The experiences of culturally and linguistically diverse people with disability

A RESPONSE TO THE ISSUES PAPER FROM THE ROYAL COMMISSION INTO VIOLENCE, NEGLECT, ABUSE AND EXPLOITATION OF PEOPLE WITH DISABILITY

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Introduction

AMPARO Advocacy Inc. welcomes the opportunity to provide input into the Royal Commission's exploration of the experiences of people from Culturally and Linguistic Diverse (CALD) backgrounds with disability.

AMPARO Advocacy is a small non-profit community-based organisation which is funded by the Queensland Department of Seniors, Disability Services and Aboriginal and Torres Strait Islanders Partnerships to provide independent individual and systemic advocacy on behalf of vulnerable people from Culturally and Linguistically Diverse (CALD) backgrounds with disability, between the ages of 0-65, living in Brisbane. Complementing our advocacy work, we also outreach and engage people from CALD backgrounds with disability to improve their access to the NDIS through the National Community Connectors Program (CALD); and build the capacity of people from CALD backgrounds with disability through an Individual and Organisational Capacity Building Project funded through the Information, Linkages and Capacity Building program. AMPARO is governed by a voluntary management committee, the majority of whom are people from CALD backgrounds with disability.

AMPARO works closely with vulnerable migrants and refugees with a disability and their families, to assist them to understand important information and to successfully access systems, services and supports that they otherwise would not receive. Through this work we become aware of the multiple layers of disadvantage which restrict their access to important information and services and limit their ability to fully participate and be included in family and community life. The systemic advocacy that is undertaken aims to influence positive sustainable changes to attitudes, policies and practices in government and community, so that people from CALD backgrounds with disability can have equitable access to information, services and supports.

In light of AMPARO's expertise, this response will focus particularly on what individuals and families have told us about their experiences. Our response is informed by our work with individuals through our advocacy, outreach and capacity building work; as well as through the findings of formal consultations, and research we have undertaken in partnership with the Queensland University of Technology.

Cultural understandings of key concepts

Question 1: How is disability understood or described in your family, culture, community or language?

Understandings of disability vary greatly both within and between cultural groups and change over time. Our views are shaped by factors such as our religious beliefs, education, life experience, exposure to media, and the views of others in our family. Individuals, families, and cultures may have different ways of thinking about how to define disability, what causes disability, and how we should respond. Cultural values influence our beliefs about the roles of people with disability and those who care for them, within our society.[1] In the Australian context, our understandings of disability have undergone radical change over the past century, with our policies and systems of support moving from reflecting predominantly a

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[1] See, for example, **Bunning K, Gona JK, Newton CR, Hartley S.(2017)** The perception of disability by community groups: Stories of local understanding, beliefs and challenges in a rural part of Kenya. PLoS One. 2017 Aug 3;12(8). https://doi.org/10.1371/journal.pone.0182214**; Mohamed Madi S, Mandy A, Aranda K. (2019)** The Perception of Disability Among Mothers Living With a Child With Cerebral Palsy in Saudi Arabia. Glob Qual Nurs Res. 2019 Apr 28(6). https://pubmed.ncbi.nlm.nih.gov/31065572/; **and Zakirova-Engstrand R, Hirvikoski T, Westling Allodi M, Roll-Pettersson L (2020)**. Culturally diverse families of young children with ASD in Sweden: Parental explanatory models. PLoS One. 2020 Jul 27;15(7), https://pubmed.ncbi.nlm.nih.gov/32716951/.

charity model, through the medical model, to the emergence of the social model; although this remains contested ground.[2]

It is important, therefore, to avoid stereotypes or to make assumptions about how individuals or families from a particular cultural background may view disability. Rather, it is important to be sensitive to some of the common ways of understanding disability which may exist, and to then listen carefully to the experiences of individuals. Some of the cultural perspectives of disability which people from CALD backgrounds with disability have shared with AMPARO include:

- Viewing disability as a product of ‘sin’ or punishment from God
- Disability being attributed to fate or karma of the person or their parents
- Disability being seen as the ‘fault’ of the parent, usually the mother, for having done something wrong during past life or pregnancy the impairment
- Disability being seen as a ‘gift’ for the parents to be honoured in caring for the person with disability
- The person with disability being seen as possessed by an evil spirit and that a healer can ‘cure’ the person
- That once in Australia doctors will be able to ‘fix’ the person.

Question 2: How are the concepts of violence, abuse, neglect and exploitation understood or described in your family, culture, community or language?

Concepts of abuse, neglect and exploitation can vary widely between cultures and contexts. The range in legal rights of women, children and people with disability between different countries both reflects and actively shapes cultural values, as illustrated in the story below.

Story 1

Research participant comments reflect different cultural perceptions of disability[3]:

One family reported to AMPARO that in their home country and in their culture “*..it’s shame to have a child with disability like that …people hide it, when I was a kid at school they asked me, do you have any brother or sister, I say no, I am an only child”.*

Question 3: How are autonomy, safety, inclusion and belonging understood or described in your family, culture, community or language?

Experiences of people from CALD backgrounds with disability

Question 4: What can you tell us about the experiences of violence, abuse, neglect and exploitation for culturally and linguistically diverse people with disability?

AMPARO has worked with many people from CALD backgrounds with disability who have experienced serious violence, abuse, neglect or exploitation. Many CALD people with disability are very isolated in their own communities and are much less likely to be accessing either mainstream services or disability supports. This isolation is a form of neglect, as without basic support, essential equipment, and access to the community, it is impossible to meet one’s fundamental needs. In our experience, people from CALD backgrounds who do gain access the NDIS often have Plans with much lower levels of support than they

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[2] See, for example**, Humpage, L. (2007)**, Models of Disability, Work and Welfare in Australia. Social Policy & Administration, 41: 215-231. https://doi.org/10.1111/j.1467-9515.2007.00549.x

[3] King,J., Edwards,N., Correa-Valez, I., Hair, S., and Fordyce, M. (2016).*Disadvantage and Disability: Experiences of people from refugee backgrounds with disability living in Australia.* Disability and the Global South (DGS).

require. This is due to a range of barriers they have experienced in communicating their needs with the NDIS Planner or Local Area Coordinator and lack of cultural competence by those undertaking the planning with the person. Furthermore, many people from CALD backgrounds with disability and their families face significant barriers to accessing the much needed supports available to them in their plans because they have not been funded appropriate levels of Support Coordination. As a result, even amongst those who can gain access to the NDIS, there are many people who continue to experience the neglect of having their fundamental needs unmet. CALD Participants are not experiencing equitable access to, and participation in the NDIS.

In addition, the experience of social isolation also means that violence, abuse and exploitation are far less likely to be reported or addressed for many people from CALD backgrounds with disability. Even more fundamentally, the diversity of views about disability, neglect and inclusion discussed in Questions 1-3 (see above) mean that many people from CALD backgrounds with disability who are experiencing violence, abuse, neglect or exploitation may not identify it as a breach of rights.

The following two stories illustrate the importance of access to information, social inclusion, and financial resources to overcome violence, abuse, neglect and exploitation.

Story 2

A young man from a CALD background with disability lives with his parents. They are from an asylum seeker background and therefore despite having a significant disability is not eligible for key supports such as the NDIS or housing assistance. The family could not afford suitable accessing housing, and so the young man was unable to access key areas of the apartment in which they lived, such as the bathroom. As a result, his parents were showering him in the backyard. AMPARO is working to access personal care support and counselling for this young man, alternative accommodation, emergency relief and additional income support. Advocacy is also connecting the family with free immigration advice as their visa status means available supports are limited.

Story 3

AMPARO contacted a woman from a CALD background with disability through our Targeted Outreach Project and referred her to the Local Area Coordinator to gain access to the NDIS. There was a history of domestic violence and coercive control. Initially, she received a very poor NDIS Plan which did not meet her needs. With support from an AMPARO advocate, Amaya requested a review of her NDIS Plan and received an appropriate level of support. The AMPARO advocate also supported Amaya to go to Centrelink to talk about her situation and gain access to income support. The combination of access to quality disability support and basic financial resources has begun to build Amaya’s capacity to access the community, understand her rights across all areas of her life and exercise independence from her partner.

Question 5: How are people with disability included, supported and welcomed by your cultural community? Are there any ways in which your cultural community excludes (for example, ignores or stigmatises) people with disability?

The diverse understandings of disability discussed in response to Question 1 (see above) leads to a diversity of ways in which people with disability are both included and excluded in cultural communities.

In a joint research project AMPARO undertook with QUT, people from CALD backgrounds with disability described the impacts of stigma and shame around disability in their communities[4]:

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[4] **King, J., Edwards, N., Correa-Velez, I., Hair, S., and Fordyce, M. (2016).** Disadvantage and disability: Experiences of people from refugee backgrounds with disability living in Australia. *Disability and the Global South (DGS).*

"The majority of people with a disability, they see them as a burden…someone who is useless. You have to be healthy."

"…. also the parent's karma…also scolded in the village that you are cursed, you are idiot."

"*In the culture it's shame to have a child with disability like that…people hide it, when I was a kid at school they asked me do you have any brother or sister, I say no, I am an only child."*

"…bad karma, they are sinners in the past and that is why they are still suffering nowadays."

"Some people say very cruel. Cruel to me, and I got very upset".

As a result of these experiences people from CALD backgrounds with disability and their families may experience ongoing exclusion from community life. This can often include:

- Being reluctant or more cautious about seeking help outside of immediate family
- Being more isolated than most new settlers and miss out on the 'sharing of information' that happens within new communities
- Having limited or no connections with other individuals with disability or families from their own cultural background
- Being unsure of what a 'good life' for a person with disability can look like and limited experiences of the opportunities or 'choices' that may be available.

Story 4

Independent advocacy supports inclusive living.

AMPARO Advocacy first started working with a woman (AA), who is deaf and of Afghan origin to provide advocacy in September 2019. She had only been living in Australia for 6 months and did not speak English and had no pre-existing language, apart from some limited sign language that she had developed with members of her family. The women's mother and siblings had been living in Australia for five years before she came to Australia, and her mother had limited English language proficiency. AA and her family experienced many barriers which resulted a need for individual advocacy support for AA to effectively access the NDIS, including:

- No evidence of diagnosis
- Lack of understanding of complex service systems here in Australia
- No knowledge of the NDIS or the rights of persons with disability regarding the NDIS
- No language and means of communicating for the person with disability and
- A need for good interpreters for the family to help them to understand our systems as well as a deaf relay interpreter for AA, once she developed some Auslan.

Initially the advocate supported AA to access services from Hearing Australia; to provide evidence of disability to the NDIS and to assist AA to receive hearing aids. Independent advocacy has meant that AA was successful in accessing the NDIS and for the first time in her life she has received supports for her disability.

Prior to receiving NDIS supports, AA spent her time home and isolated which was affecting her mental health. The advocate supported her and her family with preplanning, at the planning meeting and then to understand her NDIS plan and access appropriate services. The advocate worked with the family to help them to understand their rights in relation to the NDIS. There were some unacceptable practices by one service provider and the advocate supported the person and their family to understand that they had the right to access an alternative service, which they did.

Unfortunately, despite advocacy and AMPARO's involvement, the first NDIS Plan was inadequate for a person who has never received supports for their disability before and had no pre-existing language. The advocate worked with the family and Support Coordinator to lodge a review of reviewable decisions with the NDIS for additional funding. The outcome of this review was very positive and as a result AA received twice as much support in her new NDIS Plan. This meant that AA was now able to start learning Auslan with the help of Deaf services, which means she will now be able to communicate with others from the Deaf Community. Her supports have also been increased so that she is able to make links with the deaf community and learn about deaf culture, an I-Pad was purchased to assist AA with learning Auslan and learning to write and to increase her safety when out in the community. In addition to this, safety devices were purchased and installed in the family home, which included a flashing smoke alarm.

In October of this year the advocate visited the mother of AA and she reported that everything is going very well in relation to the NDIS supports that AA is receiving. She said that she has never seen AA so happy!

AA is making progress with her Auslan and has connected with another person from her community who is deaf, and that person is proving to be a positive support to her. AA is now able to leave her home with support to explore her community and is learning about life in Australia. This would not have been possible without the support of an advocate to help her to understand her rights and gain access to the opportunities and benefits that good support through the NDIS can provide.

Speaking up about violence, abuse, neglect or exploitation

Question 6: What barriers do culturally and linguistically diverse people with disability face when reporting violence, abuse, neglect or exploitation or making a complaint? What might help address these barriers?

People from CALD backgrounds with disability face significant, intersecting barriers to reporting abuse or neglect, or making complaints. These barriers include:

- **Lack of awareness of their rights**: Many people from CALD backgrounds with disability have come from contexts where their basic rights were not upheld. Without a framework for understanding their own rights and the expectations they can have for their lives, people from CALD backgrounds with disability may not identify that what they are experiencing is unacceptable or illegal.
- **Social isolation**: Many individuals receiving advocacy from AMPARO have few informal networks, other than their immediate family and household. Many people would have nowhere to go to escape violence or even to discuss their situation with others.
- **Lack of awareness of available supports**: People from CALD backgrounds with disability are often unaware of services or supports, or how to access them. This may be due to a range of factors including language barriers, different service systems in their country of origin, exclusion from settlement supports, etc. Social isolation also makes it more difficult to access the information that may be available and shared between others in their community.

- **Lack of culturally responsive service systems**: When people from CALD backgrounds with disability do know about services or complaints mechanisms and attempt to access them, they often encounter systems which are not culturally competent. For example, despite the Australian Government Language Services Guidelines mandating Commonwealth agencies "understand their clients and tailor the provision of language services to those who may require them"[5], in AMPARO's experience, many workers are unaware of how to engage an interpreter, have never worked with an interpreter or have never received training on working effectively with interpreters. Complaints processes may require completion of lengthy forms in English, which present another barrier. Limited English and computer literacy skills are also barriers to providing online feedback or complaints.
- **Lack of service systems that are accessible to people with disability**: Similarly, people from CALD backgrounds with disability may also encounter systems which are not responsive to their needs, such as buildings which are physically inaccessible. The impact of disability can also make it more difficult to communicate feedback.
- **Fear of making complaints due to repercussions that could occur**: Many people from CALD backgrounds (including Permanent Residents) may fear making complaints due to perceived repercussions such as having their visa revoked, being sent back to their country of origin, or being discriminated against in the future. These fears may be stoked by misinformation spreading within communities or based on experience with governments in other countries. A lack of understanding of the Australian government and service system, including the distinctions between agencies and the rights and responsibilities of service users, can also contribute to these fears.

Story 5

A mum of a young man with a disability wanted to make a complaint to his disability service provider. She was told by a worker from the service provider that if she made the complaint, he would tell the government that her husband has a drug addiction, and he would be deported.

(For information about what may help address these barriers, please see response to Question 7 below.)

Question 7: What should governments, institutions and the community do to encourage reporting and ensure effective investigations of violence against, and abuse, neglect and exploitation of culturally and linguistically diverse people with disability?

Much can be done by governments, institutions, and the community to address the barriers identified in Question 6 (see above) and to encourage effective reporting and investigation of abuse and neglect of people from CALD backgrounds with disability. These strategies are interrelated and must be implemented simultaneously to improve outcomes.

Firstly, outreach and education are urgently needed to empower people from CALD backgrounds with disability, their families and communities with information about their rights, and to raise expectations about the life they can live in Australia. This is critical to enabling people from CALD backgrounds with disability to identify abuse and neglect, and for families and communities to understand the rights of people with disability in Australia. This outreach and education must be in community languages and delivered in culturally appropriate ways which respect family structures and genuinely build people's understanding. It must go beyond translated materials, to building individual,

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[5] **Commonwealth of Australia (2019)** *Australian Government Language Services Guidelines: Supporting access and equity for people with limited English*, Department of Home Affairs, Canberra, p. 13

family and community capacity through face-to-face dialogue and education. In a recent consultation, a person from a CALD background with disability told AMPARO: *"I need someone to explain in my own language about what I can access, we are not used to 'brochures', this doesn't work."*

Secondly, people from CALD backgrounds with disability must be supported to access the services which meet their needs. For many people from CALD backgrounds with disability, simply providing information about a service or a link to a website will not enable the person or their family to access the service. This may be due to low levels of literacy or English skills, a lack of confidence in their right to request assistance, or a lack of a culturally competent response from the service provider (see further details below). Most of the people receiving advocacy from AMPARO require workers to directly introduce them to a service provider and facilitate the building of the relationship with the provider. Access to appropriate services and resources is critical for reducing social isolation, preventing abuse and neglect, and building confidence to raise concerns and complaints when necessary.

Story 6

AMPARO works with several families accessing Early Childhood Early Intervention support from NDIS-funded non-government organisations. Part of the role of these agencies is to provide "information and linkages to help [families] access supports and services available in [their] local community"[6]. The standard practice for one of these agencies is to email families with some links to websites of services in their local area. However, many of the families from CALD backgrounds are unable to use this information to access services, due to low levels of literacy and language barriers. The agency could achieve much better outcomes by directly supporting families to contact some service providers to discuss their needs.

Thirdly, the cultural competence of government agencies and service providers must be significantly improved. This must include, as a minimum:

- Informing all workers about how and when to engage interpreters, to ensure that the Australian Government Language Services Guidelines are implemented
- Monitoring the engagement of interpreters and the proportion of service users from CALD backgrounds, and taking action to improve these where required
- Providing cultural competence training, including training in working effectively with interpreters, during induction and then routinely as part of ongoing quality assurance
- Providing access to basic information about the service, such as how to access the service and how to make complaints, in a range of languages and formats.

Story 7

AMPARO is currently funded to deliver a three-year ILC Individual Capacity Building project with people from CALD backgrounds with disability in five regions across Queensland. As part of this project, Multicultural Engagement Workers outreach and engage people from CALD backgrounds with disability and support them to access services which meet their needs. However, workers and participants have frequently found that service providers lack the cultural competence to respond to the needs of participants. For example, service providers have suggested holding important meetings via telephone with several parties involved, including telephone interpreters. Such meetings are not only unlikely to produce the outcomes required but may also discourage people with disability from attempting to access services again in the future.

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[6] National Disability Insurance Agency (2021), "How ECEI works - step by step process", accessed 16/07/2021 at https://www.ndis.gov.au/understanding/families-and-carers/how-ecei-works-step-step-process.

Experiences of children and young people, women, refugees and asylum seekers from CALD backgrounds with disability

Question 8: What are the experiences of children and young people with disability from culturally and linguistically diverse backgrounds? What are the main issues and concerns they face? What do culturally and linguistically diverse children and young people with disability identify as being important in their lives?

The experiences of children and young people from CALD backgrounds with disability cannot be viewed in isolation from the experiences of their families and communities. Systemic issues such as housing stress, poverty, domestic and family violence and family separation impact upon all members of the family. However, in AMPARO's experience, in situations where families are under extreme stress, children with disability are even more likely to experience neglect than their siblings, due to the additional challenges involved in meeting the needs of children with disability. In light of this, AMPARO takes a holistic approach to the rights of people with disability through looking at the wellbeing of the whole family. If the primary caregiver in a family (often the mother) is struggling with financial, health or other concerns, it will impact upon their ability to provide the level of support and care needed to their child or family member with disability. It is necessary to look at people in their context to reduce violence, abuse and neglect, and to support full inclusion.

Another issue affecting children from CALD backgrounds with disability is that even when families do access support, service providers often fail to recognise the indicators that a family may require additional support. For example, it is rare for Support Coordination to be included in NDIS plans for children, as there is a general assumption that parents will undertake the role of finding, implementing, monitoring and adjusting services as required. However, many parents from CALD backgrounds require significant support to understand and navigate the disability support system. Without the inclusion of Support Coordination in these children's plans, their plans are unlikely to be implemented and AMPARO sees many examples of children missing out on critical early intervention supports.

In AMPARO's experience, it is also common for service providers to assume that if one parent (often the father) in a family is relatively fluent in English, he will manage the communication and organisation of supports. However, gender roles within the family may mean that it is critical for service providers to talk directly with the mother to understand the needs of the child or young person with disability. Similarly, it may be critical for the mother who may be less proficient in English, to be supported to organise services and supports, so that the child's plan is implemented, and they can access important therapies and equipment. A situation in which either parent does not speak English well, is an indicator that the family may need additional support.

Finally, the experiences of children and young people accessing supports is directly affected by the capacity of the provider to listen and respond to their needs. AMPARO has been advised that a local Early Childhood Early Intervention provider currently allocates its workers a caseload of 250 families at any one time, due to the limited funding available. Such a caseload makes it virtually impossible for workers to understand and respond to the needs of each family. Funding needs to be increased and suitable quality assurances in place to ensure that children and young people from CALD backgrounds with disability do not 'fall through the cracks' in the service system.

Question 9: What are the experiences of women, refugees and asylum seekers, people in immigration detention, and temporary visa holders with disability from culturally and linguistically diverse backgrounds? What are the main issues and concerns they face?

For women from CALD backgrounds with disability, experiences of abuse and opportunities to seek help are affected by a complex range of factors. There is substantial literature demonstrating the high rates of violence against women with disability.[7] Women from CALD backgrounds in Australia are known to experience domestic and family violence in different ways to their non-CALD peers, for example multi-perpetrator family violence and the impacts of abuse being increased by stress related to migration and visa issues.[8] In 2015 the report*, Not now, not ever: Putting an End to Domestic and Family Violence in Queensland*[9], cited a lack of suitable interpreters as a major barrier for women from culturally and linguistically diverse backgrounds to access justice and the right to be heard. This includes women with disability from CALD backgrounds. Furthermore, it is argued that Australia's reporting on domestic and family violence does not adequately address the intersection of gender, ethnicity, immigration status and other social categories, thus limiting the effectiveness of policy in responding to the needs of women from CALD backgrounds with disability.[10]

Similarly, people from refugee backgrounds with disability and people with disability seeking asylum face a complex interaction of factors in relation to abuse and neglect. Many have complex unmet health needs, as a result of having spent many years in refugee camps or countries with little capacity to provide good or even basic health care. Many people with disability and their families with whom AMPARO has worked, have reported experiencing isolation, cruelty, discrimination, victimisation, and stigma in their countries of origin and in refugee camps.[11] However, following arrival in Australia, many people from refugee backgrounds and people seeking asylum continue to experience significant barriers to meeting their fundamental needs and addressing abuse and neglect. As we noted in our submission to the Royal Commission in September 2020, refugees and asylum seekers with disabilities on Temporary Protection Visas in Queensland are experiencing systemic neglect, abuse and discrimination as they cannot access disability supports through the NDIS nor through some programs of the Queensland Government.[12] AMPARO has also found that people with disability and their families, from new and emerging communities or those who have settled under Australia's Refugee and Humanitarian Program, face particular challenges and require more intensive support to ensure their needs are met. Challenges include, the ongoing effects of trauma or torture with many experiencing Post Traumatic Stress Disorder, struggling to secure diagnosis of disability and evidence of functional impact to make a successful application to the NDIS and facing long waits to access specialist trauma counselling.

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[7] See, for example, **Kutin, J., Russell, R. and Reid, M. (2017)**, Economic abuse between intimate partners in Australia: prevalence, health status, disability and financial stress. Australian and New Zealand Journal of Public Health, 41: 269-274. https://doi.org/10.1111/1753-6405.12651; **Eastgate, G., van Driel, M. L., Lennox, N., & Scheermeyer, E. (2011)**, Women with Intellectual Disabilities: A Study of Sexuality, Sexual Abuse and Protection Skills. Australian Family Physician, 40(4), 226–230, https://search.informit.org/doi/10.3316/informit.896321430552812; and **McGowan, J. and Elliott, K. (2019)**, Targeted violence perpetrated against women with disability by neighbours and community members, Women's Studies International Forum, Volume 76, 2019, https://doi.org/10.1016/j.wsif.2019.102270.

[8] **Kaur, J. and Atkin, N. (2018)** Nexus between Domestic Violence and Child Protection: Multidimensional Forms of Oppression Impacting on Migrant and Refugee Women in Australia, Australian Social Work, 71:2, 238-248, DOI: https://doi.org/10.1080/0312407X.2017.1423092

[9] Special Taskforce on Domestic and Family Violence in Queensland (February 2015). *Not now, not ever: Putting an End to Domestic and Family Violence in Queensland,* https://www.justice.qld.gov.au/initiatives/end-domestic-family-violence/about/not-now-not-ever-report

[10] **Ghafournia N, Easteal P. (2018)** Are Immigrant Women Visible in Australian Domestic Violence Reports that Potentially Influence Policy? *Laws*. 7(4):32. https://doi.org/10.3390/laws7040032

[11] **King, J., Edwards, N., Correa-Velez, I., Hair, S., and Fordyce, M. (2016).** Disadvantage and disability: Experiences of people from refugee backgrounds with disability living in Australia. *Disability and the Global South (DGS).*

[12] **AMPARO Advocacy Inc. (2020)** Submission to the Royal Commission into violence, abuse, neglect and exploitation of people with disability.

Access to support and services

Question 10: How do culturally and linguistically diverse people with disability access support? What pathways do they follow to ask for assistance? (For example, do they reach out for direct help when experiencing violence, abuse, neglect or exploitation, or do they indirectly seek support through other channels such as seeking visa assistance, migration advice etc.).

As for all of us, people from CALD backgrounds with disability will access whatever services they know about, are easy to access and best meet their needs. In AMPARO's experience, there are a wide range of pathways people may follow to ask for assistance, based on their own personal experience and networks. Some people from CALD backgrounds with disability, or their family members, may be more likely to seek support or information from community leaders or others in their community, rather than from formal services (see Story 7 below). However, others may be less likely to talk with people in their own cultural community due to isolation, stigma, or communication barriers due to their disability. Many of the people receiving advocacy from AMPARO have limited understanding of the complex service systems in Australia or have had poor experiences trying to access service providers in the past. It is common for people in this situation to reach out to trusted individual workers with whom they had a positive rapport, to assist them when experiencing abuse or neglect, rather than attempting to access a specialist support service for the first time.

Story 8

A mother of a child from a CALD background with disability had separated from the child's father, who was now refusing to pay child support. The mother talked to informal leaders in her community who spoke to her ex-partner on her behalf to help resolve the issue.

Question 11: How accessible are services for culturally and linguistically diverse people with disability in different settings, for example, justice, health, education. What sorts of culturally appropriate supports and services should be made available?

Many mainstream services are inaccessible, or present significant access barriers, to people from CALD backgrounds with disability. For example:

- **Housing**: While many people with disability face barriers to locating and maintaining suitable accessing housing, government housing services present additional barriers for many people from CALD backgrounds with disability. Asylum seekers and people on temporary visas are ineligible for public housing. People who live in large families are also often ineligible due to combined income levels exceeding the thresholds for public housing. Furthermore, a lack of assistance to understand public housing processes and tenancy rights further reduces housing options. Those trying to access housing in the private rental market are faced with high rental prices, a lack of accessible housing and often discrimination.

- **Education and employment**: People from CALD backgrounds with disability trying to access tertiary education and employment have reported many barriers. For example, in a consultation facilitated by AMPARO in 2017, participants reported being unable to complete their university placements due to many placement options still being in inaccessible office spaces or being required to drive a work vehicle (rather than their own modified car). Others reported that employment agencies often lacked understanding of the impact of disability upon their lives. At the primary and secondary school level, it is common practice for schools to not engage credentialed interpreters when speaking with parents who have limited English proficiency. This means that parents are often prevented from being fully informed about education options and are unable to make informed decisions about their children's education.

- **Transport**: Barriers to accessing public transport include high costs, difficulties with physical access and a lack of appropriate information. For example, one participant stated:

> *"I did not know how to ask about getting on the train or that they could put a ramp out for me. No one told me these things."*

> *"It took me years to find out about the taxi subsidy scheme and that I could access this."*

- **The built environment**: Many streetscapes in Brisbane still do not have adequate footpaths that are safe, level and clear, while many non-government and private businesses are located in physically inaccessible buildings.
- **Health care**: People from CALD backgrounds with disability face significant barriers to accessing appropriate health care. These include challenges around accessing interpreters, such as GPs and hospitals not allocating additional time for appointments with interpreters, and delays in appointments meaning that interpreters need to leave for their next appointment. Similarly, it is common practice for hospitals to send letters in English requiring patients to confirm upcoming appointments; when the letter is not understood, the appointment is cancelled resulting in further significant delays. For those on low incomes, such as people reliant on the Disability Support Pension, it can be difficult to find low-cost health care without significant waiting periods. Furthermore, many health professionals have not been trained in responding to cultural needs, working with interpreters or the complexity of health needs of people with disability or those from refugee backgrounds. People with disability, particularly those who have not previously had access to good health care, may not recognise that what they feel is abnormal, or know how to describe their symptoms to health professionals. These barriers are interrelated and complex and can result in people from CALD backgrounds with disability failing to receive adequate health care, and chronic health conditions going untreated.

The key steps to be taken to improve access to essential services are:

1. **Provide accurate information through appropriate communication and engagement**. This includes appropriate use of credentialed interpreting and translation.
2. **Build the cultural competency and disability awareness of service providers and government agencies**, including providing person-centred support that responds to the needs of individuals (for example, working to understand the impact of a person's disability upon their life and health; or explaining government processes and client rights to those who are not aware).
3. **Address physical access barriers**.

What needs to change?

Question 12: What are the hopes for the future of culturally and linguistically diverse people with disability? Are there any examples of promising practice? What needs to change to make things better for culturally and linguistically diverse people with disability?

The Multicultural Access and Equity Policy Guide states: "*Australian Government programmes and services should be accessible by all eligible Australians, responsive to their needs, and deliver equitable outcomes for them, regardless of their cultural and linguistic backgrounds*".[13] However, as our discussion above has shown, this is far from the reality. Despite the continued advocacy efforts of CALD

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[13] **Commonwealth of Australia (2018)**, *The Multicultural Access and Equity Policy Guide*, Department of Home Affairs, Canberra, p. 8

communities and organisations, systems continue to be developed which are not accessible, do not meet people's needs, and result in inequitable outcomes. For example, the NDIS is a complex specialist disability service system that has incorporated many access barriers from previous systems (such as challenges engaging interpreters, and overwhelming administrative processes) and has only funded piecemeal projects to outreach and engage people from CALD backgrounds, rather than incorporating these into core business. Low levels of CALD participation in the NDIS at the Federal and State level are the result of structural and systemic barriers that restrict access and participation in the NDIS by failing to respond to the language and cultural needs of people from CALD backgrounds, particularly those with limited English proficiency.

- In Queensland, a total of **5.6%** of participants are from a CALD background, however ABS data 2016, suggests this figure should be closer to **15%.**
- Nationally a total of **9.4%** of participants are from CALD background, however the NDIA acknowledges this should be at least **21.9%.** (Quarterly Report for March 2021).

The key step that needs to occur to make things better for people from CALD backgrounds with disability is for government and service providers to design systems 'from the ground up' in meaningful consultation with CALD communities and organisations, to ensure that services are accessible, responsive and deliver equitable outcomes. The Australian Government needs to implement its own Multicultural Access and Equity Policy, and state governments need to do likewise. Government agencies and funded service providers must be held to account in their adherence to these policies. Meaningful investment needs to be made in building staff capacity to implement these policies.

There are many examples of good practice in supporting positive outcomes for people from CALD backgrounds with disability. Unfortunately, many of these initiatives are only funded on a small scale and as short-term projects, rather than their approach being integrated into core business for government and service providers. For example:

- **The National Community Connectors Program (CALD)** was funded for only 11 months as part of the NDIS. This program incorporated many of the core principles of effective work with CALD communities, including engaging bicultural workers, meeting people at times and places that suited them, and providing active support to understand and access services (in this case, the NDIS). CALD communities and organisations had long advocated to the NDIS for such an approach to be built into the core business of the Scheme. AMPARO was funded as a subcontractor to the Federal Ethnic Council of Australia (FECCA), and employed 4 part-time workers who spoke several languages, who worked across CALD communities in Brisbane, Logan, and Moreton Bay areas.

  AMPARO's bicultural Community Connectors were successful in identifying 102 people with disability from diverse communities who were not receiving supports and services to meet their most basic needs. Many were unaware of the NDIS or had been turned down by the NDIS for lack of evidence, some were unable to get appropriate evidence, others were not connected with services or connected with poor services and many not connecting with mainstreams services. Community Connectors were able to directly address many access barriers such as working sensitively with cultural taboos and stigma; building participants' understanding of the NDIS and other service systems, which in turn builds participants' confidence to engage with services; follow up and clarify important details with health professionals and service providers; provide transport to appointments; attend appointments with participants to provide support and enhance understanding; and educate government agencies and service providers about their responsibilities to provide access to credentialled interpreters.

Whilst this important National program had the potential to significantly increase the participation rate of CALD participants in the NDIS, the NDIA's assessment that the program had not achieved the intended outcomes when it had only been operating for 2 full quarters and subsequent decision to cease the program by 30 June 2021 was premature and disappointing. It showed a complete lack of understanding of the complexity of the work and failed to recognise the many obstacles and systemic barriers that this program could not possibly address, including the difficulty accessing timely affordable evidence of disability and functional impact of impairment. (See Attachment 3)

- **The QLD Refugee Health Network have developed an effective model of building the capacity of primary health practitioners, including GPs and other staff, to work effectively with CALD communities**. This pilot care coordination model builds on the colocation of refugee health nurses in primary care but is expanded to include patients from CALD background with complex health needs including people with disabilities. Mater Refugee Health nurses work in general practices in partnership with GPs and other practice staff to identify and offer care coordination to patients who are experiencing complex social and physical health issues. By collocating in the practice and working under the clinical governance of the GP the skilled Mater Refugee Health nurses offer a wrap-around support and follow up including referrals to appropriate social supports. The preliminary evaluation indicates high level of satisfaction with this model and improved patient engagement.

- **Access to independent advocacy for Queenslanders from CALD backgrounds with disability can make an enormous difference** and help to address significant disadvantage, violence and abuse this is often needed.

  Last year AMPARO advocated on behalf of Grete a young woman from a non-English speaking background who was left with significant physical and cognitive impairments after having a stroke. Grete had been living in a domestic violence situation and had experienced physical, emotional, verbal and psychological abuse over many years. After her stroke, Grete's partner left her and she became a single mother with a disability caring for two young children.

  Grete was extremely socially isolated as she had no other family living in Australia and was having great difficulties managing her home, she struggled with undertaking basic tasks such as shopping, cleaning and cooking for her family, and accessing the community. Furthermore, Greta had limited proficiency in English, no understanding of the National Disability Insurance Scheme (NDIS), and experienced difficulty accessing mainstream services and was needing to find safe and suitable housing.

  Despite the fact she had received support from a hospital rehabilitation team, to access the NDIS, her application to the NDIS was rejected twice.

  Grete had also been supported by the same team to apply for Disability Support Pension (DSP), however this and the following appeal was also rejected. As a result despite her disability, Grete remained on Newstart Allowance and was required to actively look for work, which was extremely stressful.

AMPARO became involved and was able to secure further medical evidence to support another Access Request to the NDIS and in the meantime advocacy supported Greta to access the Qld Community Support Scheme. However not long after this AMPARO was successful in securing access to the NDIS for Greta.

In the beginning of the Covid-19 pandemic, Grete's partner returned to Australia to live in the same household with her and her children. Greta's situation became more serious, but she did not feel she had the capacity or resources to find and pay for an alternative living situation and remained living in the same house with her children. Grete was hesitant for the advocate to assist her to apply for Department of Housing accommodation, as her financial situation was very unclear and she was in desperate need for legal assistance.

Over a 15-month period AMPARO'S advocacy was able to:

- Secure a specialist's assessment and further relevant medical evidence to support a new NDIS Access Request, which was successful.
- Secure a good level of funding in Greta's NDIS Plan to meet her needs, including adequate Support Coordination.
- Connect Greta with a culturally responsive and skilled service providers who could meet her specific language and cultural needs.
- Support Greta to obtain community legal assistance for advice and support.
- Make a successful application for Greta to receive the disability support pension.
- Applied for and accessed safe, affordable public housing and support to move into her new home.

The strong independent advocacy by AMPARO has brought positive and sustainable changes to Grete's life and has given her new opportunities to care for her children, participate in the local community, build her informal support network, improve her physical strength and gain control over her own life.

AMPARO Advocacy is pleased to provide this response to further the Disability Royal Commission's understanding of the specific experiences of violence, abuse, neglect and exploitation of people from CALD backgrounds with disability.

Yours sincerely

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Attachments -

1. *AMPARO's Report The NDIS and Culturally and Linguistically Diverse Communities: Aiming high for equitable access in Queensland*, October 2016.
2. AMPARO Advocacy's Response to *Towards an all-abilities Queensland Consultation Paper*, 2017
3. *Letter to Hon. Senator Linda Reynolds CSC, Minister for the National Disability Insurance Scheme, regarding the National Community Connector Program*, 4 May 2021.