Key Issues Impacting People from a Culturally and Linguistically Diverse Background with Disability, in Queensland

A SUBMISSION TO THE ROYAL COMMISSION INTO VIOLENCE, NEGLECT, ABUSE AND EXPLOITATION OF PEOPLE WITH DISABILITY

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IV Issues

Attachments:

1. **Letter to the NDA re choice and control around interpreters**
2. **NCCP Report**
3. **Letter to the Minister re NCCP**
4. **Submission to the Joint Standing Committee on the NDIS re Planning**

I Introduction

Queensland is a highly culturally diverse community; this is confirmed in the Australian Bureau of Statistics (ABS) data from 2016, which shows that 12.1% of the Queensland population were born in Non-English speaking countries. In addition to working with this cohort, AMPARO Advocacy also works with a large number of people who were born in Australia, to parents who have limited English proficiency due to being born overseas.

The ABS data indicates that 15% of Queensland participants should come from a culturally and linguistically diverse (CALD) background, however recent data from the NDIS shows that only 5.4% of current NDIS participants in Queensland are from a CALD background.

AMPARO Advocacy has been advocating for people from a CALD with disability since 2006, and has continued to identifiy, document and advocate around the key issues that impact the people with whom we work. Since the introduction of the NDIS, AMPARO has also been funded through various short-term projects to support people from a CALD background with disability to learn about and access the NDIS, and to undertake plan and service reviews. This report provides a summary of the key issues which are limiting access of this cohort to the NDIS and other appropriate disability supports and services. A range of more detailed papers have been written on specific issues and these are attached to this report. While some stories have been included to illustrate the issues, many more have been left out due the need to limit the report to a manageable length. AMPARO Advocacy would be happy to provide further illustrations, if required.

II AMPARO Advocacy

AMPARO Advocacy is a not-for-profit organisation which provides individual advocacy with and on behalf of vulnerable people from a culturally and linguistically diverse background with disability. We have State funding from the Department of Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships for one full time advocacy position. Face to face advocacy is undertaken in the Brisbane and Moreton Bay regions, but we are contracted to deliver state wide advocacy. Since January 2022, funding for an additional 0.9 of a position for specialist face to face advocacy in Brisbane and Moreton Bay has been sourced through a formal agreement with another advocacy agency. All current State funding agreements for disability advocacy end in June 2023.

In addition to our advocacy work, AMPARO has been funded for a number of short-term projects over the years, which have allowed us to share knowledge within CALD communities around disability rights and supports and the introduction of the NDIS, and to support people from CALD communities to gather evidence and apply to the NDIS and to resolve issues once their NDIS plans are in place. AMPARO currently has Information, Linkages and Capacity Building (ILC) funding to undertake individual capacity building work with people from a CALD background with disability in Cairns, Townsville, Toowoomba, Brisbane and Logan.

III People from a CALD Background with Disability

In AMPARO's earlier submission to the DRC on '*The experiences of culturally and linguistically diverse people with disability'* the diveristiy of understanding of and responses to disability within and between cultural groups and overtime was clearly outlined. The following is an extract from this report:

Our views are shaped by factors such as our religious beliefs, education, life experience, exposure to media, and the views of others in our family. Individuals, families, and cultures may have different ways of thinking about how to define disability, what causes disability, and how we should respond. Cultural values influence our beliefs about the roles of people with disability and those who care for them, within our society. In the Australian context, our understandings of disability have undergone radical change over the past century, with our policies and systems of support moving from reflecting predominantly a charity model, through the medical model, to the emergence of the social model; although this remains contested ground.

It is important, therefore, to avoid stereotypes or to make assumptions about how individuals or families from a particular cultural background may view disability. Rather, it is important to be sensitive to some of the common ways of understanding disability which may exist, and to then listen carefully to the experiences of individuals. Some of the cultural perspectives of disability which people from CALD backgrounds with disability have shared with AMPARO include:

- Viewing disability as a product of 'sin' or punishment from God
- Disability being attributed to fate or karma of the person or their parents
- Disability being seen as the 'fault' of the parent, usually the mother, for having done something wrong during past life or pregnancy the impairment
- Disability being seen as a 'gift' for the parents to be honoured in caring for the person with disability
- The person with disability being seen as possessed by an evil spirit and that a healer can 'cure' the person
- That once in Australia doctors will be able to 'fix' the person.

IV Issues

1. Residency Status

The National Disabilty Insurance Scheme (NDIS) has brought significant positive change to the lives of many people in Australia who either have Australian citizenship or who are Australian Residents. Sadly for others who do not meet residency requirements such as New Zealanders, Asylum Seekers and those on Safe Haven Visas there are very little disability supports available, despite many of their families having paid taxes and the Medicare contribution to the NDIS for many years. Such support is limited to a maximum of five hours of support per week through the Queensland Community Support Scheme (QCSS) which is far from adequate for many with high support needs.

A 39 year old man with an Acquired Brain Injury resulting from a stroke is impacted by significant hemiparesis and is no longer able to speak. As he is living in Australia on a Temporary Protection Visa he is ineligible for NDIS supports and so has been living a nursing home, away from community members who speak his language. With no funding to provide supports for community access and with no one in the nursing home who speaks his language, he is highly socially isolated and unable to pursue his interests in the community.

2. Lack of Access to Appropriate Interpreting and Translation Services

a. Learning English

Many refugees benefit significantly from the free English language education that they receive at TAFE through the Adult Migrant English Program (AMEP). Although tuition can be provided to some in their homes if they are unable to attend TAFE, many of the people we work with have very limited English proficiency as they either do not have the capacity to learn English or have not been able to take advantage of this free training due to the need to care full time for family members with disability. As a result, they do not have sufficient English language proficiency to be able to liaise with the NDIA or research and engage support services without interpreting services.

b. Knowledge of access to free interpreting services

Both State and Federal language service policies require the provision of funded interpreting services for participants with limited English proficiency. But as this is not widely promoted by the NDIA and other government departments, many government employees, NDIS employees and service providers remain unware of this. Frequently we find that services do not know that free interpreting services are available or, if they do, they are not aware of how to access them. Recently a Support Coordinator refused a referral on the grounds that they would not be able to communicate with the participant, even though others in her organisation were well aware of the availability of free interpreting services. Other services do not recognise the importance of engaging professional interpreters and choose to rely inappropriately on family members or bilingual staff.

c. Use of phone and face to face interpreting services

Government policies highlight that telephone interpreters should only be used for brief conversations and stress the need for face to face interpreting for more lengthy or complex discussions. Even the most competent and committed interpreters have informed us of the difficulty of interpreting over the phone when visual cues and body language are so important in determining what has been understood and what needs to be clarified further. However, both the NDIA and their partners in the community, Carers Queensland, continue to use phone interpreters for lengthly NDIS planning and plan review conversations, often through a three way phone conversation with the participant, interpreter and planner all in different locations. This makes active participation by the participant in the planning process impossible.

Carers Qld arranged for a face to face planning meeting for a young man with autism, but arranged for the interpreter to be present by phone. 10 minutes into the planning meeting the interpreter stated that they could no longer continue as they had not been made aware of the length of the meeting and their phone was out of power. When a second interpreter was contacted by phone it was obvious that they were driving at the time. The resulting interaction was limited to a stilted short question and answer session, with none of the required ‘conversation’ taking place.

d. Choice and control around interpreting

AMPARO has long been advocating for people to have choice and control around who they engage as an interpreter[1], but this rarely occurs when the NDIS appointed interpreting service Translating and Interpreting Service (TIS) is engaged. Often people have extended family members or well-

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[1] See Attachment 1: Letter to NDIA re choice and control around interpreters

known members of their community working as interpreters – and they may not want their personal information shared with that person. The engagement of one or two preferred interpreters also means that fewer interpreters from their community are privy to all of their personal information. While confidentiality is an important requisite for interpreting, people have had personal information shared widely in their communities through interpreters and most will have interpreters that they would prefer not to use due to personal and community connections or poor past experiences. Also, where complex matters are being discussed it is helpful if the same interpreter is engaged for multiple meetings so that the information does not have to clarified and shared with many different people within the community. Despite our advocacy, TIS continue make it very difficult to request a specific interpreter, with a new application and strict criteria having to be met each time a specific interpreter is required. This policy clearly conflicts with the NDIS legislation around participant choice and control (NDIS Act 2013, Part 2 - Objects & Principles, 3 Objects of the Act, 1e).

e. Non NDIS registered allied health providers

While NDIS registered providers have access to free interpreting services, services which are not registered but are still engaged through NDIS funding, do not have access to free interpreting services. This is becoming an increasingly significant problem for people from a CALD background as more and more allied health practioners are opting not to register due to high financial and time costs involved in NDIS registration. Given the shortage of allied health practioners and the huge demand there are long wait times for support even for those who are not registered. Without interpreters people are not able to gain appropriate benefit from allied health services and parents are often unable to provide vital information to the therapist, or support their children appropriately, when they are unable to communicate with the therapists.

f. Written materials in own language

The NDIS funds the translation of NDIS Plans into people's first language if required, and requested. Although AMPARO has requested for translated plans to be provided, despite having attended many planning meetings we have yet to have a planner offer this service to participants, even when an interpreter has been required at the planning meeting. Many people will therefore have plans that they are unable to understand. Where plans have been translated, we have been informed that some of the translations have been very poor, with the translator having been clearly unaware of specific NDIS terminology and context.

A number of people have been issued with important documents in English, for which the NDIS has refused to cover the cost of translation, such as allied health reports with recommendations for family assistance with exercises and treatment. Concerningly this also includes Positive Behaviour Support Plans.

A teenager with an acquired brain injury from a brain tumour has a emotional regulation difficulties and the need for a Positive Behaviour Support Plan. This plan provides a detailed account of his preferred support practices and guidelines on mitigating escalations in his behaviours. It is used in the training of his support and allied health workers and family members. The NDIS refused funding to have this essential document translated so that his mother could have a written copy of the document to refer to when needed.

Further interpreting and translation issues which are specific to the NDIS are outlined in Section 7d.

3. Varied Cultural Expectations, and Knowledge of Rights, Opportunities & Services

a. Home country experiences

Many people from a CALD background, and particularly those from a refugee background, come from countries where there are low levels of education, little understanding of the causes of disability and few if any government supports for people with disability. Refugees in particular may have had highly disrupted lives, may have spent much of the lives in refugee camps and may be illiterate in their own language. This lack of education can lead to very limited knowledge around the causes of disability and in turn to significant stigma. Stigma can then result in increased social isolation and decreased opportunities for those with disability.

b. Cultural variations in expectations of and for those with disability

With little or no experience in disability supports in their home country many arrive in Australia with low expectations for themselves or family members with disability and a cultural expectation that it is the role of family members to provide all supports for loved ones.

When people, who come from countries where there is an expectation of the family providing all supports, have children with disability in Australia this expectation can continue into the next generation, particularly when the parents do not speak English, do not have access to the internet and or are socially isolated.

Through our advocacy and ILC programs, AMPARO works with many refugee families to provide information about the causes of disability, what a good life can look like with disability and the range of formal support services available, but much more needs to be done in this area.

A young mother with a daughter with Downs syndrome are from a community where there is considerable stigma around disability and an expectation that people with disability should remain in the home. Once the mother was introduced to other families with children with disability and understood that people with Downs syndrome can live an active and full life in the community, and that the NDIS will provide funding to enable her daughter to pursue her life goals, she gradually developed the confidence to support her daughter to go out and about and now advocates on behalf of others in her community around disability supports. Without funding for programs to allow people from a CALD background to learn about disability rights and supports and for them to meet with others who are accessing such supports, people from a CALD background with disability will continue to be isolated and miss out on essential support services.

c. Lack of appropriate skills and knowledge around disabilty rights and supports amongst settlement services

The majority of the people with whom AMPARO Advocacy works are from a refugee background, and many of these would have been impacted by their disability prior to arrival in Australia. Settlement workers often have limited knowledge of disability rights and supports and with large case loads have been seen to focus only on mainstream settlement needs. This has led to specific disability support needs often not being addressed on arrival and to people being unaware of what a good life can look like for someone with disability given the range of disability supports available in Australia. Others are referred for advocacy for NDIS access and other disability supports by settlement workers who do not know how to proceed. AMPARO Advocacy has provided training and written materials to settlement agencies over the years but this continues to remain an issue.

When advocating for a school leaver with disability from a refugee background, it became evident when talking with the family that there were an additional three siblings with disability, only one of whom had received assistance to access disability supports from their settlement worker. When asked, the settlement worker informed the advocate that it was culturally inappropriate to suggest disability supports if they or the family do not request this. As a result a brother had attended English classes at TAFE for 2 years without support or an ability to learn English (despite TAFE having contacted the settlement service for assistance with disability supports for him), a sister missed out on NDIS funded 1:1 supports and therapies and a young boy has missed out on much need allied health therapies.

4. Social Isolation

Many of the people who we advocate for have very limited social connections, and no extended family in Australia. Some are totally on their own, and highly isolated due to mobility and or pscychosocial issues. This social isolation combined with the frequent stigma around disability in CALD communities can result in few if any informal supports and a lack of knowledge around disability issues, rights, supports and what a good life can look like for someone with disability.

For those without access to the NDIS, there are very few programs which focus on assisting people to build informal networks so people with disability, or with family members with disability, can remain highly socially isolated.

AMPARO Advocacy is currently providing essential advocacy for two men and four women from a CALD background with disability who are all totally on their own in Australia with no informal or family supports. One of these women had a stroke following a lifesaving operation, and as a result is impacted by hemiparesis. When we met her she was living in a very expensive inappropriate granny flat with internal stairs, had been declined access to the NDIS due to the GP providing insufficient information in her NDIS application, had multiple unaddressed medical conditions and was receiving no formal supports. Her brother had to fly in from overseas on a tourist visa to support her when she needed to move house, at which time her brother would purchase long life food and supplies for her in bulk. Through advocacy she now has NDIS funded support and allied health services, a great one bed apartment through the Department of Housing, a competent and caring GP, and enjoys volunteering two days a week in a charity shop.

5. Access to Internet

Staff from the NDIA and their Partners in the Community (in Brisbane Carers QLD) often assume that people with disability and their families are able to research possible services and make informed decisions as to the suitability of such services for themselves or their family member. However, many families from a refugee background do not have a computer or access to the internet, and those that do may not have sufficient English or knowledge of appropriate supports to be able to research therapists and services.

While the NDIA and their partners may provide the participant with a list of possible services, they are not able to make recommendations around services. Participants without a Support Coordinator are therefore at risk of being linked to services with poor reputations, no experience in working through interpreters, or an inability to provide the supports that the participant would like.

AMPARO Advocacy attended an Implementation Meeting with a participant, their family and Carers QLD. The family were unable to research suitable services themselves for their teenage daughter with Level 3 autism, due to very limited English and no access to the internet. Carers QLD provided them with a list of four names of potential service providers and asked them to choose between them. With no information provided about the strengths or weaknesses of the providers or how their services differed their only option was to close their eyes and point randomly at the list. This does not provide people with disability the informed 'choice and control' that underpins the whole ethos of the NDIS.

Given the number of new providers operating in the CALD space with very little understanding of what a good life can look like for a person with disability or knowledge of best practice in delivering services for people with disability, this approach to service provider selection is totally inappropriate. Often such services are listed for those from a CALD background, as the company is known to employ workers from the same cultural or language background, but this does not guarantee that they have sufficient knowledge and experience to provide good supports. Where participants receive poor services from providers from within their own community it can be very difficult to them to transfer to a new service.

Those without access to the internet are further impacted once supports are established. It is assumed that most have access to the NDIS portal through MyGov, which provides access to a participant's NDIS Plan and levels of expenditure against budget. Without access to MyGov participants can wait many weeks for a printed plan to be mailed to them and are unable to regularly check expenditure against budget if, as is the case for many, they do not have assistance from a Support Coordinator.

The capacity of people with disability and their families to research and appoint good and appropriate services should be assessed as part of the planning process. Where participants have limited English proficiency and or are unable to conduct the research required on the internet it is essential that they are funded for Support Coordination and are connected with support coordination services who are able to explain to people from a CALD background through an interpreter the range of services available and how services may vary.

6. Access to 'Reasonable and Necessary' NDIS Funding

a. Residency requirements

AMPARO Advocacy receives many referrals from people with disability who do not have permanent residency in Australia, including those who came to Australia via New Zealand, asylum seekers and those on Save Haven Visas. While they and their families may have lived most of their lives in Australia, paid taxes and the Medicare contribution to the NDIS, if they are not permanent residents they are not able to secure disability supports through the NDIS. Many have received excellent disability supports throughout their school years in Australia but once they leave school at 17 or 18 all disability related supports cease.

Those who are not eligible for the NDIS are able to receive a maximum of five hours of support a week for in-home supports and community access through the Queensland Community Service Scheme (QCSS), if they are able to make a co-contribution. For those with low incomes and substantial functional impairment, including those who require support for training, employment, to attend other post school activities or to connect with the wider community, this level of funding is far from adequate.

AMPARO Advocacy recently received a referral from a health professional who was very concerned about a young man from a refugee background who came to Australia via New Zealand. He has a significant disability and has spent the past seven years, since leaving school, at home with his parents with no formal supports whatsoever. While his peers have gained access to the NDIS and have gone on to receive training through School Leaver Employment Services, are enjoying social events with supports and are able to go shopping and access services with age appropriate supports he has spent most of the past seven years isolated from the community in his home. With long wait times for the five hours of individualised QCSS support and no access to funding for intensive therapies, school leaver employment training or day services should he wish, his long term outlook is very bleak. Sadly there are many in the same situation.

b. Specialist NDIS knowledge for NDIS Access

Through AMPARO's advocacy, capacity building, NDIS access and community connector work, we have supported many people with significant disability to access the NDIS, who had previously been deemed ineligible due to poorly completed Access Request Forms, specialist reports that did not address permanence or OT functional assessments written from a strength based rather than deficit focused perspective. Where potential participants can be supported by 'NDIS specialists' who can work with GPs, specialists and OTs to ensure that reports provide clear diagnoses and confirm both the condition and functional impairment are permanent and substantial (and exclude any mention of facts that may get them turned down) then people have a far greater chance of accessing the NDIS. Where people have limited English, no understanding of the access criteria outlined in the NDIS Act, no internet access, and disinterested health services access it is far more difficult. A number of people we have supported with access had given up after being turned down, often multiple times.

One year into the NDIS, a community representative met with AMPARO's advocates to discuss five unsuccessful NDIS applications for people from his community. Each applicant had sought assistance from their GP to confirm their condition/s and functional impairments on their NDIS application forms. Sadly, the GPs were not aware of the need to phrase their conditions in terms of 'permanent disability' rather than in 'medical terms', or of the need to confirm their permanence by listing treatments and stating that all possible treatments had been exhausted, and were unable to document clearly their substantial functional impairments. As a result all five had been turned down by the NDIS, despite having significant permanent disabilities and substantial functional impairments.

c. Access to NDIS acceptable specialist diagnosis of permanent disability.

In the early years of the NDIS rollout we were informed that a specialist diagnoses was not required for NDIS access and that confirmation by a GP of substantial functional impairment due to a relevant impairment would be sufficient. Despite this, we found that for the vast majority a clear diagnoses from a specialist clinician with confirmation of permanence of both the condition and resulting substantial functional impairment was critical for access. Now, a specialist statement of permanence including that all treatments have been exhausted is not even sufficient. The NDIA are insisting on a list of medications and other inteventions including psychological therapies utilised, plus confirmation of exhaustion of all possible pain management options from a pain clinic , if relevant, are required before permanence is accepted and access can be met.

Where GPs and or potential participants have not understood this, people have not been referred for essential assessments. Many who have had to rely on poorly written Access Request Forms from GPs have not met access. Those with referrals to specialists in the public system can wait months or years for an appointment, and then the specialist may see their role as offering assessment and treatment options to their patients and refuse to write diagnostic reports for NDIS Access. And then those specialists who do agree to write reports may not be aware of each and every criteria that must be addressed in their report. The inclusion of a list of all interventions trialled, confirmation that all possible medical and treatment options have exhausted and yet the substantial functional impairment remains and, for those with pain, that all pain management options have been exhausted with support from a pain clinic, are not matters that are usually addressed in specialist reports to GPs. Whilst, at the request of our advocates, some specialists are willing to update reports to address all necessary NDIS criteira others are not, and for those without an advocate who knows the precise wording required it is extremely difficult to get the correctly worded specialist report.

A Community Connector supported a young man with functional impairment resulting from ankylosing spondylitis to meet with his GP for a referral to his Rheumatologist so that they could get confirmation of his condition and its permanence for NDIS Access. After several months the Connector supported the man to attend the specialist appointment to assist him to outline the NDIS requirements. The Rheumatologist refused to converse with the Connector and informed her patient that it was her job to advise him of treatment options – not to write reports for the NDIS. Despite the clinic informing AMPARO that many people who attend their clinic with ankylosing spondylitis are supported through the NDIS, without confirmation of the condition, the treatment strategies undertaken and the permanent nature of the condition this young man has not been able to get NDIS access and is unable to access much needed regular therapies. Should he have been able to get funding for intensive therapies while still young, the speed of his likely decline may well have been reduced. As it is, without necessary intensive therapies, his functional capacity is likely to decline at a faster rate, leading him to require higher levels of NDIS funded support services at an earlier age.

d. No access to free functional assessments

The lack of free functional assessments is critical barrier to NDIS Access for many with disability who are on a low income, including many refugees.

Many from a CALD background do not have funds for private functional assessments and have to rely on GPs to complete Access Request Forms (ARF) for them. The NDIA have an expectation that GPs have sufficient skills, time and knowledge of their patient's functional capacity to be able to complete an accurate and detailed Access Request Form for them. Sadly this is rarely the case for a number of reasons including no GP budget line for such work, short GP appointment times, a lack of knowledge of NDIS criteria, a view that it should not be a GP's role and or that as part of a large GP practice they may not know their patients well.   AMPARO Advocacy has attended many GP appointments with potential participants to provide advice on the information required and provided feedback on poorly completed forms. While some GPs have been pleased with this support, others have not and others have declined to write ARFs for their patients. Such patients have required support to engage with a new GP, but can then face the difficulty that the new GP may feel that they do not know the person well enough to complete an ARF for them.

Through AMPARO's work with the National Community Connector Program we had identified more than 130 people from a CALD background who required help to access disability supports[2]. By the end of the program 32 whom we had supported to gather diagnostic evidence from specialists had yet to apply to the NDIS due to the lack of a functional assessment report. Fortunately prior to ceasing the program we were able to refer these people to the Assessment and Referral Team (ART) which had been recently funded by the QLD State Government. With their ability to draft detailed functional assessments for people the majority of these 32 people gained access to the NDIS over the next few months.

e. Need for OTs to focus on permanence of substantially reduced capacity in one or more of the NDIS domains

While Occupational Therapists are trained to write strength-based reports, if NDIS Access is to be met it is important that functional assessment reports provide clear evidence of substantially reduced capacity. Any therapy recommendations need a proviso that while they may assist in maintaining function, substantially reduced capacity is likely to remain. Without this there is a risk that the permanent impairments may be seen not to be so.

Potential participants who have to rely on generic OT functional assessment reports, or on reports by OTs not experienced in writing reports specifically for the NDIS, can find that given the strengths mentioned in some areas that they are not deemed to have 'substantial functional impairment'. Also, there is a chance that with the suggested therapies that such impairments may no longer be seen as permanent or substantial. Likewise, those with OTs who are not aware of the benefits of addressing each of the six NDIS domains, nor of the need to emphasise the permanence of both the condition and the permanence of the substantial functional impact, may get declined for access not as a result of a lack of permanent and substantial functional impairment but due to the OT's lack of knowledge of the NDIS criteria and their report writing skills.

f. Physical disability due to complex and chronic physical health conditions

Chronic medical conditions such as fibromylgia and oesteoarthris which can have a substantial functional impact on mobility and other domains are not deemed to be permanet conditions by the NDIS, even when GPs and specialists have confirmed otherwise and where there is clear documented evidence of permanent and substantial functional impairment resulting from these conditions. This has led to a large number of highly vulnerable people who are unable to care for themselves or leave their homes without assistance being unable to access vital support services.

g. Dual diagnoses of psychosocial and physical disability

Many people from a refugee background for whom we advocate have been impacted by war, torture and trauma and have both a psychosocial disability or cognitive impairment and a physical disability, the latter often resulting from chronic health conditions for which they have been unable

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[2] See Attachments 2 & 3: NCCP Report & Letter to the Minister

to receive appropriate treatment. Such people are often referred for advocacy as the NDIS make it very difficult to gain NDIS access for more than one condition. Also, funding is often extremely limited if the NDIA determine that their substantial functional impairment is not attributable to the condition for which they have access. Furthermore, if people are approved for both conditions, they are required to determine which is the primary and which is the secondary disability, with higher levels of funding being allocated to the primary disability. In reality, it may be difficult to determine which functional impairment is attributable to which condition, particularly when both conditions may have an equal impact on support needs.

AMPARO is currently advocating for a man from a refugee background who has both psychosocial and physical disability, but only had NDIS access for physical. He was denied access for psychosocial access due to this condition not resulting in 'substantial functional impairment'. When an OT assessment confirmed that his psychosocial disability resulted in substantial functional impairment, the NDIS responded to the Review by declining access again, this time due to a lack of permanence, despite this not being mentioned the first time around, and his psychiatrist confirming that both his psychiatric condition was permanent (all treatments had been exhausted), that the resulting substantial functional impairment was permanent and that any future treatment may assist in preventing further decline but not improve function. As a result of the OT finding that the majority of his functional impairment is due to a psychosocial condition, NDIS funding for supports relating to his physical disability, for which he did have access, are extremely limited. It was only once the psychiatrist had submitted a third letter at the request of the advocate, citing the specific psychological interventions that had been undertaken over the years, that access criteria was finally deemed to have been met and appropriate funding secured.

AMPARO Advocacy is also advocating for a woman with both psychosocial and physical disability, but she only has access for psychosocial, despite being unable leave her home, or walk to her front gate without supports due to severe osteoarthritis and fibromyalgia. As both conditions are not deemed to be permanent by the NDIA she has been declined access for physical disability. This is despite her GP confirming that her physical disability is permanent due to chronic medical conditions which prevent her from undergoing any surgery. Her GP has also confirmed to the NDIA several times that the independence that a scooter would bring is critical for preventing further deterioration in her psychosocial disability and would likely be lifesaving. But, as funding for scooters can only be provided for those with access for a physical disability, the NDIS has refused to provide the necessary $5,000 for the much needed scooter. Instead they have increased her core funding by nearly $40,000, thus increasing her dependence on support workers. She will be supported to gather further evidence of permanent physical disability from specialists.

h. Issues with NDIS Planning process for people from CALD background once Access is met

A detailed account of the issues around accessing appropriate funding through the NDIS planning process once NDIS Access has been met can be found in the attached Submission to the Joint Standing Committee on the NDIS re Planning[3]. These include lack of pre planning information and supports in the person's preferred language, the NDIS financial decision maker not being present at the planning meeting, the location of planning meetings and poor preparation of planners.

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[3] See Attachment 4: Submission to the Joint Standing Committee on the NDIS re Planning

7. Access to Approprate NDIS Funded Supports

a. Local Area Coordinator (LAC) skills and capacity

Much of the work of the NDIS, including the majority of planning coversations, is undertaken by Local Area Coordinators (LACs) employed by the NDIA's partners in the community (PiTC) which in Brisbane is Carers QLD.

There is a significant and continual turn over of LACs which has resulted in valuable lessons being lost. Amongst other continuing issues are complex planning meetings being undertaken by phone even when this is the person's first plan, the use of phone interpreters for planning and review meetings and the lack of Support Coordination funding for people with limted English proficiency.

> Carers Qld recently offered a family from a CALD background an NDIS planning meeting over the phone, for their daughter who has a severe speech and language impairment. It was only when the advocate pointed out she would be unable to participate in the meeting by phone that it was rescheduled for a face to face meeting.

There is an expectation that the the LAC who facilitates the planning conversation will assist the participant to implement their plan during a single plan implementation meeting. Due to the large numbers of participants that LACs have to work with, they lack the time required to provide more intensive support. But for those from a CALD background who have complex needs or who are unable to research and liaise with services themselves considerable more support is required with selecting services, planning supports, understanding and signing agreements and then with maintaining services. In such situations significant funding for support coordination is required, but rarely provided. AMPARO has advocated for many participants from a CALD background to have access to support coordination funding, or for a substantial increase in such support coordination funding.

Due to this heavy workload and high turn over of LACs, participants are no longer linked with a specific LAC and so the onus is on the participant to phone the generic Carers QLD number if there is an issue with implementing their Plan. The difficulty for participants to access an interpreter to make that call, and their frequent reticience to make complaints to government services, means that such calls are rarely made by those limited English proficiency. This has led to many participants being unable to utlitise their NDIS funding to secure much needed supports.

> With funding from an NDIS access project AMPARO Advocacy assisted a young girl with Downs syndrome to transition from Early Childhool Early Intervention (ECEI) funded services to the NDIS, at a time when a specific LAC was allocated to each participant. The original transition process had involved the mailing of an NDIS plan in English to the child's parents who speak no English, with no discussion whatsoever about the transition from ECEI to the NDIS. AMPARO stayed involved until a relationship had been established between the child's family and LAC. 10 months' later we received a call from a highly dedicated therapist requesting support for the family with a plan review. The family had not heard from an LAC for the past 8 months, as the supportive LAC had left and a specific LAC not reallocated. As the mother spoke no English, she had not been able to call Carers QLD for assistance to reestablish services when therapists left and as a result the majority of funded supports had not been implemented and the child had missed out on vital therapies.

b. Support Coordination funding and services

Despite many requests to the NDIA that people from a CALD background, and particularly those from a refugee background or with limited English proficiency and or no IT skills, be put the on the list of cohorts that should be considered for Support Coordination funding at the planning stage, this group is still not included on this list. This often results in participants, who cannot implement their plans and or maintain supports without a Support Coordintor, missing out on this much needed funding and to plans not being fully utilised.

Where Support Coordination funding is provided, this is often for a bare minimum of 24 hours per year. This is far from sufficient particularly when interpreters have to be engaged for all discussions, which take more than twice as long as they would do if solely undertaken in English. We have heard of participants who have been linked by an LAC to a Support Coordinator, who has then refused work with the participant once they have found out the level of funding available, but who have not referred them back to the LAC for other support or increased funding.

As Support Coordinators need no specific qualifications, experience or skills to set themselves up as a Support Coordinator there are a large number who do not have the required knowledge or skills to undertake this important work. We have come across many Support Coordinators who have no qualifications or previous work experience with people with disability or in social services, and little or no understanding of best practice in supporting people with disability or what a good life can look like for people with disability. AMPARO frequently receives referrals from Support Coordinators for assistance with Plan Reviews and from participants who, despite having a Support Coordinator, have poor or no supports in place.

Many participants ask to be, and benefit from being, connected to a Support Coordinator from their own cultural community who speak their own language. For those for whom that relationship breaks down, it can be highly problematic due to the potential loss of face within the community that would be caused by asking to change support coordinators. We know of participants who are unable to access good supports due to their fear of cancelling their contract with a well known community member.

c. Cultural competent and responsive services

AMPARO Advocacy continues to struggle to find cultural competent services to whom we can refer participants. While there may be workers within a service who are known to be experienced and highly skilled at working with people from a CALD background, rarely do we find services that provide comprehensive training to all staff. Likewise, while some may have received training in working with interpreters it is clear that the majority have not.

Often it is assumed that service providers from one CALD background will be culturally competent at working with others from their own and other CALD backgrounds, but this is not necessarily the case. People from the same country may have had different life experiences, or may be from different communites, or have different religious backgrounds or speak different languages. And those from one country may have very different cultural norms to those from another. While this may be obvious to those who are more culturally competent, AMPARO Advocacy frequently comes across participants who have been referred to a service due to both the service and participant being from a CALD background, without any checks being made as to whether the service is cultural competent, including whether they are able to access and engage interpreters appropriately.

d. Access to interpreting and translation services

Following the Federal government's language policy, the NDIA have a clear policy for providing free interpreting services to NDIS registered providers and free translation services for the translation of NDIS Plans, when the participant or primary support person does not speak English.

Issues with interpreting and translation services, including those impacting people with NDIS plans, are outlned in Section IV, 2 above. The key issues for NDIS participants are:

i. Phone interpreters continue to be used for lengthly planning meetings, with either the interpreter on the phone, or with both the planner and interpreter on the phone. This does not allow for participants or family members with limited English proficiency to participate fully in their planning meeting.

ii. Interpreters are usually not trained in NDIS terminology and often struggle to interperate essential NDIS concepts, such as goals, plan management and support coordination.

iii. NDIS Planners and LACs have often not received training in working with interpreters, and do not know of the need to explain all NDIS terms in simple English.

iv. In AMPARO's experience, even when an interpreter is required at the planning meeting, participants are not offered a translated Plan. Only when the adovocate has asked for one have they been provided, and then at times only when the advocate has insisted to the planner that NDIA policy allows for this.

v. Completed plans are usually posted or emailed to the participant in English without the offer of a translated version, or the provision of an interpreter to go through the plan with them. This has led to plans being left in drawers unread, and to plans not being implemented.

vi. Many NDIS registered services continue to be unaware of the availability of free interpretering services and many more have yet to register with TIS for access to interpreting services.

vii. The use of TIS as the contracted interpreter service for NDIA staff and services severely restricts the ability of participants to engage their preferred interpreter, and most staff and services are unaware that this is possible. Choice is therefore usually denied when it comes to interpreting services.

viii. Frequently services do not engage a professional interpreter but rely on family members or staff to interpret for them, and or do not provide non-English speakers with the same amount of information and feedback as they would do an English speaker.

ix. Although able to access interpreters, registered service providers are not able to utilise free translation services for important documents such as Behavioural Support Plans or therapist reports so family members, who are expected to provide assistance with therapies between treatments and to brief new support workers, do not have written information that they can refer to.

x. Services which are not NDIS registered, such as an increasing number of allied health therapists, do not have access to free interpreting services. While the NDIS will provide funding to pay salaries for support workers and therapists employed by non-registered providers, they will not fund interpreters to allow communication between the therapist and the participant or the participant's family member. Given the extreme shortage of registered allied health workers, and more recently support workers, this is a real issue for many from a CALD background.

e. New CALD service providers

The rapid increase in demand for disability related services has led to a corresponding rapid increase in the number of businesses being set up to meet this demand. While some are managed by highly competent people, including people from a CALD background with significant experience in the sector, many are not. As a CALD focused advocacy service, we are seeing an increasing number of small companies being run by people from a CALD background who have no experience of working with people with disability and no knowledge or understanding of best practice in the delivery of supports. Workers with no training in disability supports are being recuited from their communities to work as support workers solely on the basis of speaking the same language. There are endless stories of community access supports being limted to trips to the park or to the local shopping centre, with no support being provided to explore people's interests, pursue their goals and have meaningful roles within their local communities.

A large interstate provider employed a person from a CALD background to contact everyone she knew with a disability from her cultural background, and paid her a commission based on the number of people she signed up. She would arrive at people's homes with a fully completed service agreement written in English which she then got the family member to sign without explaining fully it's contents. Having signed up with this company the participants were then left for many months with no supports whatsoever. Advocates had to assist families to cancel contracts with this organisation before services could be secured with a more ethical service.

Another CALD provider is known for targeting people with a disability from his own community. Support services are run as one would a supermarket, with people who are on shift being allocated to jobs on the day. Participants are given no choice around supports, and are unable to develop long term relationships with their workers. Concerningly supports to a teenager with a Positive Behavoural Support Plan followed this model, so he would not know who was going to provide support to him on a given day and people working with him did not have appropriate training.

AMPARO Advocacy came across someone from a CALD background who was targeting people from a CALD background with NDIS packages. He was the main contact for three different disability organisations over a short period of time, including a direct service provider, an advocacy service and SIL provider. The contact mobile phone number for all three was the same. When we 'googled' his name we found that he had previously operated a child care company which had had its registration cancelled due to having contravened many regulations. Given the frequent organisational name changes and history with the Department of Education we asked the NDIA to investigate.

f. Recovery Coaches

Some participants with a psychosocial disability are provided with Support Coordination funding, others are provided with funding for a Recovery Coach, and some have funding for both. Allocations of such funding are often done without discussion with the participant and bare little relation to a participant's need. The role of recovery coaches is to work with people with complex mental health issues to assist them to design and implement a recovery plan, utilising capacity building funding provided in their NDIS plan. The NDIA recommend that recovery coaches have a Cert. 4 in a mental health related field and two years of work experience, but this is not mandatory.

As they are paid at a lower level that Support Coordinators such positions often attract people with lower qualifications and less experience.

In AMPARO's experience, people with a significant psychosocial disability often require considerable assistance to set up and maintain supports. They benefit from support coordination services from well qualified practioners, who have considerable experience in supporting people with mental health issues in a case management type role. People with such experience can expect to be employed as Specialist Support Coordinators or Support Coordinators, and are not going to work at the hourly rate recommended for a recovery coach. AMPARO firmly believes that the role and pay rates of recovery coaches need to be reexamined and, if continued, people with psychosocial disability should also be provided with substantial Support Coordination funding to attract and keep experienced and qualified people with the necessary skills in the mental health field to assist in establishing and maintaining services for the full length of their plan.

g. Inclusive employment services

With the exception of two well known examples, there appears to be very few organisations in the Brisbane who are successful in providing people with disability with relevant training and access to jobs in mainstream employment. Those that there are, such as Jigsaw which is based at Mt Gravatt TAFE, have long wait lists. Given the NDIS's objective to get people with disability into work, considerable effort needs to be put into growing the sector in a way that will allow people with disability real opportunities for appropriate training and support that can lead to mainstream employment. This is unlikely to happen if left to the market.

h. Workforce shortages in allied health and support services

The market has been unable to meet the huge increase in demand for allied health therapists which resulted from the introduction of the NDIS. Many participants are waiting many months for much needed therapy. Given that demand far outweights supply, therapists are realising that they do not need to become NDIS registered to undertake this work and due to the time and expense involved are not electing to re-register. While this may not be such a problem for those who speak English, as free interpreting services are only available to registered providers this is becoming a significant issue for those who require an interpreter to talk with their therapist, or for family members who need to understand how to improve their support to loved ones on a daily basis.

The market has also been unable to meet the huge demand for support workers, particulatly those with qualifications or the skills and experience required to work with people with complex health conditions or where restrictive practices are in place. Workers with no prior experience or qualifications are being recruited, which has at times lead to a rapid turn over of staff and considerable disruption to people's lives. Family members have had to step in to provide essential supports, including awake overnight supports, which puts considerable stress on families, particularly where family carers are elderly.

i. Lack of knowledge of complaints processes and fear of impact of complaints

Many people from a CALD background come from countries where they not encouraged to provide feedback to government and service providers, and where doing so can put them or their supports at risk. Without active encouragement and comprehensive education around participant rights and complaints processes in Australia many people from a CALD background are therefore unlikely to lodge complaints with services, the NDIS or the NDIS Quality and Safeguards Commission (NDIS Commission). As mentioned above, where the issue is with a service provider from their own community this is even less likely.

In our experience participants from a CALD background who are in receipt of their first plan are often more focused on getting services and supports in place and are less interested in learning about the NDIS complaints processes. If they are impacted by poor services, participants at this stage are much more likely to request a move to another service provider than challenge poor practice. Once participants have had funding and supports for sometime and have developed the confidence to challenge government funded services they may wish to learn more about the complaints process in order to challenge poor service provision and lodge complaints with the NDIS Commission.

So that participants can acquire knowledge about and confidence in the complaints process it is important that people have access to materials in their own language and are informed about possible complaints processes and available materials at each plan review. Written materials, YouTube videos, WhatsApp messages and workshops on rights and complaints processes are needed in a wide range of languages (including those of emerging communities) to encourage larger numbers of people from a CALD background to provide feedback and complaints about NDIS services and providers.

8. Supports for People with Disability, Without Access to the NDIS

a. The need for increased disability funding for those without access to the NDIS.

The wide range of factors that impact a person's ability to access disability supports through the NDIS are outlined above in Section 7, including: a clear understanding of NDIS criteria and the application process; the need for permanent residency; access to clear, detailed, NDIS focused diagnositic evidence from a specialist doctor; and funds for and access to a comprehensive NDIS focused functional assessment. As the ABS and NDIS statistics provided in Section I indicate, many people from a CALD background with significant disability and substantial impairment who should be able to gain access to the NDIS have yet to do so.

There is also a large cohort of people with substantial functional impairment that results from chronic health conditions, such as osteoarthritis, fibromyalgia, chronic fatigue syndrome, speech and language impairments, etc., who are not NDIS eligible due to their conditions not being deemed to be permanent by the NDIS. While unable to access supports through the NDIS, their impairments and support needs may have been proven to be as substantial as those experienced by NDIS participants.

A third cohort without access to the NDIS, who have a disability and require supports, are those for whom their functional impairment is not deemed to be substantial by the NDIS.

People from each of these cohorts often require substantially higher levels of support than they can currently access.

b. Queensland Community Support Scheme (QCSS)

For many with disability in Queensland who are unable to access to the NDIS, the only funding available for direct support is through the QCSS. However, with maximim funding of five hours a week, to include all domestic and community based supports, support is often limited to critical support with shopping and domestic chores. Few can use this funding for building social connections and informal supports in the community.

With no residency or permanence restrictions, there is a huge demand for this funding from those in the three cohorts mentioned above. This funding is also utilised by those who require short term supports on discharge from hospital, so demand for these funds is huge – and the current budget is limited to $37 million per year. This has resulted in wait times for QCSS funding being blown out to eight months or more, which has led to a crisis situation, particularly for those who are unable to care for themselves in their own home without supports.

Other states such as Victoria have recognised the need for higher levels of support for people with complex needs who do not have access to the NDIS, but such a program is not funded for those in Queensland.

c. Carer Gateway

Although supports for carers of people with disability can be accessed through the Carer Gateway, people with limited English proficiency have struggled to access these supports. Also, while family members may care for loved ones with disability for their life time, funding through the Carer Gateway is usually limited to a maximum of six months only. And those without a carer are unable to access these supports, however urgent their needs may be.

Through AMPARO's advocacy, a man with disability due complex health needs who is not eligible for the NDIS, has recently been given two hours per week of support through QCSS funding. He is on the waitlist for the additional three hours of support. With short notice he had to undergo day surgery but required a carer to be at home with him overnight following his opertation. Had he had a carer who was unable to provide this support he could have accessed a support worker through the Carer Gateway program, but as he is totally on his own in Queensland he was not eligible, and there were no other options available to him for paid overnight supports at short notice. The operation was only able to go ahead when an elderly neighbour agreed to stay overnight with him.

d. My Aged Care

For those under 65, who are not eligible for the NDIS, but for whom substantial functional impairment puts them at risk of entering a nursing home, in 'limited, special circumstances' it is possible to access funded supports through 'Aged Care'. But as mentioned on the My Aged Care website 'aged care should be the last resort for people younger than 65'. Applications have to be lodged through Ability First Australia. The availability of this funding is not well known within the sector. AMPARO does not have recent experience of supporting people to access supports through this program.

Prior to the introduction of the NDIS, AMPARO was successful in accessing a Home Care Package for a woman with significant functional impairment resulting from Chronic Fatigue Syndrome (CFS), for whom Disabilty Services had refused funding. Whilst this level of funding has allowed her to continue to live at home on her own, maximum Level 4 funding only pays for 14 hours of support each week, the vast majorty of which is used for essential services such as grocery shopping, cooking, cleaing and laundry. Had she been able to access the NDIS she would have access to considerably more funding, including that for community based supports to allow her to develop community connections and informal supports. Instead, with her current funding this has not been possible and she spends the vast majority of her time at home and remains highly socially isolated. As CFS is not deemed by the NDIA to be a permanent condition she remains ineligible for the NDIS, despite having had substantial functional impairment for more than 20 years and is likely to require life long supports due to this condition.

9. Lack of Long-Term Appropriate Housing

Appropriate housing for people with disability from a CALD background has always been a focus for AMPARO Advocacy, however Queensland's current housing crisis is resulting in an increasing number of referrals for people with disability who are being threatened with homelessness, and preventing highly vulnerable people from obtaining the long term appropriate housing that they urgently need. Key issues that are impacting housing availability are as follows:

A. Public and Community Housing

i. Extreme shortage of social and community housing properties

The critical issues around the extreme shortage of public and community housing in Queensland are well known and are currently being explored by the Queensland Government. Media reports state that there are over 50,000 people currently on the wait list for public housing. Although the Government have committed to building 5,000 homes a year this will do little to impact the very long wait list.

ii. Ineligibility for public and community housing: asylum seekers and people on temporary visas

The most vulnerable group that we advocate for around housing are those who, without Australian permanent residency, are ineligible for public housing (and therefore community housing) such as asylum seekers and those of temporary visas. For example, Safe Haven visas, which recognize that people are unable to live in their home countries and allow them to live in Australia are usually granted for periods of five years at a time. Whilst people on such visas may end up living permanently in Australia, they are not deemed to be permanent residents and are therefore ineligible for public housing. This cohort, having experienced trauma and or limited supports around disability in their home countries, struggle to afford high private rental rates and can be negatively impacted by the frequent moves which are often required when in private rentals.

iii. Very low income threshold levels for public and community housing

The current income level limits for those in public housing are compared with pension levels in the table below:

	[4]Household income limit / week	[5]Income with DSP / week	Income / week with 1 DSP & 1 Carer Pension[6]	Income / week with 1 DSP, 1 Carer & 1 Aged Pension[7]
Single person, no children	$609	$493.80		
2 single people	$755	$987.60	$962.20	
Couple and 1 single person	$877			$1430.60

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[4] https://www.qld.gov.au/housing/public-community-housing/eligibility-applying-for-housing/guide-to-applying-for-housing-assistance/check-your-eligibility#HouseholdIncome

[5] https://www.servicesaustralia.gov.au/payment-rates-for-disability-support-pension?

[6] https://www.servicesaustralia.gov.au/how-much-carer-payment-you-can-get?

[7] https://www.servicesaustralia.gov.au/how-much-age-pension-you-can-get?

Whilst a single person may be under the income threshold, these figures show that when 2 or more people who receive Centrelink pensions, such as a DSP, Carers Payment or Aged Pension live together, they exceed the weekly limit for public housing. If two single people with disability wish to share, or an adult child with disability lives with a single parent, or if two elderly parents wish to live with and support an adult child with disability, they exceed the income threshold for public housing. This results in highly vulnerable people with disability whose whole household income is from Centrelink being excluded from social housing. This is a very significant issue for many with disability who require a long term, accessible, safe and affordable home close to known supports and services.

iv. Availability of accessible / safe homes for people with disability

Many people with disabilities have specific requirements for their housing – such as being on one level, without access steps, having a secure garden, away from busy main roads, close to shops, services and or transport networks, or are nearby family, social or formal supports. Queenslander style homes which make up much of social housing, with entrance steps and the laundry at ground level out the back, are often not suitable. Likewise, bathrooms are often small and are unable to be modified for access. While people with disabilities are usually prioritised for accessible homes if needed, the extreme shortage of such properties can result in very long wait times, and to people having to move away from areas of existing supports and services.

v. Availability of four or five bed homes for large families

Another cohort that are particularly vulnerable are those with large families. The majority of social housing properties in Brisbane have three or fewer bedrooms. There is a real shortage of 4- and 5-bedroom homes, and people need to know about and prioritise suburbs with 4- or 5-bedroom homes to have any chance of securing one. Many of the families that we work with from a refugee background have large families for whom 3- or 4-bedroom homes, with only one toilet often located in the bathroom, are wholly inadequate. Those requiring larger homes for larger families, such as one we advocated for with 8 children, social housing is a near impossibility.

Large families are also often excluded from social housing for financial reasons, with Family Tax Benefits providing large families with incomes above the household income limits. While this may result in higher incomes, the issues around inaccessibility, high rents and the short term nature of many private rentals remain. Frequent moves can result in significant cost and disruption to families, the need for frequent changes in services and schools and moves away from vital informal and formal support networks.

B. Private Rentals

i. Availability and cost

With current vacancy rates at 0.6%. and Brisbane's median rental asking price for housing rising by 16.9% in 12 months[8], landlords are taking the opportunity to increase rents to rates that are unaffordable to people with disability on low incomes or who are in receipt of a Centrelink pension.

With many being priced out of the rental market, caravan parks are at or beyond capacity, with one community organisation providing people with tents for accommodation. Single renters are particularly vulnerable, with those on Centrelink incomes struggling to afford even a room in a share house. This has increased demand for places in hostels; the Queensland emergency homeless service informed us recently that the closest available bed to Brisbane in a hostel for a single adult woman who was about to be made homeless was in Harvey Bay.

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[8] https://www.brisbanetimes.com.au/national/queensland/a-landlords-market-brisbane-records-steepest-rent-rises-in-city-s-history-20220713-p5b19v.html

Sadly, increases in Rent Assistance from Centrelink have not kept up with the significant rent increases and so the percentage of income having to be spent on rents is increasing rapidly to unaffordable levels. Current levels of Rent Assistance for those living in private rental are as follows[9]:

If you're	Your fortnightly rent is more than	To get the maximum payment your fortnightly rent is at least	The maximum fortnightly payment is
single	$135.40	$337.54	$151.60
single, sharer	$135.40	$270.16	$101.07
couple, combined	$219.20	$409.60	$142.80

Given the very low household income threshold for social housing, families on more than one Centrelink income who are deemed not to be eligible of social housing are being impacted by severe housing stress. While those in social housing are expected to pay 25% of household income in rent, many of those in private rental, even when in receipt of Rent Assistance, are impacted by significant housing stress, having to pay upwards of 40 to 50% of their income on rent.

AMPARO Advocacy advocated for a young woman with psychosocial disability for access to the NDIS and social housing. She and her parents were living in a cramped 'granny flat' with 2 small bedrooms and a very small kitchen diner, without a lease and in much need of repair. They had been deemed ineligible for social housing due to being in receipt of a DSP, Carers Payment, and Aged Pension. At today's rates they would exceed the income threshold by $533. They required a 3-bedroom home, which in their suburb on average costs $740/fortnight in rent[9.] With a combined income of $1430.60, and possible Rent Assistance of $243.87 (couple plus single sharer) they would have had around $150 each / week to live on for all other expenses, including bills. Given the importance of them living in an affordable long term home in a known area close to where all social, medical and disability supports were being provided, through AMPARO's advocacy the income threshold was waived, and they were provided with a 3-bedroom home. With social housing rents being charged at 25% of income they will be paying around $357 in rent.

ii. Availability of accessible / safe homes for people with disability in the private rental market.

The acute shortage in availability of private rental properties is exacerbated further when people require homes which are accessible for those with mobility issues or for whom wheelchair access is essential. Very few rentals allow for wheelchair access, particularly to bathrooms, and it is usually impossible for any necessary modifications to be made to rental properties. While the Department of Housing will fund necessary modifications in their homes and the NDIS will fund modifications for people who own their own homes, any modifications which are allowed in a rental property would have to be funded by the person themselves – and there is no guarantee that they would be able to live long term in the property once the modifications have been made.

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[9] https://www.servicesaustralia.gov.au/how-much-rent-assistance-you-can-get?

[10] www.realestate.com.au/qld

10. Services Australia

a. Applications for Disability Support Pension (DSP)

AMPARO Advocacy receives many referrals for assistance in completing DSP applications, due to a lack of assistance provided through Centrelink. Many are not able to apply for a DSP on-line (Centrelink's preferred option) due to a lack of computer literacy or limited English. Others are unable to understand the application form with its 192 questions, plus several supplementary forms. As a small agency with limited funding, we are unable to provide such support unless we are advocating for the person on other issues. We have been able to advocate for Multicultural Officers at Centrelink or for other services to assist people with their DSP applications however it often takes a request from an advocacy agency for them to get such supports.

A further barrier to the DSP is the need for the applicant to have a Tax File Number (TFN) prior to the application being submitted. This is regardless of whether or not they have or will ever have the capacity to work. Again it is recommended that an application for the TFN be lodged on line through a MyGov account, if not, the person needs to access the TFN application form on line as they are no longer available from post offices. Many who we work with are unable to do this. Recently an 18 year old applicant has had his DSP turned down due to lack of a TFN, despite his substantial functional impairment.

b. Applications for Appeal re Disability Support Pension (DSP)

Many people with disability are turned down for the DSP initially due to poorly completed forms, or poorly completed medical evidence caused by a lack of understanding by doctors of the level of detail required. It can take many months for an Appeal decision to be made.

AMPARO Advocacy advocated for a highly vulnerable young man who had been deemed ineligible for a DSP and fit to work at least 14 hours per week, despite having a significant intellectual disability (intellectual and adaptive functioning in the extremely low range) plus a psychosocial disability resulting from acute agoraphobia, with recurrent depressive disorder. Even with our advocacy, it took Services Australia 3 months to consider the appeal and to overturn the original decision and grant him a DSP.

11. Support for People from a CALD Background to Access Disability Supports

a. Disability Advocacy

Disability Advocacy Network Australia (DANA) and its members have long been campaigning for a coordinated long-term approach to State and Federal funding for disability advocacy. The importance and benefits of disability advocacy, the need for a significant increase in funding and the importance of expanding the reach of disability advocacy targeted at high risk populations, including those from a CALD background, are all clearly outlined in DANA's recent submission to the DRC.

Despite these ongoing campaigns, the Queensland State Government has only committed to fund disability advocacy until June 2023. This last round of funding is for only for an 18 month period, and was granted following a significant campaign by people with disability and by those working in the disability sector. This short term nature of advocacy funding results in significant uncertainly around much needed advocacy supports for Queenslanders with disability, and to insecure employment contracts for the highly skilled advocates. Significant time also has been spent in advocating for advocacy when it should be being used to advocate for those who are most vulunerable in our society.

AMPARO is the only CALD focused disability advocacy service in Queensland, with only one funded position for the whole state. Fortunately the funding for an additional 0.9 of a position secured through another service, together with our ILC funding, ensures the viability of AMPARO. However demand for our services continues to far out strip our capacity and there are many highly vulnerable people from a CALD background with disability who require advocacy but for whom we cannot advocate.

While similar organisations in other states which advocate for people from a CALD background with disability, such as Multicultural Disability Advocacy Assoc. NSW, also receive Commonwealth funding due to agreements being established many years ago, since AMPARO's incorporation in 2006 Commonwealth advocacy funding has not be made available to specialist advocacy organisations such as AMPARO.

b. Information, Linkages and Capacity Building (ILC)

AMPARO was fortunate to secure ILC funding for 2020-2023; this has recently been extended until June 2024. Funding is used to employ six part-time Multicultural Engagement Workers plus a coordinator who work to build the capacity of vulnerable people from a CALD background with disability, and their families, around disability rights, supports and services. This very successful program has led to many being able to understand what a good life can look like for someone with a disability in Australia, and how to obtain that life through accessing appropriate supports through the NDIS, Centrelink, Dept of Health and Housing, etc.   Sadly this program will end in 2024.

c. Short term nature of programs targeted at addressing CALD NDIS access and implementation barriers

Whilst the Tune Review of the NDIS Act in 2019 recommended the NDIA develop a comprehensive National Outreach Strategy to address the additional access challenges experienced by particular cohorts, including those from a CALD background, measures have been piecemeal and inadequate.

Prior to the role out of the NDIS, AMPARO was funded for 18 months to provide information about the NDIS to CALD communities. Through this Targeted Outreach Participant Readiness Program we were able to recruit 18 bicultural workers who undertook extensive community engagement work to provide information about the NDIS to more than 200 people within their communities.

Once the NDIS was established, in 2019 we received a new State grant for six months to provide support for people from a CALD background to access the NDIS, but we were not funded to provide much needed supports with pre-planning, planning and connecting with services. As a result many that we had worked with for access were referred back to AMPARO for advocacy when they received poor plans, no or little support coordination and or were unable to implement their plans.

In 2020 AMPARO was funded for 11 months as part of the NDIS Community Connector Program, which allowed for the recruitment of part-time Community Connectors from 5 different CALD communities who were able to identify and support people from their communities who had yet to gain NDIS access or who were struggling to implement their plans. Through this program we were able to identify more than 130 people who required disability related supports[11], but due to the length of time it takes to obtain necessary evidence of disability from specialists in the public health system, the difficulty in accessing functional assessments and the short term nature of the program

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[11] See Attachments 2 & 3: NCCP Report & Letter to Minister

69 people continued to need support once the program funding ended. Fortunately AMPARO was able to refer 32, for whom we had accessed appropriate evidence of disability, to the State funded Assessment and Referral Team for functional assessments, and the remainder to our ILC and advocacy workers, but we are very aware that had we'd been able to continue the program and work with a wider range of communities we would have been able to locate and support many more highly vulnerable people who still require NDIS access or other supports.

This outstanding demand for support with NDIS access was confirmed the following year, when in 2021 we received six months' funding for a part time worker through the Targeted Outreach Program. Through our advocacy, ILC and NCCP contacts and with the recruitment of four bicultural workers for five weeks, we were able to indentify a further 99 people from a CALD background with disability who required support to access the NDIS and other disability related supports.

The short-term nature of all these programs meant that AMPARO spent considerable time and expense recruiting, training and mentoring bicultural workers only for them to have to find new employment within the year. And then a few months later we had to recruit and train a new cohort for the next short-term NDIS related project. The long-term nature of this work makes these short-term funded programs particularly frustrating for the participants, as given the stigma involved it can take some time for them to develop confidence in their workers, only to have the program close and workers leave before the much needed supports are in place.

At a recent meeting with the NDIS it was declared that now that those who need it have access to the NDIS, focus will be placed on improving community participation and employment supports. But as the ABS and NDS data outlined in the introduction shows, for the CALD community this is far from the case. There continues to be many more highly vulnerable people from a CALD background with disability who require support to access the NDIS and other disability related services and, with the exception of our 1.9 State funded advocacy postions, there are no CALD targeted programs providing this support in Queensland.

V Conclusion

Despite high levels of vulnerability, many people from a CALD background with disability remain without supports or receive insufficient or poor quality supports. Significant work continues to be required to educate communities about disability rights and the availability and real benefits of appropriate disability supports. GPs, specialist doctors and OTs continue to require training in how to address the full range of NDIS specific criteria in their NDIS related reports and, many would argue, be paid to write such reports and assist with NDIS applications.

The huge overdemand for the QCSS funding shows that far greater funding is required both in individual and scheme wide budgets to provide the much needed supports for those with disability who are not deemed eligible for NDIS supports, and particularly for those with complex chronic health issues which may be life long, but are not deemed permanent by the NDIA.

Significant work also needs to be done within the NDIS, their partners in the community and with service providers to ensure that they and their workers are culturally competent, are able to access and work well with preferred interpreters and are able to provide culturally appropriate services which meet the needs of those from highly diverse cultural backgrounds.

Through the NCCP and TOP programs, AMPARO was able to target seven CALD communities however due to the short-term nature of and the limited funding available within these programs there are many more CALD communities that we have been unable to work with. AMPARO's experience has clearly demonstrated that when we are able to work with bicultural workers who are well known within their specific CALD communities, large numbers of people with disability who are missing out on much needed disability services can be identified and supported to gain access to the NDIS and other funded supports. But despite this, and the low numbers of participants from a CALD background in the NDIS, there are no current programs funded specifically to address this issue.

Through our advocacy work AMPARO has been able to make a significant difference to many people from a CALD background with disability, but with only one position funded, plus the recent additional 0.9 position, to provide specialist advocacy for the whole of Queensland, demand for our work far exceeds what we can do. Despite this, there is no long-term commitment to State funded disability advocacy, and our current 18 month agreement is due to end in June 2023. And although available in other states, there is no Federal funding in Queensland for CALD specific disability advocacy.

For increasing numbers of people from a CALD background with disability to be supported to access mainstream and specialist disability supports, including the NDIS, there needs to be a significant increase in longer term CALD specific disability advocacy funding. Funding also needs to be provided for long-term NCCP type programs, which allow trained bicultural workers to build capacity within their own communities around disability rights, the NDIS and other supports. If experienced disability advocates and bicultural workers who are well known and trusted within their own communities can be funded to work together in support of people from CALD backgrounds with disability many more highly isolated individuals can be identified and supported to gain access to the NDIS and other much needed supports.

AMPARO Advocacy is pleased to provide this Submission to further the Disability Royal Commission's understanding of the specific experiences of violence, abuse, neglect and exploitation of people from CALD backgrounds with disability.

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