Ethnic Communities' Council of NSW Inc.
Representing all communities

ECCNSW Response to the Disability Royal Commission Issues Paper on

'The experiences of culturally and linguistically diverse people with disability in Australia'

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DOCUMENT NOTICE

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Table of Contents

Introduction

The Royal Commission into Violence, Neglect, Abuse and Exploitation of people with a disability is seeking a response to the issues paper, "*The experiences of culturally and linguistically diverse people with disability*". This is the NSW response, compiled by the Ethnic Communities' Council of NSW (ECCNSW), to the issues paper, seeking information on the attitudes, experiences and understanding of disability in these communities, with the goal of moving towards a more inclusive society. The response draws together comments from interviews of people with disabilities or their carers from several cultural backgrounds.

NSW's population is drawn from various cultural and linguistic traditions, with 28% of people born overseas and 25% speaking a language other than English (LOTE) based on the 2016 ABS Census data[1]. Those communities that have lived in Australia for longer periods of time have better English skills and have had longer exposure to Australian community attitudes and education on disability. Newer migrants tend to bring their culturally based beliefs and attitudes about disability from their country of origin.

The State's cultural diversity is changing over time with some communities such as those from Chinese and Indian ancestries, the top 2 of non-European migrants with long settlement histories still showing strong growth. Filipinos comprise the third largest group with decreasing growth in newer migration. They have also settled in significant numbers in regional NSW, unlike other non-European migrants who have settled in specific local government areas (LGAs) in Greater Sydney that provide familiar environments for their communities.

There is increasing migration from countries such as Nepal, Samoa (largest of the Pacific Islander communities), countries from Central and West Africa, Somali, South Sudanese, and of the Arab ancestry, those from Afghanistan and Iraq. Larger groups from Southern and East Africa who settled earlier has had slower growth in numbers. Data has been sourced from 2106 ABS Census from the Multicultural NSW database. [2]

Non-European Settlement in NSW

Non-European Migrants	Numbers in NSW 2016	% NSW population 2016	% Increase since 2011	Main LGA locations and Regional NSW
China (incl 2 SARS)	514,595	6.8%	36%	Burwood, Georges River, Willoughby, Ryde, Strathfield and Parramatta LGAs, representing 20-32% of the LGA population, 0.99% in regional NSW
India	211,931	3%	52%	Strathfield, Parramatta, Blacktown LGAs 11-13% of the LGA population, 0.67% live in regional NSW
Philippines	117,354	1.6%	24%	50% of Filipinos live in NSW, in Blacktown LGA, representing 9% of the LGA. 14% live in regional NSW

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[1] https://multiculturalnsw.id.com.au/multiculturalnsw?COIID=281
[2] https://multiculturalnsw.id.com.au/multiculturalnsw?COIID=281

Non-European Migrants	Numbers in NSW 2016	% NSW population 2016	% Increase since 2011	Main LGA locations and Regional NSW
Vietnam	109,593	1.5%	33%	Fairfield (20% of LGA, Canterbury-Bankstown (7.3%) 0.15% live in regional NSW
Nepal	36,244	0.5%	119.5%	Burwood, Georges River, Strathfield LGAs
Iraq	23,674	0.32%	55.90%	Fairfield and Liverpool (3% of these LGAs), only 0.32% in regional NSW
Afghanistan	15,586	0.21%	57%	Cumberland 3% of LGA, Blacktown 0.96%, 0.04% in Griffith and Wagga Wagga in regional NSW

Methodology

The sample interviewed included people with a disability, carers or front-line workers providing services to a of diverse community of people across which there is great variation in terms of types of impairments, whether acquired or genetic, social status, identities, and life circumstances. It is a challenge to represent such a varied and diffuse community, however, they have a shared experience of impairment and social disablement, with mixed experiences with their own communities and/or the general Australian community.

Interview Sample

Number	Method	Ancestry	Type of Disability	Years in Australia	Role
1	Phone Interview	Vietnamese		>20	Mental health worker
2	Focus Group	Mainland China	Autism	15-30	2 Carers
1	Focus Group	Mainland China	Stroke	10	Person with disability
1	Focus Group	Mainland China	Mental Health	17	Person with disability
1	Phone Interview	East Africa	Mental Health	10-20	Person with disability
1	Phone Interview	East Africa		10-20	Community development in African communities
1	Phone Interview	West Africa		10-20	University lecturer in Mental Health assisting African refugees
1	Phone interview	Samoa	Paraplegic	<10	Person with disability

1	Phone Interview	Samoa	Cerebral Palsy	10-20	Carer
1	Phone Interview	Samoa		20	Community development
1	Phone Interview	Filipino	Amputee, Chronic dialysis	>30	Person with disability
1	Phone interview	Filipino	Cognitive disability	>30	Carer
1	Phone interview	Filipino		10-20	Community worker
1	Phone interview	Arabic	Various	20-20	Disability worker
1	Phone interview	Nepali	Various	10	Disability worker

Question Schedule

The same question sets were used across all interviews, including the focus group where the facilitator used their own experience to balance the need to allow discussion to flow naturally while also refocusing participants on the details of the concepts. Front-line bilingual community workers were asked to confirm the generalisability of the interview responses from members of their own community.

For the focus group, an interpreter was required as English was not well spoken or understood by some participants. Although it was requested that translation of their actual responses was required, and not an edited version, it must be acknowledged that the responses are not verbatim.

Consent and Ethics

All interviewers were provided with the purpose of the interviews and provided verbal consents. Those who participated in the focus group provided written consents. All interviewees were assured of the rights to privacy and confidentiality, as all chose to be anonymous.

Interview Responses

1. **We want to understand how culture and language may affect the life course of someone with a disability from a culturally and linguistically diverse background**

Different experiences were reported of having a disability and from a CaLD background. Those that spoke English well and who have been longer term migrants reported little or no impact of culture or language on their experience with disability. Those who were exposed to overt acts of discrimination and bullying noted the negative effects on mental health. Others felt unsafe outside their communities.

Chinese	"We have a lot of support from the government and medical care looking after my son. We are lucky to be here in Australia than what my friends are experiencing in China. They are isolated there with only their family or thrown into institutions. The doctors and the government will allow only

	positive aspects of living with a disability". They remain in contact with family and friends in China.
	"There are some good people who gave my mother a lift when she was walking up the hill carrying packages to visit me in hospital. I will always remember their kindness."
	"I have a child with autism, and I feel safe within my local community, because they are from the same cultural background. When we travelled by train, I did not feel safe and people in the country town were not nice to me because our appearance and poor English, more than the disability. Someone else in the queue is served before me even though I was at the top of the queue. I get ignored."
	"I have been here a long time. Attitudes to disability and Chinese have changed a lot. Much better now. But I can speak English."
	"I don't speak English very well and my daughter and I experienced racism."
Indian	"My son has cerebral palsy, and he is articulate, but people assume he has an intellectual disability. He didn't have many friends when he was younger, but he has friends who are more accepting now that he is in 2nd year university. Being in Australia a long time and speaking English, culture and language was not really an issue, but disability was."
Samoan	"Caring for my daughter with cerebral palsy was easier when she was a child. As an adult, giving her personal care is much harder, even though she has an NDIS package. She needs help with everything."
	We can speak English well, as most of us came through New Zealand. No discrimination."
	"It did not affect me that much as my accident was during my schooling. I felt confident of my ability as a man, I had a positive mindset. The traumatic effect psychologically and physically was undeniable. I was 11 months in hospital. My family was very supportive when I went home to my village. The transition from Samoa to New Zealand a year after helped my mental and physical recuperation. I determined to go to return and complete university and eventually got a job again. I became very involved in disability advocacy so the community sees me as someone in a leadership position. I didn't see myself as dependent on anyone. I make my own decision and also a decision-maker in the community. I am very honest how I feel. I am not inferior to anyone."
African	"Racism and discrimination is experienced by most people from Africa who have a disability. It is because they have a disability, but more so because they look different and because of language. All Africans who come here speak English, but their accents are very heavy and difficult for Australians to understand. They think we are stupid and uneducated. I was severely bullied, and this caused my mental breakdown.
	Trauma from where they came from but also racism and discrimination experienced here are the causes of mental health problems in people from Africa". These 'generalising' comments were confirmed as accurate

	observations by the University professor and community development officer who both work with African refugees and migrants.
Filipino	"We've been here most of our lives and always spoke English so there was no problem with language. My daughter has a cognitive disability and did not make any friends in school. She is working part time and they keep giving her the same tasks for the last 7 years, judged as too hard to teach. NDIS helps her achieve some of her goals. There are different challenges, at childhood, now adulthood. We are uncertain of the future."
Arabic	"Newly arrived families of children with disability need extra help. People get frustrated with them, like social workers, school principal. A speech therapist is needed but they are pushed into ESL classes. No one is monitoring these things".
Vietnamese	Mental health disability is not visible. They tend to stay in their own communities. Easier with to be understood and feel comfortable. Those who have been here a while are good with English.
Nepali	Being a new migrant, not knowing the context is difficult. In Nepal, they can't work if they can't talk or see. The definition of disability is different in Nepal – only physical, usually from accident, also if born with physical disability. Mental health is not considered a disability.

2. **We want to understand how culturally and linguistically diverse people with a disability overcome language barriers when trying to access support, and the pathways they follow to ask for assistance**

Language can be a barrier when accessing support. Improvements have been made by government to support those that do not speak English though interpreter availability. Language, access to technology and computer literacy still pose barriers when accessing support online or by phone.

African	"I have been to Centrelink and saw a different person each time for the same thing. They have difficulty understanding." "Sometimes I have to write it out to the provider so they can understand me"
Chinese	"The staff in hospital were very attentive but there was a problem with when they wanted to discharge me. The interpreter was not provided. I was so relieved when a Mandarin-speaking provider came when I was discharged"
Arabic	"There are many employees who speak Arabic, like in Centrelink, or Council. The government recognises this by having translators and printed translated pamphlets. But the problem is technology. Those who unable to speak English can't follow the telephone prompts or the website are left behind."

Vietnamese	"A lot of translated material now. But we had to make an effort to produce these. The younger people help the older ones."
Samoan	"The young translate for older people who cannot speak English well. There is always someone in the community or relative who can translate." "English language is not a barrier as I have university-level as well as fluently in Samoan."
Nepali	"Not sure where to go, where to ask, language is a big barrier. Information available in Nepali would be a great help. English can be understood by some, but competency may not be high. A service provider may not realise that the English-speaking ability not is not high and the person did not fully understand so Nepali translation is still required.

3. **We want to understand cultural attitudes and the language of disability within culturally and linguistically diverse communities. We want to hear about how these influence individuals with disability, and how they interact with their communities.**

Myths and stereotypes still exist in some communities on physical and mental health disabilities, and these can often be viewed as 'curses'. There is greater stigma around having a mental health issue more so than other types of disability[3].

Chinese	All participants described some form of community marginalisation, mental health disability in particular. Migrants brought their cultural attitudes to Australia; however, they all believed these attitudes have shifted more positively over time due to better community awareness about disabilities. For example, "I got my mental problems only when I was an adult. It's a chemical imbalance in my brain." There is a physiological reason, rather than a curse. "I go to my Church. They give me support and acceptance. I feel connected with that community." "I am Buddhist and I regularly visit the temple. That helps me feel connected with my community"
Vietnamese	"Mental health disabilities are considered a social stigma and the community needs to understand it is not a curse. We developed a booklet in Vietnamese giving stories of those who are living well with mental health conditions."

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[3] A. Milner c , Z. Aitken c , C. Vaughan c , G. Llewellyn a , A.M. Kavanagh; Centre for Disability Research and Policy, Faculty of Health Sciences, University of Sydney, Australia b Centre for Disability Research, Faculty of Health and Medicine, Lancaster University, UK c Centre for Health Equity, Melbourne School of Population and Global Health, University of Melbourne, Australia,   April 2020

African	"Physical disabilities, if acquired, are generally more accepted in the African experience, but they are considered 'inept'. Disability due to mental health problems carries a significant stigma because it is considered a demonic perception, blamed on the mother's sin, especially if a single mother." "Disability is a term described as a 'cripple' and the myths on mental health, which is not physical is not understood and they must be isolated away from others." "Religion is a major part of our lives. If you were born with a physical disability, there is also a stigma. It is a punishment from God. Mothers of people with mental health issues are considered promiscuous in the Church." "Racism starts with us and should stop with us." These statements were confirmed by the community health worker and the University professor who are from African background.
Filipino	"You know, Filipinos talk and gossip, but generally there is no overt discrimination within the community."
Arabic	"There have been shifts in attitude, but more education in awareness to seek help is required." "In Islam, mental health is recognised as an issue. You need to seek help, medication, spiritual belonging. Find a hobby."
Indian	Disability is accepted in our culture. We look after our people with disability. Hindu faith accepts it. "My son attended all the Indian cultural events.
Samoan	"The Samoan community totally accepts disability, including mental health,. They are just another human being." "The Samoan community nurture their children." "In my experience, I need to educate the community to speak in positive language so they feel they are valued members, like how I feel. Disability is still seen as causing shame to the family. Weird ideas and superstitions about how disability has evolved. I understand different causes of disabilities. Those with mental health issues are called shameful names – 'stupid', 'idiots', 'useless'."
Nepali	"The parents of child with autism may not understand this is a disability, for example. They will say it is something else. Mental health problems are not considered a disability. Dyslexia, for example, is a condition that can be cured. Disability is considered a stigma in the community. The person with a disability did some sin in the past life so he is experiencing a hurdle now. We believe in reincarnation. So, seeking help is limited"

4. **We want to know how communities can have positive or protective attitudes towards disability. We want to understand the reasons that people may not identify as having a disability even though they have an impairment.**

Disability remains an embarrassment in some communities, and totally accepted and even receive community support in others. In some cultures, mental health disability is not evident but in certain cases great efforts are made to keep them hidden because of social stigma.

Arabic	"Physical disability is explained or excused by blaming something or someone." "Mental health – hide it. I'm normal, I'm not crazy." It is usually blamed on a traumatic childhood."
Vietnamese	"You cannot see mental health problems. It is hidden. They do not like to speak about it"
African	"Mental health problems are taboo. It would be hidden." "Even a nurse from an African background who worked in the psychiatric unit told me 'You don't belong here'. Is it because I admitted I have a mental health problem?"
Filipino	"My cognitive processing problems after my stroke is not visible so I never mention it. People can see I don't have fingers." "My daughter looks normal, and it isn't until she talks that people realise she has a developmental delay. The Filipino community accepted her, but they don't seek her out to make friends. They are embarrassed if she can't keep up or participate fully in conversations. She feels left out, excluded."
Chinese	"The negative attitudes have changed over time. We still prefer to be within our community." "My Church accepts my mental health problems. They support me."
Samoan	"We rely on the community to help out." "Very often, parents are very protective, but really are controlling. I don't think that's the way. They can decide for themselves. Because of the stigma, especially invisible disability or minor one, they will not admit it. They would be isolated. If the disability is severe or obvious, they have no choice."
Nepali	"Those will mental health problems are reluctant to seek help as they may themselves not see it as a disability. A person with a disability, because of the social stigma or taboo, prefers to keep it hidden."

5. **We want to know how the different ways disability is understood in culturally and linguistically diverse communities and how they may support and include people with disability, or how they might exclude or disadvantage them.**

The Circle of Relationships, based on "Circles of Intimacy"[4] was used as a tool for participants to describe their relationships based on love and closeness (Intimacy), friendship and allies (Friendship), those who share common interests and activities (Participation), including neighbours and those in paid relationships (Exchange), to analyse how engaged they were with others, and where they spend their time.

Chinese	"Most of the time is spent with close and extended family and friends." "I do not have time to connect with other people in the community. I look after my disabled husband and my son who has autism." "I had trouble taking my son out to the coffee shop or other public places. I avoid those places." "I like going to my Church". "I like going to the temple"
Samoan	"We feel comfortable with all the circles." "There is a lack of opportunity to improve their social life. In a small community, there are no resources, so they are dependent on the family. They are not seen in the community, The family may not want the person with the disability go out because of the shame."
Vietnamese	"Just close and extended family and friends." "Some are now working or studying"
Filipino	"I tend to stick to my close friends and extended family. I wish I could work." "My daughter can go out to concerts or to the club with another friend like herself. This would not have been possible if she did not have NDIS."
African	"My close family and friends rejected me completely. They have isolated me. I have had to establish a new network of friends." "We have African associations that are supportive."
Arabic	They are accepted in the Arabic community, but they tend to stick to their own community."
Nepali	"If the doctor or specialist tells your family member has a disability, the family will accept. But the community will still gossip about the person. Those with disability will always still worry about how the community feels about them because the gods have punished them."

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[4] Zawisny, Adam, "Circles of support: Supporting people in making decisions and living independently", Europe in Action, Vilnius, 5 June 2019

6. Best Hopes

The participants were asked a question about their best hopes – If a miracle happened overnight. Your life was just the way you want it, even with a disability. What would you notice?

- "I want to be around long enough to keep caring for my son."
- "I wish independence for my son."
- "My English and that my memory has improved."
- "I want to live longer than my daughter and improve her language."
- "No more racism and discrimination in our community and in Australia."
- "I am able to get a job and work."
- "I don't know. I worry about what will happen when I am gone. What will happen to her?"
- "The mindset and attitude of the community toward disability has changed, everyone's behaviour has changed, more supportive of others' needs, everyone is equal. Government policies, processes reflect this positive mindset."