- Hi, everyone. Welcome to the disability and identity webinar today. This is the fourth webinar in the series. This webinar is brought to you by the youth branch of the group. This webinar will feature four speakers with different intersecting identities speaking about the experiences of being disabled and identifying or not as a member of the disability community. The discussion will cover a number of topics including the experiences of -- being women, LGBTIQ+ and or CALD experiences of having a disability.

So, firstly, I would like to introduce myself, my name is Akii and my pronouns are they, them. I'm delighted to be your host today. I acknowledge and pay respect to traditional custodians of the land on which I'm virtually streaming today. I'm in Naan, Wurundjeri country of the Kulin nation also known as Melbourne Victoria. Before I start, a little bit of information about me. I would like to give you a visual description of what I look like and my environment for any blind or low vision folks. I am Asian, with long wavy faded dyed blond, purple and pink hair and black roots, from lockdown. I'm wearing aviator style glasses, knows ring piercing, white T-shirt that says you are doing amazing sweetie, black pompom ergs. I'm sitting in a manual wheelchair. Just a bit of information about me you may already know -- I'm a passionate disability and gender equity advocate with over 10 years experience working in Australia and overseas in public health, policy and capacity building. I'm a first generation Aussie from refugee background with a lifetime of personal lived experience of the chronically disabled peer nonbinary person of colour. I live with chronic pain, spinal injury, and a genetic disorder. I'm on the board of disability justice Australia and am a company director. Presently I work at disability sport and recreation managing a wonderful team of five to help support and recite lies the disability sport and recreation centre in a COVID normal world with the aim of helping as many Victorians with a disability to participate in sport or active recreation in a meaningful and safe and supported way. I serve on many advisory panels and committees in the health, disability, gender and LGBTIQ space including the wonderful project steering committee.

Enough about me. I will go through some housekeeping and get into this fabulous webinar today. First off with housekeeping -- for everyone to ensure you are accessing this webinar however it suits you, the top right-hand corner of the screen you will see an X symbol and a circle in the middle of it. That will allow you to enlarge and minimise the full screen. The view will highlight the speaker and the Auslan Interpreter. For closed captions we have a separate screen on the bottom left-hand corner. You can click on the screen to make closed captions your main viewing window and you if want to access the closed caption New Zealand a separate screen altogether click on the icon with an arrow in it located on the top right-hand side of the screen. This will pop out the win doe. All of the screens on the right-hand side have a box with two back and forth arrows. If you click on the start icon of the screen it should take you back to the all screen view. We encourage you to have a play to see which of these functions works best for you. Also at the bottom of the screen on the right-hand side there is an icon with a speech bubble. If you select this, it will allow to you submit questions. You do not need to wait until the end of the webinar to submit questions. We encourage you to submit questions as you go. If at any stage during the webinar you experience any technical difficulties and cannot continue to watch on, this webinar will be recorded and will be available to access later using the same link. You will be sent it via any registration emails. Speaking of technical difficulties, right next to the speech bubble icon is a circle with the letter I in it. If you click this there will be a link called webcast support/live chat. Please use this option if you have any technical difficulties or need any support. Before we start today's exciting webinar I acknowledge -- sorry, I would like to acknowledge and welcome our aunty Yvonne Weldon, who I'm honoured to welcome and hand over to aunty Yvonne Weldon, from the metropolitan land council. Welcome Yvonne.

- Hello, everyone. As was said, my name is Yvonne Weldon. I'm a Wiradjuri woman from Cowra in New South Wales. My ancestors have a continuous connection to the land and waters of the Clare. I'm a representative of the metropolitan local Aboriginal Land Council sill, who are the cultural authority under the Aboriginal land rights act for the land that I am on. I would like to pay my respects to all Elders past and present. To all First Nations and to you and the many Aboriginal nations ancestral lands you are on and representing virtually today d the boundaries of our traditional owners are embed needs the Earth's natural landscapes. The boundaries of the Eora are the Hawkesbury, -- we are the oldest living culture of the world. Wherever you travel on this beautiful country of ours, understand you are enter willing the lands of nations, tribes and clans and that existed before all written words and all history and it continues here today. On behalf of the Metropolitan Local Aboriginal Land Council sill, the Elders and members, I welcome everyone to the land of the Gadigal. I acknowledge the Gadigal people, loss spirits and ancestors will always remain with these lands, other mother Earth. Aboriginal people are inclusive of all from across these lands and crosses the globe.

So whether you come here via foot, air or water, our people include everyone, we don't turn away. We honour all living things. This is who we are will continue to be. All of us must work together to building a cohesive, inclusive and harmonious society that enriches the lives of all of us. We all play an important part of accepting and celebrating all of our differences an we need to do this every day. Bringing us altogether. We can make positive changes for this country now and into the future. And we need to reflect upon the footsteps we're leaving to know where we're heading, shaping our society, our country we can be proud of. All of us together can bring about positive changes to multiple generations starting with healing of past generations by declaring what should not have taken place. To the present-day generations, giving them hope. And creating a future for the next generations for everyone in this country. We are in this together. And we must achieve positive change each and every day. No matter what walks of life we come from we all need to support each other and think about what difference you can make today that will become the mile stones for the future, all of our futures. So, let us all draw upon my people's spirits as we continue on our journey and may my people's spirits walk with you and guide you as we strive forward for us all. Again on behalf of the Metropolitan Local Aboriginal Land Council welcome to Gadigal land. This always was, always will be Aboriginal land. Thank you and have a wonderful day.

- Thank you, aunty Yvonne once again for that heartfelt and incredibly important Welcome to Country. So for those who don't know much about women with disabilities Australia, we're the national disabled person feminine identifying and nonbinary people with disability across Australia for -- almost over 20 years. Our goal is to be the national voice and national force that leads the way for women and girls feminine identifying and nonbinary people to improve the lives and opportunities for our community. We use the term women and girl was disability on the understanding it is inclusive of women and girls, feminine identifying and nonbinary people with disabilities across Australia. The Lead project is an exciting information linkages and capacity building project using step by step co-design and meaningful intersectional community representation to develop sustainable and accessible outcomes in leadership, networking, engagement, empowerment and opportunities to build the capacity both individual as well as community capacity for all women and girls with disability. We are very thrilled to be able to deliver a huge range of activities and initiatives to build capacity and leadership of our community over the next two years using a wide variety of leadership, peer networking and mentoring opportunities including scholarship, online programs and activities. We would like to sincerely thank the department of social services for funding the WW DA lead project. Today's webinar is part of a series of webinars we have been and will be delivering throughout the year. You will be provided a link to access previous webinars and this one when it becomes available today or tomorrow. Towards the end of the webinar I will highlight some key activities and potential opportunities for getting involved in WWDA lead. So the introduction of today's wonderful speakers and guest line up. We have Ash, pronouns they, them. Lee, pronouns, she, her. Margot and Carly OAM. Pronouns, she, her. Firstly I welcome Ash. Ash is 22, neurodivergent, queer, Asian and passionate advocate for centring the lives of lived experience. They work to make space available for people who are often dismissed because of their backgrounds. Bend and would find the lived experience of others and supporting others to share their experiences. Welcome, Ash.

- Thank you. I would like to start by acknowledging that I'm coming from the lands of the Wurundjeri people. I pay respect to Elders pasts, present and emerging. And all Aboriginal and Torres Strait Islander people here today. I acknowledge that the impacts of colonisation are ongoing but this always was and always will be Aboriginal land. I recognize as a child of migrants from Australia I benefit from the colonisation and therefore I must first listen to First Nations people and do the work they require of me. I encourage you to pay the rents and support First Nations people around you and around Australia. Hi, Ash, a 22 year old Asian person with lightish tan skin, long black hair that fades into a brown purply colour and said shave. I'm wearing a purple jumper, orange, red and pink green sleeve and green purple and pink right sleeves. I'm sitting in a room with a mirrored closet behind me to the right and a wall of colourful art on the left. I will start with a general disclaimer and content warning. I will talk about both external and internal racism, homophobia and transphobia. I will use language I use and recognize this is not language everyone else uses. I recognize our communities and cultures are diverse in themselves and I hold a lot of privilege despite my marginalised background and do not want to diminish those who have not been given a chance to have such privilege. I can only share my experiences from me and my perspective. Today I specifically wanted to talk about my experience of reconciling my disability cultural and queer identities. And experience that is come with them and how it affects how I experience the world as inclusive or exclusive. I'm definitely more than queer disabled and Asian but time is a thing so we will stick with those! Going back to when I was a kid, I think my first real reconciliation of my identity that I recall is that mess of unlearning, internallised racism. A big yikes. I remember clearly dreaming most nights that if I magically woke up with blond hair and blue eyes all of my problems would go away. It's horrifying to think about now. I thought being Asian was the reason that things didn't work out. I regret how much I pushed my culture away because I was so afraid of not fitting in. I was embarrassed by my food and my language, my family, my cultural events as a child just because other kids never got the chance to appreciate the things that weren't colonised Aussie culture. I had to allot of internal work there. I'm in a place now where I'm finally coming back to my culture and feeling like I can embrace it and relearn it, which sucks because I shouldn't have to relearn it but I'm glad I am in a place where I'm not rejecting it. It's a low bar, I recognise that. It's very unfortunate. Then I also went through a journey of embracing my queerness, of working through all of the things I was taught. Puberty made it a hard one. But I slowly understanding gemmed what it was for me to be me as a queer person and in all of the ways that I am queer. Then I went on a journey of embracing my disabilities, of being comfortable with being disabled and autistic and so on and allowing myself to find pride in it.

To be honest it still feels like a new journey for me. Whilst I have been advocating for my needs for a long time I was so caught up with trying to make the world accessible to me I didn't get the chance to internally embrace and reflect on that until, well, now, where I finally got some stuff in place that gives me space to navigate how I feel in my disability and have pride with it. I went on all of these journeys and I am definitely still going on them and probably 1,000 more. But there was so much in each that I kind of had to split them off. I'm thinking wow, wouldn't it be cool to have them all fused together and be in a little compact package together? It would be but I'm finding it's really danged hard to actually do that. For example, I have been trying to work out how to reconcile this desire and want to be super openly proud and loud about being queer and disabled. Because that feels really right to me but I have no idea how to fit that into my sense of culture and connection to my family who are the only real connection I have to my culture. This is because my family, especially the side that are refugees are just trying to survive in an Anglo colonial system that is racist. They worked so hard to fit in and force a space here for us to do well. Doing that has included fitting their values into the ones here. Unfortunately, those values tend to be pretty ableist, homophobic and transphonic. This is not me blaming their culture. I'm just saying that for people from marginalised cultural backgrounds, having your identity repeatedly attack and made lesser can push you into adopting whatever you can from the dominant culture to survive and feel valued or accepted. This has made it really hard for me to find a way to reconcile my identities in like an outward way. I am really working at a system that pushes anyone that is different to assimilate and we have to conform to live any sort of easyish life. My current identity struggles and thoughts have on on this and how I could ever reconcile my identity without landing myself beyond my family and beyond my connection to culture. I have done all of this internal work I'm proud of and I want to express that and be really open about it but I feel like I can't or at least not yet and it really does feel like it will be a lifelong work in progress. Some of that is beyond me. I feel this struggle to reconcile identities is a really big thing for people with multiple marginalised identities and also the work that is beyond me needs to started in every space and organisation and person and community, working in intersectional ways. Intersectionality gets thrown around a lot but in a way that actually disregards what it intends to mean. I know some people do it amazingly well and a lot of those people are here today but I have experienced so many thing that did not recognize my identities as being part of a person with experiences that affect that identity. So being diversity inclusive is not being intersectional. Diversity recognizes people are varied and that people are many. Intersectionality recognizes that the specific situation of a person and the way their identities and experiences connect and overlap and merge and shape and all of that in kind of like how that affects how they are made to navigate the world and how the world navigates them, and I kind of need both, so there is an understanding of how I am experiencing the world as a disabled Asian person with my privileges and disadvantages and how it shapes my ability to access things and do things and just be me in the world.

So, yeah, it's like more than having a diverse range of employees and recognising there is a diverse range of experiences; it's actively working with people in a way that recognises their situation and their experiences. That it's intertwined and having really big impacts on how the world sees them and lets them do things. Which is why we have to actually listen to people and take their experiences with as much seriousness and legitimacy as we take the information from academic papers and statistics. It's also why we have to recognize the boundaries of those who are sharing, boundaries of those who do not want to retell their stories. There are limits on what marginallised individuals should be expected to do. Because the world positions marginalised people in specific ways. Sometimes it means we expend all of our energy just trying to survive. And that really can take a lot out of you. I'm trying to reconcile all of these bits of me. I just want people, organisations and the world and everything to start realising that I'm not like one thing. And that all of my bits are not sitting on their own somewhere in my being. I'm not like queer over there and Asian over there and like a young person over here and disabled over there. I'm always all of those things. And I need everyone to start thinking about that and start getting that. Yeah, that's me. Thank you for letting me share my thoughts with you. Hopefully there was something there. Yeah.

- Thank you so much, Ash, for sharing your story and experiences. For those who could not see me I was nodding along with practically everything Ash said as I rest nature with a lot of them, all of the things Ash experienced I have experienced quite often and regularly. We share very similar experiences and backgrounds. Thank you so much for sharing. Next I would like to introduce you to Lilly, who is a proud Wiradjuri woman who suffers severe PT SM, functional neurological disorder or FND and ADHD. Lily comes from a very strong family who survived the stolen generations, intergenerational draw marks identity stripping and poor physical and mental health, inclusive of disability which is a common theme for many First Nations families and individuals including Lily. Lily's goal in life is to show others how to break free from this Commons of having disabilities and other ideas of disabilities and how it has impacted and actively show others you can be stronger than you believe you are. Lily loves connecting with people, connecting to culture and in doing so connecting to others through her art and her voice. Welcome, Lily.

- Hello, everyone. Yes, my name is Lily, -- just like my aunties who were stolen -- I have come interest a stolen generation family as was just described. I would like to pay respects to my traditional owners of the land I'm on, to the ancestors, my ancestors, Wiradjuri ancestors and to Elders past, present and emerging. I will also say my background is blurred. I have reddish faded hair. I have brown hair. I have my emu feathers on. I was found but the women's disability association through a video eI had done about me being described of my identity because of the stolen generation and how it affected my family. And about how my functional neurological disorder and PT SH and ADHD affects my daily life. That was through a blog I had done. As for being a stolen generation family, I have had to fight long and hard about I had identity and connecting back with my family. When the same year of finally being in contact with my family, so last year, I was also given my official diagnosis of my functional neurological disorder. A little bit about FND -- to shorten it up -- basically and the way my newer Rollings likes to explain it, you can be -- it's the brain is totally overloaded. You -- if you imagine yourself sitting still, you are trying to do the task you are attempting to do and the brain just goes I'm going to go over there and do what I want to do, which is nothing. I'm a visualiser. I hope this helps with my explanations through my talk. If you think of it as in a computer. You have got a million and one tabs open. The next thing everything freezes. It's like someone completely wiped the hard drive and there is absolutely nothing there. A lot of the time with FND I get asked is it like executive dysfunction with ADHD. I have both. Executive dysfunction is there are a million and one tabs open at once and you are trying to complete a task from each tab. Eventually you will get it done. It's not frozen, but with FND it's like I said the hard drive has been wiped and there is nothing there and there is nothing you can do about it. It's not something you can fight against it. Commonly the more you fight against to the worse your symptoms will get. For me I'm affected by fad. My brain will not tell my body that I'm hungry until it's too late. At that point I can't physically make myself food. When someone talks about FND ass it's not exactly a disability. I shake my head and I get really frustrated and try to explain to people that it is so debilitating and it varies so much between person to person. You can have someone like myself who I have been told is very articulate and I can present myself very well compared to someone else sitting next to me with the whole right side of their body paralysed for the last three months because they had something trigger them into that state with FND. It's a hugely under researched condition. To help explain that or to look into it further -- again we only acertain amount of time. Please head to neuro symptoms.org. It explains the condition and symptoms. It's seriously debilitating and needs more research put into it. That's how it affects me, in a snap shot T affects all areas of my life. I can forget what I'm talking about as I talk about it. Which I really hope doesn't happen today. If you see me glance down I'm looking at some of the things I wanted to tell you guys about. The other thing is neurological pain. If I'm doing something that I love and that's something that my neurologist explained to me as if you can find something your brain clicks with, like with mine, sharing culture and connecting with art, it's like everything flows through the head, it's not like a huge wall comes up. The more you can do something that you enjoy the better it is for that stress to come off the brain and less symptoms you have. It's about living with as minimal stress as possible, which is so hard to do, especially in 2021. Everyone is dealing with so much stress at the moment.

Dealing with physical and neurological pain. Being unable to speak. My speech will be slurred, reverting back to that food idea. I can't make myself food and I will stop being able to speak and I won't move properly and I will be in serious physical pain. You can have me one minute being able to talk to you guys and in an hour's time I might not be able to move from the same spot in the kitchen for half an hour. That is how crazy the condition can kind of be. One of the things I wanted to touch on is how frustrating it is to live with an invisible disability. Like I said, I was only diagnosed -- got the official diagnosis last year, in December, but there was a point that I wanted to make about I was in high school -- so we're talking about 6-7 years ago. It was the start of year 11. I was struggling badly in schooling because nothing was lining up properly. It just wasn't connecting up. My principal pulled me into the office and said we're removing you from the ATARs section of your HSC because it will affect our ranks and you're not smart enough to do it. I would like to mention that it's about the environment that you're in and you need to be in a space where you are supported by people who understand your conditions and understand that your brain doesn't work like everybody else's. Because I left school and went to uni and I did open foundations, where I submitted a paper for social inquiry or sociology. And I actually topped the sociology degree in my Aboriginal essays that I submitted there and got 86 -- out of the entire university. Just as a note there, please don't give up. You have got something that ticks with your brain, go with it. And just go with it until you can get people to listen to you and understand you. Because the school is not the be-all and end-all and that's the one thing I want to get across to young people especially. Outside of school and having an invisible illness and having people also understand your condition – in a previous workplace I have been in, having somebody say to you oh my God where is your brain today, that's not something that will support you in that environment. If you are in an environment where you are not being supported in that way that that your condition needs, please speak up, say something. It is 2021. People can't get away with talking down to people who have whatever condition it is that is going on.

As far as my FND and with the way it gets talked about in relation to where it comes from -- like I said, head to neuro symptoms.org, but it is said it's related to PTSD symptoms. As I mentioned earlier I'm a stolen generations surviving family. My aunts and uncles were taken as young as the I think of three years old. They all also experience FND symptoms. They have not been officially diagnosed, but disassociation and brain fog are two of the huge ones we all experience. Being able to connect to culture and connect through people is a huge way that we can push through that, especially for myself -- culture is imperative to my condition and being able to deal with it. I don't know how much more time I've got. But that's basically about me and my condition and how important it is to find something that your brain connects with and being able to push through it and have people around you understand and be on your corner. Stay true and stay strong.

- Pardon me. I was on mute. Thank you so much, Lily, for sharing your experiences with FND. As someone with FND as well who was recently diagnosed at the end of last year, beginning of this year I completely understand those challenges. It's a very under researched -- very little understood condition. You have explained it really, really well. Thank you for that. Definitely makes me feel quite valid. Thank you for sharing your experiences. The next speaker we have is Margot, who is a political economy and history student at the University of Sydney. Where she has been a disability office bearer since 2019. She is a current member of the WWDA youth advisory group and PWDA's pandemic project. And has been involved in the disabled and neurodivergent workers alliance and disability justice network. Her analysis has been published in militant monthly. Welcome.

- Thank you. I acknowledge I'm calling in frat land of the Gadigal people of the Eora Nation. This land was never ceded, never sold, nor bartered. This always was and always will be Aboriginal land. My name is Margot, by way of a visual description, I'm a 27 year old white trans woman with very dark inky blue hair. I'm wearing a thick gray jacket and big set of black over the ear head phones. So, I, like all of today's speakers, am a disabled person. I suspect though that I come at it from a different angle namely as a historians and as the political economist. This might seem a strange way to approach identity. Something so intensely individual, so personal and shaped by lived experience. To me, however, both history and political economy are about lineage. We aim to understand where something has come from and in so doing understand how that something was created, what it is made up of and ultimately how we can shape it, change it or indeed overturn it depending on the particular something we're looking at. And often what we end up finding completely revolutionises the way we understand ourselves, our world, and future possibilities that up until our discovery were completely hidden to us. I think this is particularly true of disability, certainly for me. For a start, archeological and source evidence shows that any discrimination suffered by people with impairments where such miss treatment did exist almost always paled in comparison to that our community deals with today. Fossils dated as 2.5 million years old found in Kenya demonstrate well organised social mechanisms of care that enabled otherwise profoundly disabled people to live well into old age within some of the earliest human societies. Across many nations throughout pre-colonial Australia deep respect for the elderly was and is the norm. People with impairments were and are broadly well integrated within the societies they inhabited. At the site of Pompeii, buried by an eruption archaeologists found the body of a wealthy young woman, heavily pregnant who examination revealed must have had CP. Documents unearthed from the Middle East from 1200 AD indicated numerous Islamic societies treatment of people who had what we now understand as intellectual disabilities treated them with a degree of respect that would put us to shame. In great Britain people with impairments were the beneficiaries of small local networks of communal care and support. Work was centred not around deadlines or time for efficiency but instead of photo cause was on specific tasks. Things got done when they were done and people rested when they needed rest. So what happened? This is where we need to start talking about the social model of disability and this is where I want to start talking about identity -- for me. Often when we talk about the social model, the focus is placed on the idea that society disabled us. It comes about because of a lack of access, because of widespread ableism. What seems to be often forgotten is the purpose of the social model to begin with. Firstly, and perhaps most confrontingly, it holds that disability did not exist until the transition to capitalism. Now, this may seem like a wild statement, but recognize for instance that outside of those -- sorry -- but recognize for instance that outside of those predominantly western advanced capitalist nations most languages to this day do not have a broad umbrella term for impairment like the word disability. In fact, English didn't have one until shockingly recently. The earliest possible estimates of the word being first used were not until around the mid-1600s. In reality the term didn't have the concrete meaning we understand today until a century later. So around 1750. About 250 years ago. It is no coincidence that disability gets the name in Britain at the precise moment that works characteristics changed from the earlier task orientation that I was talking about to time orientation. Workers were now paid a wage often weekly which meant anyone who could not work as quickly or for as long was worth less to the bosses. As communities were forcibly up rooted and moved to the industries disabled people, a group that had only just got a name, had no established community to turn to, and no support to fall back on. They either found a way to work, somehow usually just worsening their impairments until they could no longer go on or else were forced away either to starve or into the newly constructed institutions and asylums springing up everywhere. The -- secondly, as important to me, is that the university of physically disabled against segregation created the social model in the 1970s. When they pushed the social model it was as a way of naming and understanding their oppression. In this sense, disability is not something that we can see. Or touch or even identifying outside of our relations; the world that we live is in -- disability is a process. It is a set of actions. It is not something that we are as much as it is something that happens to us. It's why most people with a seriously developed social model rarely use first person language. To say we are people with disability suggests we have them. That they are identifiable characteristics and are intrinsic. Instead I choose to say that society disabled me. So long as this social process continues, I shall remain a disabled person.

The history of disability we are fed by media, by poorly researched history texts and popular culture is a lie. Those who benefit from current exploit creative social configurations need you, me and all of us to believe in the western white supremecist liberal myth of unending progress. That everything started awful and has only gotten better. If we knew the truth we would know a better more equitable world is not only possible but existed. Proof that such a world exists and continues to exist today in places with better ways of doing things and treating people. That is what disability identity means to me. It is a reminder that a better world is possible, for me, for you, for our community and for everybody.

Thank you very much.

- Thank you once again so much, Margot for sharing that. Some very interesting and shocking information. But what you want to see for the world is I think what all of us want to. So I completely resonate with that. Our next speaker is Carly fin lay OAM, an award winning writer, speaker and activist. Who first book, a memoir, say hello, was released in January 2019. Carly edited the anthology, growing up disabled in Australia with black ink books. It's in store now and a wonderful read. I'm reading it right now. She writes on diversity issues for news outlets including ABC, the Age and SMH and SBSN2020 Carly received a medal of the order of Australia. OAM for her work as a disability activist and advocate. She was named one of Australia's most influential women in 2014 under the Australian Financial Review and Westpac 100 Women of Influence Awards. She has appeared on the ABC's you can't ask that and cyber hate with Tara Moss. She has spoken at Melbourne's writer's festivals, the university of western England and -- has organised a history making access to fashion a Melbourne fashion week event featuring disabled models. She has a masters of communication and bachelor of e commerce. Welcome, Carly.

- Hello, thank you, everyone. Everyone's stories are so amazing. Thank you. I'm coming to you from the land of the Wurundjeri people in Naam here on the Kulin nation. And I too would like to pay respect to Aboriginal Elders past and present. And also that as a guest on the land I want to acknowledge that Aboriginal people have been telling stories for over 60,000 years. It's a privilege to listen to those stories and learn from them. Thank you very much. I'm going to talk a bit about my journey to disability identity. I have some dot point. I will flick between the screens. I was born with a skin condition -- scaly red skin. It's not very well-known at all. There are lots of different types of icthyosis and lots of different severities. My type is called nefertint syndrome. I edge to the more severe or quite severe end of the ichthyosis spectrum. Some people can easily pass as not having it. It might be limited to a body part or can be hidden easily or doesn't affect their appearance or facial features as much. For me it makes me have scaly red skin. I need to use soft white parrafin for moisture every day, twice a day. It also results in a lot of pain and itchiness. Mostly pain. It can result in infections which is quite difficult. Fortunately I haven't had one for a while. When I do I have to go to hospital and be bandaged like a mumm y. Aside from that the hardest thing for me is the social aspects of living with this condition. As I said, it's not very well-known. So people assume that I'm either sun burnt or burnt myself like in a fire or hot water. I have to constantly prove myself to people that I'm capable. You know I wouldn't say that I'm more than my appearance because absolutely my appearance is totally a part of me. But that I can do stuff. Because the expectation is so low. And then there is the ridicule and the low expectations and overt discrimination as well. Things like not being taken via taxi because apparently my face scarce the driver. So they are all really challenging on top of living with a rare skin condition. I grew up in a small town near Albury in New South Wales on Wiradjuri country. My parents came to Australia in the early eighties. They came to Australia because they fled South Africa due to the apartheid. My mum is what she terms a coloured South African. My dad is a white English man. They couldn't marry or court in South Africa legally because of the racial segregation laws there. So, they moved to Australia in 1981. And they know one. I think they maybe knew one person. Their condition -- the condition that they could start or certainly that my mum could stay was she had to marry my dad within a month. They had people at their wedding they didn't even really know. Later that year I was born. I am actually not a youth. Even though I look very young, thanks, genes, I'm not a young person; I'm almost 40. I'm sorry, I forgot to do an image description. But I think I described myself through talking about my skin condition. Yes. For those of you, I have a red face, short dark curly hair and I'm wearing a pink dress with green jumper underneath and hello Kitty broach. And an -- I'm sorry for the oversight. My parents had very little support when they came to Australia. They didn't know anyone. I was born -- they moved from Sydney to Albury just before I was born. They really knew no-one. The doctors diagnosed me straightaway. But also I was thinking about this the other day. I wondered whether racism played a part in this. When I didn't get better after a week the dermatologist told my mum she wasn't looking after me properly. So, there is no cure for this. I wondered whether that was some kind of unconscious racism there or conscious racism. Who knows. Anyway, they did an amazing job in instilling a lot of confidence in me despite the whole medical system telling me I needed to be fixed, that I have to be a specimen for medical textbooks et cetera. And all of the hospitalisation. My parents gave me a really good sense of self. But I never identified as disabled when I grew up. And I didn't identify because I didn't see anyone like me. Before I grew up before the internet I'm one of those people who have had half their life with the internet and half not. Or more than half with the internet. It was only when the internet came that I met other people with this condition. But I still didn't see myself as disabled because I would only see people who are Paralympians or who were so-called rorting the system on ACA. But it's not true, you know. Awful, awful gutter journalism. I really enjoy whad Margot said about the language around disability. One, it's -- it has such negative connotations to some people. But when you have the language for disability you can ask for what you need. Because I really didn't identify I still had to do the things I couldn't do, because I didn't have a way of convincing. For example it's very hot near Albury and I would not be able to go swimming at carnivals or do outdoor sport. But I would still have to sit and watch in the 40 degree heat in the summer. That kind of thing, I wish I had the language there. It wasn't until I was in my mid to late 20s that I talked to my doctor at royal Melbourne hospital. I said I really want to do some work around young people and body image and confidence. He put me in touch with a program called the chronic illness peer support program. It was amazing because I got to learn about the impairments. I didn't even know what the social model was then. I got to learn that even though we had different impairments we had a lot of similar experiences, lots of doctors, time off school. Lots of time trying to find a diagnosis or treatment. Lots of miss treatment by other people due to ableism. So I realised then I have a chronic illness too. I have had it all my life and there is no cure; I'm like these people. Then I started writing, I was at university at the time doing a master of communication and I knew I had to do some public writing. I started writing more about disability and my experience and that led to a writing career. I feel like when I found my identity I found community and I found a whole sense of self-acceptance which has been amazing. A whole heap more opportunity than I had beforehand. I had some notes around some things I really wanted to impart around connection. I really wanted to say that sometimes I feel there is a divide between visible disability and invisible disability. I want to say for me there are so many invisible symptoms like inability to regulate temperature, pain on the skin. I can people nice to with the invisible parts. I also feel like we shouldn't be a competition. There are no wins in having it worse. We have so much in common as disabled people. We really have to think about coming together. Lots of people will tell me it's okay for you because people can see your disability. But with that comes real difficulty. It comes with direct discrimination. I absolutely understand that people with disability experience discrimination as well. But we are collectively stronger together. It can be hard knowing whether you are disabled or not or identifying or calling yourself disabled because it is seen as such a broad term but also a negative term. Also, disability can be changing. Something I only discovered this year, I feel like we're always learning around disability -- a term called dynamic disability. It was by Briana and Joanna -- I don't think it's her real name. It's her Instagram handle. If you have a look at Brianna and Joanne online. There are pieces around how your disability changes. One day you might be absolutely able to do everything on your to do list but the next day you might be in bed because have you pain. Those articles acknowledge that and say that, yes, it's absolutely okay to call yourself disabled, to have different disability experiences as well. The other thing I absolutely encourage you to do and if you are watching this you are already doing it, come to different events by disabled people. The internet has made that possible. Come to our events, connect on social media. Talk about commonalities. The other thing is to read books, read writing by disabled people because it's life changing. I think that's it from me. So, thank you.

- Thank you so much, Carly. I could not agree more. Connecting with Carly and myself and be friending Carly has been a validating and supportive experience for me and my identity with disability and being part of WWDA. It really does support and make you feel validated and welcome and actually gain pride in who you are, particularly disability pride. When Margot talked about language and negative connotations associated with disability, it doesn't make it easy to have pride. When you see these wonderful people you can gain pride from everyone. It's something I would wholeheartedly recommend, including the books that Carly has written and been part of because those have really validated a lot of experiences I have gone through as well. Now we have some time for questions. They are addressed to all panel members. Feel free to jump in and answer them as you please. The first question is: Has being a youth shaped your experience of identifying with disability? Does anyone want to go first?

- I will jump in a little bit just to say that, yes, I think like it's actually what has shaped the experience is that I kind of got into it like now. This is my shaping of the identity, and it's happening right now. Because school is just so intense and it's just so many things and you are trying to survive. Especially if you are disabled. And schooling is horribly ableist, you really do spend all of that time advocating for the fact that you need the space to educate yourself and space to be educated in your schooling space. But, yeah. I think it is really common, but you don't get a chance to grapple with your disability identity until later on. I guess it's also a privilege in some sense that some people do have to work out their identity really early on potentially because their disability is really visible or society sees it in a certain way. Yeah, I think there are pros and cons to both of those and whether it's good to work out what your identity is early or whether it is a weird thing to also work it out later on. You are like, wow, I thought I knew myself and now I don't. So, yeah, those are my thoughts.

- Definitely, follow on from that, Ash, you are forced into in some instances knowing your identity and having that and losing the time you should be spending with everything else is very, very taxing on your identity. So definitely.

- As a semiyoung person I still fit within the bracket but just. I didn't -- like, I wish I identified when I was younger. I wish I spoke up for supports when I was younger. Like Carly, I didn't identify because I didn't know I could. I never sought support. I never sought anything I was entitled to. Which looking back I wish I did. Because I wouldn't have been as challenging and as isolating and painful as it was if I had those supports. Yeah. That's why I definitely encourage people to get connected as Carly mentioned. The next question is: Has your experience of disability changed over time? Alternatively, does it present differently in different socio cultural contexts?

- I like that question. I was thinking about what Caroline Bodich says. Caroline is an amazing woman who is an artist, arts worker, Arts Access Victoria, she often says if she goes to different places that are less accessible she is more disabled. I was thinking about that, how it turns out for me. I feel very fortunate that we're there Australia with access to free health care. And a relatively -- well, I wouldn't say nondiscriminatory system. I know if I lived somewhere else looking like this, knowing what other people with icthyosis face in other countries, it's very difficult. A friend in America was saying she has had five months without her ointments because she couldn't afford it or get it on health care. I thought, wow. So that in effect make US more or less disabled by what access to supports you have. Living in Australia, I have got everything I need to live a functional life but then sometimes like I have been traveling and I absolutely acknowledge my privilege but when I travel to say, Bali, it's been very hard for me because of the heat, because of the weather, but also I have to prepare by taking all of my ointments over. You know, having all of these supports in place to make sure that I'm going to be okay. Then even if you can't drink the water what is that doing to your skin? I ended up very unwell in Bali with my skin. I was more disabled in that situation than I might be here.

- I think too, it's important to think about -- like with what I was say being how disability is defined around people, different people, particularly around axes of race, talk about intersectionality a lot, if you look at the history of immigration law, for instance, that's a really, really big one in the way that you see how disability is defined completely differently for different groups of people. And so if you were trying to get into America and you were disabled, you might be able to get in as a white person. But if you weren't white, there was no chance at all. The reason was because, if you were deemed white, they were like, okay, we can get you a respectful job working at a desk. But it was never on the cards. They were like if you can't do hard physical labour then we don't want you. So literally yeah, how disability was defined.

- Along the lines of that question, as far as being accepted in say with the mob for myself with my FND or my -- the way my brain works, any time I have a conversation with how things are going with the mob or community, it's totally accepted, it's totally -- it's just like a normal conversation. It's not clinical, it's not conned sending. It's not questioning in a way that has to delve so much into the intricacies of everything. We talk about it from a perspective of we just look after ya. Compared to if I was to talk to someone outside of the mob, it's, "How many questions can I throw at you before you are so stuck in the condition in itself that it's tote --" -- it's totally clinical and not really em pathetic. It's interesting talking about it in a cultural setting, being in a mob, to anybody else.

- I think with what Carly was saying, recognize the privilege of travel -- I'm be holden to how much medication I can take with me, because of authority scripts and so on. Being a wheelchair user, it changes a lot of things. Quite a lot of people would have seen damage to wheelchairs on air lines and how often it happens. I think the 125 wheelchairs are damaged a day. Things like that. Obviously it worsens your access to society. And makes things much more difficult. We have a few other questions many of you -- sorry about my dog -- many of you have mentioned intersectionality. Some marginallised communities are insular to other marginallised communities. How do you bring together different parts of your identity while navigating these communities?

- I don't know if I'm taking this question or I'm thinking about it the wrong way. But I think as in like having some communities and feeling like those communities are separate to other communities -- is that what we're going for a little bit? Okay. Because, yes, and I find this is a lot with how -- this is my whole thing. I feel like I am part of a community, only if I separate some of my other identities out of it. I don't understand -- it's not that I don't understand -- I can't work out how to fit them together in a way that is cohesive and recognising the marginallisations of communities and why they are finding it difficult to accept certain identities or finding it difficult to reshape their values. This is not really an answer to the question of how to do that because I don't know how. But recognising that that is really difficult. It's almost like competing access needs in a way. There is a competing marginallisation kind of thing happening where people are marginallised by values that are complex and really hard to work through and they clash with other communities' values and why those people have had those values. I don't know what the answer is to solving that. But I think recognising that that is an issue is a good start and recognising that people will find it hard to merge communities or merge certain areas or identities of their lives because of that. Maybe that's a good start.

- Thank you, Ash. We are unfortunately out of time. However, if you have submitted a question, they will be addressed particularly the questions regarding people's interest in Margot's work and wanting to know more, as well as some other reading and references. The team at WWDA will get back to you and inform you of the information regarding that. I wanted to say thank you to everyone who has attended today's webinar. Thank you to our amazing guest speakers for sharing your diverse experiences. All of the challenges with identity and all of that and what Ash talked about, the separate parts and what Carly and Margot and Lily have spoken about, it's been really insightful. Really wonderful. Like I said, you can continue to submit more questions if you have them. The team at WWDA will address them. Even if they weren't addressed on air today. We would like to again thank the department of social services for the funding for the WWDA lead project. We value everyone's time and engagement with the webinar. We would love to receive your feedback and appreciate it. If you could participate in the survey by click willing on the i icon. We will send you a link to today's recording and an ability to provide feedback. We would love for you to connect with WWDA and all of the work we're doing in the WWDA lead project. You can do that by becoming a WWDA member and joining our closed Facebook group. Follow us on all social media platforms at WWDA. Current activities include -- up coming activities include our near peer networking event. It's a great way to interact with other WWDA members. The next session is on Wednesday, 27 October at 1-2 p.m. Visit the WWDA website to register. Anymore information about anything that was shared today please visit WWA's website. Or get in touch with WWDA via socials. The next webinar we have planned is for 19 November. The topic will be LGBTIQ+ A people. Keep an eye out for details. More to be announced. Thank you to all of our speakers and guests. Thank you so much. Have a lovely evening. Thanks, everyone. Bye bye.