Hi, everyone. It's a pleasure to join this Autism MOOC. My name's Chris Varney. I'm national director of an organisation called the I CAN Network, which is a movement of young people on the spectrum driving a rethink of autism from "I can't" to "I can".

I'm joining you to speak about the label of 'autism' and about labelling in general, and in doing that, I wanted to kind of walk you through my perception and view of the stigma surrounding autism that continues in our community.

I think the first thing in this big bucket of worms to talk through is to talk through the label. The label... In labelling a child as being on the autism spectrum, for me, the purpose of that is really to alert that family and that young person and, you know, what will be a future employee of how to best enable that kid and that young person and that future adult. Sometimes I see the diagnostic process work in an opposite way to that, where it's not necessarily done in an enabling way, and it's almost a kind of label... discriminate or implicitly talk about the things that that kid can't do. And I'm someone that says that we don't have the label 'autism spectrum' for kids to be saying, "I can't." We have it so that kids can say, "I can." And together, we need to enable and NOT label.

Now, the label is helpful to have to alert families of differences, of an enabling environment, and to bring out the best in that kid. The other question I hear a lot from parents, and if you're a parent listening, is, "When do I tell my son or daughter "that they're on the spectrum?" And I think this is something that is profoundly your decision. I think there is something quite helpful... in raising your son or daughter is to work out, "Does my son or daughter have the maturity "to take this information in their stride "and to let it be something that doesn't feel like a hindrance "and kind of...you know, just folds into their existing sense of self "and their confidence?"

I'm someone that found out I was on the spectrum when I was 14. I was diagnosed by my mum... sorry, by psychologists when I was aged five. And my mum had kind of decided to withhold that information from me because I was a pretty melodramatic kid and she didn't feel that that information would help me. But I also have to say that I've met six-year-olds who are aware that...
they're on the spectrum and they are confident, they're happy, they take it in their stride, you know, it's part of their sense of self, and it will never be a source to opt out of things or to excuse themselves from living. I was a kid that probably WOULD have excused myself from living should I have had a label. And so I think that that kind of is a good comparison. If your kid has the maturity to take it in their stride, then it can be helpful information, but absolutely, it is your decision.

Now, we know that the stigma is very alive and present, and I think the data that supports that is the fact that only 42% of Australians with autism are employed. That means that 58% of them are on some form of welfare benefit, and I think that that is... I think that's a real travesty, because there's an awful lot of creativity and talent there that isn't being tapped and harnessed by our economy.

Now, with the labelling, how we work through it - currently, it isn't safe for a young person to disclose broadly that they're on the spectrum. It is safe in SOME schools. It's safe with SOME individuals. It's safe with SOME employers. But in a blanket way, we need to do a lot more awareness and education of the community to help them understand what the spectrum is and to help them enable, not label.

Now, what that looks like is two things. It's supporting the young people who do want to disclose to develop their communication skills and create platforms for them to safely disclose and walk their audience or their community or their workplace or their school through what their autism looks like. And then the second thing we need to do is we need to raise the myths to break the myths. There are a lot of myths out there about what autism is - that it can be, you know, captured from a vaccine, that it can be caught from certain things, that...you know, that there's particular things that we do or that we're a blanketly disruptive group or that we're only visual learners. Like, there are an amazing number of myths that are out there associated with autism.

The most important thing to understand is that no two people on the spectrum are the same. And it's key to not just focus on the communication and positive storytelling and confidence of young people on the spectrum, but it's equally as important to focus on the wider community, and this is where the value of advocacy really comes into play. And so by 'advocacy', I'm talking about transforming the systems of power and the public attitudes that perpetuate the "I can't" around the childhoods of these kids.

And so it's when community leaders, when media personalities, it's when people with influence come out and talk about their connection to autism or their understanding of autism and celebrate the quirks and the talents and the creativity of these people that I think that we'll really see attitudes towards autism change.

Um...I think sometimes a lot of our talk about autism can get a little too serious. I think if we really bring the fun into this conversation and celebrate the quirks that people on the spectrum have, and, of course, their talents, then I think that will... You know, a sense of humour is so powerful. That needs to come into play in talking about autism so that, you know, the community can engage with this more.
Of course, I say that with an appreciation that I've got a lot of friends on the spectrum who have severe autism, whose families and who themselves as individuals... You know, life can be extremely tough and challenging for them, depending on their point of the spectrum. I think the most important thing is to appreciate the lived experience of people on the spectrum no matter where they might be on it. Assuming that someone with severe autism doesn't like their life or that wishes they were different is an assumption.

It's really important to hear the voice of young people with severe autism, and equally, to create a platform for them. I'll give you an example. My friend, who I talked about, Tom, who I actually live with - he's my next-door neighbour and we share a backyard - he is an amazing listener. He has shown my family and his family how to be great listeners. He is someone that's non-verbal. He communicates via a keyboard and typing with support. He uses his amazing listening skills, his insight, his depth of analysis and his English skills to very much pivot conversations and make great contributions. And this is the important thing. So many - the majority - of people on the spectrum can participate, can contribute and have a voice that we can tap.

The idea of participation is a very broad one, and there are many different types of participation, and it's so important to create great channels through which young people, no matter where they are on the spectrum, can contribute and be heard. And so, to summarise, share the diagnosis of autism with your son or daughter when they have the maturity to just let it fold into themselves, let it not be an overwhelming source of worry, and for it to just, you know, form part of their confidence.

Focus on enabling and not labelling, and what that looks like is supporting young people who might have the confidence to share their diagnosis and to create platforms that are safe for them to do so. And if you are someone out there that has influence, whether you're a teacher or a principal, take it upon yourself to be an ambassador for people on the spectrum and to educate people that no two people on the spectrum are the same, to find ways for these young people to contribute and to have voice and be heard, and you will create a safer environment for autism to be understood and for more people to disclose.

And lastly, to summarise, raise the myths to break the myths. Talk about the things that people say. Bring them out into the open and say, "Actually, that's not true." And you know what? The best people to show you that that's not true and to show you, um...the... you know, the sheer vastness and creativity of autism is people on the spectrum themselves. Create platforms for them to share with you the lived experience of autism. I'm someone who's 27, I'm on the spectrum with Asperger's, and I can say that autism is the best thing that ever happened to me. I know that, you know, in sharing my diagnosis with people, I've been connected to a community that really have expanded my understanding of human potential, and I'm a better person for knowing people on the spectrum.