturer and researcher at the Department of Developmental Disability Neuropsychiatry (3DN) School of Psychiatry NSW. Just finishing a postdoctoral position with the Autism CRC, the current Collaborative Research Centre for Living With Autism. And I'm also the convener of the Australian Psychological Society (APS), the Psychology of Intellectual Disability and Autism Interest Group.

MAULISHA:

Thank you, Samuel. We have Aaron Bugge from the Faculty of Science.

AARON BUGGE:

Hi, my name's Aaron. I started studying at UNSW in 2020. And I'm in Advanced Bachelor of Science

and we're majoring in Neuroscience and Microbiology. I'm a Neurodiversity student and a proud member of the LGBTQ community. I was diagnosed almost four years ago, well just a little bit of four years ago, with ADHD and all the other subset disorders that are associated with it, like dyslexia, anxiety and mild depression. I've also been diagnosed with binge-eating disorder and dissociation disorder stems from childhood trauma. I struggle with being organised and get overwhelmed really easily. All that being said, I love advocating for neurodiversity, and I'm also part of a first of its kind, student project called Diversified, which I'll discuss later on. They'll also be links added into the chat for those who are interested in finding out more about Diversified and also who people who are wanting to register to the event as well, which will be discussed later on. Thanks.

MAULISHA:

Thanks, Aaron. We have Associate Professor Iryna from the School of BABS as well on the panel.

IRYNA:

Hello, everyone, and thank you very much for inviting me to be part of the panel today. I'm in the squad of Biotechnology and Biomolecular Sciences. I'm a geneticist and my research is on the molecular genetics of autism spectrum disorder. So that's one of my links to neurodiversity from a research standpoint. I have also been involved with Albert, in a relatively small capacity, but have been involved in the Autism Cooperative Research Centre that was mentioned earlier. And I'm aware of people on the autism spectrum being heavily involved in the governance of that Cooperative Research Centre, which is a very interesting approach to driving research. Also, from a more personal standpoint, I really think that, you know, diversity is a very important concept in the way we all live and work, especially in a highly creative research space such as, you know, running a lab on understanding the genetic basis of neurodevelopmental disorders, but also in education where we work with students with so many talents and so many different neurocognitive traits. So, I'm very grateful that you guys have organised this event.

MAULISHA:

Thank you so much to all the panel members, and we truly appreciate your time to be on the panel today. So, just to give a little bit of context. Our discussion is based on two articles that explore different concepts and issues about Neurodiversity. First is a scientific article published in The Lancet titled,

THE NEURODIVERSITY CONCEPT:

Is it helpful for clinicians and scientists?" It expands on the benefits of adopting a neurodiversity-based approach to research, in addition to the disorder-based framework, both of which have one aim; to provide evidence based strategies to support people who identify as neurodiverse. The second is a Forbes article titled "From

DEFICIT TO SUPERPOWER:

Is It Ableist To Focus On Neurodivergent Strengths?" It is authored by Nancy Doyle, who is the CRO of Genius Within, a company specialising in the organisational science of neurodiversity. The article focuses on the delicate balance between celebrating the strengths of our diverse people and placing too much pressure on people who identify as neurodiverse to perform and demonstrate unique abilities and to be superhuman. But before we dive into this, we think it is important to understand the term neurodiversity itself. It is very broad and general term and different people can have

different interpretation of what it includes. So, we might start off with Dr Arnold. Sam, what is your understanding of the term neurodiversity and how might you define it?

SAMUEL:

Thank you. So, I think in understanding neurodiversity, I think of biodiversity and its link to that term, and we all know how important biodiversity is. And so neurological diversity would also appear to be very important, and that helps us to focus on difference as opposed to deficit that, you know, there's no one single way for a human brain to be wide, that is the wide way. And that generally difference is a good thing. It's not good if everything, when everyone is the same. It's a benefit to all of us, to the human project, if we do a better integrating, accommodating and supporting neurodivergent people. That's what I think.

MAULISHA:

Yes, thank you for that definition. Isabelle, what's your viewpoint and how would you define neurodiversity?

ISABELLE:

Thank you. I was thinking about this question and I was thinking about it more potentially from a bit of an advocacy and disability perspective. And I was looking at two models of thinking, and I know that these are brought up a little bit in the articles as well. But we have been mostly brought up and a lot of conversations still to this day is around thinking about the medical model of disability. So, in this model, we look at an individual and we look at what makes them abnormal. We look at what makes them dysfunctional and especially in the neurodiverse space. We've looked at the person and seen what was wrong. And generally, this is a model where we look at somebody as well and think about how they need to be fixed or cured in order to participate in society. But now, what we're really trying to push for and what we're trying to get people to think about a little bit more is the social model of disability. So, the social model of disability looks at disability being a social construct. So, this indicates that the disability is caused by barriers in society, which is very relevant when looking at the terminology of neurodiversity. It's not to say that there isn't difference or that people don't have an impairment or that that's not impactful, because that would be to discount the challenges that neurodivergent people have overcome, as well as their strengths and uniqueness and their individuality. But it's the notion that people should be neurotypical in order to enjoy the full range of extreme and experience, and that that shouldn't be the case. An impairment shouldn't constitute a limit to access or inclusion, and the onus should be on society to change in order to create a more inclusive space. So, I think that one of the ways that we kind of picture this and this is actually taken a bit of a quite taken by People with Disability Australia, which is a really great organisation that really encourage people to check out. And they say it is not the inability to walk that keeps a person from entering a building by themselves, but the stairs that are inaccessible, that keeps a wheelchair user from entering that building. So, it's really flipping that model on its head. And I think that that space really gives us a lot of room to celebrate difference and to encourage and celebrate looking at people's strengths.

MAULISHA:

Absolutely. And just on, you know, the importance of accessibility and the importance of including the social model of neurodiversity, The Lancet article also talks about the importance of adopting a neurodiversity-based research. So maybe, Iryna, can you give us a brief outline of your research,

potentially also examples of projects where neurodiverse individuals have collaborated on research, design and the advantage of this?

IRYNA:

Sure. So, I'm working on understanding the genetic basis of autism, particularly from a molecular genetics standpoint. And as The Lancet article mentioned, autism is a very heterogeneous condition in that a lot of people who have the same clinical manifestations, in fact, have very different genetic makeup. And so, that is something that we're trying to understand in terms of the focus of research. And we're also trying to understand how these different genetic makeups converge. Because they do converge at some point in terms of cellular functions and their behavioural outcomes. Now, what I would like to mention in terms of the definition of neurodiversity as well and relating to the Lancet paper. So, definitely, a lot of us have been brought up with the thinking of psychiatric and neuropsychiatric conditions in general as being a dysfunction. And what everyone in the research space is more and more recognising is that it is really a very wide spectrum. And it's not only ADHD and autism spectrum disorders, anxiety, depression, psychotic disorders, bipolar disorder, all of these things actually are neurocognitive traits that exist in the general population on a spectrum. And so it is this diversity that is important and that is a rich resource of us humans, right? So, all of these traits exist on a spectrum, and that's what constitutes diversity. Now, it is, you know, there is a neurotypical model. And so each of these traits would represent some sort of a difference from being neurotypical. But at the same time, it does not mean that it is something wrong or a disorder for everyone who has some variation across the spectrum.

But at the same time, one needs to acknowledge that there is a point where a trait becomes a disease. And I think this is a very sort of difficult line to draw, perhaps, but it is also important to draw it. And it is important for helping out people who need the help. And I would be curious to know what other people think. But personally, I would say that at the point where someone suffers because of a neurocognitive trait, that's when we go from a trait to a disease. And now, we can discuss the fact that oftentimes the suffering, as Isabelle said, it can be caused by the way the environment is structured around you. And so there are situations in which society contributes to these suffering and stigma is an important way in which this happens. And so in terms of research projects where neurodiverse individuals have contributed to research, I briefly mentioned the Autism Cooperative Research Centre, where people who are on the spectrum contribute to and make decisions on the type of research that is undertaken. And I think that is an incredibly important contribution to selecting the research that is relevant to people with lived experience. Now, at the same time, at the very severe end of the spectrum, there are people who don't have a voice. So, people with autism who are so severely impaired that they cannot speak or so severe in their repetitive behaviours that, you know, they really suffer from self-harm. At that end, people don't have a voice. And I am wondering and I feel a need to be cautious in terms of how far we draw the distinction between diversity and disease to not ignore that and where people can't really communicate how severe their suffering is and how much help they do need in that space as well. And that's all from me. I think I may have overrun my time.

MAULISHA:

Thank you very much for that explanation and your interpretation of it and the importance of, you know, getting appropriate help for the people who need it. I just wanted to also quickly ask Sam, can

you give us a little bit of an outline about your research and maybe some projects that you've collaborated with neurodiverse individuals?

SAMUEL:

Thank you. So, for the last four years or so, being primarily focused on the Australian Longitudinal Study of Autism in Adulthood, which has been funded by the Autism CRC. And then a lot of related projects and student projects relating with autism and all of this work and work into the future as well, we really try to use an inclusive research approach. There's different levels of inclusive research, sort of consultation at the lower end up into co-production, where the research is done together in partnership with autistic researchers and even other levels where the autistic person does the research supported by as needed academic colleagues. I guess the ones that might be of interest to talk about have done some things around employment and loneliness. But perhaps going back to some of the earlier discussion, I think one that's interesting in this space is recently we co-produced and I should also mention, sorry, that the licensed co-production partner with the Autism CRC in recognition of some of this work. So, with Julianne Higgins, who's an autistic adult and peer-researcher, I'm really disappointed that Julianne's won't be talking about this with us today. So, Julianne, together, we've done a project around autistic burnout. So, autistic burnout is a condition which can be quite significantly impairing. It's characterised by social... you know, social, interpersonal, aural, and exhaustion. And it can also impact on functioning and executive functioning in other areas of life as well. And this autistic burnout appears to arise from the stress from autistic person in their everyday life, the stress of unaccommodating neurotypical world, amongst other stressors.

And there's also conceptually this concept of masking or camouflaging, this idea that an autistic person needs to hide their autistic traits and their identity in order to interact with the neurotypical world. And then over extended periods of time with that that the effort of masking and interacting in a world that's the other level than your typical world can lead that autistic burnout. So, I think that sort of gets to that social model aspects around where does the disability arise from. And going back to collaboration to do that research on autistic burnout, to do it well, I really couldn't have done it by myself. I really needed Julianne who is an insider researcher having experienced autistic burnout, being an autistic person, to really understand and communicate in that depth of existential experience. It's not something that could be done without using an inclusive research approach. In just one or two last examples, I'll try and make it quick. Loneliness, we're doing student projects around loneliness, which I thought was really interesting, and the inclusive research is through a consultation process. The autistic advisors, they're ready to highlight it to us that although you might want to be alone, that doesn't mean that you also experience loneliness, so understanding sort of that concept. And then in the future and inclusive research approach that with people with intellectual disability, I'm excited to be starting a project that's looking at contribution as an outcome measure that we all make contribution and that sometimes the contributions that we make, unless they're valued with the dollar figure, are sort of overlooked. And so we're trying to refocus how we value people focusing on the contribution that we all contribute in different ways and looking to measure that as an outcome linked to a happy, valued life. So, hope I haven't said too much. I hope that was interesting. I'll hand back.

MAULISHA:

Absolutely. And just about speaking on the importance of the experiences of individuals who identify as neurodiverse, I think both articles indicate that environment structured based in accordance with neurotypical perspectives can be limiting for neurodiverse people. So maybe, Aaron, could you reflect on the experience of neurodivergent people in higher education and their experiences?

AARON:

Well, reflecting my own personal experience of being at a neurodiversity at UNSW, which I would definitely say is probably a neurotypical environment, it's been quite challenging. As navigating my way through my first year has been really tough, like starting uni at the age of 30 and being diagnosed (UNKNOWN) ago I signed up to be at UNSW and for me academically, it's all just so new to me and I feel that it sounds like a brand new environment to adapt to. I'm trying my best, but it's like fitting a circular block into a square hole, it just doesn't fit. And it just makes me question myself over again. And, I guess, like things like neurodiverse movements like this, for example, and also did the Diversified project that I'm part of. I slowly, through that university environments, will have to adopt. I'm like more like circular-shaped holes.

In order to cater to neurodiverse perspectives to be heard, so the current framework can be upgraded because it just, yeah, it doesn't work for me, and I'm sure there's many other students that feel the same way. And also the distance being...like, more awareness around neurodiversity now like, I guess, neurotypical perspectives and neurodiverse perspectives can somewhat intertwine into a more manageable, feasible, yeah.

MAULISHA:

Yeah, thanks for that, Aaron. And speaking of that intertwining of narrative, I think the Forbes article discusses like the deficit versus superpower narrative. So maybe, Isabelle, could you explain how important it is in terms of our community?

ISABELLE:

Yeah, sure. When I was looking at this article and I was looking at how they were talking about the deficit versus superpower narrative and how to find balance in this, I think that the conversation is at a base level around how we value people. So, I think it was great that Iryna brought up the real variety of experience of people who are neurodiverse and that you have people in that experience as well who have very high support needs. And why is it that we value people more if they have that quality or contribution that can be capitalised on or has some economic benefit? But we have people with high support needs who are valuable because they exist and because they are a beloved family member and they are a person who should have just as much value in society. But we can't monetize that so they don't get that same level of respect and value. So, I think it's a question around the fact that people should potentially never have to earn their value and respect. And when we're looking at this deficit versus superpower narratives, we're sometimes focusing very heavily on the superhero strengths, which is great. I don't think that there should be a situation where we have people who do wonderful things that benefit society and we don't celebrate them. There should definitely be space to celebrate greatness, celebrate skill and celebrate wonderful achievements. But what are we leaving out of the picture and are we not discussing people who have potentially the soft skills, you know, and that's a term we generally use around qualities that are a bit more loving

or bring joy to people's lives or are really empathetic or maybe creative in musical ways or other things like that, potentially they don't get the same kind of spotlight. And so then when we're looking at a UNSW context and maybe why this is important in the UNSW framework and in our community, in our society, I think that it's important that we continue to praise, highlight and create disability across a variety of human experience. So, we look at all kinds of different kinds of experience with new diversity, and we celebrate achievements and strengths and skills and wonderful things that people are doing in lots of different areas, and not just areas that are going to benefit capitalism or benefit our economy. But we look at lots of different wonderful ways that people are contributing, and we try to continue to have these kinds of conversations as well, because I think that there's nuance and we need to continue to talk about these sorts of things so that there is space for everyone. And it's the space for us to talk about all different kinds of people and think about how and question how we value people. So, I think that this is a really great first step, but we also just need to keep pushing for greater visibility. We need lots of wonderful, complex, intersectional people getting highlighted for lots of different, wonderful reasons. Thank you. That's me.

MAULISHA:

You know, I absolutely agree with you that the importance of having a continued conversation about this. Just as well, Aaron, maybe what was your insight on this from your own personal experience?

AARON:

Oh, I totally agree with what Isabelle has just said. It just makes so much sense just to not like value someone's like (UNKNOWN) as well. I think that like, in a neurodivergent perspective in, say, like a problem-solving kind of environment, it's just so valuable. And I think that's maybe definitely more awareness and just more movements like this starting to happen because we don't know where it's got to end. And I think from my own experience, I find that like being diagnosed four years ago with all the disorders that I mentioned before was just like such a blessing in disguise.

Like, it just feels like there's like an invisible weighted blanket being lifted off you. And I just, like the more light you feel, the more capable you feel that you are within society, if that makes sense. And like, on this path of like being four years diagnosed, like it's taken a lot of energy and effort, and... a lot of time and energy. It's like find out what the strengths and weaknesses are. And even though there's been a lot more troughs and peaks on this journey, there has been much light at the end of the tunnel. And even though I don't have consistency yet with like what I would call like an activated state of flow, like a flow state, which like when I'm involved in something that I'm passionate about, like it's like I feel capable and I just feel that knowledge and fully functional. But that doesn't happen all the time, and I feel it like, yeah, it's just hard to keep consistency with those types of things. And that can be classed as a superpower for me, but also like some like being organised on a daily basis, especially like factoring in things outside of duty. It's just so difficult for me to manage that. And also, I can label hydrophobicity like being in a flow state, a superpower for me, but there's many people that can't identify or associate like their journey, and they're just sort of that. So I guess we just have to be mindful. Remember that like, not everybody sees that sort disorder as a superpower as well. So, yeah, that's all for me.

MAULISHA:

Yes. Thank you so much for sharing your experience. I really wanted to hear from you and how diverse the experience can be. The Lancet article states that individuals with similar clinical presentation can have very different neurocognitive and genetic profiles. Arina maybe this question is to you. What does this mean in terms of the significance of the clinical model of neurodiversity? I know you indicated a little bit about it in your first question, but if you have something on it?

IRYNA:

I mentioned that and indeed there is evidence that people with very similar presentations have quite heterogeneous neurocognitive and genetic makeups part of it can be about the way we measure things. So there is a lot more to be done in the research space for us to be able to measure the neurocognitive traits in a way that is reliable. So part of the heterogeneity that we observe can come from the way the things are measured. But at the same time, there is undoubtedly a wide range of neurocognitive phenotypes within groups of people that are diagnosed with autism spectrum and even the same disorder within that. And moreover, the parents of people who are diagnosed with autism spectrum disorders very frequently have measurements of the different neurocognitive traits that are not in the disease range, but are quite far away from what one would consider the standard range. So there are even from a genetic standpoint, we can see this wide spectrum of neurocognitive traits. So that does link into the neurodiversity concept, which again, I do want to mention that it applies to almost all areas of mental health. We do think about it, and the discussion has come about a lot more for autism and ADHD, but we can definitely apply it to anxiety, depression, and so on.

MAULISHA:

Yeah, and while we are on the subject, speaking about the clinical model, I wanted to touch on diagnosis, so the fourth article says that the only way to apply to, the only approach to the diagnosis of ADHD, autism, dyslexia or Tourette syndrome was to focus on what is perceived as broken. Sam has this approach changed in diagnosing neurodivergent people? I think you are on mute.

SAMUEL:

Thank you. I've got it. So I think it comes down to individual practitioners and diagnosticians that we are seeing a shift in just to say, well, your diagnosis is a tricky hard task, though, and it does come from a medical model that's still value and utility. Definitely in diagnosis, though, the hard and fast lines as being discussed are difficult at times and some are grey. Focusing on autism again, the Autism CRC released diagnostic guidelines. I think one of the interesting parts of that is that in these guidelines for autism diagnosis, they recommend a support needs assessment is done prior to the diagnostic assessment. So shifting that focus away from just simply deficit to perhaps also more importantly, what supports recommendations it might need to be put into place to help empower and achieve a good life back to the individual practitioners part and one of the projects that I've been involved in with being developing an impact of diagnosis scale. So trying to understand sort of the psychological impact when somebody receives one of these diagnoses focusing on autism to begin with, but it might be an area that we can explore, something we can explore in other areas as well. And what's been at least somewhat heartening from our Australian data that we've gathered so far focus on autism is that most autistic adults sort of were relatively positive about the clinicians who were helping and supporting them through the diagnostic process. Then what was really

problematic was the post-diagnosis support that there was very little for autistic adults once they received the diagnosis, and almost to the point of why do I go to all this effort to get a diagnosis when it doesn't make me eligible for NDIS and doesn't really help me access any other support because there's not a lot that was out there. So I think that's an area I need more work on. Another thought is I was chatting with Tony, Dr Tony Attwood, many of you might be aware of and something that he does, which I think is really great, and to help shift that deficit focus is when for anybody recently diagnosed through his clinic, he has a resource CD, DVD and a sort of a something that he shares with people that talks about both the strengths and the difficulties and possible avenues of access, support, and strategies that might be helpful. And just the last thing, if I could, I just want to go back to the Forbes article. I think sometimes it can be a language that we use sometimes, and it might be better for us to talk about aptitudes and abilities rather than superpowers or genius or things like this, that not all autistic people have genius-level abilities. And though the majority of autistic people, I'd suggest, would have their differences and different ways of thinking, that can be really useful in the employment work that we did in this area, they're starting to talk about the autism advantage. I think that's a good way of thinking about some of these things. And for somebody who is newly diagnosed, that there might be individualised accommodations that are needed to harness this autism advantage and there might be difficulties still, even with accommodation. So there is strengths and differences that are important that we need to harness here. Some of those accommodations that we need to make overall is that to achieve, you're trying to achieve a more inclusive and welcoming society where people are allowed to be themselves, amongst others, and they don't have to mask or camouflage their identity. Thanks.

MAULISHA:

Thank you for highlighting on that language barrier when it comes to either addressing neurodiversity or addressing individuals who identify as your device is definitely something that we need to learn from and also from what you mentioned before, the need for support. Maybe, Aaron, if you could comment from current initiatives and programs that are in place or in place at UNSW for students and how might we improve them to better support students?

AARON:

So, as I mentioned previously that I'm working on a project to student-led co-production project called Diversified, which has the aim to alleviate neurodiversity awareness and the student voice and costs. So we are wanting to create an inclusive, accessible world that works on replacing the typical hierarchical teacher-student relationship with peer-to-peer relationship, creating a culture of cooperation and inclusivity. Information about this project has been added into the chat, so if anybody's interested in registering, please register and come along to the up and coming events. The first workshop is this Friday and workshops will be mapping issues and responding as a team. It's also producing activities, creating prototypes and strategies to make courses more inclusive for everybody. So basically, we want to get like the students' perspective. Can you re-diverse student's perspective specifically, just to find out what problem students are having in regards to anything really related to UNSW like their coursework? Because, like I for sure have many problems that I've kind of experienced, and we just basically want to cluster all these problems together and then run workshops to find solutions which will then be showcased to UNSW to gain traction, to try and change and raise awareness for these things. It's exciting times. And yeah, the links have hopefully,

then added into the group chat for everybody to see and potentially register if they're interested. But yeah, that's it for me.

MAULISHA:

Thank you for that. And just on that in our post-event email, we'll make sure to add that if anyone's interested to take part in the Diversified program. Speaking of program control, maybe Isabel, if you could quickly give like an outline of the connections programs that you've been involved with at UNSW for students and the opportunities that people can get involved in.

ISABELLE:

Absolutely, thank you, and thanks, Aaron, your project sounds so fantastic, I can't wait to check it out. That sounds so cool. That's amazing to hear about students doing such amazing things like this for other students.

So from my perspective, what I've been working on most recently is I have started up a program called Activate UNSW. It's on its third iteration now, so it's starting to really gain momentum. And essentially, this is a peer support program for students who are new to UNSW who identify in some way with having a disability, a long-term illness, or mental health condition. And they can join this program and be mentored by senior students who also identify in the same space and also had some social opportunities. Because something that I feel really passionately about is I think we have some fantastic in classroom sports, our educational adjustments through the equitable learnings, our team is fantastic, but I'm really passionate about the co-curricular space and making sure that there is still space alongside our learning and our academic lives for fun where people feel like they can be included, they can really let go and have fun because I know as a young person back in the day, I feel that that is a space where you really find yourself. You really have opportunity to be trusted, to take risks, and be silly, and date, and all of those things. And these are really important to finding our identity, and I feel that everyone should have access to this. And so I've started this program is a little bit of a start to build some community because I think something that we need to work on a little bit more at the university is being a bit more proud of having disability. There's absolutely nothing wrong with having a disability with needing some extra supports. Disability isn't a dirty word. It's not a rude word to say about somebody that they have a disability. It's something that we need to talk about a little bit more, and it's something that we need to create more space for as well. So I wanna start promoting all kinds of social opportunities around the university that are accessible and make sure that all of our different kinds of opportunities as well have space for people to say what their needs are. And I think that's a really important thing.

And we do have quite a few accessible, different events through ARC and all of these sorts of things, but we need to just talk about it a little bit more, promote it as an accessible event and a space where disability inclusion is welcome and these sorts of things. So I'm definitely working on that. In activate, we also run a live chat online peer support program as well, which essentially is a very non-committal way of coming online and getting a little bit of support. It means that it can be a little bit more anonymous. It means you don't have to sign up for a program. And we have some really great trained students who are senior students, and they can then help you out. You can ask any question you want and they can talk you through finding a good community space as well. Something that I do recognise, though, is that we are complex, intersectional beings, and I want us to have choice. I

don't want us to feel like if we have a disability, we have to go into the disability program. So something I'm trying to do with my team is to work on every different kind of peer support program around the university and see how we can make them more inclusive as well. And likewise, in my disability champion work, we're looking at the whole university. We're doing a bit of an audit at the moment and seeing where people are being left out, where there are barriers and how we can break them down, and where we can make spaces more inclusive. But yeah, that's just a little bit of what's going on. And I hope that actually next year as well, we're going to have a little bit more to promote as well while we continue to grow and create more community spaces. And absolutely the most important thing as well in all of this work is that everything is done in collaboration with students, students as partners, students, voices at the forefront of everything that we're creating. So it's that real nothing without... nothing about us, without us, and I really wanna make sure that that is at the heart of everything we do. Thank you. Thank you for that run down, Isabelle. And just on promoting a great deal of discussion, I can see that a lot of people have raised some questions in the chat, so maybe we'll go through some of them and address them as well. So just having a look right now. There's a question from a panellist, Josie B. I understand she might be also involved in Diversified. That said, as someone who has ADHD, anxiety, severe TBI depression, I completely understand the burnout so much closer. But I wonder how much of this is environmental. And so maybe Sam, if you want to address that question?

SAMUEL:

So I can only speak to the autistic burnt-out research that we did and which suggests that the environment plays a large factor in the stresses leading to the autistic burnout from what our participants and were telling us. And I think in other areas that will probably apply. Also, the burnout construct itself is a bit separate to autistic burnout, that there is a burnout construct that's a bit contested around what's burnout, what's depression, what's the separation between them? Burnout historically has been linked more so to employment, but there's this, then you're seeing it applied in other areas like autism, of course then. But,, students and other people who aren't necessarily employed or carers getting burnout. So I think it's an area that's a bit contested and controversial at times. But I think you have the autistic burnouts going back to the question. Definitely, the environment and accommodating aspects of the environment that the person has to navigate daily, the toll and the ongoing stress and fatigue that's leading to the more acute intense debilitating burnout states.

MAULISHA:

Absolutely. Just on that, as well as some people asking, is there a way for them to take part in research such as yours?

SAMUEL:

Unfortunately, at this point, all the studies are not recruiting at this point for these studies, the autistic brain out. We were hoping to continue work in this area, but we haven't secured funding to do it at the next stage of research that we would like to do, though hopefully into the future. The work I'm doing around contribution is only starting in the near future, though we're not recruiting at this point. My apologies, but thank you though, for participating in research, we need people to participate in research in order to move things forward. So when you see the research, recruitment

things come out is very difficult to recruit. So I encourage people when you see recruitment opportunities come up to take them up then.

MAULISHA:

That's a great point, you bring through. A lot of folks here are researchers or students who are in science or researching and part of research. So it's a really good point you bring this and moving, and the next question is probably to Isabelle or maybe Aaron as well. How can service delivery for people who identify as neurodiverse be improved and adapted to meet varying individual needs? So maybe Aaron.

AARON:

I guess through this Diversified project, students are going to be able to bring their personal problems into this project and then find solutions on bringing forward from this, but also like how to implement these solutions within a university environment. So I think getting on board for this project would be one thing, but also like I think that like this might have something to do with ELS or something like that, but equitable learning services, but potentially like a more, (SIGHS) what's the right word?

More suited kind of like learning plan for students, more personalised, I think, would be a better way to go through this, I think as well. Yeah, I think, yeah, yeah.

MAULISHA:

Thank you for that. Isabelle, do you have anything to add to that?

ISABELLE:

Sure, I absolutely agree with you, Aaron. It's all about personalisation. And the only way that we can do that is to ask the question, ask students what they need, what they want and create programs that suit that and then be willing to adapt because times change. Look at this year we've had a year of constant change and constant uncertainty. We need to move with what the students need and how they move and change. So we need to be ready to be adaptable and flexible and constantly have our ear to the ground. So making sure that there are very clear feedback channels so that students can speak to us at any time of the program, but so that they also have choice and control. And I know that this is an NDIS catchphrase that choice can control one, but it is really important for empowerment for students to feel like they are being heard, they're being understood, and that we're creating solutions to their problems that they've addressed. So I think that's the most important thing for creating things that suit diverse and individual needs and making sure that we have programs that are set up so that we have support for each person as an individual and we're not creating big blanket. It rolls because one person has expressed one need. That's for me, thank you.

MAULISHA:

Thank you for that insight, and we're going to move on to the next question on, someone asked, is it common for people diagnosed with autism to also have other neurodivergent relatives who may be probably to you Arina have you seen that in your study?

IRYNA:

So I think Sam could answer that question, so probably he's more in the clinical space than I am, but that is absolutely the case. So, for example, anxieties of frequent traits associated with autism, obsessive-compulsive behaviours are part of the autism spectrum. Sam, any other thoughts from you? You're muted.

SAMUEL:

Just to the concept of the broader autism phenotype, I think is related to this question where they find I think it was touched on before that there can be, yes, there's more often that there will be siblings in the family or other relatives who are also autistic if there is an autistic person in the family. But then they can also be people who might make what's called the broader autism phenotype where they don't have that, meet that sort of cut off the diagnosis of autism. But there are still several traits or characteristics that are more heightened levels than you might otherwise expect.

MAULISHA:

Thank you. And that gonna answer the question. Just maybe last question before we start wrapping this event up. Chelsea also say that, I think that there is way too much shame wrapped up in the neurodiversity experience. How do we lift that change in a tangible way? And I think, Isabel, you were talking about creating sort of community and listening to individual needs.

That might be helpful?

ISABELLE:

Yeah, I think that shame is the result of us fearing ridicule is the result of us hiding things away. It's the result of not having visibility and not having open conversations. It's the result of students having educational adjustments, but feeling like maybe if they talk to their tutor that there's something wrong with them or that that tutor doesn't know how to speak to them and they feel there's an all, there's real awkwardness about it. All of this is part of the student experience right now, around shame and shame around who you are and needing support. And I think that the best thing that we can do to try to keep lifting that stigma and keep lifting all of our appearance of disability at the university is the opposite of shame, which is pride and showing that we are a proud community and that we are proud of our identity as disabled people or as people with disability and continuing to create more and more visibility. Continuing to create more conversations, continuing to have spaces where students with disability can talk about how they want to speak about their disability and if they have a disability support plan or an educational adjustment that they need a space to say to tutors, OK, this is you can ask me about this. I'm not ashamed of it and we need to start having more spaces like this where we can have really great conversations. And I know that they're going to be some really great more talks coming up in Diversity Phase two. So I definitely encourage everybody to go along to that and encourage your friends to as well, because the more that we have visibility and pride in who we are and have more people with disability coming out and speaking about their strengths and about the challenges as well and about how they wanna talk about the challenges, this is a really good thing and this is gonna keep moving us in the right direction.

IRYNA:

If I can just quickly follow up on what Isabel just said. It's really so important, and I'm really hoping that everyone who struggles with any kind of disability really nurtures that sense of pride. And the reason why I'm saying that is that oftentimes, when someone has a disability and achieves something, the effort that it takes to get there is so much greater. And believe it or not, a lot of people who cheer for you just last semester I had the student in class was doing so despite a disability that was, I could see how much effort went into that and I was quietly cheering that he would do amazingly well in in the course, just because I realised that that really we should probably even mark twice as much for getting to the same point for the effort that went into that. So, yeah, I really hope that everyone is trying to nurture that sense of pride and all of these initiatives that you guys have on the programs are really great.

MAULISHA:

Absolutely agree with you there. Keeping in mind the time we have now reached the end of today's event. Thank you everyone for joining us virtually. And I would also extend a sincere thank you to our wonderful panellists for sharing your expertise, experience, and time with us today. I have learned a lot and I know the audience have also learned a lot and hopefully, we've gotten a few more initiatives that we can get behind. A huge shout out to Natalie, Lee, and Zoe Webster, as well as the entire team of BABSOC for helping make this event possible. I would also like to thank Mikaela and Carlo, from UNSW Science EDI, for guiding us and helping us with the first student-led Inclusive Science Seminar. And again, this presentation is being recorded and will be available to those who have registered for this event. We also have a limited number of copies of the book 'Nothing About Us, Without Us' that we are sending to people who might be interested. It is a great resource to learn more about neurodiversity. If you're interested, please fill in your details in the post-event evaluation form, which will be posted in the chat. Also next week, UNSW inclusive science series event will take place on October 28 and will feature current UNSW Science students as well as they tell stories of their science role models and reflect on the importance of inclusive representation in science history. You can register for the event by clicking on the link in the chat. Thank you everyone and have a lovely day ahead.