

CULTURAL IDENTITY AND DISABILITY: Diverse Perspectives from young people

MYAN National Youth-Led Panel, 30 November 2020

Speakers

- Cindy Liu (She/Her)
- Ashleigh Hem (They/Them)
- Varsha Krithivasan (She/Her)
- Markos Hasiotis (He, him)
- Grace Edward (They/She) - Moderator

Acknowledgment of Country

Jagera and Turrbal; Darug; Wurundjeri Kulin; Bunurong

NB:

- Webinar is based on personal experiences (not representing the views of all young people living with disabilities)
- Content warning: ableism + mental health issues
- “We worked hard to make this group a reality along with the support of MYAN to address the strengths, concerns and opinions of young people from culturally diverse backgrounds...”
– Cindy

Panel discussion

Life living with a disability

- Denial to acceptance
 - Easy to frame disability as negative when it's not
 - Part of identity, pride, sense of self
- Challenge and opportunity
 - Negative emotions, social difficulties, anxiety and depression
 - Not knowing about disability → not knowing where to seek support
vs.
 - Unique way of looking at things being neurodiverse, interests, rewarding outcomes
 - Building community connections with others with a disability
 - Adapting, connected to community

Community, culture and identity

- *Culture*
 - Migrant, refugee, Australian, young (seen not as wise), disability (can be seen as weakness, leading to shame and denial)
- *How different cultures view disability*
 - Family seeing disability as a burden/curse, where disability was never spoken of or if so never in a positive way.

- Stifled ability to identify as someone with a disability
 - Work to overcome things
 - **Experienced “fix it” culture**
 - “push through”
- *Impacts accessing and connecting with community*
 - Children removed from culture to provide support
- **Avoid Culture Blaming and ableism**
 - Instead of blaming culture, address the structures around cultures and people
 - Quick to blame other cultures → education is needed to understand each other

Different education experiences

Markos: victim of school system that didn't fully understand mental issues; experienced bullying (rarely punished); went to an all-boys private school. Bullied for being fat, lost a lot of weight. Became anorexic which made mental problems worse. There was a “boys will be boys” attitude. ore awareness now.

“These stories need to be told.” – Markos

Varsha

- Very well supported in school versus on your own at uni (bureaucracy)
- Assumption to just “push through”

Changes from COVID-19

- Increased flexibility at school, at work
 - (Disability advocates have long fought for this)
- Understanding competing access needs
- Anxiety about going back to an ableist normal after Covid

“Australia has been sent to its room to think about what it's done.” – Markos

- Time of reflection and deep thinking has led to very direct action on financial support/homelessness/health/online misinformation etc. There's also been a lot of research and policy work done. Which benefits us all.

Service gaps

- We are more than one thing
- The importance of lived experience
 - Embedding lived experiences in services can allow you to open you service to what people actually need and want
 - Speech services was a one size fits all: services will work completely differently for each person (Varsha)
- Harmful expert mentality
 - Services specialising in one thing (e.g. young people, migrant and refugees) can reduce people to that one thing and they just address that one thing, as if it's not intersecting with anything else
- Young people have less sway than elders

- This where services can really shine and make a difference
- Move away from culture blaming and individual medical model (what can we fix about them?) to social model (structures around the individual that we can change and support)

Ideal world

- Inclusive supportive community
- Young people are supported to enjoy ourselves!
- Embed lived experience in to our world – not just services, but in everything
- End of ‘misinformation epidemic’ (distorting truths, underpins misunderstandings between and hate towards people) → enlightened and understanding world
- It isn’t just about making services and our communities safer and more inclusive/accessible; it’s about other industries as well e.g. arts sector, for everyone to be able to participate and create, share their story

“When we share our stories we gain more understanding of each other and our various intersections.” – Grace

Q&A

Themes:

- Language/terminology: a personal preference
 - Some people are afraid to use the word ‘disability’ as if it’s a bad thing and something to hide or is an insult...?
 - Even in the disability community there’s a lot of discussion on how to use the disability identity first language (e.g. disabled young person) – person first language e.g. person with a disability
 - It’s OK to:
 - identify with different words
 - not want to offend people
 - not to know
 - Just ask! (Respectfully)
- Inclusive practice
 - Can you give an example of when you felt truly included and catered for?
 - I work in a pretty disability friendly workspace, where they do ask you and check in on what is going to be accessible; they’re pretty flexible; spaces that they’ve found inclusive is they recognise that every day is not the same – Ash
 - Mental Health Foundation for Australia – welcoming, diverse groups, can say all sorts of unusual things and everyone just accepts each other – Markos
 - I had a really great experience with uni. When I enrolled in university I didn’t need to find anyone ... they came to me, it was very obvious in the enrolment ... faculty are very aware of disability services available. Level of understanding and awareness. – Cindy
 - Zoom has been the most included I have been in class, in particular, I do a degree in politics, and everyone loves to talk! In person classes in the first

two terms, I didn't talk at all, it was so new and scary, I didn't know anyone. It's been two years now, and in Zoom I feel so okay to ask things, I put in the chat, you can't actually see me when I'm talking.

- Practical recommendations services
 - Offer examples of what you can offer and what you can change to tailor support
 - Come with an open mind, no preconceived notions
 - Start a candid dialogue, allow us to be vulnerable, create a vibe that allows us to know you
 - Even if you're having a bad day, be patient and kind
 - Young people might need support in self-care
 - Engagement Tips:
 - Use social media
 - Individualise service
 - Thinking about what young people enjoy (what did you do when you were younger...?)

“The best way to make it is be so good they can't ignore you.” – Markos

- Navigating culture, acceptance etc. as people with intellectual disability
 - NB: Panellists don't have an intellectual disability)
 - A lot of people with an intellectual disability don't have a wide support system
 - Tend to be segregated from mainstream
 - The people around them would be most important

- Experiences with parents and family
 - Depended on how much support parents needed
 - Their preconceived views of my disability are going to be quite entrenched
 - It's important to know that they don't come with bad intentions to these conversations; learn with them at the same time

“It's about awareness and experiences that we intergenerationally take along with us.” – Varsha

Visual notes by Sienna Aguilar, @Shenna_Aguilar