

Accessing Formal Supports in Australia: The Experiences of Culturally and Linguistically Diverse (CALD) Women with Disabilities

Report of a Joint Project between:

Women With Disabilities Australia (WWDA)

Harmony Alliance: Migrant and refugee women for change

National Ethnic Disability Alliance (NEDA)



HARMONY ALLIANCE
MIGRANT & REFUGEE WOMEN FOR CHANGE



N E D A

National Ethnic Disability Alliance

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Formatting, editing and design by Chai Oonnankat (Harmony Alliance).

Contact

Women with Disabilities Australia (WWDA)

Contact: Carolyn Frohmader, Executive Director

PO Box 407, Lenah Valley, 7008 Tasmania, Australia

Phone: +61 438 535 123

Phone: +61 438 535 535

Email: officeadmin@wwda.org.au

Web: www.wwda.org.au

Facebook: www.facebook.com/WWDA.Australia

Twitter: www.twitter.com/WWDA_AU

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ABOUT US

The organisations engaged in this project are committed to establishing an evidence base to support our ongoing advocacy work. We seek to make change both systemically and individually. This research report aims to provide direct evidence for Australian governments (including policymakers), the non-government sector, the academic sector, and other key stakeholders, to better meet the rights and needs of culturally and linguistically diverse (CaLD) women with disabilities. The term 'CaLD women and girls with disabilities' is used on the understanding that this is inclusive of trans women, intersex people, non-binary, gender diverse and gender non-conforming individuals.

About Women With Disabilities Australia (WWDA)

[Women With Disabilities Australia \(WWDA\)](#) is the national Disabled People's Organisation (DPO) for women, girls, feminine identifying and non-binary people with disabilities in Australia. As a DPO, WWDA is run by and for women, girls, feminine identifying and non-binary people with disabilities. WWDA represents more than 2 million women and girls with disabilities in Australia, has affiliate organisations and networks of women with disabilities in most States and Territories, and is recognised nationally and internationally for our leadership in advancing the rights and freedoms of all women and girls with disabilities. Our organisation operates as a transnational human rights organisation - meaning that our work, and the impact of our work, extend much further than Australia. WWDA's work is grounded in a human-rights-based framework which links gender and disability issues to a full range of civil, political, economic, social and cultural rights.

About Harmony Alliance

[Harmony Alliance: Migrant and Refugee Women for Change](#) is Australia's national migrant and refugee women's coalition, one of six National Women's Alliances supported by the Australian Government to promote the views of all Australian women to ensure their voices are heard in decision-making processes. Harmony Alliance's purpose is to provide a national, inclusive and informed voice on the multiplicity of issues impacting the experiences and outcomes of migrant and refugee women and to enable opportunities for women from migrant and refugee backgrounds to directly engage in driving positive change.

The Harmony Alliance membership comprises over 180 organisations and individuals representing and/or working for the advancement and inclusion of migrant and refugee women. We acknowledge the diversity of experiences of women from migrant and refugee backgrounds and recognise the inherent value of each person of all backgrounds, genders, ages, social standards, sexual orientations, or religions. We promote the principles of dignity, equality, autonomy, non-discrimination and mutual respect.

About the National Ethnic Disability Alliance (NEDA)

The [National Ethnic Disability Alliance \(NEDA\)](#) is the national Disabled People's Organisation (DPO) that advocates federally for the human rights of people with disabilities, and their families from culturally and linguistically diverse (CALD) and non-English speaking backgrounds (NESB).

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ACRONYMS

CaLD	Culturally and Linguistically Diverse <i>Note: We use the term 'CaLD' to include any person from a non-English Speaking Background (NESB) or who identifies as being from a cultural and/ or linguistic background other than Australia or another Western English-speaking country. This definition includes those who are born in Australia, who have migrated from overseas, or for whom English is not their first language. This includes differences in cultural/ethnic identity, language, country of birth, religion, heritage/ancestry, national origin, and/or race and colour. This term does not include Aboriginal and Torres Strait Islander Peoples and does not aim to provide an exhaustive definition.</i>
CRPD	United Nations Convention on the Rights of Persons with Disabilities
DES	Disability Employment Services
DPO	Disabled People's Organisation
DPOA	Disabled People's Organisations Australia
DSP	Disability Support Pension
DSS	Department of Social Services
FPDN	First People's Disability Network
NEDA	National Ethnic Disability Alliance
NESB	Non-English-speaking backgrounds
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
OFW	Office for Women
WGwD	Women and Girls with Disabilities <i>Note: We use the term Women and Girls with Disabilities throughout this document as an umbrella term for all women, girls and gender diverse people, including trans women, intersex people, and non-binary, gender diverse and gender non-conforming individuals.</i>
WWDA	Women With Disabilities Australia (WWDA)

GLOSSARY

Ableism: A system of beliefs, practices and processes that places value¹ on 'certain typical characteristics of body and mind as essential for living a life of value'. It is based on strict and socially constructed ideas of normality, appearance, behaviour, intelligence, functioning, desirability, and productivity. These constructed ideas are deeply rooted in racism, eugenics, misogyny, colonialism, imperialism, and capitalism. This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person's language, appearance, functioning, and ability to satisfactorily [re]produce, excel and "behave." Ableist beliefs conceptualise disability as devaluing human life. Ableism may be implicit and/or explicit and pervades the beliefs and practices of individuals, communities, systems and structures.

Administrative burden: Administrative burden refers to the labour people have to do when they access government support.² This includes:

- learning costs (how hard it is to learn how to apply for and use a program);
- psychological costs (how emotionally draining or confronting it is); and
- compliance costs (how difficult it is to comply with program rules and requirements).³

Autonomy: The agency to choose whether or not to act in a certain way or have certain experiences. A person has a right to determine their own life and make their own decisions, even when those decisions are not ones others would make.

Co-design: Co-design is a collaborative, participatory approach to design that actively engages and places decision-making capacity in the hands of end users. Co-design goes beyond simply involving stakeholders in the beginning stages of design. Participants engage in problem-solving, decision-making and feedback processes throughout the project cycle, allowing for genuine and meaningful contributions, and the sharing of power.

Non-binary: Genders that sit within or outside of the spectrum of the male and female binary are non-binary.

Segregated and/or closed settings: A place/context in which people are kept away/apart from the rest of the community, such as disability group homes, prisons, youth detention centres, residential aged care facilities, psychiatric wards, 'special' schools, or Australian Disability Enterprises (ADEs), also known as 'sheltered workshops.' The sheltered and/or 'hidden' nature of segregated and closed settings means it is difficult for people with disabilities, to speak up about violence, harassment, abuse and/or exploitation in these settings, make a complaint, or seek information or assistance.

Support services, also referred to as 'formal supports': Formal services outside of the person's immediate family, kinship and friend networks that support their overall wellbeing. These can be provided by a state or federal service, a non-profit community organisation or a private body. This report focuses mostly on services specialised in disability support. However, it is important to recognise that equitable access to services such as housing, education and gender-based violence support is also integral to the wellbeing of CaLD women with disabilities.

INTRODUCTION

Across Australia, there is a lack of information and disaggregated data on the experiences of CaLD women and girls with disabilities within Australian society. Importantly, there are growing appeals for research that analyses how gender, disability, race, ethnicity, culture, language, visa status, and citizenship status intersect. Recognising this gap, WWDA, NEDA and Harmony Alliance combined efforts in 2022 to examine the experiences of CaLD women and girls with disability (WGwD) when accessing formal supports, and the impacts of gender, disability, race, ethnicity, culture, language, visa status, and citizenship status.

Broadly, the project focused on how CaLD WGwD experience access to support services in the health and disability sectors, and barriers that they face.

Due to its timing, the project also provided insight into the impact that the COVID-19 pandemic has had on the ability of CaLD women to access formal support and services.



LITERATURE REVIEW

This report focuses on a relatively new area of research which has emerged from disability studies and it addresses a challenging problem that has been inferred by existing literature, namely that there is a lack of understanding about the experiences of CaLD WGwD within Australian society. Importantly, there are growing appeals for research which analyses how gender, disability, race, ethnicity, culture, language, visa status, and citizenship status intersect. The purpose of this research is to explore how gender impacts systemic barriers to the inclusion of CaLD people with disabilities, focusing on CaLD WGwD experiences with support services.

Despite the importance of taking a 'complete picture' approach to social research,⁴ there is a significant gap in existing literature, both within Australia and globally.⁵ A growing body of research indicates that people from CaLD backgrounds with disabilities across Australia experience significant barriers to accessing support and services. However, there is a gap in the literature in relation to how gender, disability, race, ethnicity, culture, language, visa status, and citizenship status intersect to influence access to support and services from the perspectives of CaLD WGwD. This has a substantial impact on policy and service delivery, as this constrained attention means that service design rarely reflects the transformative changes required to ensure support services are accessible and culturally appropriate.⁶ Thus, this research is important to explore the intersectional barriers that CaLD WGwD face to accessing support and services.

Previous studies have emphasised that CaLD WGwD are underrepresented in support services.⁷ This can be demonstrated through an analysis of the National Disability Insurance Scheme (NDIS), an Australian scheme that aims to provide funding to eligible people with disabilities on a needs basis. The funding is designed to provide participants with access to supports such as transport, assistance with household tasks, assistance with social and community participation, capacity building services, home modification, or mobility equipment. It is clear that this scheme fails to provide adequate support to CaLD WGwD, with only 8.4% of NDIS participants coming from a CaLD background⁸ and only 37% of participants identifying as WGwD.⁹ The NDIA does not publicly report data disaggregated by both gender and indicators of cultural or linguistic diversity, such as country of birth, nationality, race, ethnicity, or primary language spoken. Current research suggests that the underrepresentation of these demographics may be due to a range of overlapping factors. These factors include stigma, ableist community attitudes, and social exclusion.¹⁰

CaLD people also face language and communication barriers,¹¹ and a lack of cross-cultural understanding by disability support and service providers who do not receive culturally appropriate training.¹² This is a greater problem where the nature of the service being provided requires complex explanations of, for example, diagnosis, treatments, or medications. People who lack health literacy may not be able to understand

technical information that is delivered in a culturally incompetent manner, such as the details of what a medical procedure involves or the contraindications of a prescribed medication. People who are not Australian citizens and do not hold permanent visas face further barriers whereby restrictions are imposed based on visa status, which prevent them from accessing support.¹³ As a result, CaLD WGwD and their families and carers are more likely to have inadequate outcomes when utilising supports and services. This includes in relation to the strict eligibility criteria imposed by the NDIS. Additionally, it should be recognised that culturally and linguistically diverse women are not homogeneous groups. The individual circumstances of different cohorts - such as refugees and asylum seekers - should be addressed when planning and implementing support services, including their lived experiences.¹⁴ This is critical as a person's previous experiences of displacement may have contributed to or exacerbated their disabilities, alongside creating further challenges to accessing disability supports.¹⁵

While not all who experience mental health-related conditions are considered to have psychosocial disabilities, the lived experiences of displaced people (such as asylum seekers and refugees) may increase their risk of developing anxiety, depression and/or post-traumatic stress disorder.¹⁶

Moreover, displaced people with disabilities are often not counted in data collection.¹⁷ Refugees are also more at risk of having their mental-health related conditions exacerbated due to Australia's punitive immigration policies.¹⁸

A failure to understand the diverse lived experiences of CaLD WGwD leads to a lack of identification by mainstream service providers, resulting in supports and services which are not tailored to the needs of migrant and refugee people with disabilities.¹⁹ This conclusion can be drawn from the standardised supports and services that are provided to migrants and refugees which fail to acknowledge the extensive differences between different communities and individuals.

A closer look at the literature regarding the stigma that CaLD people with disabilities face from the Australian public reveals that there are numerous gaps and shortcomings in the research. It can be inferred from this review that there is a deficit in literature written by women and girls with disabilities who are from CaLD backgrounds. The existing research focuses on the stigmatisation perpetuated by people's country-of-origin communities from a Western perspective, inferring that no such discrimination occurs within Australian communities.



A report written by the First People's Disability Network (FPDN) draws attention to this issue.²⁰ FPDN notes that the concept of disability does not translate into Aboriginal cultures and languages.²¹ There are terms, within the Pitjantjatjara language for example, used to explain various disabilities.²² However, these are merely describing words and they are not associated with negative connotations.²³ This differs from Western constructs of disability where the term 'disability' is used derogatorily.²⁴ As such, whilst this is not an example that is specific to CaLD communities, it illustrates the importance of research addressing particular communities, by people in those communities, and demonstrates the need to understand 'disability' as a concept that is shaped and constructed by culture.

A number of factors contribute to the exclusion of WGwD from formal supports and services regardless of cultural or linguistic diversity, including that healthcare providers

fail to utilise appropriate information and formats to raise awareness about such supports and services.²⁵ The available information is often not offered in accessible formats, such as Easy Read or Braille.²⁶ There is a shortage of professionals in healthcare who are trained to provide trauma-informed supports and services that are appropriate for WGwD.²⁷ Where WGwD are able to access support and services, they are often challenging to navigate.²⁸

A more in-depth understanding of how these barriers interact with CaLD, migrant and refugee WGwD experiences is vital to ensuring the accessibility of health and disability support services.²⁹ This project aimed to partially address this gap by examining how gender intersects with ableism, racism, and cultural discrimination prevent or discourage WGwD from CaLD backgrounds from accessing formal supports and services.

STUDY DESIGN AND CONTEXT

Project Methodology

The Harmony Alliance, WWDA and NEDA research teams engaged in a literature review to better understand existing knowledge of the experiences of CaLD WGwD when accessing supports and services in Australia at the intersection of gender, disability, race, ethnicity, culture, language, visa and citizenship status. The existing gaps in research reaffirmed the need and aim of the project to provide evidence-based and meaningful research that assists with policy and service design and delivery.

The literature review also offered a broad overview of past key issues and experiences faced by CaLD people with disabilities in Australia that informed the online focus groups and the national online survey design.

The survey instrument was co-designed by Harmony Alliance, WWDA and NEDA, with input from bi- and multi-lingual experts who assisted with the translation and ensured consistency of meaning and adjusted terminology to reflect conventions in different languages. The survey used an intersectional feminist approach that recognised the overlapping and concurrent forms of oppression experienced by CaLD women and girls in relation to their age, disability and gender, as well as other factors such as socio-economic status, sexual orientation, appearance, race, ethnicity, religion, nationality, citizenship, language,

political, religious or spiritual beliefs, marital or relationship status, pregnancy or parental status, or criminal record. This approach specifically acknowledged that identity markers (such as “Woman”, “Disabled”, “Culturally and Linguistically Diverse” or “LGBTIQA+”) do not exist independently of each other, but rather inform each other.³⁰

The focus group interviews were conducted in a semi-structured format with transcriptions generated digitally. Reflexive thematic analysis was employed to examine the data and to structure report findings. The coding framework was not pre-determined. Instead, initial codes were generated and reflected upon to determine how they might aggregate into themes. The data was returned to multiple times to refine coding and the thematic structure of the report.

In response to the lack of existing information, the research project was designed to collect both qualitative data (through discussions facilitated in focus groups) and quantitative data (through a structured online survey). Participants were engaged through the combined online networks of WWDA, NEDA and Harmony Alliance. A clear overview of the purpose of the research, including information about privacy, age restrictions and remuneration was provided and participants were able to opt in by registering online. The research design is explained in greater detail below.

Focus Groups

The focus groups were designed to create a space for CaLD women with disabilities in Australia to share their stories and experiences, and their ideas about what can be done to improve access to formal supports and services. Participants were recruited via the three partner organisations, WWDA, Harmony Alliance and NEDA. Participants were invited to share anything they deemed important to this topic, for example, issues or challenges they faced with services; any barriers that have stopped them from accessing formal supports and services; their experiences accessing and using formal supports and services; and any ideas they have to improve these systems.

Three group sessions were held via Zoom between May and August 2022. Each session ran for two hours and was facilitated by staff from WWDA, Harmony Alliance and NEDA. Each focus group also had a community facilitator who identified as a CaLD women or gender diverse person with disability. In acknowledging that the research relates to sensitive topics, a wellbeing officer was present to provide support and make referrals to additional resources if needed. The sessions were audio captioned and an Auslan interpreter was available on request, with any other accessibility requirements addressed at the point of registration.

Contribution to the focus groups was entirely voluntary and free to be withdrawn at any stage during the project. Participants are de-identified in the findings. Audio and visual recordings were made during the focus groups but have not been shared outside

those involved in writing the report. Consent has been granted to use quotes and stories shared during the sessions. To acknowledge the time, energy, and expertise provided, each participant received a \$50 gift card after the consultation.

Participants were required to be over 15 years of age, with those under 18 requiring permission from a parent or guardian to participate.

The focus groups aimed to allow participants to share their experiences in open discussion. For this reason, the questions put forward by facilitators were not strictly structured but served as prompt questions and addressed the following topics: inclusion and equality, access to formal supports and services, the impacts of the Covid-19 pandemic, access to information, stigma, and access barriers.

Survey

To ensure diversity of data and accessibility, the survey was available in six different languages: Arabic, English, Mandarin, Nepali, Spanish and Swahili. These languages were selected based on census data and analysis conducted by NEDA and Harmony Alliance.

The survey contained a total of 35 multiple-choice questions, including skip questions based on responses to several questions, offering different paths according to the participant's experience and choice. It was not intended that any participant would be required to answer every question and follow-up question. The survey included questions about the participants' demographic

information and their experiences accessing healthcare and formal supports. Involvement in the survey was voluntary and unremunerated, with consent to participate gained at the beginning of the survey.

An acknowledgement at the beginning of the survey alerted participants that the research content may be personally triggering. Participants were asked to discontinue the questions if this was the case and directed to support services, including Disability Gateway, Lifeline, Beyond Blue, 1800 RESPECT and Kids Helpline.

The survey opened on the 13th September 2022 and was available to be completed online for a total of 24 weeks.

Intersectionality

Intersectionality is a tool for revealing and transforming the interworking of power and oppression. The term was coined by Black legal scholar Kimberlé Crenshaw in 1989, drawing from Black feminist voices who had been making this analysis for decades.³¹ Intersectionality reveals the “conceptual limitations of single-issue analyses.”³² As Crenshaw demonstrated in her work, “intersectionality was a prism to bring to light dynamics within discrimination law, regarding racism and sexism specifically, that weren’t being appreciated by the courts”.³³

An Intersectional approach allows for the analysis of how the multiple, different identities that individuals hold intersect with one another, influencing their interactions

with systems, services, and the broader community. For CaLD women with disabilities, intersectionality serves to reveal the human rights violations they are subjected to, not only on the basis of gender, but also disability, race, ethnicity, migration status and cultural and linguistic diversity – all factors which serve to compound one another. This framework challenges the way Australian law attempts to neatly compartmentalise forms of discrimination like sexism, racism and ableism, rather than recognising the complex interplay between systems of oppression and power structures. Critically, intersectional analysis also serves to demonstrate the compounding oppression specific communities of CaLD women with disabilities face. This can serve to highlight, for example, the specific forms of violence and abuse experienced by queer CaLD women with disabilities, who are subjected to the compounding impacts of racism, ableism, sexism, homophobia, and/or transphobia.

Defining ‘Culturally and Linguistically Diverse’

The term ‘Culturally and Linguistically Diverse’ (CaLD) was introduced by the Australian Bureau of Statistics in 1999 and is frequently employed by state services for data analysis. Recent figures from the ABS revealed that over 300 separate ethnic backgrounds were identified in the 2016 census, with over 300 separately identified languages spoken in Australian homes.³⁴ In 2016, one-fifth of Australians spoke a language other than English at home.³⁵ One in every four people

with disabilities in Australia is culturally and linguistically diverse.³⁶ CaLD is rarely a term used by communities to define their own identity, however it has become standard identifier within formal support services that CaLD women with disabilities depend on. As a project led by lived experience, this report seeks to understand their diverse experiences from their own perspectives.

We recognise that communities described as CaLD do not all experience cultural and linguistic barriers in the same way, and that their experiences are mediated by intersections with race, gender, religion, disability status, sexuality, experiences of migration, citizenship and visa status, class and socioeconomic means and other factors. Although the impacts of gender and disability may 'add up' over time and increase in intensity, researchers have asserted that an additive model will overlook the interactions that occur between them, as well as the distinct ways different configurations of gender and disability result in differing experiences for individuals and groups.³⁷

The individual circumstances of different groups - such as refugees and asylum seekers - must be understood when planning and implementing support services, including their lived experiences. This is critical as a person's previous experiences of displacement may have contributed to or exacerbated their disabilities, alongside creating further challenges to accessing disability supports.

Language and Gender

WWDA, NEDA and Harmony Alliance are committed to highlighting the lived experiences of people with disabilities who are impacted by systemic gender oppression. This includes trans women, intersex people, and non-binary, gender diverse and gender non-conforming individuals. Our work strives to accommodate anyone who identifies outside of the gender binary. We acknowledge that the experiences of trans, non-binary and gender diverse people are also likely to be influenced by their culturally and linguistically diverse identities and communities.

We are committed to acknowledging the need for gender inclusive language. This report aims to include the experiences of anyone with disabilities who identifies with the term 'woman'. To reflect this, the phrase 'CaLD women and girls with disabilities' is used on the understanding that that this is inclusive of trans women, intersex people, non-binary, gender diverse and gender non-conforming individuals. WWDA, Harmony Alliance and NEDA took steps to recruit gender diverse participants to ensure that their voices were included in this report. Recruitment information explicitly referred to a focus on woman-identifying, non-binary and gender diverse people.

Limitations of the Research

This project was designed to serve as exploratory research. Given the small sample size and the diversity of lived experience among CaLD WGwD, it is not intended to be generalised to all individuals within this cohort.

While the survey was available in six different languages, the majority of responses were recorded in English. Focus groups were also conducted in English and recruitment information was distributed online and through organisations' networks and available in Easy English.

Whereas English may or may not be the primary language for many of those who completed the survey and participated in the focus groups, the data should not be considered a representative sample but an important snapshot of a sample of CaLD WGwD across Australia. The additional barriers that this cohort faces should be considered an area for further research.

Conducting research online also limits access for women who don't have access to the internet or devices. Survey and focus group

participation was dependent upon having access to the relevant technology, skills, and support to participate in focus groups via Zoom. A useful expansion of this research would be focused recruitment on CaLD WGwD who experience barriers to online participation and require more extensive communication support.

No participants who currently live in a disability group home or care facility, an aged care facility or an immigration detention facility participated in the research. Therefore, participant responses cannot represent the specific and additional forms of oppression CaLD WGwD are exposed to in these places. There is a pressing need for further research into the experiences of these communities.

The final limitation relates to the migration status of the survey and focus group participants. This study sought to include a broad population sample from newly arrived migrants, temporary visa holders, and non-citizens to different generations of CaLD WGwD; however, WGwD with permanent residency and Australian citizenship are the most represented in this study. A key reflection is to consider if migration health requirements are interconnected with the visa status reflected in this study.



PARTICIPANT DEMOGRAPHICS

Focus Group Participants

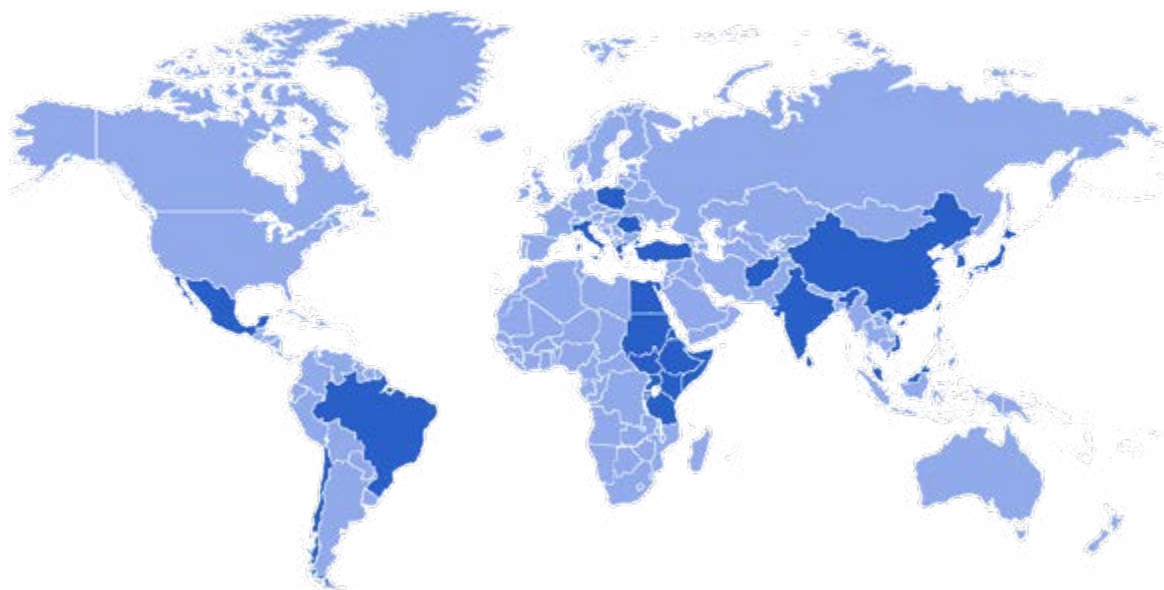
The focus group participants represented a wide range of lived experience across cultural heritage, disability status and gender identity. A total of 15 CaLD people, predominantly identifying as women and some as non-binary, took part in the focus groups.

The participants identified their cultural heritage from a wide variety of countries, including China, Poland, Japan, India, Vietnam, Malaysia, Afghanistan, Turkey, Scotland, Italy, East Africa, Brazil, Hong Kong, Greece, Egypt, Mexico, Romania, Chile and El Salvador. Some participants identified

as having Jewish and Arabic heritage. Participants joined from across Australia and were mostly located in the capital cities of Queensland, Victoria, Western Australia and the Australian Capital Territory.

There was a wide variety of experiences of migration. Roughly half identified as first-generation immigrants to Australia. It was not compulsory for participants to identify their migration status, but some responses indicated experiences of refugee, humanitarian and temporary visa status. Some identified migration due to economic reasons. Some had migrated with their families as children while others had relocated as adults or belonged to second generation migrant families.

Figure 1.
Focus Group participants' identified cultural heritage.



Participants had lived experience of a wide range of disabilities, including:

- Cognitive/Intellectual disability
- Physical disability
- Neurodivergence
- Psycho-social disability/Mental illness
- Sensory disability
- Blindness or vision impairment
- D/deafness or hard of hearing
- Chronic illness and/or medical condition.

Survey Participants

A total of 59 CaLD WGwD completed the survey. The majority (90.5%) identified as women, 2.4% as non-binary and 4.8% preferred to use another term.

69.3% of participants were born overseas.

31.2% preferred to use a language other than English at home. Of this cohort, 9.4% used English Auslan and 3.1% used another sign language.

While some participants chose not to answer, those who were willing to identify their migration status were all citizens, permanent residents or held a permanent partner visa. The majority have lived in Australia for more than 10 years (79.4%), with 11.8% having lived in Australia for between 5-10 years, and 8.8% for less than five years.

Figure 2.
Survey participants' identified genders.

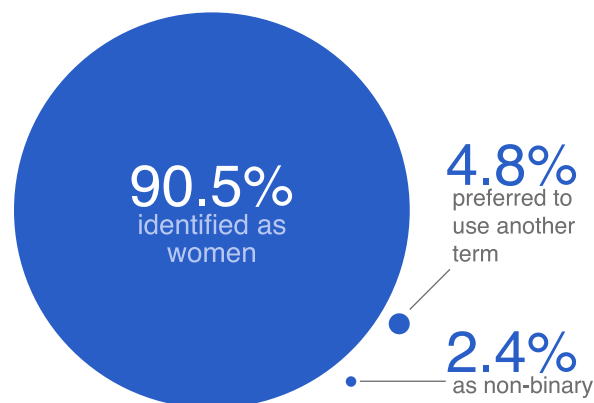


Figure 3.
Survey participants' place of birth.

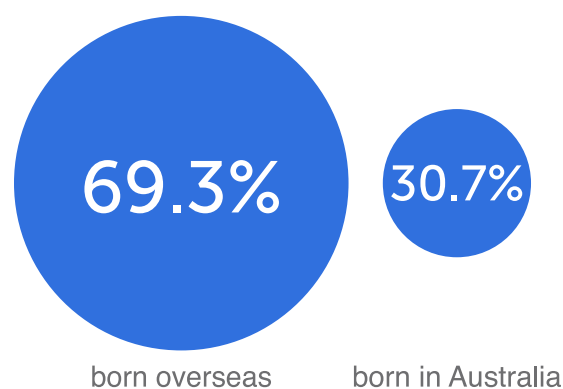


Figure 4.
Survey participants' length of time in Australia.



Table 1.1
How old are you?

Answer choices	Responses
15-17	0.00%
18-25	14.63%
26-30	4.88%
31-35	12.20%
36-40	19.51%
41-45	2.44%
46-50	14.63%
51-55	4.88%
56-60	7.32%
61-65	7.32%
65+	4.88%

The age range among participants was diverse, with the most common age group being between 41-45 years of age. (See Table 1.1)

Table 1.2
Who do you live with?

Answer choices	Responses
Alone	24.24%
With friends or family	24.24%
With spouse/partner	24.24%
With spouse/partner and children	6.06%
With children only	21.21%
With spouse/partner and other family members	0.00%
With spouse/partner, other family members and children	0.00%
I live in a disability group home or care facility	0.00%
I live in an aged care facility	0.00%
I'm in an immigration detention facility	0.00%

Respondents were asked to indicate who they live with. The most common responses were 'alone', 'with family or friends' or with 'spouse/partner', followed by 'with children only'. (See Table 1.2)

Table 1.3
How big is the place where you live?

Answer choices	Responses
Small town (more than 200 but less than 10,000 people)	8.82%
Medium town (more than 10,000 people but less than 50,000)	11.76%
Large town (more than 50,000 people but less than 100,000 people)	8.82%
Major city (100,000 or more)	70.59%

The majority of respondents were located in major cities. (See Table 1.3)

Table 1.4
How do you categorise your disability?

Answer choices	Responses
Cognitive/intellectual disability	15.63%
Physical disability	21.88%
Neurodivergent	21.88%
Psycho-social disability / Mental illness	15.63%
Sensory disability	0.00%
Blind or vision impaired	9.38%
D/deaf or hard of hearing	9.38%
Chronic illness or medical condition	6.25%

Participants identified varied forms of disability, with the most common being physical disability and neurodivergence, closely followed by cognitive/intellectual disability and psychosocial disability/mental illness. Other participants also identified being blind or vision impaired, D/deaf or hard of hearing, or as having a chronic illness or medical condition. (See Table 1.4)

REPORT FINDINGS:

KEY BARRIERS TO ACCESSING FORMAL SUPPORTS

WWDA, NEDA and Harmony Alliance identified a number of common themes during the course of the focus group discussions and a review of the survey data. These themes, addressed in detail below, included the role of stigmatising attitudes; self-advocacy and community perspectives; representation and lived experiences; administrative and financial burdens; previous negative experiences within service systems; access to information; digital literacy and the digital divide; COVID-19; and family, domestic and gender-based violence services.

Stigma and Attitudes of Service Providers

Focus group discussions spoke extensively to the compounding stigma that CaLD women with disabilities experience due to their gender, race, migration status, disability status and cultural and linguistic backgrounds.³⁸ Participants felt there was little representation of CaLD WGwD in the broader community and that lower expectations existed for their wellbeing and success. Many reflected feeling that they were too 'complex' to have their needs adequately met by service providers.

I think there's a lot of pressure to appear perfect but you're walking the tight rope to be accepted. And if you have a less visible disability, you better not show it because you can so easily be judged.

In this context, stigmatising attitudes from service providers were identified as a key barrier to CaLD women with disabilities engaging with formal supports. Many perceived the need to minimise their differences from dominant cultural, gendered, and able-bodied norms to be treated equitably by service workers. This included attempting to minimise their accents, using Westernised aliases, masking certain behaviours, and hesitating to clarify important information, such as complex medical terms.

I get the sense that if the doctors relate more to you, so, you don't have this aura of - I don't know, foreignness and being hard to interact with or whatever else they see, then they are more likely to actually engage with you in your treatment and be like, 'OK, I think this is a good approach, what do you think?' versus a lot of what I have heard from women and migrants with all types of health professionals, where they say 'this is the thing, we do this now'.

The denial of decision-making rights to women with disabilities within formal services is pervasive.³⁹ Survey results showed that almost one in three respondents felt they did not have full decision-making power over their own lives. According to focus group participants, the addition of cultural and linguistic differences exacerbates the perception that women with disabilities are

not capable, or that it is too difficult for them to engage in comprehensive consultation and decision-making. This is intensified by a frequent lack of communication supports, such as interpreters or Easy English resources.

When I'm non-speaking or stimming, I've found many people regard me as stupid. Some think I don't understand them because English is not my first language, which is not true. Usually, I struggle with processing information and cannot respond well, but when I'm low spoons, I also find it hard to explain my circumstances.

Unless there is an interpreter there, or someone guiding them, yeah, you would be too embarrassed to ask, 'what does this mean?' Or they will think I am dumb. You have to speak without an accent, you have to understand what they are talking about because otherwise you are less than.

While there was acknowledgement among participants that discrimination and bias were not always intentional, many found that service workers were not culturally responsive, and were unwilling, or unable to acknowledge the compounding impacts of racism, sexism, and ableism on their experiences of services and their wellbeing. Participants found that this contributed to a victim-blaming mentality and the pathologisation of individuals' attempts to cope with systemic discrimination.

Before I was diagnosed, I noticed I was having various issues. One of them was casual racism in the workplace and bad attitudes and that sort of thing. Whenever a couple of times that I asked a psychologist about this, they immediately went to things about my self-esteem, like I noticed these things or I think that people are picking on me because my self-esteem is low. They didn't actually acknowledge that there is such a thing as racism.

I find that a lot of medical professionals, they tend to medicalise everything, including social issues, that they just ignore these intersecting social factors. They don't understand the severity of racism and sexism and so on.

Participants reported experiencing significant emotional distress when attempting to access services. Across stories shared in the focus groups, emotions ranged from confusion, shame and humiliation, anger, fear, frustration and overwhelm. These emotions were linked to negative perceptions and experiences of services and service providers that discouraged future engagement. While existing literature suggests that CaLD people with disabilities are often hesitant to access formal supports and services due to family and cultural stigma about disabilities,⁴⁰ the experiences of project participants largely indicated that it is misunderstanding and discrimination from service providers that drove their disengagement. Overall, participants reflected a deep sense of enforced powerlessness and denial of agency when engaging with support services; which is reflective of the experiences of women with disabilities in Australia more broadly.⁴¹

Non-binary and gender-diverse participants also described further difficulties having their identities affirmed and recognised when accessing services. Several participants hesitated to share non-binary pronouns with service providers as they felt their identities were already stigmatised and too complex for others to understand. This was seen to perpetuate feelings of being at odds with the service system, and to decrease service providers' ability to provide holistic care.

There are a lot of people who have to just hide it basically. They can't say anything. They can't reveal their gender. They would have to go with whatever the system thinks they are.

Confidence, Community Perspectives, and Self-advocacy

Access to disability services in Australia, particularly personalised funding schemes such as the NDIS, are predicated on high levels of self-advocacy.⁴² However, some participants noted that the pressure to assimilate contributes to shame within CaLD communities when accessing support services; which is reflective of broader literature which indicates that there is shame attached to public identification as a person with disability.⁴³ The intersecting stigmas and pressures of being feminine-identifying, culturally and linguistically diverse, and disabled have direct impacts on self-esteem, potentially repressing self-advocacy.

They don't want anybody in their community to know that (they are) getting a government handout. And that is fine, but if you are getting government benefits, you shouldn't be ashamed.

You can't find anyone who comes forward from CaLD backgrounds, it's very difficult. I know some people are being made passive by their communities. It's hard to assert ourselves.

How do we reach CaLD people and let them know it is OK to have a disability? It is OK to have a member of your family with a disability. You don't need to be ashamed; you can access support...

Across Australia, there is evidence that some CaLD communities retain negative perceptions from their countries of origin about disabilities bringing shame to their families and communities.⁴⁴ While there is a lack of research on how this stigma impacts CaLD WGwD, it has been argued that many CaLD families traditionally consider women to be the primary caretaker, and as such, it is not considered a cultural norm for them to seek outside help from governmental support or services.⁴⁵ Among participants, these social pressures were seen to decrease their likelihood to seek assistance for support services. Having spent years minimising their disabilities, some participants spoke to their fears of being perceived as 'not disabled enough' to warrant support and assistance.

I myself use a wheelchair and there were times I think to myself, "Oh my God, do I deserve to use a wheelchair?" Of course, I need a wheelchair. Like that's the fear everyone has and it is because of the system that just polices people's identity.

Some participants spoke to anxiety or concern from their families about disclosing disability or seeking formal supports. There was some recognition of the aforementioned cultural stigma existing within CaLD communities. However, it is important to note their consensus that this existed in response to exterior social pressure and discrimination.

There is so much pressure on the parents, the migrant parents, not just to make sure that their children adjust but also to make sure that they conform to the standard.

They (my parents) knew that I struggled academically and socially, and they knew I had a diagnosis of Asperger's coming here. They did not know how and where to focus on themselves to establish a stable life again... They do not want me to miss out on opportunities. They think if I tell people I have a disability, it limits me.

There is the cultural stigma and the parents seem to go to the extremes of either ignoring the disability or, and I don't like this word, but basically having to lower expectations for the children and thinking they will not do much with their lives.

One participant explained that some parents from CaLD communities were not able to assist, or demonstrated resistance to, their children accessing formal supports due to a lack of familiarity with support systems.

If you have someone who is 16 or 17 and capable of setting themselves up on the NDIS but they need parental consent - but the parent is trying to wrap their own head around the NDIS and English is not their first language - I've heard of some cases where people have to wait until they're 18 so they don't need parental consent to sign off and get support.

My mum and my sister's friend's mum, also from CaLD background, they were comfortable with us becoming independent but as long as they knew every single step of the way to make themselves feel more comfortable and I think that's a general parent thing, but the language barrier doesn't help.

Participants reflected that their families had typically received little to no support in the past. This was seen to contribute to continuing attempts to 'make do' without assistance from formal supports.

When we came here, mum took me to the Children's Hospital, but no support was ever given to her or to me... My parents coming from a coloured background, they didn't speak the language, they didn't know the system. And you know, I like to say that in brown cultures, you do what you've got to do.

It is important to note that perspectives from communities and families towards accessing disability support are varied and nuanced. Participants also spoke of the essential role their families played in supporting them, nurturing their confidence and sense of identity.

My parents never asked if I was sure I wanted to do something and if I wanted to do something, they just let me. I think that's a good thing.

Representation and Lived Experience

In the limited existing research, there is some evidence that there is a lack of knowledge about how to support CaLD people with disabilities within formal support services. While there is no literature about how this impacts CaLD WGwD specifically, existing literature suggests that there is a critical need for educated and trauma-informed support and services that are culturally responsive. In the focus groups and survey, this lack of understanding was directly linked to a poor representation of CaLD women with disabilities working within the sector, especially in decision-making roles.

So many people are not getting the help and support they really need and deserve, because on disabilities, this definition is based on stereotypes and assumptions. It is being made by people who do not have lived experiences of it and do not understand it and yet they are making these policies. They are making these rules on who gets to be called disabled and who gets these supports.

We need more disabled people in the workforce and that includes the healthcare system.

My psychiatrist comes from a very similar cultural background as my family. I do realise how statistically lucky I am to have found someone like him... I think affirmative action programs are probably a really good idea. Or kind of specialised incentives to try to get specialists to move to areas that have large populations from within their own background.

One participant linked this to the existence of segregated employment for people with disabilities, rather than the integration and valuing of their perspectives, skills, and experience within the broader workforce.

There is normal work and there is also a workplace for people with disability. How dividing is that? They separate people who are able-bodied from disabled people and that tradition is causing the major separation. People in healthcare, they don't understand the lived experiences better because of this.



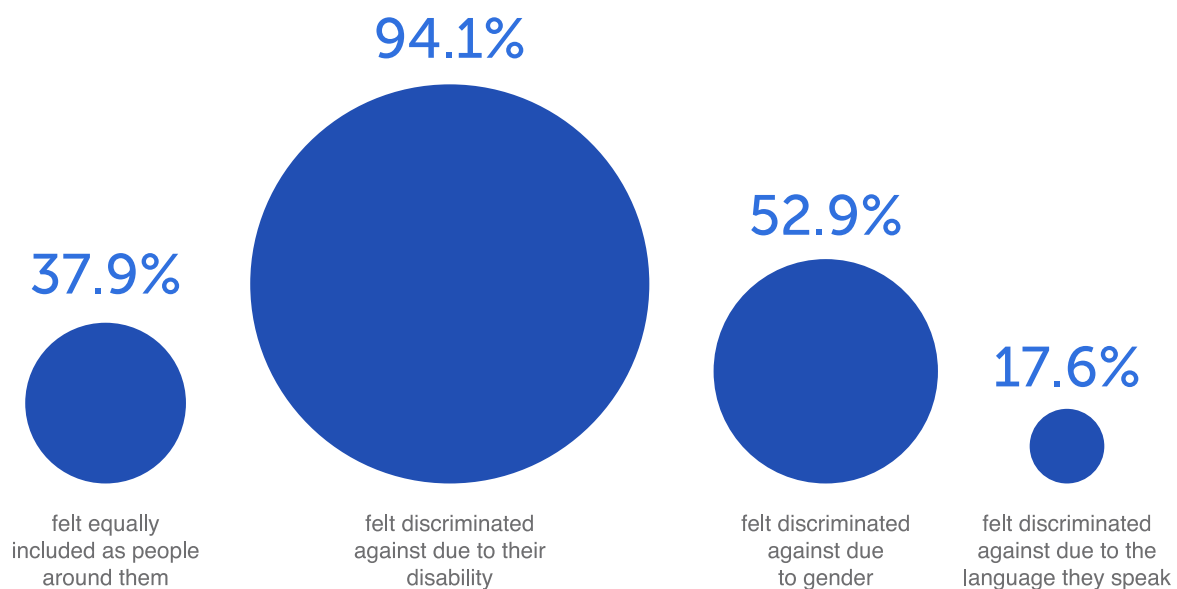
Within the focus groups, 'lived experience' was discussed in relation to experiences of disability, gender, migration, and cultural and linguistic diversity. Workers with these forms of lived experiences were seen by participants as imperative to both elevating the status of CaLD women with disabilities in broader society, as well as for improving the accessibility of services, and trust in service providers. The absence of these perspectives across all levels of formal support services was seen as a major barrier to holistic engagement of CaLD women and gender diverse people with disabilities.

I think a lot of these issues are because the people who run the system, the healthcare system and other decision-making systems are largely privileged and often white people and quite often male. They're not reflective of the general population.

Lots of staff shortages in every aspect of employment, but especially we need more psychologists, psychiatrists, specialists, doctors, GPs, etcetera. But immigration law is so strict, and the point system, unless you're from a British or North American or European background, it just eliminates everyone. We don't get to find anyone who speaks our language.

Stigmatising attitudes within formal support services are inseparable from prejudice within the broader community. Only 37.9% of survey respondents felt as equally included as the people around them in their families, neighbourhoods, schools, workplaces or faith groups. The majority (94.1%) felt discriminated against due to their disability, while 52.9% felt the discrimination they experienced was gender-based. 17.6% felt discriminated against due to the language they speak. Raising the status of CaLD WGwD therefore requires broader representation

Figure 5.
Survey participants' experiences of discrimination.



within media, politics, and community activism. Participants expressed a strong desire for representation of diverse forms of disability among CaLD women, including invisible disabilities. There was a call for representation of what a particular disability can look like for different people, within different cultural and gender-diverse contexts. Broader community representation as well as professional education was seen as essential to empowering other CaLD WGwD to seek formal supports.

I have a vision impairment, but I also have ADHD. People will see my cane and based on that, will assume my capabilities and assume everything is so difficult for me, poor disabled woman, but I actually find it's the things that aren't visible that are more difficult, like my ADHD.

I think education to the doctor to help your workers that can be passed on to others. Culturally competent training and I think that should be for everybody. Hospitals, universities, perhaps. Before the doctors go into the real world, get this into them.

Administrative Burden

Administrative burden was another issue identified within the research. Administrative burden refers to the labour people have to do when they access government support.⁴⁶

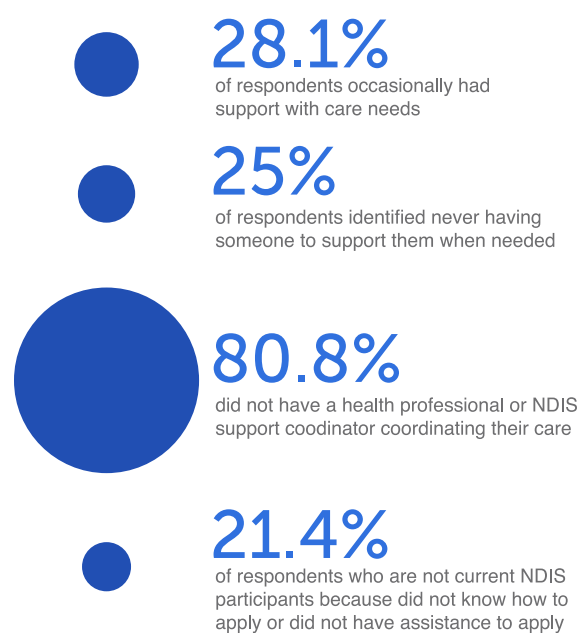
This includes:

- learning costs (how hard it is to learn how to apply for and use a program);
- psychological costs (how emotionally draining or confronting it is); and
- compliance costs (how difficult it is to comply with program rules and requirements).⁴⁷

Academic literature is beginning to examine how this burden falls unevenly on certain groups, including women, people with disability and those from non-English speaking backgrounds. At the intersections of disability, gender, and cultural and linguistic diversity from Anglo-Saxon norms, CaLD women with disabilities are likely to experience the heaviest forms of administrative burden. This entrenches their exclusion from critically needed formal supports and reproduces marginalisation and social inequity.

Some academics have argued that administrative burdens and their uneven distribution across populations are not accidental but a form of 'policy making by other means', which is used to include and exclude particular social groups.⁴⁸ It has been noted that administrative burden is particularly high among personalised funding schemes such as the NDIS, because these schemes are predicated on very high levels of self-advocacy.⁴⁹ The more successful an individual is at articulating their needs within a Westernised, bureaucratic environment, the more likely they are to access funding. This can be particularly difficult for CaLD WGwD.

Figure 6.
Survey respondents' administrative burden barriers



Among participants, the presence of unmet care needs was extensive. More than half of participants identified needing assistance with personal care or mobility at times. Yet 28.1% of respondents stated they only occasionally had someone to support them with care needs and 25% identified never having someone else to support them when needed. The majority, 80.8%, did not have a health professional or NDIS support coordinator coordinating their care. The convoluted processes involved in accessing vital support were identified as a key reason for unmet care needs. Participants spoke of a 'burden of proof', a phrase which highlights the seemingly punitive nature of application processes. Of those who are not current NDIS participants, 21.4% identified that this was because they did not know how to apply or did not have assistance to apply.

Another barrier in gaining access to services just generally, but also NDIS, the burden of proof. And having to get re-diagnosed in some cases, to be able to access to supports. The amount of documents you have to submit and provide is ridiculous and leads to burn out.

I have applied for NDIS three times from each and I got rejected. Three times and I did so many things. I got depression, two years I'm on antidepressants. Getting more support, going on trams, it's really struggling for me. I tried everywhere, they said it's not effective, still you need more documents, even to provide more psychologists, doctors, GPs, everything diagnosis. Three times got rejected, no point. So I stopped it, maybe I'll apply next year.

Participant responses reflected the toll that inaccessible application processes took on their wellbeing. In particular, the inconsistency of outcomes within services such as the NDIS was noted to contribute to confusion, extended periods of inadequate support and overall burnout.

There are just general concerns about consistency with the NDIS.

I mean, if you don't have the language skills, if you don't have the social skills, you're not gonna make complaints, you're not going to speak up for yourself and you'll just be denied services because you don't have the funding to get those services. If you don't have the advocacy skills or the support services around you, it's really tricky to get support from the NDIS.

Respondents who were able to access the NDIS spoke extensively about the difficulties they had experienced in accessing much-needed support.

Yes I can technically advocate for myself but the time and energy it takes up is really very taxing.

It's the admin and the pre-work, I call it the pre-work, once you are on it, it can be good. Not always, but it really can be helpful and do what it's meant to do.

Existing data indicates that while feminine-identifying people make up half of the disability population, they represent just over a third of NDIS participants.⁵⁰ The National Disability Insurance Agency does not publicly report on data disaggregated by both gender and other participant characteristics, and therefore does not provide insight into NDIS outcomes for CaLD WGwD. Further, data from the National Disability Insurance Agency on rates of participation for CaLD people with disability should be considered with caution.⁵¹ According to the most recent NDIS Quarterly Report, the definition of CaLD has only excluded participants identifying as First Nations since September 2021.⁵² This suggests that the data collected prior to this date may not be an accurate representation of participation rates for either CaLD or First Nations communities, and may be unable to inform policy development for CaLD communities and First Nations Peoples in Australia, given their unique needs.

Due to the gendered nature of caregiving, many respondents who were NDIS participants were not only managing their own access to disability support services, but also facilitating care for family members. This can contribute significantly to a lack of time and capacity to persevere with excessive application processes. One participant recounted her experience assisting her mother, whose health was permanently impacted by surgery waitlists during the Covid-19 pandemic. Another spoke of being relied on to support her parents with application processes from a young age despite having a visual impairment.

Thankfully, myself and my younger sister we are on the NDIS so we can help out in that regard and I'm actually a plan nominee. But the fact that her surgery was delayed multiple times and the fact that it took her more than six months for us to get an answer for if she was eligible for the NDIS... The process is leading to burnout for me because I have my own issues as well.

My parents' first language wasn't English, and I found that I always had to help my parents understand documents that they were required to fill out. I have a vision impairment, so that was a lot of fun because I didn't know what was on the printed page. So you can imagine what that was like.

The administrative burden experienced by CaLD WGwD accessing formal supports is compounded by increased barriers to formal documentation of disability. Focus groups identified that CaLD women face additional and deeply entrenched barriers to providing evidence of disabilities. Within Australia, access to key disability supports and services such as the Disability Support Pension (DSP), Disability Employment Services (DES), NDIS and other schemes is dependent upon extensive medical documentation and assessment. For this reason, living with undiagnosed conditions, receiving incorrect diagnoses or delayed diagnoses later in life has far-reaching impacts for accessing formal services.

Getting a diagnosis is harder for people from different migrant backgrounds, especially for something like autism, because when you act differently, people tend to think it's part of your culture. Because you need to act more like an Australian. You need to change your ways. That's how they tend to look at different kinds of behaviour.

Formal documentation of disability is often evidenced by previous medical records. This can be difficult for migrants to access from their country of origin and may require additional fees and time for extraction and translation if they are available at all. For those who have fled their country of origin as refugees, documents may have been destroyed or may be impossible to obtain. Following diagnosis and documentation, difficulties maintaining continuity of treatment and care can persist for similar reasons.

It's a problem because when you receive a diagnosis in one country, you have to start the process all over again. A lot of people don't realise that. It is not easy to start in a new country and when you migrate to a new place. You have to learn how the system works to access the services all over again. Sometimes it means getting a re-diagnosis which takes a ridiculously long time.

Providing evidence of disability requires extensive engagement with medical services. According to participants, however, the

ways in which disability is understood by various cultural and linguistic groups can be fundamentally at odds with the Australian medical system. The social model of disability highlights how definitions and perceptions of disability are tied to cultural, social, and environmental contexts.⁵³ Within Australia, diagnostic approaches to disability are reliant upon Western biomedical norms.⁵⁴ These may not capture how CaLD women understand their wellbeing and support needs within their own gendered, cultural, and linguistic contexts. In addition to communication barriers, stigma from service providers and structural discrimination, differing understandings of disability and support needs can further prevent CaLD women from obtaining formal medical diagnosis and documentation.

Age and generational differences were also identified as a barrier to diagnoses and formal documentation of disability. Many participants shared experiences of diagnosis later in life. Others were aware of family members or others in their community who had experienced late diagnosis or appeared to be living undiagnosed, without access to formal supports. One participant shared the experience of being diagnosed with autism only after her daughter received the same diagnosis. Late diagnosis not only prevents early access to formal supports but can be more difficult to adjust to for those marginalised from support systems.

A lot of migrants, they wouldn't even know that they were on the spectrum and there's various issues that I felt would face migrant women on the spectrum. I speak up about these issues whenever I can because I think that voice is lacking.

Financial Barriers

Based on existing evidence, it is likely that accessing specialist and multidisciplinary teams for evidence of disability would be financially inaccessible for many CaLD WGwD. While there is little to no specific data on the economic status of CaLD WGwD, data shows that 45% of people with a disability in Australia live in poverty and only 47.3% of CaLD women are employed, compared to 69.5% of CaLD men and 59.2% of all women nationally.⁵⁵ Unfortunately, the lack of data on the economic status of CaLD WGwD and specifically migrant and refugee WGwD means that these statistics do not accurately represent the situation for these cohorts.

The financial disadvantage that impacts CaLD WGwD was reflected in the survey results, which demonstrated that 60% of participants experienced difficulties accessing healthcare. 80% of those participants indicated that the cost of services was a key barrier and 60% indicated that necessary services were not covered by their health insurance. Of those who were not NDIS participants, 35.7% stated that this was because they could not afford assessments (e.g. Occupational Therapy reports) for their application.

While the burden associated with proving disability is recognised as a barrier to formal supports for all WGwD, the unique situation of CaLD WGwD presents further challenges. For example, restrictive eligibility requirements mean that most CaLD WGwD who are on temporary visas may be unable to access support through the NDIS, the Disability Support Pension, or Medicare.⁵⁶ For example, for migrants to access the Disability Support

Pension, they must provide evidence that they have lived in Australia for ten years, unless they fall under one of the following exceptions: they are a refugee; they are a humanitarian entrant; or they are a permanent resident who has acquired a disability while living in Australia.⁵⁷ Further, as a result of strict eligibility requirements for Medicare, one-third of asylum seekers are ineligible.⁵⁸ Strict eligibility requirements across these service systems mean that many CaLD WGwD are left without support.

The NDIS only caters to people who have 'significant disability'. But that doesn't give a lot of funding or support for people who are on the mild spectrum and struggle in general, but it's not considered significant.

For those CaLD WGwD who are eligible for the NDIS, the aforementioned administrative burdens involved mean that accessing support is extremely difficult. For one participant, a previous rejection from the NDIS was reversed after consulting with a different specialist. Although their circumstances had not changed, accessing NDIS funding was dependent on their ability to afford another consultation.

I got rejected the first time. I saw my psychiatrist and I paid for them. They were able to do a more detailed one. That got me approved. If you can get a more detailed diagnosis, and if you have a cooperating psychiatrist who is able to talk to NDIS, that transition will be a lot smoother.



Another participant with a physical disability had previously relied on GP consultation and support from a community health organisation to apply for NDIS support. Her application was rejected. She reported being unaware that paying for specialist consultation could have changed the outcome.

My GP was clueless. She knew I needed help. She is like 'I can't believe you've never received any help'. She didn't know what to write, how to fill out the form. There was some lady, it was a one-year project, they were helping people apply to NDIS and what not, people from coloured communities and so they helped me. And I guess yeah, maybe their report was not enough.

As mentioned above, CaLD WGwD without citizenship or permanent residency status are under additional financial pressure to manage disabilities. Having no universal access to social supports and basic healthcare as well as restrictions on working rights places those on temporary visas in a position of heightened vulnerability.

As a temporary resident from Japan, I am not eligible for any support from Australia. It was my own decision to stay in Australia during the lockdowns, but it was a bit tough to survive the lockdowns without support. I have been interested in autism intervention to learn social skills and other skills necessary to survive or thrive, but I'm not eligible for such service in Japan, and I assume I can't afford one in Australia without NDIS or Medicare.

Previous Negative Experiences with Service Systems

Undergoing testing for diagnosis and liaising with healthcare providers is often highly confronting, physically invasive, and emotionally taxing. This is particularly the case when additional needs, such as translation and cultural liaison services, are not readily accessible and when a patient has had negative or traumatic experiences with service systems in the past. Several participants spoke to their discomfort and fear surrounding collection of data when accessing services, particularly in relation to citizenship status, employment status and cultural background. For some, these procedures are reminiscent of migration and asylum-seeking processes. The sharing of sensitive information with service workers without adequate explanation of the relevance and purpose for doing can be a source of extreme anxiety, particularly in the context of negative prior experiences.

I have ADHD and Bipolar Disorder and I was diagnosed with both of those here and I had the quite frightening experience, I suppose, of going through the immigration process and kind of like being doubly scrutinised for something that was picked up on here while I was using the healthcare system within the bounds that I am entitled to use it.

I think some places ask for a whole bunch of religious or cultural background, which I personally don't always feel it's relevant to know that information.

International students, for example, we never stated in our visa applications that we are disabled... We have to look perfect.

Access to Information and Knowledge of Support Systems

A central barrier that CaLD WGwD face in accessing services is access to information.

Current research suggests that lack of education and awareness of available services in Australia may be one of the main access barriers to women and girls with disabilities.⁵⁹ For example, for women who are victim-survivors of violence, the perpetrator may actively limit the information available about accessible support and services.⁶⁰ This is particularly common for women and girls with disabilities who are under guardianship arrangements or who are living in institutions, which gatekeep their access to information.⁶¹

In the project survey, 61.5% of survey respondents felt they did not have enough information about health services available to them. 64% indicated some level of difficulty in navigating the Australian healthcare system, with 28% finding it very difficult. Within focus groups, participants spoke of being unaware of key support services or that they were eligible for support.

Figure 7.
Survey respondents' awareness of services

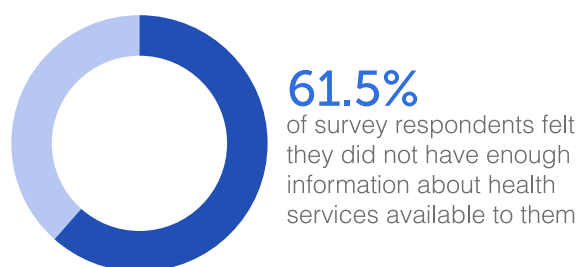
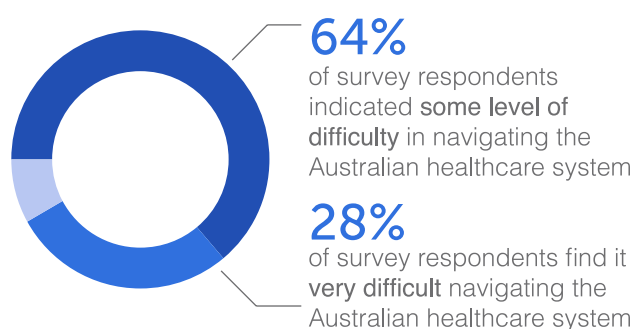


Figure 8.
Survey respondents' experience navigating the Australian healthcare system



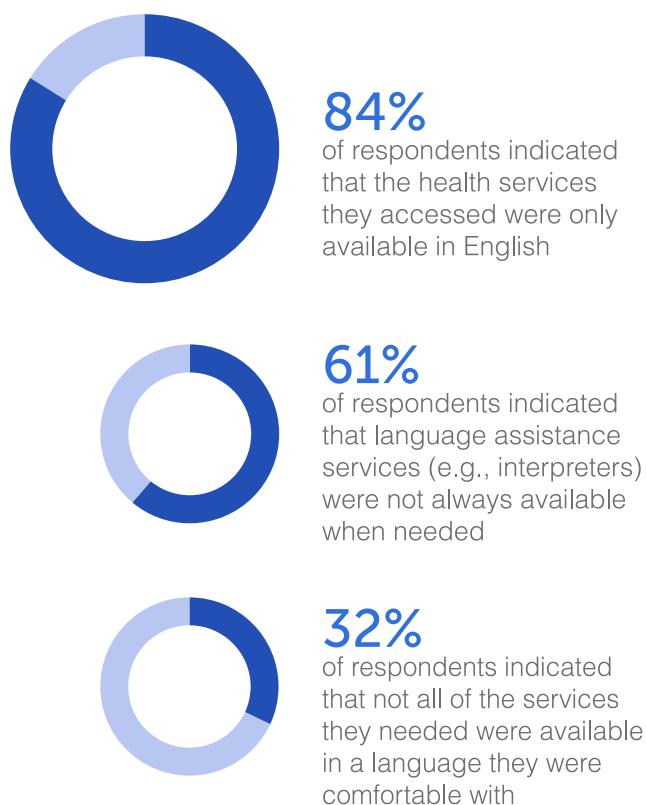
According to participants, there is a consistent lack of clear, accessible information in diverse formats and languages. This includes a lack of Easy Read or multi-lingual translations for CaLD communities in which English is not the primary language and interpreter services for people from non-English speaking backgrounds. 84% of

participants indicated that the health services they accessed were only available in English. The majority (61.1%) indicated that language assistance services (e.g., interpreters) were not always available when needed. 32% found that not all of the services they needed were available in a language they were comfortable with. Where communication supports were available, participants felt they were not adequately consulted with about their needs. For example, two participants shared the experience of being assigned interpreters that did not speak the relevant language or dialect. Frequently, assumptions were made about the participants' capabilities according to visible disabilities or linguistic differences. These assumptions often stood in lieu of personal consultation.

English is not my first language as I am hearing impaired. I never learnt Auslan growing up, I'm having to learn it now. So even if they do offer services, they see, "Oh, they're hearing impaired, I want to get an Auslan interpreter". That doesn't really help me at all because I don't really know what they're saying to begin with.

They gave me an interpreter. My mum was there and she started laughing. And the reason she started laughing – she said, '[name removed], you're going to need an interpreter for the interpreter'. I think, when in doubt, it's okay to ask directly from the person what they need.

Figure 9.
Respondents' experience of accessing language services



This experience is reflected in existing literature which suggests that service providers are unequipped to understand cultural differences in communication and not resourced to provide interpreters or information in different languages.⁶² Additionally, while the use of interpreters can be of practical assistance, anecdotal evidence suggests that requesting an interpreter can also further complicate the process of service access.

In the focus groups, one participant demonstrated how trying to access a service in a language other than English drastically slowed the processing time of applications for support.

I requested an access request form in Spanish, because I speak Spanish...I did two separate emails, I did one in Spanish requesting the form and did one in English requesting the Spanish form and got two different responses. I did both emails at the same time and one was sent a lot faster than the other.

Participants also spoke about their access to information being affected by poor communication from service providers. Inconsistency, extended response times and an overall lack of clarity were noted as serious barriers to requesting support. Poor communication was seen to add to participants' administrative burden and create additional burnout, frustration and disengagement from services.

It's about consistency. I can call the NDIS right now and ask a question about something and for example, I can call up another day or you know, you can call up the same time as me. We'll both get different people who'll give different answers. I think that's a big part of the problem because there is no one kind of consistent thing that can be applied. In some circumstances, I understand that, because there are so many nuances to disabilities, but I would appreciate if two different people could give me the same answer.

It's really difficult when you're waiting to hear back and you just want that closure so you can move on and explore other options.

CaLD Women with Disabilities and the Digital Divide

Evidence suggests that access to information and knowledge of services for CaLD WGwD is also strongly influenced by their digital divide from the broader population.⁶³ For some, this is related to financial barriers; for others it relates to a lack of accessible content and tools.⁶⁴ Women globally are less likely to have internet access than men and lower levels of digital literacy. Specifically, CaLD WGwD may struggle to access service providers and infrastructure, such as mobile networks and agents, or lack the formal identification required for an internet connection. Harmony Alliance members have also reported uniquely gendered barriers to digital access and inclusion, including those associated with competing family priorities and caring responsibilities, online safety, and control of access to devices in the context of family and domestic violence.⁶⁵ They have also reported that their experiences of digital exclusion were exacerbated in the context of Covid-19.⁶⁶

Digital access and inclusion has important implications for accessing formal supports. 53.9% of participants identified that they used internet or over the phone services as a main source of access to health care. However, only 42.3% of participants felt

very comfortable using these methods, with 15.4% stating they felt very uncomfortable. 47.1% indicated that having to adjust to new ways of communicating with services since the spread of COVID-19 (e.g. Telehealth) had a significant impact on their access to healthcare. One focus group participant reflected that information about formal support services is now often exclusively promoted online, while another spoke about their difficulties affording internet-enabled technology.

I'm always on social media and always registering myself to different organisations, but I don't find them implementing it in person. A lot of workshops email me about bringing awareness, but there's not enough leaflets or visual things for people to see what's out there.

I have trouble getting tech funded because they don't do tech and it is - I think the reason for that is - like I get why they do that. And they think everyone's gotta buy a phone. And - but not everyone can work to buy a phone and you know, I do lots of advocacy groups, about three different advocacy groups and I need my phone. When my laptop dies I will not be able to do Zoom.

It is concerning that existing formal supports may be underutilised by CaLD WGwD due to a lack of awareness. One participant spoke to a range of programs and formal supports that they found extremely helpful but noted that these were not well publicised.

The GP does offer a mental health care plan and, um, I'm in WA and they offer a women's health clinic which also offers free domestic violence women's groups which I have also been a part of and it's very, very helpful. Because they also have free creche, free yoga classes, I really like it.... I don't think people are aware enough of these services.

As well as highlighting the need for internet access, participants spoke about having to raise awareness of available services directly within CaLD communities. There were requests for information and support to be available within the broader community, for example, in community centres, schools and universities.

I think for someone who is CaLD and English is not their first language, it's about bringing that awareness to them and simplifying it, so it's easier for them to apply.

Impacts of COVID-19

The COVID-19 pandemic has exacerbated disparities in access to healthcare and support services globally. In Australia, CaLD communities were disproportionately affected by poor public health messaging, financial precarity from over-representation in low-paid, insecure work and unemployment, and over-policing.⁶⁷ During the Delta wave, people born overseas had a COVID-19 mortality rate close to four times higher than that of people born in Australia.⁶⁸

When reflecting on the impact of COVID-19, participants spoke to a 'snowball' effect. This referred to the increased pressures on CaLD WGwD spiralling out of control as access to services diminished. For those managing disabilities as well as cultural and linguistic barriers, the dwindling pool of 'essential' services during lockdowns was wholly inadequate.

A lot of my services for pain management dried up because some of them, I use free clinic hours with students that are trying to get qualified. They all disappeared. And there was no way to replicate that because I didn't have the money and I was already doing other things that we use in funding as well, and some things don't use funding that I paid for out of pocket.

It's really hard when government services say that essential services should continue... Sometimes they don't see what we see as essential to be essential.

Increased delays for elective surgery had severe impacts on several participants. One participant said her mother's extended wait to access surgery for a nerve condition contributed to her mother later requiring NDIS support. Others shouldered additional chronic pain burdens while waiting for surgery.

During that surgery which did take longer than initially expected, she ended up having two small strokes and as a result of that, she was at less capacity than what she was beforehand and she was put onto the NDIS.

I hate the term elective surgery; Had cancer that needed to be removed from throat so I could breathe properly. That was considered elective surgery as I wasn't actively dying. But I wasn't living if that makes sense.

The strain on mental health services since the pandemic began has been well-documented across Australia. However, for CaLD WGwD, many spoke to the increased difficulties accessing mental health specialists capable of working with cultural sensitivity. In addition to existing shortages and out of pocket costs, this caused many to go without adequate support. Loneliness and precarity were noted to be particularly difficult for CaLD WGwD, being already disproportionately isolated prior to COVID-19.

It's extremely difficult to access mental health services as well. To find a psychologist or mental health worker who understands culturally diverse issues and doesn't treat culturally diverse people with disabilities like mainstream people because there are lots of variation between the two cohorts. I think the governments have neglected mental health services for culturally diverse people for so long.

Survey results found that 64.7% of participants felt their general health had worsened due the impact of the pandemic on access to healthcare services. 35.3% felt isolated without access to their regular services. 41.2% found that not being able to see family members for extended periods of time impacted their health and/or disability.

People with disabilities are used to the isolation. We're used to being slimmed down to 'this is all we get to have'.

I like planning everything ahead of time, so when I booked GP appointments before COVID, I preferred to book a week or even two weeks advance. But after the lockdowns, I often hesitate to book in advance because I feel anxious while I'm answering the COVID screening questions that circumstances might change before my appointments.

Participant responses indicated that multiple modes of access to services were helpful during state lockdowns. This included Telehealth appointments, continued in-person access to support workers, phone services and online communications. The increase of flexible work and study methods was also indicated as a positive development.

What I found really, really, useful was nurse online - to call a nurse online if you needed to talk to someone. I had a side effect after one of the vaccinations that I had for COVID and nurse online was awesome because I rang her at 11 o'clock and they helped me. Even just to have a little bit of interaction with a human being just to assess you and actually ask a couple of questions, ask how you are going today and just go through some questions with you.

53.9% of participants identified that they now use internet or over the phone services as a main source of access to health care. However, the overreliance on technology and navigating rapid disruptions to services poses challenges for some CaLD women with disabilities. Many reported that additional in-person support was needed to navigate cultural and linguistic communication barriers to Covid-related services. Moreover, services have generally failed to provide information and support for those who struggle with digital literacy, or those who have restricted internet access. This is discussed further

under Access to Information. As online delivery becomes more frequent and has increased access for some, it is apparent that this is not the case for all. More research and analysis into the barriers that CaLD women with disabilities face in accessing online services is needed.

I'm registered with the Monash care Covid hotline and they do ring me every day, just to see how I'm progressing. But a person with a language barrier, that'll be so hard. I've got this information because I asked, but if you have no idea...

We are in a different world now. I mean, it's all about working from home and using the internet a lot more. But again, a person with a language barrier and a woman with a disability, that would be quite difficult unless I've got that one to one to educate them.

The increased risk of hospitalisation and continued strain on services disproportionately affects CaLD WGwD. As the 'new normal' of living with Covid has been imposed nationally, many continue to live in a state of perpetual lockdown.

People say we should live with COVID but as people with disability who are at higher risk of being hospitalised, we have to live with the prospect of going to hospital all the time.

Domestic and Family Violence Services

While the research project did not intend to analyse the experiences of CaLD women with disabilities within domestic and family violence services, the focus group participants frequently raised this topic, highlighting its persistent relevance.

One area of concern related to a lack of knowledge about legislation and systems when coming from a different place or culture, as well as a lack of services that cater to the needs of CaLD WGwD.

When you come from a different background, there are different laws applying to domestic violence in different places. Sometimes, in Australia, some people don't know about that. That can also create a barrier to getting support because in their culture, back in their country, it's quite different.

I see an inclusive Australia as where domestic violence services are tailored for the needs of CaLD women who have disabilities as well, who are isolated in the community and have nowhere else to go and stay in the abusive relationship because they have nowhere else to go because DV services don't cater for their need. I'd also like to see primary health services utilise free interpreting services more for people who don't speak English. I'd like to see that people are not discriminated against, denied services, because of their names and sort of feel, what's the word that I'm looking for, almost forced to change their names to be accepted in the mainstream.

Another issue raised by participants was around not being believed or having experiences minimised when trying to report experiences of violence and abuse; an experience which is discussed in existing literature as common among CaLD women and gender diverse people and people with disability.

I'm going through a really hard time, there was a counsellor, that was like, 'oh, so it's not physical abuse?' She was almost minimising my experiences because it wasn't physical or whatever. And I told her like whatever happened in childhood. The way that she engaged with me made me feel really disconnected and made me doubt my own experiences.

Ableist and paternalistic attitudes often infiltrate services across sectors and create a situation where the experiences of women and girls are often not taken seriously or not believed by service providers. Many providers lack trained staff who are able to provide trauma-informed supports and services. This, along with the discriminatory perceptions that providers hold, creates 'a culture of silence' as women fear the consequences of accessing supports and services.

Additionally, due to the ableist nature of the service and justice system, many CaLD WGwD also fear experiencing institutional violence. This was reflected in a statement made by one participant.

Providers for disability services could actually be the perpetrators of violence. I've heard stories of people with disabilities trying to get support but someone that they really trusted that was supporting them actually abused them. I think it's something that's quite common and it's something to keep in mind.



RECOMMENDATIONS

In addition to exploring the barriers that prevent CaLD WGwD from accessing formal supports, the project also aimed to identify solutions or opportunities for improvement. In this section, key themes that emerged in the data have been translated into 15 actionable recommendations for governments and stakeholders to consider.

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|-------------------------|--|
| Recommendation 1 | Recognising evidence that the presence of CaLD workers with lived experience of disability improves the service experiences of CaLD WGwD, the Australian Government should provide targeted funding to public services to employ and retain frontline CaLD peer workers in all levels of service delivery. |
| Recommendation 2 | Recognising the value that being connected with community brings to CaLD WGwD, the Australian Government should provide ongoing targeted funding for sustainable community led peer-networking opportunities for CaLD WGwD. These opportunities can also be used to share information and build awareness of available supports and services. |
| Recommendation 3 | Recognising that there is a desperate need for specialist services that cater to the needs of CaLD WGwD, the Australian Government should work with state and territory governments to develop a trauma informed national strategy on the provision of health and disability services to CaLD communities that is co-designed with CaLD people and their representative organisations, and incorporates an intersectional lens throughout. |
| Recommendation 4 | Recognising that there is a significant shortage of skills and knowledge needed to support CaLD WGwD, the Australian Government should fund the development and delivery of tailored, trauma informed cultural competency and disability awareness training to all frontline service staff working in disability, health, and community services, including frontline domestic and family violence services. |

Recommendation 5

Recognising that there is a significant gap in understanding and awareness of available formal supports and services among CaLD WGwD, the Australian Government should work with state and territory governments, relevant agencies and ethnospecific organisations to develop, resource and implement clear, accessible, and widely broadcasted information campaigns on the availability of and process to access formal supports and services. This must be translatable into a broad range of languages and dialects, and include Easy English versions and visually accessible information.

Recommendation 6

Recognising that the current eligibility criteria for access to the NDIS restricts participation to only 10% people with disabilities⁶⁹ and 8.4% of CaLD people with disabilities,⁷⁰ the Australian Government should, as part of its response to the Review of the NDIS (or other relevant initiative) conduct a comprehensive review of the NDIS eligibility criteria, with an aim to expanding the NDIS to include currently excluded cohorts such as migrants, refugees, people on temporary visas and people with life impacting disabilities that are currently not considered 'significant'. Alternatively, the Australian Government should provide comprehensive, funded, and quality assured services and supports to people with disabilities that are not considered 'significant' within the meaning of the NDIS, to remedy this crucial gap.

Recommendation 7

Recognising that WGwD participate in the NDIS at a much lower rate (37%) than men and boys (62%),⁷¹ and that this rate has not improved since the scheme began, the Australian Government must work urgently with the NDIA to develop an intersectional NDIS Gender Strategy, in consultation with CaLD WGwD and their representative organisations.

Recommendation 8

In order to address the lack of available data and information about CaLD WGwD participation in the NDIS, the Australian Government should enact regulatory requirements on the NDIA that facilitate the regular monitoring of and reporting on the NDIS participation rates of all WGwD, including those who are CaLD.

Recommendation 9

Recognising that several reviews of the DSP have indicated that the current eligibility criteria for access is too restrictive, the Australian Government should act urgently to:

- abolish the eligibility tests used to access the DSP based on the Medical Model of disability, and reframe the definition of disability under the DSP to reflect the Human Rights Model of Disability
- remove the 10-year qualifying residence period for migrants with disabilities to access the DSP.

Recommendation 10

Recognising the evidence that financial barriers often prevent CaLD people with disabilities from accessing essential healthcare, the Australian Government should expand the eligibility for Medicare to include all migrants and refugees in Australia, including those on temporary and student visas.

Recommendation 11

Recognising that there is a significant administrative burden associated with applying for support through agencies like the NDIA and Centrelink, and that these processes often prevent CaLD WGwD from accessing formal supports, the Australian Government should work with relevant agencies and actors to:

- do a comprehensive accessibility review of application processes, incorporating a cross-cultural lens;
- fund the translation of application processes into different languages and dialects where they do not already exist, including Auslan and Easy Read; and
- fund ongoing formal supports to assist applicants with lodging applications, including through in-person workshops, information sessions and individual advocacy and supported-decision making services.

Recommendation 12

Recognising that the use of technology and internet are becoming increasingly essential for the purpose of accessing essential information, resources, formal supports and community; the Australian Government should work with state and territory governments, internet and technology providers, and people with disability and their supporters and representative organisations to develop and implement a national, time bound strategy to support nation-wide, universal access to a stable internet connection.

Recommendation 13

Recognising that the cost of technology is a barrier that prevents CaLD WGwD from accessing essential services, the Australian Government should work with the NDIA to ensure that the cost of relevant devices and programs such as laptops, smartphones, screen readers and translation software are included in individual NDIS support plans where required.

Recommendation 14

Recognising that the state sanctioned segregation of people with disabilities is a blatant contravention of Australia's obligations under the CRPD and other international human rights treaties to which Australia is a party, the Australian Government should work with state and territory governments to develop and implement a national, time bound strategy and framework for the closure of all segregated and closed settings for people with disabilities, including those operated by non-government and private sectors.

Recommendation 15

Recognising Australian Disability Enterprises (ADEs) and other segregated models of employment as being in contravention of the CRPD, the Australian Government should act to:

- cease the continuation of any government process that endorses ADE participation or the Supported Wage System (SWS); and
- develop and implement a national, time bound strategy to transition workers with disabilities out of segregated employment, into open, inclusive and accessible forms of employment that:
 - › ensures equal remuneration for work of equal value;
 - › incorporates recommendations from previous employment inquiries, such as the Willing to Work Inquiry; and
 - › contains targeted gender, age and culturally specific measures to increase workforce participation and address structural barriers.

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