

# Self Advocacy and Diversity

A model for CALD inclusion

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**Diversity and Disability Migrant Resource Centre North West**

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## 1.0 Summary

**“To promote self advocacy for people with disability in CALD communities we must rethink the Western approach and pathways to self advocacy.”**

*DnD Partnerships Project Worker*

This project investigated ways to support the growth of self advocacy for people from CALD backgrounds in Broadmeadows and Shepparton. Findings suggest that there are multiple barriers to people with disability from CALD backgrounds developing self advocacy skills. Different cultures have different attitudes, beliefs and approaches to supporting people with disability; growing self advocacy requires an approach that values the diverse needs of communities, and strengthens the capacity of organisations to understand and work alongside people with lived experience.

When information about disability in Australia is presented by CALD self advocates, families and communities are better able to understand the rights of people with disability. Involving families and communities in self advocacy education supports people's broader understanding of contemporary disability culture in Australia. This, coupled with sharing food, stories and the arts encourages communities to come together and create new understandings. It is important that the voices of people with lived experience of the intersection of disability and cultural diversity are central throughout this process.

Though the pathways may diverge, the goals of self advocacy for people with disability from CALD backgrounds are the same as people from non-CALD backgrounds; that is, to support the independent capacity of people to speak up for what they want and need, and be active valued citizens in the community.





## 2.0 Background

**“It is estimated that people from non-English speaking background with disability comprise 1 in 20 Australians, or approximately 1 million people.”**

*National Ethnic Disability Alliance, 2012.*

As part of the transition to the NDIS the Self Advocacy Resource Unit (SARU) was funded by the Victorian DHHS to co-ordinate a Self Advocacy Partnership Project. The goal of the project was to develop recommendations for self advocacy groups to work in partnership with other organisations. Three diverse Victorian self advocacy groups were chosen to be part of this project; Brain Injury Matters (BIM), Positive Powerful Parents (PPP) and Diversity and Disability (DnD). Each group had its own individual project that included working in partnership with a mainstream organisation.

Once a month the three groups came together as a working group to discuss their progress, learnings and challenges, and to share skills and ideas.

### 2.1 About Self Advocacy Groups

Self advocacy groups are run by people with disability for people with disability. Self advocacy groups support people with cognitive disability and complex communication support needs to come together and develop their own agency and power. Self advocacy groups also bring people together with shared purpose to work toward all people with disability having equal access, participation and influence in civic and community life.

**“People with disabilities and their families, friends and carers from a range of cultural backgrounds often have to deal with multiple issues on multiple fronts—their cultural background can act to complicate and compound issues associated with disability.”**

*Shut out: The experience of people with disabilities and their families in Australia, 2009.*



## **2.2 About Diversity and Disability (DnD)**

Diversity and Disability is a self advocacy program delivered at the Migrant Resource Centre North West Region (MRCNW) in St Albans, Victoria. DnD provides support to people with a disability from a culturally and linguistically diverse (CALD) background to speak for themselves and achieve their full potential as valued citizens of the community. DnD aspires to enhance the freedom, independence, knowledge and opportunities for people with a disability from a CALD background.

Although a program delivered through the MRCNW, DnD is managed by a steering committee made up of people with disability from CALD backgrounds. The majority of staff who work on and deliver DnD programs are people with disability from CALD backgrounds.

## **2.3 About the Self Advocacy Resource Unit (SARU)**

The SARU resources and supports Victorian self advocacy groups run by and for people who have an intellectual disability, acquired brain injury or complex communication needs; complex communication needs include people with disability whose first language is not English.

## **2.4 About this project**

DnD's project was to develop a model to support the growth of self advocacy in two communities in Victoria, one metropolitan and one regional. Based on research into the demographics of various communities DnD identified Shepparton and Broadmeadows as two areas with a high population of people from CALD communities and chose to focus their work there. DnD worked in partnership with the Ethnic Community Council of Victoria (ECCV) and the Ethnic Council of Shepparton and Districts (ECSD) to develop this model.



### 3.0 Key Project Activities

- DnD has an ongoing partnership with the Ethnic Community Council of Victoria (ECCV).
- DnD has an ongoing partnership with the Ethnic Council of Shepparton and Districts (ECSD).
- DnD facilitated two community self advocacy feasts, one in Shepparton and one in Broadmeadows.
- DnD facilitated self advocacy community consultation in Shepparton.
- DnD conducted self advocacy and ethnicity face to face research, and surveys in Broadmeadows.
- DnD developed Self Advocacy and Diversity (SAnD) model.
- Three people with a disability were employed on this project.
- A member of DnD sits on a regional NDIS CALD advisory group.
- A member of DnD sits on the metropolitan CALD disability and NDIS ILC advisory group.
- DnD have identified two key self advocates to mentor Shepparton.
- DnD are engaging with a CALD community reference group in Broadmeadows to support self advocacy.





## 4.0 Key Findings

- People with disability from newly arrived CALD communities are a hard to reach population.
- Stigma, fear and discrimination toward people with disability is prevalent in some CALD communities.
- The needs of people with disability who are newly arrived or born outside of Australia are different to people who are second or third generation migrants.
- Some people from refugee backgrounds are not literate in any language, this makes Easy English resources essential. Easy English uses short, clear dot point sentences, minimal grammar combined with easy to understand words and images.
- Education is needed to ensure that people who are newly arrived understand the rights and supports that people with disability are afforded in Australia.
- Limited services in regional areas prevent people with disability having choice and control over their lives.
- Disability advocacy is under resourced in Shepparton.
- CALD/migrant services and disability services are not well connected.



**DnD encountered multiple barriers when trying to connect with the CALD community in Broadmeadows.**

**Conversations with workers revealed that community organisations were *fed up* with other organisations working with community then disappearing when a project was over.**

**Building trust and creating change takes time, there was a sense that the community had been let down by their past experiences with other organisations.**

- Projects that run for 1-2 years can leave communities feeling abandoned when they end.
- A more sustainable approach to working with CALD communities is needed; one that recognises the limitations and risks of short term engagement.

**“Research indicates that people with disability from non-English speaking backgrounds are often stigmatised and isolated because of attitudes and misconceptions prevalent in their own communities and in the broader community. In respect of the broader community, disadvantage is compounded by discriminatory attitudes towards disability and ethnicity”.**

*National Ethnic Disability Alliance, 2005.*





## 4.0 Key Findings *continued*

- There is a lack of disability cultural competence training available. Organisations are likely to have expertise in one or the other; understanding about the intersection of disability and ethnicity is limited.
- A new approach to self advocacy is needed to engage and empower people with disability from CALD communities.
- Identifying and supporting leaders to emerge within the CALD community of people with disability requires a sustained and coordinated plan of support, engagement and activity across sectors and organisations.
- Outreach and connecting with people in their own community is needed to reach people who are not accessing services.
- One to one interactions may be more appropriate than group settings for people who are newly arrived.
- Community organisations can be reluctant to work on projects due to previous experiences of being let down by partners.
- The lived experience of people with disability is *different* to the lived experience of carers. This project has discovered that some CALD organisations and projects do not differentiate between these two lived experiences. The 2017 report *Lived Experience Workforce Positions in Victorian Public Mental Health Services* found that there are clear differences between these two roles, and these differences create ethical issues when one lived experience represents both. It is important for organisations to recognise and understand that the voice of carers is not a substitute for the voice of people with disability.



## 5.0 Barriers to people with disability from CALD communities self advocating

The National Ethnic Disability Alliances' 2012 report *Perspectives of People with Disability from non-English Speaking Backgrounds Living in Australia* found that there is a need for disability support and services to be culturally sensitive and appropriate for people with disability from CALD backgrounds. The report raised issues such as lack of information and accessibility to support services, lack of Easy English information and resources, lack of cultural sensitivity by workers and professionals, lack of participation in the community, language and cultural barriers, and the multiple layers of discrimination as challenges that need addressing.

Through consultations and discussions with people with disability and service providers working in Broadmeadow and Shepparton in the CALD sector DnD identified 14 barriers to people self advocating and establishing/joining self advocacy groups.

### The 14 barriers fit into 3 broad areas:

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1. Supporting access and inclusion
  2. Understanding disability and human rights in Australia
  3. Understanding cultural sensitivity and disability
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# Barriers to people with disability from CALD backgrounds self advocating

## 14 barriers for People with disability from CALD community

### 1 Supporting access and inclusion

- Very few self advocacy pathways are targeted to people from CALD backgrounds
- Disability advocacy services are inadequate, particularly in regional areas
- People fear the consequences of speaking up
- Inaccessible rights, service and NDIS information
- Limited access to interpreters and translated documents
- People may not be connected to the wider community or support networks

### 2 Understanding disability and human rights in Australia

- Some cultures emphasize family and community decision making over individual decision making
- A person's country of origin may not have not provided support to people with disability
- A person's country of origin may not have recognised the rights of people with disability
- Some communities have shame and fear about disability
- Some communities lack information about the rights of people with disability in Australia

### 3 Understanding culture and disability

- CALD services do not always understand the needs of people with disability
- Australian disability services do not always understand the needs of people from CALD backgrounds
- There can be racial discrimination in disability service provision

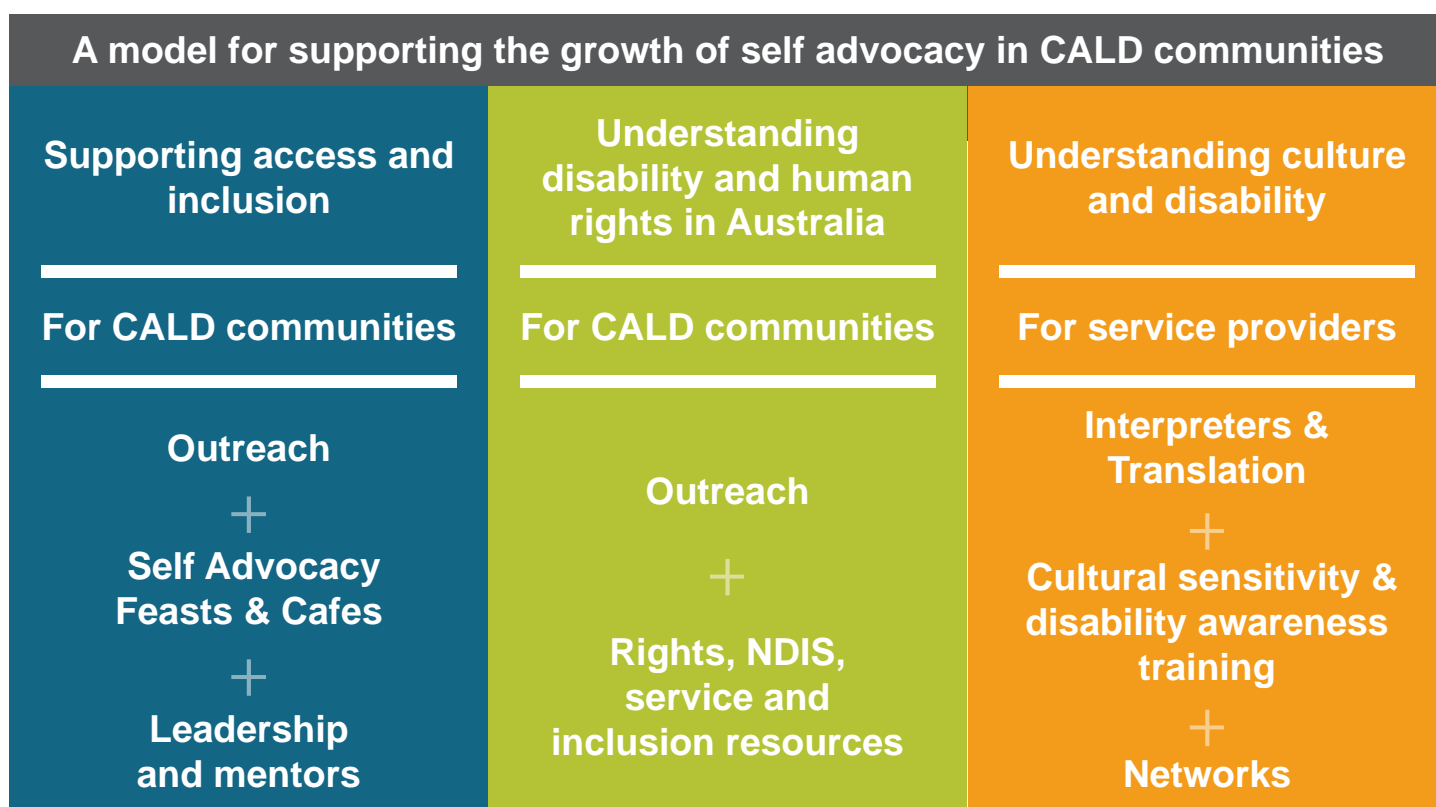




## 6.0 SAnD: A model to support the growth of self advocacy in CALD communities

Drawing on the data gathered through community consultation this model acknowledges that the pathway to self advocacy is different for people with disability from CALD communities compared to other people with disability in Australia.

This model has been developed through direct contact with people with disability from CALD communities and CALD service providers. Outreach, understanding, long term engagement and connecting contemporary Australian disability culture with CALD communities are at the heart of this approach.





## 7.0 Supporting access and inclusion

**“Families come in for advocacy and settlement, but they leave the person with a disability at home. We need to go to them.”**

*Staff member from ECSD*

### 7.1 Outreach

Self advocates and peer leaders going to community to meet with people in their place is critical to connecting with people who are hard to reach.

Information from community consultation sessions revealed that there is significant stigma and fear associated with disability in some CALD communities. This can prevent people from accessing the information and services that are available. Changing attitudes and beliefs needs a long term plan that includes people witnessing and understanding the benefits of inclusion of people with disability.

Empowered, confident and knowledgeable CALD self advocates have significant power in this space. Self advocates demonstrate the potentials and benefits of full citizenship for people with disability in CALD communities.

Research conducted through the Peer Support Practice Review found that it can be unrealistic to expect people from CALD communities to come to organisations. People often need individual time to tell their story and build trust. For this reason going into community and into people's homes to speak with family and community is important.

Self advocates need intensive support and group specific cultural awareness information to do this work in a safe and effective way.

This project has identified that meeting people in community and sharing Easy English and translated rights, service and inclusion resources is the first step to building trust and changing attitudes.





## 7.2 Self Advocacy Feasts, Cafés and beyond

**“The peer connector was sometimes the first person who had gone into some communities to ask people with disability what they wanted and needed, as many people from rural and remote communities had no prior contact with disability services or community organisations. This meant peer mentoring focused on educating people about their rights and entitlements and how it is okay to speak up about their needs and wants.”**

*Peer Support Practice Review: Stage 1A Findings, 2018*

## 7.3 Self Advocacy Feasts

As part of this project DnD ran two self advocacy feasts, one in Broadmeadows and one in Shepparton.

The aim of the feasts was to share self advocacy stories and information with CALD community members and organisations, and bring the disability community and CALD community together.

Local CALD catering companies provided a feast for each event. DnD also engaged local CALD community arts practitioners to perform at the events; the intention was to equally promote CALD and disability culture, bringing them together and opening the door to a new way of working together.

DnD followed up the feasts with community consultation sessions.

In Shepparton a group consultation session was held and attended by people with disability, staff from ECSD and Intereach and local Council representatives.

In Broadmeadows organisations were followed up individually and an online survey was undertaken by 20 people working in the sector.





## What did we learn?

### 7.3.1 Key Learnings

- We learned that feasts have fantastic potential. Bringing people together to discuss and share their experiences of disability and ethnicity brings the possibility of real and sustainable relationships forming. Engaging the local CALD community as active designers and presenters at an event rather than passive recipients of information engages the community in an empowering way that recognises the value of culture.
- Finding ways to include consultation and community discussion during a feast may support broader community engagement and connections.
- Outreach, one to one engagement and going out to community can happen before and after running a community event such as this.
- Self advocates have the power to change attitudes and perceptions of disability.
- Self advocates need more opportunities to share difficult stories.
- Swift event follow up supports the growth of self advocacy.
- Having the committed support of a partnering organisation with aligned values has a big influence over the success of an event.
- Sharing food and culture supports connection.
- Venues matter. Holding events in venues that the community have a connection to supports attendance.



### 7.3.2 Key Challenges

- Promotion and building relationships with community takes time; a minimum of six months preparation is needed before an event if moving into a new area or community.
- Identifying relevant community connectors is crucial to getting members of the CALD disability community to attend.
- People with disability who are dependent on service providers support to attend events continue to experience barriers to exercising choice and control over their own activities. Some service providers are yet to understand that people with disability have a right to make their own life choices, including attending cultural and self advocacy events.
- Travelling to regional areas is time consuming, labour intensive and involves logistical barriers. Accessible transport can be difficult to co-ordinate.
- It was easier for DnD to make connections with the community in Shepparton than in Broadmeadows. Higher populations and greater diversity in metropolitan areas pose challenges for small organisations such as DnD having an influence.
- It was difficult to engage with people who attend day services. Service providers were reluctant to engage with the project and pass information on to their clients.

The experience of hosting the feasts and consulting with the community taught us that events such as these can build momentum and community expectations. Therefore, it is important to have an ongoing plan for engagement post-event.



## 7.4 Cafés

Following the feast theme, a travelling self advocacy café session would provide opportunity for ongoing relationship building.

Cafés could be focussed around specific ethnic groups, genders, be geographically based, or all of the above.

Holding café sessions in venues that are culturally appropriate and discussing relevant topics combined with a culturally appropriate arts based practice may support harder to reach members of communities to get involved.

A community based approach to bringing people together to support the growth of self advocacy is different to the group/meeting based model that people with disability from non-CALD backgrounds tend to take.

Meeting people in their own community, sharing their foods and cultures while sharing stories and relevant information is a more culturally sensitive way of growing self advocacy in CALD communities than the traditional group based approach.

Over the longer term this model could support the emergence of local issues-based self advocacy projects. Campaigns, community murals and story sharing exhibitions run in collaboration with disability and community organisations can grow from gentle beginnings.

Supporting people with disability from CALD communities to develop their own authentic voice, power and agency takes time. These things cannot be given by well-intentioned service providers, ongoing relationships between self advocates and people in community is the way forward.





## 7.5 Leadership & Mentors

Experienced self advocates can provide peer mentoring and support to people with disability who are interested in becoming leaders in their community.

Time is needed to connect with CALD people with disability, identify those interested in leadership and connect them with a suitable mentor. Developing effective leaders is a long term goal of self advocacy in CALD communities.

DnD has skilled and experienced self advocates who are willing to share their expertise with emerging self advocates.

Digital technologies offer significant opportunities for DnD to mentor other self advocates from around Victoria (and Australia).

DnD have identified two self advocates in Shepparton who are interested in being mentored by DnD; these relationships are in the early stages of development.

Through connections made at the Broadmeadows feast, DnD members have identified a CALD disability community reference group.

Currently there are significantly more carers in this group than people with disability.

Discussions are underway to facilitate DnD to mentor the people with disability in this group and support the development of their self advocacy skills.

Conversations with the facilitator of this group indicate that although people are interested in self advocacy, fear of the consequences of speaking up pose a significant barrier.

DnD will work with this group to address this concern, supporting emerging self advocates to have a full understanding of their rights in Australia.



## 8.0 Understanding disability and human rights in Australia

**My experience of being a self advocacy mentor:**

**“Mentoring a self advocate from a CALD background is conversational, telling my own personal journey of self advocacy. It involves being a role model and demonstrating the actions of self advocacy to families and community members as well as the individual.**

**Mentoring and leadership require time to explore ideas, an open willingness to listen and a genuine wanting to understand the person with a disability from a CALD background.**

**Identifying people with disability who are interested in being leaders in their local community takes time.”**

*DnD self advocate.*

### **8.1 Rights, NDIS, service and inclusion resources**

The community consultations exposed the lack of CALD targeted Easy English resources about rights, the NDIS, services and disability supports.

During a consultation session a staff member from Interreach recommended that CALD organisations and communities use the AMPARO Advocacy resources to support disability and NDIS information sharing. However, after looking at the resources, staff from ECSD commented that the resources were text heavy and not appropriate for the people they support. ECSD staff also commented that many of the people they work with are not literate in any language, and there is a strong need for image-based resources.

The need for resources that are genuinely Easy English (as opposed to plain English) was discussed throughout community consultations.



Staff at the ECSD spoke of the need for Easy English resources that list local disability supports and services, and Easy English resources that communicate the rights of people with disability in Australia.

Single page image-based postcards and brochures were recommended. Having this information available in CALD health, advocacy and settlement services and using this as part of an outreach project was acknowledged as a first step in raising awareness.

This information also needs to be available in relevant community languages.

Translation services do not diminish the need for resources to be image-based.

Combining image-based locally relevant resources with translation into community language was seen as the most effective way of communicating rights, NDIS, service and inclusion information.

**A staff member from one organisation recounted that when promoting an NDIS information session in the local community one community leader said they would not be attending because of their belief that this (disability) was associated with 'voodoo'.**

**The consultation group discussed ways to support ethnic communities to have accurate and positive beliefs and attitudes toward disability.**

**Outreach and education about disability and the rights and supports afforded to people with disability in Australia were seen as the best response.**





**“We can tell the families that people with disability have rights but it’s not enough. We need you, the self advocates to show them. You are the ones that can change their minds.”**

*Staff member from ECSD*

## 8.2 Outreach

Community consultation and survey results overwhelming indicated that educating CALD families and communities about the rights of people with disability was an important first step in supporting the development of self advocacy. Feedback also indicated that when that information came from CALD self advocates, families and communities were better able to understand the rights of people with disability in Australia.

Skilled and experienced self advocates embodying and discussing the rights of people with disability in Australia is an effective way of ensuring that

information is easy to understand. Face to face contact with CALD self advocates was identified as an essential strategy to reducing the stigma of disability in CALD communities. This can involve self advocacy organisations such as DnD partnering with local CALD services when delivering information sessions. It can also involve self advocates working with ethnic services to travel to smaller communities to talk about their journey as self advocates and share accessible resources, including information about rights and local services.

Connecting self advocacy with basic on-the-ground information sharing through outreach is a way of supporting communities to see the connection between the two.

It is important to note that because CALD communities are extremely diverse, timelines and pathways need to be flexible and responsive to locally based challenges and opportunities.



## 9.0 Understanding culture and disability

### 9.1 Interpreters and Translation

It may seem obvious to say, but people with disability from a CALD background may need interpreting and translation services!

Although an examination of interpreter and translation services is outside the scope of this project DnD did learn that language barriers and access to interpreters is a continuing issue in metropolitan and regional Victoria, particularly in relation to NDIS information.

Organisations reported that NDIS information targeted to CALD communities is often text heavy and difficult to understand.

People from refugees and asylum seeker backgrounds may not be literate in any language, which makes simple image-based information essential when providing digital and hardcopy resources.



## 9.2 CASE STUDY

“When I facilitate a CALD Vietnamese parent group it is imperative that an interpreter is present. The interpreter not only decodes what is said, but just as importantly gives a context to the information and conversation.

The interpreter allows for free speech and supports people in the group from different CALD backgrounds to speak to each other. This is especially important in a self advocacy group because it means an equal exchange of ideas and feelings is possible.

Given that in some languages and dialects there isn't a specific word for disability or self advocacy I need to brief the interpreter on the materials that we will be handling out that day, with a discussion about what the major points I want to get across.

I also think it's also important to brief the interpreter on access needs of the group whether it be anything from someone's hearing needs, or the use of easy language before facilitating the group.

When an interpreter has not been present it is very difficult to facilitate a session. All of the information and context is disjointed and lost, the flow and ability of a two way exchange is impossible and the material I prepared for presentation feels tokenistic and a waste of time.

When there is a need for an interpreter and one is not there it is not just unfortunate, it is a gag for everyone present and it results in useless meaningless work and opportunity lost for everyone involved. Being disabled on top of disability.”

DnD Group Facilitator





### 9.3 Cultural sensitivity and disability awareness training

Staff from ECSD commented that although they run cultural awareness training for community service organisations and students they themselves have very little training and knowledge of disability awareness. They also commented that they had little knowledge of the intersection of ethnicity and disability.

Connecting people with disability with organisations running cultural awareness training to co-design modules specific to ethnicity and disability will fill this gap and ensure that training genuinely addresses the challenges of this intersection.

It is also important that CALD people with disability are involved in all aspects of training, from planning to delivery and evaluation.

Moving from ambassador or champion roles to co-design and facilitation is an important step in ensuring people with disability take up equal roles in projects and have equal opportunities to extend their professional practice.

Ensuring that bilingual workers have completed disability awareness training that has been co-designed and led by people with disability from CALD backgrounds will support a greater understanding of the intersection of disability and ethnicity within CALD service delivery.



## 9.4 Networks

DnD's work on this project has revealed that there are often few connections between disability service providers and CALD service providers.

Formal networks engaging both CALD organisations and disability service providers are needed to fill this gap.

CALD and disability local working groups that bring traditional disability service providers together with self advocates/peer leaders, advocacy services, local council, and CALD health and settlement agencies will begin to bridge the gap between disability and CALD services.

These networks need to extend beyond NDIS readiness to include community development and ongoing working relationships between the two sectors.

All levels of government have a role to play in bringing organisations together to develop a greater understanding of the needs of people with disability who do not speak English as their first language.

Ensuring that network meetings and communications are accessible, and self advocates/peer leaders are not isolated in their position is crucial to ensuring the voice of lived experience is heard and actioned. Two or more people with intersectional lived experience sitting in a group or network is far more effective than one person.

**“When attending board meetings, advisory committee meetings and roundtables I am often the only person with a disability. I find this frustrating and disempowering since the person organising those meetings has a clear expectation that I’ll be the voice for all people with a disability. Part of my role is to clarify and educate that this is not the case.”**

*DnD Project Manager*



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