# Disability Service Access Issues for People of Refugee Backgrounds Living with a Disability in Victoria

*December 2022*
*Prepared by the Victorian Refugee Health Network*
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## About the Victorian Refugee Health Network

The Victorian Refugee Health Network (The Network) was established in June 2007 with the aim to ensure that all Victorians of refugee background, including those seeking asylum, have timely access to appropriate services and other resources required to build and maintain health and wellbeing. The network does this by facilitating greater coordination and collaboration amongst health and community services to provide more accessible and appropriate health services for people of refugee backgrounds. The network harnesses the expertise from the health sector and the community to identify and respond to systemic issues and provide credible, trusted advice towards policy and service development.

The Network reports regularly to the Department of Health in Victoria providing advice on the most significant issues that are impacting refugee and asylum seeker health and wellbeing at the current time. More information about the Network may be found on our website: www.refugeehealthnetwork.org.au

DISABILITY SERVICE ACCESS ISSUES FOR PEOPLE OF REFUGEE BACKGROUNDS LIVING WITH A DISABILITY IN VICTORIA

victorian refugee health network

# GLOSSARY

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| Aidacare | Australia's Healthcare Equipment and Service providers. |
| BVE | Bridging Visa E |
| CALD | Culturally And Linguistically Diverse |
| FRP | Family Recovery Program |
| HAP | Health Assessment Portal[1] |
| HAPlite[2] | is a subset of the HAP system, that can be accessed by registered health providers |
| HSP | Humanitarian Settlement Program |
| IME | Immigration Medical Examination |
| LAC | Local Area Coordinator |
| LGA | Local Government Area |
| NDIS | National Disability Insurance Scheme |
| RCH | Royal Children's Hospital |

[1] To record IME and manage health undertakings
[2] Offshore health assessment and the HAPlite system
https://www.rch.org.au/immigranthealth/clinical/HAPlite/

## Introduction

In this submission, the Victorian Refugee Health Network (the Network) will provide a summary of the key issues and concerns impacting people from refugee and asylum seeker background in Victoria with a disability. These issues and concerns have been identified by refugee health and community services who work with people of refugee backgrounds. This paper has been informed by the following strategic aims and directives:

- The Network has recently finalised its Strategic Plan for 2022-2024 where 'disability' was identified as a key priority area to focus on over this time. This area of focus was identified through a deliberative engagement process that included a panel of 26 Victorians with lived experience as refugees or seeking asylum and frontline workers and leadership in the refugee health sector that helped guide the development of the Plan. This focus area resonates with feedback the Network has received from its members regarding significant service gaps in provision of services for people from refugee and asylum seeker background with a disability.
- The Victorian Department of Health, Diversity and Access division has recently asked the Network to provide a briefing paper regarding disability access issues for people of refugee backgrounds in Victoria. The Network has welcomed this initiative by the Department of Health to better understand the key issues and concerns and will be presenting to the Department on these issues in early 2023.
- Ensuring that people from refugee and asylum seeker backgrounds have equitable access and inclusion to services and initiatives for people with a disability consistent with the values and commitments presented in Australia's Disability Strategy 2021–2031[3], and the Victorian Government's Disability Plan (2022-26)[4].
- The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is currently open to submissions to hear experiences of people with a disability from culturally and linguistically diverse background. The Network has taken the opportunity to collect case studies and concerns from Network members who support people of culturally and linguistically diverse people with a disability, in particular people of refugee background and seeking asylum in Australia.

The Network therefore welcomes this opportunity to provide a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability outlining our key findings.

## Who did we consult for this report?

For this report, the Victorian Refugee Health Network Executive Group consulted with workers from various organisations including case managers from settlement services, refugee health nurses in the Refugee Health Program and English Language schools who offered sector insight into the barriers and need for appropriate disability services for their clients with refugee backgrounds.

[3] Australia's Disability Strategy 2021 –2031
https://www.disabilitygateway.gov.au/sites/default/files/documents/2021-11/1786-australias-disability.pdf
[4] https://www.vic.gov.au/state-disability-plan

In addition, the Network also conducted a brief survey that was distributed to subscribed members of the Network. The Network received 39 responses to the survey from people who work across health, settlement, housing, legal and asylum seeker agencies, including 77% of people who worked in Metropolitan Melbourne and 23% who worked in rural and regional areas.

To understand the distinct experiences for those people who are seeking asylum in Victoria (temporary protection visas or bridging visas) and those who have refugee status (permanent protection) the findings will be outlined accordingly. The following information is based on the collection of both the survey responses and consultation sessions with the sector.

## Background

Up until 2012, people who had a disability and/or significant health concern were excluded from settling in Australia under the Australian Refugee and Humanitarian Settlement program. Due to welcome changes in Commonwealth migration policy in 2012, the Australian Government streamlined a health waiver for humanitarian visa applicants that had previously assessed and created these exclusions based on costs that may be incurred on health or community care services. This has meant that prior to this policy change, health, and community services, including settlement support services, had limited resources for, and experience in dealing with the added complexities of supporting people from refugee and asylum seeker backgrounds living with a disability.
The welcome change to the waiver in 2012 has meant that people of refugee backgrounds with a disability and/or significant health concern have since been granted visas and have been able to resettle in Australia through this program or have been granted Temporary Protection and Safe Haven visas. Due to this policy change, there has been increased prevalence of, and more diversity of disability among people who arrive in Australia as refugees. However, this has not been matched with sufficient resourcing or support to address the needs of this group and promote their inclusion and belonging in the community.

This report highlights the challenges that people with a disability who are from refugee backgrounds face when trying to access support for their health and disability needs. Feedback from organisations who work with people of refugee backgrounds have highlighted inadequacies in timely and continuous access to assistive equipment and technology; referral pathways to specialist services; difficulties in applying for and accessing NDIS; low levels of literacy in health and service navigation and access to culturally appropriate support services among other pertinent issues.

There are noted variations in the eligibility criteria of vital support services for people of refugee backgrounds which is dependent on visa status. Eligibility criteria for the National Disability Insurance Scheme (NDIS) that was rolled out in 2013 require an individual to hold permanent residency to gain access to this scheme and associated support. Therefore, people seeking asylum, people who hold bridging visas (BVE), Temporary Protection Visas (TPVs) and people with Safe Haven Enterprise Visas (SHEVs) are ineligible for the NDIS. It is also important to note that people with Temporary Humanitarian Stay (449) and Temporary Humanitarian Concern (786)[5] visas who have more recently arrived from Afghanistan and Ukraine are not eligible to access Medicare and are ineligible for NDIS. This has resulted in significant delays in accessing immediate health and disability support needs for this cohort as they arrive into Australia.

[5] Temporary Humanitarian Stay (449) Visa & Temporary Humanitarian Concern (786) https://www.homeaffairs.gov.au/help-and-support/ukraine-visa-support/australian-government-offer-for-temporary-humanitarian-stay-in-australia

# Findings

The information below outlines the current gaps and barriers in accessing systems and service delivery models. These barriers are impacting on the health and wellbeing of clients living with a disability from refugee backgrounds. Areas of concern that have been identified by the sector include: the offshore and onshore health assessment process, disability service system navigation, disruptions to settlement outcomes, health literacy and disability, access to culturally safe and linguistically diverse services, referral pathways and intake to the NDIS.

## I. Health Assessment: Early identification of disability support needs

### Immigration medical examination (IME) Offshore health assessment and the HAPlite system

Before clients arrive in Australia, clients complete an IME offshore health assessment and settlement services are subsequently informed by the Refugee Health Program whether there is a health alert on the HAPlite system. An alert may indicate whether an individual has any mobility issues or diagnosed health conditions identified in this offshore health assessment. However offshore health assessments reportedly do not incorporate specific sections on disability causing inconsistencies in capturing health information and assessing for disability in this process.

Reports from the Networks consultations with the sector indicate that offshore health information is not always provided in a timely manner and/or information is often outdated e.g., offshore health information has been reported to be 12 months old. Health and settlement workers are, at times, only notified of the need for complex healthcare on or after arrival. This places new entrants at risk and puts strain on state health systems. With an increased government commitment towards regional settlement, a coordinated, integrated approach is essential to ensure that health providers in regional communities are prepared, upskilled, and appropriately resourced to deliver healthcare to new arrivals. This includes a targeted focus on improving the quality of health alerts identifying people with a complex disability.

### Onshore health assessment

Currently there is no mandated process or measure on how many individuals and families arriving under the Humanitarian Settlement Program (HSP) have completed an on-arrival refugee health assessment. Previously there was an MBS item that specifically provided the billable means for General Practitioners to conduct a 'Health assessment for refugees and other humanitarian entrants' (Items 714 and 716)[6]. These specific MBS items recognised that differing practice standards for health assessments are required for this cohort consistent with good clinical practice. These MBS items have since been removed and this assessment now fall under MBS item numbers 701, 703, 705 and 707 for general health assessments. At this stage it is unclear how many people have these assessments on arrival, as the MBS billing item number is the same item as these other assessment types. Without these MBS items there is no visibility on how many individuals and families arriving under the Humanitarian Settlement Program has completed an on-arrival refugee health assessment raising concern on the delay in identifying health issues which may lead to complications and thus high costs for individuals and the health system. It also highlights that there is reduced visibility on who is required to conduct these assessments.

[6] [6] Australian Government Department of Health and Ageing (2006) http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/B55546F33798EF39CA257CD00081F202/$File/2006-11-MBS.pdf Pg.50-53

Without mandated and comprehensive onshore health screening processes, there are substantial delays in accessing urgent support for individuals who have arrived with significant health conditions, including disability treatment and support needs. Often these individuals and families require immediate linkages with specialists to assess and facilitate the process of a NDIS referral or state-based disability services. Ensuring access to complex tertiary care requires as much notice as possible to ensure continuity of treatment after arrival and adequate handover to the treatment facility.

## II. Access to Equipment and Service System Navigation

### Access to appropriate mobility equipment and assistive technology

Feedback from settlement services have outlined that the only option to provide newly arrived clients with appropriate equipment through their contracted funding arrangement is by submitting a referral to the contracted provider in Victoria, Aidacare. Aidacare is a provider of healthcare equipment and assistive technology; settlement services are allocated up to $210 per client to hire equipment for short term use[7]. When these funds are exhausted, the client is required to either purchase the equipment through their own financial means, rent the equipment for a weekly fee or send it back to Aidacare. Additional feedback from this survey highlighted that when services have been able to secure access to equipment, this has not always been useful or appropriately suited to the fit and/or size of the client.

> *"Current client who has cerebral palsy no motor control requires 24-hour support from her family. Unable to sit safely in a wheelchair spends most of her day on the floor or on the couch. Arrived end of May still without any formal OT assessment or services in place. Both client and mother extremely isolated as they are unable to leave the house as client unable to be transported safely." (Settlement Service Worker, VRHN Survey respondent, 08/22)*

The Victorian state-based Aids and Equipment Program outlines that both refugees and asylum seekers are eligible to receive "subsidised aids and equipment, home and vehicle modifications to help people live safely and independently in their own home."[8] Part of the eligibility for this program is obtaining a "copy of the prescribing therapist's assessment report".

There are currently significant delays and barriers to receiving a professional assessment for the provision of equipment and services, which will be explained further below. It should be noted there are notably more complications for asylum seekers who are Medicare ineligible; lack of access to Medicare impacts the financial means for asylum seekers to cover the cost of therapist reports, equipment and required medication.

The time elapsed between the short-term provision of Commonwealth funding for equipment hire for refugees and a professional assessment that outlines the clients permanent or long-term requirement for aids and equipment leaves a significant gap in the provision of mobility equipment and assistive technology through State and Commonwealth funded programs.

[7] 'About Us' https://www.aidacare.com.au/

[8] 'Victorian Aids and Equipment Program' https://www.health.vic.gov.au/supporting-independent-living/victorian-aids-and-equipment-program

## Service system navigation & GP access issues

When a person from a refugee background who has a disability first comes into Victoria, in addition to setting up a bank account, registering for both Medicare and Centrelink and finding longer term accommodation, they must begin the process of navigating the health system. This includes setting up an appointment with a General Practitioner or the Refugee Health Program to be referred to a specialist to obtain a formalised diagnosis to be eligible for disability support.

There continues to be significant challenges in identifying GP practices that have an interest in, and capacity for, refugee primary healthcare provision. Obstacles to engaging and maintaining GPs in both private practice and community health include concerns about time constraints and the financial viability of service provision, given language difficulties and the often complex medical and psycho-social health needs of refugee patients. Many GPs feel they lack the training, skills, and knowledge to be able to address their more complex and less common health concerns, despite the range of resources and training opportunities that have been developed. There are ongoing reports that GP's and practices are not taking new clients, which is a significant issue for new arrival clients. There are also reports that some practices are charging an initial fee for a first consultation and then subsequently bulk billing. This out-of-pocket expense is often a deterrent for people of refugee background especially those who have recently arrived and may experience delays in receiving their Centrelink payments.

## Delays and barriers for formalised assessments and diagnosis

As previously mentioned in this report, there is often no diagnosis, health information or documents that report on mobility issues or health concerns before the client arrives in Australia. An Occupational Therapy (OT) report, among other therapist assessments is often required to apply for and be approved for Disability Support Pension (DSP), My Aged Care (MAC), NDIS & other relevant State based disability support services available. Findings from the survey and consultation with the sector suggest that in many cases it is taking up to a year to access OT assessments. In addition to time delays, the costs for this assessment can be an additional barrier for families experiencing financial hardship as these assessments are not fully covered by Medicare or funded by the NDIS scheme. Without a formal diagnosis this also prevents access to early intervention supports for children, including enrolment in special needs schools. Occupational Therapy Australia (OTA) is a membership association who represent the interest of OT's and advised the Network that there is no regulation of the pricing on OT assessments; the price can vary according to each service site. The costs of these assessments are not inclusive of additional costs charged for OT assessment reports that are used for NDIS applications.

It is important to acknowledge the additional barriers that are faced by asylum seekers to access allied health services, caused by Medicare ineligibility and/or disruption to their Medicare access. Without Medicare, people seeking asylum are further excluded and locked out of disability supports in the community as this depends on having financial means to fully fund these health appointments, assessments, and equipment.

## The inadequate use of interpreters in allied health appointments

Translating and interpreting services are not funded for all allied health services including services such as OT, physio and speech pathology which are often crucial in disability care plans. It is the responsibility of these services to organise their own interpreting services, typically from fee-for-service language service companies or by directly employing accredited interpreters. This has meant significant language barriers for both refugees and asylum seekers in seeking help through allied health and for practitioners to conduct accurate assessments. Translating and Interpreting Service (TIS National) has recently expanded the Free Interpreting Service (FIS) as part of a pilot program to select Local Government Areas

(LGA) in each State or Territory[9]. Allied health professionals within these LGA's will require significant guidance and encouragement to opt in and register for TIS to ensure they are an accessible service for all Victorians. [10]

## III. Disruptions to settlement outcomes

Without a formal assessment and confirmation of diagnosis, it can be complicated to assist refugees and asylum seekers with entry into appropriate services, including NDIS; support to find appropriate, affordable, and accessible housing; enrolling children who have a disability in a special needs school (either with support in mainstream education or in specialist education) and accessing governmental/non-governmental financial assistance. It is also important to note that a formal diagnosis may require several different components of assessment, and even when a person from a refugee background has a formal diagnosis, they are faced with additional barriers when navigating and using the disability services that are available. This will be explored further below.

### Impact on education for children with a disability

While children and families are waiting for a formal assessment, there are often barriers for children to attend school as schools are not able to access appropriate supports unless children meet strict support criteria (which require confirmation of diagnosis and multiple assessments). Even if a child has a confirmed diagnosis and the school has accessible infrastructure, there are reports that without the appropriate mobility equipment and assistive technology, children are remaining at home as they are unable to transport safely to school.

Feedback from consultations with service providers have indicated that certain schools are not enrolling children with an intellectual disability who have not yet received an assessment. While our understanding is that schools should help arrange an assessment for the child, there are often delays. In other instances, children's conditions have reportedly been misidentified with confusion between language barriers and presentations of cognitive/developmental delays and/or trauma which will be explained further below.

Barriers to aids, equipment and disability support services are causing significant disruption to the settlement process for children and families. Without essential equipment and linkages to disability support services, this has contributed to social isolation, limiting opportunities to connect with the community and/or to engage in education and employment opportunities.

> *"I have a client still waiting for NDIS to approve a wheelchair so that he could take the school bus. The wheelchair that he is currently using does not meet school bus safety standards."*
> *(Settlement Service Worker, VRHN Survey respondent, 08/22)*

[9] Casey, Greater Dandenong, Hume, Wyndham, Brimbank, Melton, Greater Geelong, Greater Shepparton, Mildura, Wodonga

[10] 'Find out if you are eligible for the Free Interpreting Service' https://www.tisnational.gov.au/Agencies/Charges-and-free-services/Free-services-through-TIS-National.aspx

## IV. Health literacy and disability

The communities limited health literacy regarding disability was identified as a key area of concern in both the survey and in consultation with the sector, creating barriers for service access and help seeking behaviour. Barriers related to this theme included "comprehension of disability and mental health", "language and cultural barriers, but also complex systems", "stigma about disability within refugee communities" and, "community stigma that can act as a barrier to accessing services"[11].

Many people from refugee backgrounds have complex unmet health needs due to protracted time in precarious living situations, refugee camps, detention centres or countries with limited health care capacity. This may have included no prior access to an assessment and/or support for a disability, early intervention, and other appropriate services. Lack of education around health care and illness prevention lead to a limited understanding of health information that is required to make appropriate decisions. When refugees and people seeking asylum arrive in a new country such as Australia, health and service literacy is often low and the extent to which they engage with health information and the healthcare system, preventative health activities, and management of their own health can be limited if without adequate support.
The Australian healthcare system places onus on the individual to seek information for their health needs. Consequentially, individuals with low health literacy, such as refugees, have a reduced inclination to play an assertive role in their health care and may delay seeking help take on the responsibility of understanding health information and systems. The 'Report of the Victorian 2014 Consultation on Health Literacy' published by the Department of Health noted that a more "considered response was needed" regarding improving health literacy that moved beyond the translation of written health information[12]. A review of health literacy and information initiatives by the Department of Health related to disability and service navigation would be a welcome approach to respond to the identified barriers of this cohort.

Healthcare providers and services play a crucial role in promoting and developing health literacy skills for service users. For healthcare providers to effectively work with people from refugee backgrounds there must be adequate training and resources to better understand previous experiences compounded by trauma, limitations in health literacy skills and resettlement challenges.

### Stigma and family roles as barriers to service access

Families and individuals from refugee backgrounds hold varying beliefs related to the cause of and treatment for an illness or disability[13]. Consultations with the sector noted that clients from refugee communities may experience discrimination and feelings of guilt, shame, and/or stigma in relation to varied cultural and religious beliefs regarding disability. These experiences are reportedly inhibiting help seeking behaviour outside of the family unit. It was also noted that there are some learnt cultural norms that have involved taking care of family members without assistance and not expecting, understanding and/or wanting assistance.

[11] VRHN Survey Response, October 2022
[12] Hill, S. (2014). Report of the Victorian 2014 Consultation on Health Literacy. Melbourne: Centre for Health Communication and Participation, La Trobe University.
[13] 'Overview of responses to the Experiences of culturally and linguistically diverse people with disability Issues paper' The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, November 2021 https://disability.royalcommission.gov.au/system/files/2022-03/Overview%20of%20responses%20to%20the%20Culturally%20and%20linguistically%20diverse%20people%20with%20disability%20Issues%20paper.pdf

In addition to this, principles relating to informed consent and confidentiality can be new concepts and people often need reassurance about the latter. Given the fear they may experience of their community's judgement, building trust in interpreters and in services is essential to people reaching out for support. This needs to be articulated by providers as a consent form may create anxiety rather than reassure people that their information will remain private.

*"Born in Australia to Hazara parents, permanent residents, so they have Medicare. Only child. Seen by paediatrician. Have applied for NDIS. Access to services including speech, physio, and OT, but parents don't understand condition, and keep thinking she will start to talk. A lot of cultural community shunning and shaming, so mum doesn't want to engage socially, furthering isolation, and lack of awareness of 'normal'. (Now moved to Shepparton and services continuing there.) Swan Hill has limited paediatric services, so there is always a need to travel +/- long wait times for paediatrician." (Refugee Health Nurse in rural program, VRHN consultation 2022)*

## V. Limited training and resources to work with people from refugee backgrounds

"GP's and service providers limited understanding of clients refugee background"[14] was identified in the survey as a barrier for clients to access relevant disability service access. Health providers require resources and training to adequately respond to and understand the experiences and needs of clients from refugee backgrounds. This includes using interpreters, skills in cross cultural negotiation, and health system barriers.[15] Cultural sensitivity training across all health and disability services would help understand varying community views of disability and ways to engage with that community sensitively and respectfully. Resource development and information dissemination is one of many approaches that would help ensure a consistent 'best practice' standard for health care provision in disability, such information would need to be regularly reviewed and updated. [16]

It is also important that services employ a holistic, trauma-informed and client-centred approach when supporting culturally diverse communities with a disability as without this, added complications can occur including misdiagnosis of certain conditions.

[14] VRHN Survey Response, October 2022

[15] Wittick, T., Walker, K., Furler, J.,& Lau, P. (2018) 'An online resource supporting refugee healthcare in Australian general practice: an exploratory study', *Australian Journal of General Practice*. 47(11) 802-806.

[16] Wittick, T., Walker, K., Furler, J.,& Lau, P. (2018) 'An online resource supporting refugee healthcare in Australian general practice: an exploratory study', *Australian Journal of General Practice*. 47(11) 802-806. (p.806).

## Misdiagnosis of conditions

Concerning feedback from this survey and consultations highlighted that in some cases, particularly with children, cognitive/developmental delays were misidentified as language barriers. This delay in diagnosis can severely impact the individuals access to appropriate support and service provision in addition to social and psychological impacts. Signs and symptoms of cognitive impairments have reportedly been misidentified as 'trauma responses' and not seen as requiring relevant medical interventions.

> *"Young person late teens, school thought it was a language barrier as to why A* was struggling. After she moved onto another school and over a year on a waitlist for school psych assessment, she was given diagnoses of IQ of 62." (Settlement Service Worker, VRHN Survey respondent, 22/08)*

## Investment in Bi-Cultural workers

There are often very limited support options for culturally diverse community members who are wanting to engage with a disability service provider who speaks their same community language or are from the same cultural background. This is even more limited in regional and rural areas where there are already limited options for disability support services. Stronger investment in bicultural workers would help develop organisational capacity to engage with people of refugee backgrounds who are looking for and accessing disability support services.

Bi-Cultural Workers are an important resource for any service, using cultural knowledge, language skills, lived experience and community connections to work with people who share a lived experience[17]. Investment in bicultural workers is especially important to ensure health information, prevention, and health promotion activities are as effective as possible. Both State-based and National Disability services should be employing bicultural workers according to best practice standards as they are instrumental in facilitating effective community engagement. In addition to this, bicultural workers understand cultural norms regarding disability and facilitate cultural safety in connecting refugee background communities with the disability service system.

[17] https://www.cohealth.org.au/get-involved/bi-cultural-work-program/

## VI. Issues concerning NDIS provision

### Applying for and navigating NDIS

As previously highlighted, acceptance into NDIS is based on diagnosis, and new refugee arrivals with a disability often do not have a formal diagnosis prior to entry into Australia. Once a formal diagnosis is obtained this can then be used as evidence for a NDIS application, provided they meet the other eligibility requirement as a permanent resident of Australia. As of 30 September 2022, "756 (11.3%) of the new active participants this quarter are Culturally and Linguistically Diverse (CALD) [4], taking the total number of CALD participants in VIC to 17,386 (11.7%)"[18]

Local Area Coordinators (LACs) are often the first point of contact for community members accessing the NDIS. The role of LACs is to help individuals and families learn about supports that are available in the local community and help create, implement, and change a NDIS support plan.[19] Feedback from consultations with the sector highlight that LACs are not adequately resourced to work with the specific needs of people with a disability and their families from culturally and linguistically diverse backgrounds.

Often newly arrived refugees have limited/no prior knowledge of the Australian health system and require additional support and consistent use of interpreters to effectively understand information about the NDIS, services and supports. Whilst settlement service workers have outlined that they can help submit a NDIS application on behalf of the client this can take much longer than referring a client to a NDIS provider if they were to provide appropriate language support and time to explain and complete the application and plan with them. This is also not currently funded as part of the Humanitarian Settlement Program and requires additional capacity for services to assist with these additional needs.

There are reports from consultations that the Early Childhood Intervention Services - Continuity of Support (ECIS-CoS) Program can be very difficult to navigate. Refugee Health Nurses who refer clients to ECIS-CoS and LACs have reported a lack of communication and feedback on the outcome of submitted applications which interrupts continuity of care.

> *"Another family had been struggling to access speech therapy for their son for almost 9 months of trying to navigate the NDIS system independently. The father had contacted a speech therapy service via phone and thought his referral for his son was complete. He reported to the FRP case manager that he was very concerned as the service had not yet contacted his family to commence services. The case manager followed up with the service who emailed the father a referral form and were waiting to receive the completed referral form from the family. Due to language barriers and the service not engaging with an interpreter during the initial phone conversation with the father, this was not adequately communicated to the family, and they were unaware that they had been emailed the referral form. The FRP case manager advocated that the service completes the referral with the family over the phone as they were unable to complete the email referral form due to language and computer literacy barriers. As a result, the service completed the referral over the phone (it took approx. 10 minutes) and the child commenced speech therapy services 3 weeks later." (Refugee Health Program, VRHN consultation 2022)*

[18] NDIS Quarterly Reports: https://www.ndis.gov.au/about-us/publications/quarterly-reports
[19] https://www.ndis.gov.au/understanding/what-ndis/whos-delivering-ndis/lac-partners-community

## Lack of culturally and linguistically diverse support

Feedback from this survey suggest that without formalised and appropriate supports for CALD community members available, NDIS rely on the support from family, friends or community services to provide information about the Scheme and complete Access Request forms.

> *"A 6-year-old child with Global Developmental Delay had a Self-Managed NDIS Plan that was unused for over 12 months. Her mother was experiencing significant barriers in navigating services, didn't know how to access support and did not know how to Self-Manage the plan (i.e., pay invoices and etc). The mother had not received any support from her LAC to navigate supports or training on how to self-manage the plan. This resulted in the mother feeling completely overwhelmed and concerned about her daughter not having access to the disability support she required. This impacted the child's ability to engage in school and access to early intervention. The FRP case manager supported the mother to request a NDIS Plan Review and based on her preference, change how the NDIS plan was managed. The original plan was set to Self-Manage and following the review, this was changed to Plan Managed with funding included for a Support Coordinator to work alongside the family in identifying and accessing appropriate supports." (Family Recovery Program, VRHN consultation 2022)*

Support Coordination can be an additional component of a NDIS plan as part of the Capacity Building budget which provides a "fixed amount for a support coordinator to help you use your plan"[20]. This additional support can be critical to support many culturally and linguistically diverse community members who face language barriers and have a limited understanding of supports available under NDIS. Support Coordinators can help with accessing these supports and advocate for funding during Plan Review meetings. There is also additional support in paying invoices/ disability supports Unfortunately, not all NDIS participants receive funding to access support coordination so are reliant on LACs and other services to help navigate and self-advocate through this system.

Based on the way the NDIS is structured, the outcome of Planning meetings or Plan Review meetings often reflect the ability of the individual to self-advocate for the continuation and increased provision of resources. Limitations in health and service literacy mean there can be a deficit in CALD communities' knowledge of service navigation and their rights as a NDIS consumer. This, added to possible reluctance to criticise or complain, means that people are less able to self-advocate than others with better understanding of the system. Without appropriate supports, culturally and linguistically diverse community members can experience challenges communicating their needs and consequently receive less funding.

[20] 'Support coordination' https://www.ndis.gov.au/participants/using-your-plan/who-can-help-start-your-plan/support-coordination

## Use of interpreters in NDIS Services

NDIS providers have free and unlimited access to TIS, including for support coordination. Once someone has a plan, all services included in the plan, as long as they are registered with the NDIS themselves, can use free interpreting through TIS[21][22]. Reports from consultations with the sector revealed that disability service providers do not consistently engage with interpreters and referral forms are often only available in English. These complex referral pathways without support available from the service to assist linguistically diverse community members create barriers in completing the referral and ongoing engagement with services.

## NDIS eligibility criteria create exclusions for asylum seekers in the community

A key issue that has been identified is lack of access to NDIS services for people of refugee backgrounds who do not meet Commonwealth determined eligibility requirements of permanent residency in Australia. In particular, people who have been found to be refugees and granted protection visas that are temporary (subclass 785 Temporary Protection Visas & 790 Safe Haven Enterprise Visas) do not meet the NDIS residency criteria, so are unable to access services regardless of the impact of their disability on everyday life.

For people seeking asylum living with a disability, the exclusion from formal disability supports that other Australian residents can access, has a negative impact on physical and mental health and on their disability. Without formal pathways to interventions such as NDIS, people seeking asylum in our community are structurally disenfranchised and excluded from basic support services based on their visa status.

People who hold protection visas that are temporary have access to most universal services including Medicare and Centrelink payments and to State funded health services. Lack of access to the NDIS for this group is a significant gap which is greatly impacting people with disabilities, their families and carers. Furthermore, as community mental health services have transitioned to NDIS, there is inconsistencies in access for children and people with serious mental illnesses who hold protection visas that are temporary. This is illustrated in the two case studies below.

*"I'm in contact with a family who have a child with autism spectrum disorder. They are not eligible for NDIS because of their visa. Father has own mental and physical health issues and has no capacity to work. Mother must look after her small child who is still at home and going to Kinder just 2 days a week. Due to the financial hardship, they are not able to see private health services for their child. All these issues plus the uncertainty they've been experiencing due to their visa impacting the mental wellbeing of the family which might result in more severe issues for them." (Settlement Service Worker, VRHN Survey Respondent, 08/22)*

[21] Accessing Interpreters and the NDIS Fact Sheet https://www.ceh.org.au/resource-hub/accessing-interpreters-and-the-ndis-fact-sheet/

[22] Language interpreting services https://www.ndis.gov.au/understanding/language-interpreting-services

*"A family of six, mother, father and 4 boys-2 of whom have a cognitive and intellectual disabilities, both have also been diagnosed with an ongoing muscle wasting disease which will deteriorate over time. The family survive on a 6-month bridging visas with no disability support or respite, with the mother having comorbidities of physical and mental health issues. The family arrived from, Iraq in 2013 via boat… and one parent must supervise them at all times and they are not eligible for NDIS funding. Eventually the school decided they were unable to support one of the boys and due to their Bridging Visa requirements, their sons were not able to engage with TAFE study/ be supported by a special school. This has resulted in both now adult young men being unable to work due to their education level. Both mum and dad worry that when they pass away their sons will not have the capacity to look after themselves and may become lost in the system (even if the family get a permanent visa). There is also a compounding issue that both boys have limited communication and only speak Arabic, meaning if they could gain support funding language may be a massive barrier…during the Covid-19 pandemic the family's situation worsened, exacerbated by the high needs of the now adult children. The father was able to work up until 2020 at which times he lost his job during the pandemic and has been unable to find work due the manufacturing industries downturn… Due to no external disability support the mother and father must spend much of their time with their 2 children who are living with the cognitive impairment to ensure they are safe, meaning this family has a further barrier to work and engaging in the community... Previously the family were able to be linked in with the Developmental Service at the Royal Children's Hospital however are now unable to access disability care with the only support being their regular GP. They were provided sedative medications however no external organisation has engaged the family to assist with their disability needs… With no access to NDIS, support workers or disability specific services this family worries about the life their now adult children will face going forward on top of their current Bridging Visa E and asylum-seeking status. As a project worker who has a background in disability it has been extremely tough to see the ongoing issue for the family and the restrictions that they face due to their visa status... Due to their muscle wasting disease without physio and OT support, things will only get more difficult for the family, and this doesn't take into account the immense emotional stress the family and the two now young men will face in the coming years." (Health Service Provider, VRHN Survey respondent, 22/08/22)*

These findings have highlighted the significant challenges and barriers that people from refugee backgrounds who are living with a disability face when trying to access support for their health and disability needs. The Victorian Refugee Health Network have listed several recommendations to help improve the systems, service delivery models and support that are available for culturally and linguistically diverse communities, in particular refugee communities.

# Recommendations

## Systemic Improvements

i. **Recommendation:** To ensure people who are on temporary protection visas (Safe Haven Enterprise Visas (SHEV), Temporary Protection Visas (TPV), Bridging visas (BVE)) are eligible and have full access to NDIS.

ii. **Recommendation:** For better health care outcomes for refugees in the Humanitarian Settlement Program, quality control measures related to Health outcomes should be considered.

iii. **Recommendation:** Extend funding for disability support aids and equipment through HSP until other equipment is acquired.

iv. **Recommendation**: To ensure Interpreter Services are used by all Allied Health Professionals and Disability Services.

v. **Recommendation:** Improvements with Medicare to mitigate gaps in eligibility.

vi. **Recommendation:** Improvements in data to better identify refugee cohort & their disability support needs.

vii. **Recommendation**: Fast-tracking access for OT assessment and other specialised assessments based on specific delays in diagnosis and obtaining relevant health documents for this cohort.

## Workforce Development

i. **Recommendation**: That Bi-Cultural workers are employed and adequately resourced in disability services.

ii. **Recommendation**: Disability providers are trained in culturally safe and appropriate practice standards.

iii. **Recommendation:** Specialised training is provided to better identify differences between language barriers, trauma & developmental delays.

iv. **Recommendation:** To ensure there is culturally and linguistically appropriate support for Carers available.

## Appropriate CALD Support Options

i. **Recommendation:** Bi-cultural casework support for broader service navigation of disability support services.

ii. **Recommendation**: Support with disability service access for people seeking asylum without Medicare.

iii. **Recommendation**: Building health literacy around disability & supports available.

iv. **Recommendation:** Culturally and linguistically appropriate support for NDIS application process, Planning, Review meetings & advocacy.

v. **Recommendation**: Transport access options for those who are not on NDIS.

vi. **Recommendation**: Financial assistance with medicine, care & assessment reports.