AMES Australia

# Submission to the Victorian State disability plan 2021-2024 consultation

Submitted to:

The Office for Disability, Department of Health and Human Services, State Government of Victoria

April 2020

# Overview

AMES Australia provides this submission to the Office for Disability, Department of Health and Human Services, State Government of Victoria.

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. AMES also works with the community, business and Government to develop sustainable and effective settlement solutions for the whole Victorian community. AMES evidence-based *Settlement Framework for Social and Economic Participation* addresses successful settlement of recently arrived migrants and refugees through four key domains: Employment, Education, Health and Wellbeing, and Safety and Security.

AMES experience lies in working with migrants and refugees from culturally and linguistically diverse (CALD) backgrounds and directly, or indirectly, their families. This submission draws on our extensive experience working alongside CALD communities within the disability space. AMES successfully received an Information, Linkages and Capacity Building Grant from DHHS with the National Disability Insurance Scheme (NDIS) Awareness Project starting in November 2018. The project was designed to provide CALD people with disability with information about how to access disability support services in their first languages. AMES has achieved this through the recruitment of 12 Community Champions from seven target communities - Iraqi, Afghan, Syrian, Somali, Afghan, Chin and Karen who delivered information sessions to their communities. Together they speak over 20 languages. By the end of the project, the Community Champions had delivered over 60 information sessions to 1,050 community members.

More recently, AMES has been running two Peer Support Groups for the Afghan community in the South East of Melbourne and the South Sudanese community in the West for people with a lived experience of disability or carers. Two Community Champions facilitate the peer support groups, conducted in first language. The project builds knowledge and self-advocacy skills of participants through shared lived experience, learning from each other and group activities. Participants have responded positively as to their increased knowledge and awareness in relation to the NDIS.

**In summary, we recommend the Office for Disability:**

1. *Consider including 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.*
2. *Ensure that the next description of disability has been tested through a cultural awareness lens and that it makes sense in a variety of CALD communities.*
3. *Consider how intersecting characteristics, such as ethnicity and disability, make up a person's identity and how it affects a person's needs and wants in relation to service provision.*
4. *Ensure that the next State Disability Plan includes a particular focus on specific CALD communities and recently arrived cohorts as they can be harder to reach than other well-established CALD communities.*
5. *Collaborate with organisations who already have well-established contacts and relations with hard to reach communities, such as certain CALD cohorts and recently arrived migrants. This includes AMES Australia.*

[1] AMES considers 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).

6. *Acknowledge that when engaging with CALD communities they may hold a variety of attitudes towards disability.*
7. *Consider how mainstream services can provide disability support to cohorts who are ineligible for the NDIS; or eligible but unable to access due to long waiting lists and complexities in the system. This would allow for recently arrived communities to gain access to support services and mobility aids immediately upon arrival.*
8. *Consider how mainstream services can support the NDIS in facilitating better uptake of CALD clients by employing strategies which:*
    a. *Promote cultural awareness training with a specific CALD disability focus for service providers, NDIS staff and partners such as Local Area Coordinators*
    b. *Promote the benefits of hiring client-facing staff from a CALD background and where possible lived experience of disability*
    c. *Develop training materials that include guidance on how to work with interpreters, translators and bicultural workers*
    d. *Promote training for service providers, NDIS staff and partners on prevention of violence for people with disability in CALD communities.*
9. *Revise existing, and develop new, disability information materials and outreach activities to reach CALD communities.*
10. *Develop disability information materials in additional languages and at more accessible levels such as simplified versions and web-friendly content.*
11. *Systematise knowledge and experience about disabilities by empowering CALD communities in Victoria through commissioning research and evaluations, and supporting platforms for service providers to share results about the needs and priorities of their clients.*
12. *Ensure that those with disability are included in Australia's national plan to reduce violence against women and children by integrating a complete intersectional approach when designing policies, programs, resources and in the provision of training focused on the prevention of violence.*

We expand on these recommendations in the remainder of this document. We would welcome the opportunity to assist the Office for Disability further in its development of the State Disability Plan, where relevant.

# Topic 1: Improving how we describe disability and disability inclusion in the next plan

**How should we set out a description of disability and a human rights approach in the next state disability plan?**

As described in the social model of disability, disability is socially constructed and should be seen as a consequence of people living with impairments and an environment filled with barriers – may they be attitudinal, physical or social. This understanding therefore implies that the environment must change to enable people with impairments to participate in society on an equal basis. A social model of disability seeks to change the society; it does not seek to change the people with impairment. This model is now recognised internationally in the United Nations Convention on the Rights of Persons with Disabilities and aims to change how broader society view people with impairments.

***Recommendation 1:*** *Consider including 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.*

**Are there other statements you'd like the next plan to say about what disability is, what it means to you, and how Victoria needs to do its work to be more inclusive?**

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. From 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.

The description of disability in the next State Plan needs to consider these varying interpretations of disability. In the context of AMES response the possible options for descriptions and a human rights approach should first be tested and tried with CALD groups. It needs to be tested to see how it translates into various different languages and cultures.

***Recommendation 2****: Ensure that the next description of disability has been tested through a cultural awareness lens and that it makes sense in a variety of CALD communities.*

Furthermore, studies have shown that compounding challenges of intersectional disadvantage requires greater policy attention.[2] Intersectionality needs to be further considered as disability is only one of many characteristics that makes up a person's identity. Intersectionality can lead to an increased risk of discrimination that a person with a disability may face. The varying social and political identities of people with a disability needs to be considered to really address their needs and wants in the wider community. Intersectionality, and not 'just' the disability must be considered when making decisions directly impacting people with disability from CALD backgrounds. We recommend a tailored, nuanced approach to service delivery, especially when CALD intersect with disability.

***Recommendation 3:*** *Consider how intersecting characteristics, such as ethnicity and disability, make up a person's identity and how it affects a person's needs and wants in relation to service provision.*

[2] Hirsh et.al. (2019). "The changing face of disability and refugee services and policy in Australia: Implications for social work"

## Topic 2: Finding better ways to include people with disability in making the next plan

**What are other groups that we need to reach out to?**

It is vital for the success of the next State Disability Plan that the needs and wants of CALD communities are heard and considered. It needs to be recognised that there are differences within CALD groups and as a consequence there are varying needs. For example, recently arrived communities such as refugees often have compounding issues deriving from their settlement journey, such as trauma, limited health literacy and unfamiliarity with the complexity of Australian systems. Asylum seekers' needs are further compounded through the ineligibility to many services, including the NDIS. These needs, of course, will vary from individual to individual and community to community. We recommend that there needs to be a particular focus on smaller CALD communities and those who are recently arrived as they are often left out of these processes and can be harder to reach compared to more established CALD communities who have been in Victoria for a long time and are well known in the broader community.

***Recommendation 4:*** *Ensure that the next State Disability Plan includes a particular focus on specific CALD communities and recently arrived cohorts as they can be harder to reach than other well-established CALD communities.*

**What are some of the specific things we can do to engage effectively with particular groups?**

To effectively engage with CALD groups the Victorian Government needs to work with organisations that are well connected with CALD communities such as AMES Australia. Recently, AMES Australia has been running a project to increase CALD communities' awareness of the NDIS. This was done through the recruitment of 12 Community Champions from seven target groups which included the Syrian, Iraqi, South Sudanese, Somali, Afghan, Karen and Chin communities. These Champions were selected due to being well connected within their community and also having established links with the members who have a lived experience of disability. For the NDIS Awareness Project, we were funded to deliver 16 information sessions to our target communities. However, by the end of the project, due to demand, we delivered over 60 information sessions to 1,050 community members demonstrating our reach into the community as well as understanding the appropriate approaches to discuss disability. We have found that it is vital to utilise community members to effectively engage with our target communities.

**What co-design approaches do you think would be good for the next state plan?**

It is essential that participatory approaches such as co-design are utilised when working with CALD communities to engage with community and build ownership and involvement. Consultations need to be facilitated in the communities' first languages to reach the more vulnerable groups, attract people to the sessions and ensure effective participation.

AMES Australia would welcome the opportunity to collaborate with the Victorian Government to host consultations with CALD communities. Through our projects working with CALD communities on disability topics, we have developed numerous contacts within 'hard to reach' communities. We have learnt many things from conducting and evaluating our projects including the best approaches to discussing disability; methods of community participation that work; understandings and perceptions of disability; and the appropriate use of language. With this relevant experience we can share these learnings through hosting consultations with CALD communities for the State Disability Plan.

***Recommendation 5:*** *Collaborate with organisations who already have well-established contacts and relations with hard to reach communities, such as certain CALD cohorts and recently arrived migrants. This includes AMES Australia.*

## Topic 4: Introducing overarching approaches to strengthen government commitments under the new plan

**What do you think about including community attitude and universal design as guiding approaches in the new plan?**

A guiding approach in developing the new plan should be recognition and understanding that community attitudes vary significantly among and across different CALD communities. In order to effectively strengthen community attitudes, there needs to be an understanding of what people's baseline knowledge or understandings of disability are. Findings from our recent work in this area have identified that there is little understanding of rights for people with a disability, including the right to participate in society such as working and receiving an education. Stigma is present in many communities presenting in understandings 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 being isolated from the wider community. We have found that through education and information sessions, positive role modelling of people with disability and the use of positive language can have a significant positive impact on community attitudes.

Engagement with CALD communities needs to consider this background knowledge and reflect human rights principles and approaches. Consultations with CALD groups through the AMES network can build on and extend these previous learnings to inform the new State Disability Plan.

***Recommendation 6:*** *Acknowledge that when engaging with CALD communities they may hold a variety of attitudes towards disability.*

## Topic 5: Strengthening the NDIS and mainstream interface

The scope of Commonwealth service provision for cohorts from CALD backgrounds has expanded in recent years. For example, prior to 2012, the Australian government required every humanitarian offshore visa applicant to meet a set of health requirements which enabled the Immigration Minister to refuse a visa if a person had a 'disease or condition' and if health services provided to that person were likely to 'result in a significant cost to the Australian community in the areas of health care and community services.' Subsequently, in 2012, a Parliamentary inquiry into the treatment of people with disability in Australia's migration system resulted in a policy change being the introduction of a health waiver. With this change, costs for health or community care services would not be considered and all offshore refugee visa applicants (including their family members) with disability or health conditions would be considered for the health waiver.[3] The implementation of this new policy has resulted in an increase in the number of refugees arriving with disabilities and complex physical and mental health issues.[4] In addition, some refugees with disabilities arriving in Australia

[3] http://refugeehealthguide.org.au/people-from-refugee-backgrounds-living-with-disabilities/

[4] https://anglicaresa.com.au/wp-content/uploads/NDIS-CALD-Report-FINAL-2017.pdf

present with conditions typically treated in childhood, while others arrive without necessary aids and equipment.[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 rest of the population. At the end of 2017, an estimated 22%[7] of NDIS clients would be expected to come from CALD backgrounds. However, the data identifies that only 7% across Australia identified as CALD; and 9% in Victoria.[8]

**What are the gaps between NDIS and mainstream services?**

As previously mentioned, recently arrived communities face an array of compounding challenges upon arrival, especially those who arrive through the Humanitarian Settlement Program as they obtain access to the NDIS. However, the NDIS requires a formal health diagnosis, extensive evidence and medical history to gain access to its services. This restriction puts those who are recently arrived at a disadvantage as they rarely come to Australia with a formal diagnosis of disability. Therefore, prior to accessing the NDIS they need to obtain a diagnosis and evidence in Australia which is a lengthy process due to medical waiting lists and the expense of seeing specialist medical services. Meanwhile, they are missing out on vital services available through the NDIS.

Mainstream services need to be able to assist with filling this gap, especially the Early Childhood Early Interventions services as without early invention there can be detrimental lifelong effects on these children.

At present, asylum seekers and temporary protection visa holders are ineligible to access the NDIS which creates further vulnerability to an already vulnerable cohort. A review as to how mainstream services can support service provision for asylum seekers with disabilities is a positive step to bridging this access gap..

Based on our experience with CALD and recently arrived communities, we have found that without the benefit of a formal and accepted diagnosis pre-arrival, new migrants face multiple disadvantages, including delays in access to services and other disability supports. These disadvantages may force families to navigate an expensive healthcare system with long waiting lists leading to unnecessary costs while health conditions deteriorate.

***Recommendation 7:*** *Consider how mainstream services can provide disability support to cohorts who are ineligible for the NDIS; or eligible but unable to access due to long waiting lists and complexities in the system. This would allow for recently arrived communities to gain access to support services and mobility aids immediately upon arrival.*

The quality and efficiency of the NDIS is intended to be driven by consumer demand and market competition and aspires to promote people with disabilities to be 'active agents' to enjoy full social and economic participation equal to all Australian citizens.[9] As a choice-model relies on the principle that individuals have equal capacities to articulate their needs, groups that may not have all the

[5] NEDA, FECCA, RCoA and SCoA (2019). *Barriers and exclusions: The support needs of newly arrived refugees with a disability.*
[6] Settlement Services International (2018). *Still outside the tent: cultural diversity and disability in a time of reform – a rapid review of evidence.*
[7] NEDA (2016) in AMPARO Advocacy Inc. (2016). *The NDIS and Culturally and Linguistically Diverse Communities: Aiming high for equitable access in Queensland.*
[8] The Ethnic Communities' Council of Victoria (ECCV) (2019). *It's Everybody's Business' Multicultural Community Perspectives on Disability and the NDIS.*
[9] Hirsh et.al. (2019). "The changing face of disability and refugee services and policy in Australia: Implications for social work".

relevant skills to self-advocate for their needs, for example, fluency in English or informal support networks, may struggle to navigate social services, procedures and requirements. CALD communities may also be unfamiliar with the concept that they might be able to have choices within social services at all.

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 the NDIS.[10] Implementing a choice model that successfully includes CALD clients requires additional support such as access to professional interpreters and caseworkers, as well as a broader cultural understanding by the service provider of a given individual or group. Effective and practical strategies may include engaging disability support staff from similar CALD backgrounds; and for carers to be of the same gender.

We believe it is important that the Office for Disability acknowledges that a choice model is not well-suited to many CALD clients with disabilities as, rather than support choice and engagement, it may reinforce disadvantages. The individualised choice model should be adapted to better address the needs of people with disabilities from CALD backgrounds to increase their participation to achieve levels similar to the rest of the population.

The following case study from AMES Humanitarian Settlement Program highlights the difficulty clients from CALD and refugee backgrounds face when trying to interact with the NDIS.

***Case study from AMES Humanitarian Settlement Program***

*A non-English speaking family wanted to register with the NDIS. Their Case Manager had to help the family accessing the NDIS via telephone with the clients in the room. During the conversation with the NDIS provider the family were not able to hear the conversation due to hearing impairment, lack of English skills and confidence and could therefore not answer the questions asked.*

*The Case Manager tried to speak on behalf of the clients, however the phone was disconnected by the NDIS provider due to the rule that only clients can access and speak on their own behalf. Another option for clients trying to access the NDIS is to nominate someone to speak on their behalf but in this case the family had no one to nominate and the Case Manager could not be a nominee as they would not be working with the family on an ongoing basis.*

*The Case Manager called the NDIS partner back and attempted to get the couple registered but the Case Manager was accused of coercing the clients and helping them answer questions. The client became very stressed and overwhelmed by the difficulty in registering for the NDIS and started to cry. The client suffered from incontinence issues and was very ill which made it hard to sit through such a lengthy process. It was a negative and discouraging experience for all parties.*

*Case Manager, AMES Humanitarian Settlement Program*
*Melbourne*

***Recommendation 8:*** *Consider how mainstream services can support the NDIS in facilitating better uptake of CALD clients by employing strategies which:*

*a. Promote cultural awareness training with a specific CALD disability focus for service providers, NDIS staff and partners such as Local Area Coordinators*

*b. Promote the benefits of hiring client-facing staff from a CALD background and where possible lived experience of disability*

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

*c. Develop training materials that include guidance on how to work with interpreters, translators and bicultural workers*

*d. Promote training for service providers, NDIS staff and partners on prevention of violence for people with disability in CALD communities.*

**How do we ensure mainstream services are inclusive of all people with disability?**

Low or limited levels of English language and literacy are often seen as main barriers to access services. However, this may be due to unsuitable or inappropriate delivery of information to cohorts such as CALD people with low or no literacy skills. There also appears to be an overreliance on family members as informal interpreters which in many situations is inappropriate[11] but may also hinder the correct sharing of information about the client needs.

Enshrined in legislation, it is required that information about the NDIS is provided in accessible formats and technologies and "to the maximum extent possible … in the language, mode of communication and terms which that person is most likely to understand".[12] However, the United Nations Committee on the Rights of Persons with Disabilities identified the inaccessibility of the NDIS as a concern due to complex procedures, limited publicly available and accessible information, and lack of services in remote areas.[13]

Furthermore, a 2018 Advance Diversity Services study[14] suggests that existing communication tools and strategies in the NDIS are neither adequate nor effective in addressing information needs of CALD participants accessing the NDIS. Often the generic information content is overly complex using a formal language style and lexicon CALD participants cannot understand. Lack of appropriate information may result in NDIS participants not being able to practically apply the information to their circumstances leading to ineffectiveness of the system for them. Notably, the study indicate that participants prefer to learn about the NDIS through peer to peer sessions or one-on-one sessions for targeted support using bilingual workers.

AMES recommends that in order to be inclusive of all people with disability, information needs to be accessible for all residents in Victoria. This includes offering information in a variety of languages, different levels such as simplified versions, targeted information to specific disability types but also consider the mode of information sharing.

***Recommendation 9:*** *Revise existing, and develop new, information materials and outreach activities to reach CALD communities with disabilities.*

***Recommendation 10:*** *Develop disability information materials in additional languages and at more accessible levels such as simplified versions and web-friendly content.*

[11] https://anglicaresa.com.au/wp-content/uploads/NDIS-CALD-Report-FINAL-2017.pdf

[12] The Australian Government - Federal Register of Legislation (2013). National Disability Insurance Scheme Act 2013

[13] Committee on the Rights of Persons with Disabilities (CRPD) (2019). *Concluding observations on the combined second and third reports of Australia*

[14] Senaratna T, Wehbe A, and Smedley C (2018), *Accessing and Using the National Disability Insurance Scheme (NDIS): views and experiences of Culturally and Linguistically Diverse (CaLD) communities (Report).* Sydney: Advance Diversity Services.

Within both the research and policy domains, little information exists on how refugees and asylum seekers with disabilities experience the resettlement process in Australia and there is even less data as to what types of services are required to support their settlement process.[15]

Furthermore, there is no available data on participation of people from refugee backgrounds in the NDIS. This significant gap exposes the disadvantage this cohort experiences through the intersection of cultural, social and disability exclusion. The lack of data on the experiences of people from refugee backgrounds with disabilities has also hindered service responses and further added to the cohort's "invisibility" in the community. AMES recognises a need for further research to better understand the challenges and barriers for different CALD communities in Victoria in gaining access to disability support services in general, and the NDIS in particular.

***Recommendation 11:*** *Systematise knowledge and experience about empowering CALD communities in Victoria through commissioning research and evaluations, and supporting platforms for service providers to share results about the needs and priorities of their clients.*

People with a disability have a much higher risk of experiencing abuse and violence, often by their carers and in their primary place of residence both at home or within a care facility, with women and girls particularly vulnerable.[16] There is significant stigma attached to disability and domestic violence in our community. These risks are further amplified for people from culturally and linguistically diverse 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.

When considering the interactions between the NDIS and the mainstream services it is vital that safeguarding measures are relevant to all the communities accessing the services to ensure prevention against violence for all those with disability, but particularly violence against women and children. There needs to be relevant training and measures of communication between the NDIS and the mainstream interface to ensure that people being affected by violence do not slip through the gaps. When designing policies, resources and services intersectionality between disability and violence in CALD communities must be considered in order to protect all communities.

***Recommendation 12:*** *Ensure that those with disability are included in Australia's national plan to reduce violence against women and children by integrating a complete intersectional approach when designing policies, programs, resources and in the provision of training around the prevention of violence.*

## Topic 6: Strengthening disability inclusion under the Disability Act 2006

**Are there any specific groups of people that it is important we speak to during the review? Are there particular issues that we need to talk to them about?**

The purpose of AMES submission has been to highlight the complexity of accessing disability services and how it impacts vulnerable cohorts in Victoria. Most often, it results in CALD communities,

[15] Soldatic. K, Somers. K, Buckley. A, Fleay. C (2015). 'Nowhere to be found: disabled refugees and asylum seekers within the Australian resettlement landscape' in *Disability and the Global South*, vol. 2, pp. 501-522.
[16] Stop the Violence: Addressing Violence Against Women and Girls with Disabilities in Australia, 2013

including refugees, not accessing services they are entitled to and therefore running the risk of suffering from health issues that could otherwise have been addressed and prevented.

AMES seeks to ensure that the Victorian State Disability Plan identifies and responds to these shortcomings advised in this response and offers services where most needed. It is important that the intent of the Act reflects the needs of all Victorians including smaller, recently arrived and often the most vulnerable communities. Without this, the needs of all Victorians will not be met through the State Disability Plan.

In conclusion, CALD communities need to be included and their voices heard through the development process of the State Disability Plan. The most effective way to do this in through consultation with targeted and appropriate participation methods. Consultations with CALD groups should include information about understanding their rights in relation to disability services, how they can inform the State Disability Plan and why this is important or could affect their community.

Contact for further information:

Maria Tsopanis
Senior Manager Community Development & Social Participation
TsopanisM@ames.net.au
+61390921503