# Inquiry into the experiences of culturally and linguistically diverse people with disability

Response to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability | July 2021

## Overview

AMES Australia (AMES) provides this submission to The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - *The experiences of culturally and linguistically diverse people with disability.* In addition, AMES refers to previous submissions made to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, referencing the experiences of culturally and linguistically diverse (CALD) people with disability in relation to particular issues:

- Response to the Rights and Attitudes issues paper;
- Response to the Emergency Planning and Response issues paper;
- Written feedback provided to the Commission's CALD engagement strategy and principles.

AMES is a statutory authority of the Victorian Government and provides a comprehensive range of settlement services to support recently arrived[1] migrants, refugees, and asylum seekers in Victoria, South Australia, Tasmania and New South Wales. AMES also works with the community, business and Government to develop sustainable and effective settlement solutions for the whole Victorian community.

AMES experience lies in working with migrants and refugees from CALD backgrounds and directly, or indirectly, their families. This submission draws on our extensive experience working alongside CALD communities through prior and current projects including:

- A **National Disability Insurance Scheme (NDIS) Awareness Project** in Victoria (2018-2020). The project provided information to CALD communities about disability support services in their first languages through recruitment of 12 'Community Champions' from seven communities - Iraqi, Afghan, Syrian, Somali, Afghan, Chin and Karen. By project completion it had provided over 60 sessions reaching 1,050 community members.
- **Two peer support groups** for the Afghan community in the South East of Melbourne and the South Sudanese community in the West of Melbourne (2019-2020). The project supported people with disability, or experience as carers, and employed two Community Champions as facilitators. At the conclusion of the project 71 sessions with 35 individuals (18 with disability) had been facilitated in first language, building capacity for self-advocacy and increased knowledge of disability and the NDIS. These groups were facilitated throughout COVID-19 and the subsequent lockdowns. AMES provided additional support through in-language resources and sessions about COVID-19 and available supports. This provided AMES with key insights into the challenges CALD communities face during lockdowns, including inadequate access to key health messages.
- A three-year project (2020-2023) called **'Business Matters'** is underway, designed to increase entrepreneurial skills for people with a lived experience of disability from the Arabic speaking community in Melbourne. Despite challenges due to COVID-19 AMES has successfully delivered the first cohorts' training course.
- AMES is implementing the **National Community Connectors Program** (NCCP) in Greater Dandenong and Casey (2020-2021). The program is focused on connecting CALD communities with the NDIS through increased awareness of the NDIS, NDIS eligibility criteria, support with access, and assistance with utilising supports. AMES recruited four staff from CALD backgrounds

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[1] AMES identifies the term 'recently arrived' to refer to migrants who have been residing in Australia for less than five years. This rationale is based on the five-year settlement period outlined in settlement services such as the Adult Migrant English Program (AMEP) and Settlement Engagement and Transition Support Program (SETS).

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to provide support in first languages. To date, 24 people are registered with the project but it is anticipated that the number of registered project participants will increase as the project progresses. The Connectors provide additional support to a large amount of people on a regular basis outside the project scope due to their increased knowledge and role in their communities.

AMES work to date has provided insights into what issues CALD communities with disability face. In particular, **access to the NDIS requires more effort** if Australia is to realise equitable delivery of disability services to all Australians. Many clients first engaging in AMES disability focused programs report they are unaware of the NDIS and what the NDIS can offer them. There are cases when individuals have been given a formal disability diagnosis, however, their families often do not know what the disability is called or what impact it may have on the family member. Additionally, some community members who have applied for NDIS support do not know the outcome and have experienced difficulties when contacting the NDIS to find out. When they are able to access information, it is typically provided in English. Additional challenges CALD communities face when accessing disability support relate to needing medical reports; a certain level of understanding of disability, diagnoses, their rights; and how to advocate for themselves or their family members. AMES identifies the key success factors for mitigating these barriers as including building trust with communities and providing information in first language.

AMES congratulates the Commission for focusing on the compounding, intersecting experiences of people with disability from CALD backgrounds and welcomes the opportunity to provide further evidence in addition to our previous submissions. AMES submission focuses on three areas specifically; **CALD communities' understanding of disability, underutilisation or exclusion from services,** and **intersectionality – the nexus of CALD, disability, gender and violence.**

**AMES re-emphasises the following recommendations (1, 3, 4, 5) put forward in AMES previous submissions and presents an additional recommendation (2) for consideration by the Royal Commission.**

1. *Recognise that community attitudes towards disability and levels of knowledge vary significantly among and across different CALD communities when developing policies, information materials and when engaging with different cohorts.*
2. *Continue to fund programs such as the National Community Connectors Program to support CALD communities' access to disability services.*
3. *Develop and support outreach activities to engage CALD communities in increasing their involvement in mainstream disability services.*
4. *Develop accessible disability information materials and web content in additional community languages.*
5. *Develop specific responses to the prevention of violence against women with disabilities in CALD communities.*

We expand on these recommendations in the remainder of this document. We welcome the opportunity to assist the Commission further in its Inquiry.

# Key challenges

## CALD communities' understanding of disability

Throughout the Australian population, there are varying definitions or descriptions of what people consider a disability to be. This is particularly true within CALD communities. What we have learnt from working with CALD groups is that **'hidden' or 'invisible' disabilities such as intellectual disabilities, including autism and psychosocial disability, are not always considered a disability**. CALD communities have varied belief systems around what constitutes 'disability' and its cause(s), which may influence how medical interventions and care are pursued. For example, in some cultures, specific disabilities evoke reactions of pity or fear, and in others, people would not consider

themselves as having a disability.[2] A 2010 study identified that acceptance of disabilities is low and stigmatisation of disabilities is high in several CALD communities.[3] In many communities, stigma presents as understanding that people with a disability cannot lead a 'normal life' and have lower expectations than community members without a disability. In some communities, there is a belief that people with a disability have done something wrong or bad in a past life resulting in people with disability being isolated from the wider community. Through program evaluation[4], AMES has found that **education and information exchange sessions, positive role modelling of people with disability, and the use of positive language can have a significant and positive impact on community attitudes.**

AMES has found that **the social model of disability is not widely understood**. This can lead to people not having their disability diagnosed or recognised, not having their disability rights respected, and being at greater risk of abuse. There is the need for a stronger focus on the term 'impairment' as found in the social model of disability, rather than 'disability' as a term that reflects the negation of abilities. The descriptions of disability need to consider the varying interpretations of disability. In the context of AMES response, possible options for descriptions and a human rights approach should first be tested and tried with CALD groups to determine how it translates into different community languages and cultural fit.

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*Recommendation 1: Recognise that community attitudes towards disability and levels of knowledge vary significantly among and across different CALD communities when developing policies, information materials and when engaging with different cohorts.*

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## Underutilisation or exclusion from services

CALD community members often underutilise, or are excluded from, disability services. Consultations with refugee communities, asylum seekers and service providers conducted by the Refugee Council of Australia between 2014 and 2016 identified that people from refugee backgrounds with disability were excluded from mainstream disability services due to changes at policy level, barriers to service access and the consequences of poor service provision.[5] Available data indicates that CALD communities in Australia have similar rates of disability to the rest of the population.[6] However, since the NDIS commenced in 2013 there has been a lower uptake by CALD communities compared to the broader population. At the end of 2017, an estimated 22 per cent of NDIS participants would be expected to be from CALD backgrounds.[7] However, most recent data identifies that only 10.5 per cent of NDIS participants across Australia identified as CALD; and 11.5 per cent in Victoria.[8]

Common barriers to services include; complex assessments and access request forms, long waitlists and the cost of reports; need for a formal diagnosis and explanation and understanding of a diagnosis if it has been made; long waiting lists for advocacy supports; inadequate information in community languages; visa eligibility issues; lack of culturally responsive support coordination as well as language proficiency and lack of understanding of what services are available. **CALD communities may be unfamiliar with the concept of a consumer-directed care model** with choices or do not have these explained to them. According to NDIA staff, participants who are confident, educated and able to articulate their needs have better outcomes than those with less capacity to understand and navigate

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[2] Heneker, K.J., Zizzo, G., Awata, M., Goodwin-Smith, I. (2017). *Engaging CALD Communities in the NDIS.*

[3] Thompson, D. et al. (2011). *Community attitudes to people with disability: scoping project,* Sydney: UNSW

[4] An evaluation of the NDIS Awareness Project indicated that 100% of Champions stated that their perception of disability had changed and 99% of attendees of community sessions agreed that they knew more about disability in Australia as a result of the project.

[5] Heneker, K.J., Zizzo, G., Awata, M., Goodwin-Smith, I. (2017). *Engaging CALD Communities in the NDIS.* Australian Centre for Community Services Research, Flinders University.

[6] SSI (2018). *Still outside the tent: Cultural diversity and disability in a time of reform— a rapid review of evidence.* Settlement Services International.

[7] National Ethnic Disability Alliance (NEDA) quoted in AMPARO (2016), The NDIS and Culturally and Linguistically Diverse Communities: Aiming high for equitable access in Queensland.

[8] National Disability Insurance Agency. (2021). NDIS Quarterly Report to disability ministers Q3 2020-2021. 31 March 2021.

the NDIS.[9] The case study below highlights the issues a person with disability from a CALD background can face when trying to access the NDIS.

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## Case study

*Ali\* approached AMES through the National Community Connectors Program in December 2020 seeking support with access to the NDIS. Ali speaks Dari and uses Auslan as he is deaf. Ali's brother is also deaf and is an NDIS participant. Their sisters frequently support them with translation.*

*Ali made an application to the NDIS in 2018 and believed he had been denied access. However, after AMES sighted paperwork from the NDIS it was confirmed that Ali had been granted access and had been invited to a planning meeting in early 2019.*

*AMES completed the necessary paperwork to be able to act on Ali's behalf. In raising the case with the NDIS it was advised that a planner would be in contact soon. Once AMES started making contact to the NDIS on Ali's behalf, Ali started receiving phone calls from the NDIS despite his disability being listed as deafness. Several weeks later and after significant follow up from AMES staff, a Senior Planner confirmed that Ali had a plan approved since April 2019 for $52,000. The Plan was being managed by the NDIA and no funds for services from the plan had been utilised. Ali was not aware that he had an NDIS plan. Ali and his sister recall attending a meeting with the NDIS where both brothers were present. They do not recall what this meeting was about and do not remember being asked if they would like their plan to be managed by the NDIA or the Local Area Coordinator. A plan had not been sent to Ali and the NDIS confirmed that it had not been translated into Dari. A Dari interpreter was not present at the initial planning meeting.*

*The NDIS Senior Planner was unable to explain why Ali was unaware that he had a plan or why he was not contacted over the last 18 months. No support was given to find a Support Coordinator and no follow up checks were conducted to see why there was no utilisation of the plan. When enquiring further, AMES was told to focus on the future for this participant rather than the past failures. When the Community Connectors team requested a meeting with the NDIS to discuss methods to move forward and assess the failures of the last plan being implemented they were informed that this was not possible. A planning meeting was requested for Ali's new plan taking several weeks to be arranged. Only two platform options were provided for the meeting, Microsoft Teams and telephone, neither of which were suitable for Ali's needs. Ali did not want to make a formal complaint as he thought it might harm his relationship with the NDIS. Once a new plan was developed, AMES were required to research and find an appropriate Support Coordinator for Ali. After 25 months after first being granted access to NDIS support, Ali is now receiving services.*

*\*Name has been changed*

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Through the delivery of the NCCP, AMES has found that past efforts by the NDIS to reach out to diverse communities have failed as the responsibilities of the NDIS, Local Area Coordinators and Early Childhood Early Intervention Partners do not include providing the intensive access support many CALD people with disability need. AMES Community Connectors have successfully engaged with 'hard-to-reach' CALD communities as the Community Connectors are, by definition, well-known and trusted in their communities. Their roles have also helped to establish confidence in the program and in the NDIS from the outset. AMES is seeing community members previously supported through our disability focused projects referring other people to the program. **AMES concern is that if programs like the NCCP are not extended and continued, under-representation of CALD communities in the NDIS will continue; and in combination with underutilisation of disability services, people with disability will be prevented from exercising their right to fully participate in society and to lead the life they wish**.

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[9] Mavromaras et.al. (2018). *Evaluation of the NDIS: Final Report.* National Institute of Labour Studies Flinders University, Adelaide, Australia.

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> *Recommendation 2: Continue to fund programs such as the National Community Connectors Program to support CALD communities' access to disability services.*

> *Recommendation 3: Develop and support outreach activities to engage CALD communities in increasing their involvement in mainstream disability services*
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> ***a. Utilise participatory approaches*** *such as co-design, when working with CALD communities to engage and build ownership and involvement. Consultations with CALD groups need to be facilitated in the communities' first languages to reach more vulnerable groups, attract people to the sessions and encourage effective participation.*
> ***b. Build partnerships with key CALD organisations*** *based on locality to identify, recruit, train and support networks of community leaders who are known and respected in their community and can act as liaison with isolated, new and emerging communities.*

> *Recommendation 4: Develop accessible disability information materials and web content in additional community languages*
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> ***a.*** *Offer information in a variety of languages, simplified versions, visual and audio information, and consider the mode of information sharing.*
> ***b.*** *Consider the demographic profile of CALD communities, especially in relation to newly arrived communities, when resources are being developed. Newly arrived communities, even if a small language group, need information as they may not be aware of disability rights in Australia or the social model of disability. This is particularly relevant for those 'hard to reach' communities.*

## Intersectionality – the nexus of CALD, disability, gender and violence

Intersectionality, and not 'just' the disability must be considered when making decisions directly impacting people with disability from CALD backgrounds as it can lead to an increased risk of discrimination. **People with a disability have a much higher risk of experiencing abuse and violence**, often perpetrated by their carers and in their primary place of residence, both at home or within a care facility, with women and girls particularly vulnerable. Women and girls with disabilities are twice as likely as women and girls without disabilities to experience violence throughout their lives, with over one third of women with disabilities experiencing some form of intimate partner violence.[10]

Risks associated with **stigma attached to both disability and domestic violence** in Australia are further amplified for people from CALD backgrounds. A number of factors influence a person's access, ability and opportunity to get support and report any violence or abuse from a family member or carer. Some of these factors can be systemic or organisational, such as accessibility to services or information, and therefore easily identifiable. Others can be cultural and within a community or family. These can be difficult for others from outside the community to identify or be vigilant about.

Violence against women with disabilities (WWD) has not been rigorously or systematically researched in Australia, leading to **a paucity of data and gap in the evidence base** to inform practice response and policy development. Women with disabilities make up approximately 19 per cent of Australia's female population and while there is clear evidence about the high rates of violence and risk of violence to women from their intimate partners, disability and CALD is not fully delineated in this data.[11] Recent localised research and "grey data" – data collected from advocacy organisations, medical, legal and other institutional sources - indicate that women with disabilities and those from CALD backgrounds are at far higher risks of experiencing violence.

**Women from CALD communities are more vulnerable to family violence**, particularly during early years of settlement and are less likely to report violence. Lack of knowledge of local laws and

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[10] Krnjacki, L., Emerson, E., Llewellynn G., Kavanagh, A. (2015). 'Prevalence and risk of violence against people with and without disabilities: Findings from an Australian population- based study', Australian and New Zealand Journal of Public Health 40(1), December 2015

[11] Woodlock, D., Western, D., Bailey, P. & Healey, L. (2013). *Voices Against Violence: Paper 6: Raising Our Voices - Hearing from with Women with Disabilities,* Melbourne: Women with Disabilities Victoria

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protection, fear of authority, entrenched attitudes towards women and their roles in families, language barriers and fear of discrimination are some of the key drivers of both higher rates of violence and lower rates of reporting. In 2017, researchers analysing policy responses towards violence against WWD found significant gaps in data collection, particularly in police reports or presentations to hospital.[12] This research identified that details of disabilities and cultural or linguistic diversity would significantly assist in forming more effective responses.

While there is **little access to sufficient prevalence data**, data do exist that tells us what people think about the issue through the National Community Attitudes Survey (NCAS) on Violence Against Women (VAW). This is important because attitudes toward violence is an important indicator of the extent of the problem. A consistent finding in the 2009, 2013 and 2017 NCAS is that people born in non-English speaking countries are more likely to have a lower level of understanding of the nature of VAW, a lower level of support for gender equality and a higher level of endorsement of attitudes supportive of VAW than those born in Australia. This was especially the case for respondents who were recently arrived or who had poor proficiency in English. The 2017 NCAS report in particular, provided some insight into current attitudes within CALD communities towards women and gender equality and highlighted continued regressive attitudes and dated norms, with rigid gender stereotyping, undermining women's roles in home and work and condoning and victim blaming scoring significantly higher. In all these areas, respondents from CALD communities were twice as likely to have regressive views than the main stream community.[13]

CALD communities are affected by the same risk factors for violence as experienced by the general community. However, through the provision of AMES settlement services we also know that **women remain vulnerable to violence during the settlement phase** and in fact, this vulnerability escalates. Women and girls with a disability face these additional barriers to support and protection inside the broader categories of newly arrived refugees and migrants.

> *Recommendation 5: Develop specific responses to the prevention of violence against women with disabilities in CALD communities*
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> *AMES recommends the development and promotion of cultural awareness training with a specific CALD disability focus for service providers. This approach should include developing training materials that contain guidance on how to work with interpreters, translators and bicultural workers. These resources should be co-designed with representatives of the CALD communities with disability, with a particular focus on newly arrived refugee and migrant communities.*

For more information, please contact Cath Scarth, CEO on scarthc@ames.net.au

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[12] Didi, A, K Soldatic, C Frohmader, and L Dowse. (2007). "Violence against women with disabilities: is Australia meeting its human rights obligations?" *Australian Journal of Human Rights* 22 (1): 159-177.
[13] ANROWS (2019). *Attitudes towards violence against women and gender equality among people from non-English speaking countries: Findings from the 2017 National Community Attitudes towards Violence against Women Survey (NCAS).* (ANROWS Insights, Issue 02/2019). Sydney, NSW: ANROWS