



53 Prospect Road, Gaythorne, QLD 4051
PO Box 2065, Brookside Centre, QLD 4053
phone 07 3354 4900 fax 07 3355 0477
email info@amparo.org.au
web www.amparo.org.au
ABN 56 876 279 925

13 August 2020

Inquiry into the NDIS market in Queensland
PO Box 12112
George Street
Brisbane 4003

Attention: Dr Karen Hooper Principal Commissioner, Queensland Productivity Commission

AMPARO Advocacy welcomes the opportunity to respond to the *Inquiry into the NDIS market in Queensland*. AMPARO Advocacy is a small non-profit community based organisation which provides independent, individual and systemic advocacy with and on behalf of vulnerable people from culturally and linguistically diverse backgrounds (CALD) with disability.

AMPARO is governed by a voluntary management committee the majority of whom people from a CALD background with disability and is funded by the Queensland State Government Department of Communities, Disability Services and Seniors. AMPARO Advocacy's vision is for people from a CALD background with disability to be accepted and respected as part of the diversity of Australian society, with access to information, services and benefits, so that they can be included, participate and contribute in family and community life.

AMPARO's advocacy addresses issues of social and economic isolation, unfair treatment and discrimination. We represent those who are least able to defend their own interests, and who may not have close family or friends who can support their aspirations or speak on their behalf.

Most individuals that AMPARO works with are from a refugee background experiencing multiple and complex layers of disadvantage and have generally missed out on accessing specialist disability services, including early intervention for their children. They are often marginalized, and isolated from their own communities and not accessing services, including the NDIS, to the levels they should be.

Since January 2018 AMPARO has provided intensive support to Queenslanders from people new and emerging communities and refugee backgrounds to access the NDIS in the Brisbane, Logan and Strathpine areas. AMPARO has witnessed the enormous difference the NDIS can make in people's lives when they are well supported to undertake preplanning and to navigate this complex new system.

CALD PARTICIPATION RATES AND ADDITIONAL BARRIERS

However we are also well aware of the many obstacles and barriers that prevent people from CALD backgrounds having equitable access and participation in the NDIS, including the prohibitive cost of diagnosis of disability and impact of impairment.

The COAG Disability Reform Council Quarterly Report for March 2020 reports the following:

- In Queensland, a total of **5.4%** of participants are from a CALD background, however ABS data suggests this figure should be closer to **15%**
- Nationally a total of **9.1%** of participants are from CALD background, however the NDIA suggests this should be at least **21.9%**.

AMPARO is pleased that Queensland's Productivity Commission highlights these figures in the June 2020 Issues paper and acknowledges that these figures indicate that people from CALD backgrounds with disability experience additional barriers to accessing the NDIS.

Barriers in Accessing and Participating in the NDIS

Queenslanders from CALD backgrounds with disability and their families experience additional barriers to accessing important information and services, identifying supports, understanding their rights, exercising choice and control and resolving concerns. Expectations among this cohort for what a good or ordinary life can look like for people with disability can be low and issues of stigma can mean they experience isolation from their own communities.

Applying to access the NDIS is a complex and timely process and more difficult for people from CALD backgrounds with disability and their families. AMPARO's experience confirms that people from CALD backgrounds with disability and their families require intensive culturally appropriate support and information, delivered with the assistance of bicultural workers and certified interpreters, to ensure they can:

- Access interpreting services to ensure accurate understanding and effective communication
- Understand their rights and to know what a 'good life' for people with disability looks like.
- Understand the opportunities available under the NDIS and the necessary steps to access the NDIS
- Gather eligibility "evidence", including the impact of impairment on their functional capacity
- Access to timely, affordable allied health and other medical assessments
- Contact the NDIA to make an access request and complete documentation
- Complete preplanning and articulate their needs for support
- Respond to requests from the NDIA for additional information
- Effectively participate in NDIS planning meetings.

Without targeted culturally appropriate engagement and specialised assistance, through each step of the process, many Queenslanders from a CALD background with disability and their families have either:

- not submitted an access request to the NDIS
- had their NDIS access requests rejected, often due to lack of evidence
- not known how to respond to requests for further evidence
- received poor plans that cannot meet their needs, or
- not been able to implement their plans, due to receiving inadequate or no funding for support coordination.

1. Accurate communication and the need to engage interpreters

Access to face to face meetings with certified interpreters is vital to ensure people with limited English proficiency are able to understand information, communicate their needs, make informed decisions and experience real choice and control under the NDIS.

The NDIS recognises the need to provide access to certified interpreters, however LACs and registered service providers often fail to provide them when needed. Only recently Ferros Care in Townville advised a settlement worker who requested their support to assist refugees with disability to access the NDIS, that they did not have capacity to provide access to interpreters. The NDIA must promote more vigorously people's right to interpreters and the processes for engaging them to their own staff, Partners in the Community and registered service providers.

The current NDIS information on accessing interpreters refers to the participant's right to request a specific interpreter when issues of confidentiality and continuity of care are a concern for them or their families. Due to issues of confidentiality and the stigma attached to disability and mental health in some communities, many people with disability and/or their families prefer to use a specific interpreter they have had previous contact with and trust. However, in practice this is extremely difficult to do.

The memorandum of understanding developed between the NDIA and TIS National does not address the difficulties experienced when requesting a specific interpreter. This process is administratively time consuming and cumbersome, with TIS National often refusing applications for a specific interpreter or those making the booking giving up because the process is so arduous.

As the NDIS and NDIS service providers can only use TIS National for interpreting this is a highly significant and concerning issue for many.

A core tenet of the NDIS is 'choice and control'. The NDIA's website clearly states that 'participants control the support they receive, when they receive it, and who provides it'. TIS National's policy of refusing to allow the majority of participant's choice when booking an interpreter conflicts directly with this guiding principle of the NDIS.

This in itself should be sufficient grounds for participants to be able to choose their preferred interpreter, but there are also many other reasons why a participant's choice of interpreter should be respected. (See Attached Letter to CEO NDIS, Martin Hoffman).

2. Evidence of disability and access to functional assessments.

▪ **Difficulty accessing affordable, timely assessments and reports for NDIS Access.**

There is an assumption that referral pathways to clinical support are available, which can provide evidence of disability to help with Access Requests to the NDIS. Unfortunately, this is not the case and people experience lengthy wait times, they can be advised it may be years, when trying to access affordable allied health assessments through the public health system. Alternatively undergoing an assessment and obtaining a report by an Occupational Therapist (OT) or Psychologist, even with a Chronic Disease Management Plan from your GP, can be cost prohibitive for many families. An OT Report can cost up to \$700, most of the individuals we advocate for cannot afford this.

This issue alone presents a major barrier to effectively accessing the NDIS or means applications are made with inadequate evidence and are rejected. This is a contributing factor to why *“nationally a lower proportion of CALD applications have been found to be eligible for the scheme”*.

- **Diagnostic and functional impact reports written by General Practitioners, psychiatrists and allied health workers lack clear evidence.**

Unfortunately, many GPs, specialists and therapists lack knowledge of the NDIS requirements for a person to make effective access, and their reports unfortunately reflect this. Many individuals are referred to AMPARO for advocacy after they have been rejected by the NDIS. A large proportion of these are the result of poor reports.

AMPARO's advocates provide high levels of support and information to these practitioners so they understand what necessary information to include in their reports and what is irrelevant or detrimental. Some GPs are charging well above what is reasonable to complete access requests forms and to print off reports for their patients. This has been reported to the NDIA.

3. Targeted Measures to increase participation in the NDIS in Queensland.

In the Issues Paper the QPC refers to measures being undertaken to increase participation in the NDIS, unfortunately AMPARO experience is that LACs rarely provide the level of intensive culturally appropriate support that people from CALD backgrounds with disability and their families require, to understand and access the NDIS, nor the necessary support to implement their plans.

AMPARO has provided this feedback on these concerns directly to Carer's Queensland and they advise they are taking steps to improve their engagement and support of people from CALD backgrounds, time will tell how effective this will be.

4. Lack of culturally competent service providers and skilled workforce

Generally, most established disability service providers have had little experience in providing culturally appropriate support to people from CALD backgrounds, as prior to the NDIS roll out in Queensland, only 2.6% of those receiving disability support were from a CALD background.

Whilst there has been an increase in CALD specific providers, there have been some concerns raised by community members that many providers have little or no experience, skills or qualifications to support good practice in delivering support to people with disability. Earlier this year AMPARO Advocacy raised several concerning allegations, brought to our attention by a community leader, with the NDIA Fraud team for investigation.

There also seems to be an assumption that if you are a CALD provider then you will also be able to deliver culturally competent and person-centred support to this cohort. This is a false and potentially dangerous assumption.

In addition, Sole Trader registration obligations means that some providers are not renewing their registration and only providing NDIS support to participants who are Plan Managed or totally ceasing their involvement in the NDIS. Those providers who are not registered with the NDIS are not then entitled to access free interpreting services for NDIS Participants they are supporting. Subsequently if interpreters are required funding for this is being taken by the provider from the Participants Plan, this is to their disadvantage, but they are often not even aware of this.

High quality innovative support services are extremely limited, and many providers are offering group home support with inadequate real opportunities for choice and control. Many providers are reluctant to engage bicultural workers that speak the person's language and some that will find it difficult to attract skilled or experienced bicultural workers and there is little training being provided to upskill the workforce to meet the needs of this cohort.

Through our work AMPARO has identified several factors that impact on whether CALD Participants and their families are able to effectively participate in NDIS planning processes and whether as a result they receive a plan that is comprehensive with the appropriate supports to meet their needs.

5. Pre-Planning Issues

▪ Lack of pre-planning support and information

Critical to a participant receiving a good NDIS plan is the pre-planning process, and for people and their families from CALD background this is often not available. Most people from a CALD background have not previously been accessing or connected to specialist disability services and have no access to preplanning support.

They often have no assistance to think through what their needs for support are and what supports, and strategies will help them to achieve their goals. This means they often attend NDIS Planning sessions with little understanding as to what supports, capacity building, therapy, or equipment they would benefit from receiving.

Planning resources provided by the NDIA are often not in languages of new and emerging communities and some individuals and families may be illiterate and unable to read resources that are available. Without direct support to explain information in these documents they are of little value.

However AMPARO Advocacy has been able to meet participants from a CALD background with disability and/or their family members in their homes with certified interpreters and have face to face discussions to provide important information, answer their questions and assist with preplanning.

All individuals and families AMPARO has worked with required significant support in the preplanning process to:

- Understand their rights
- Explore what a good life for a person with disability can look like
- Understand the opportunities available under the NDIS
- Identify their specific needs for support/ therapy/ equipment/ capacity building
- Understand complex terms and language of the NDIS.
- Document this information to take to their planning meeting

Unfortunately, our capacity to do this work is limited.

▪ Processes to arrange planning meetings do not meet the needs of participants and their families from CALD backgrounds

Unfortunately process the NDIS and LACs are engaging in to arrange planning meetings is not meeting the needs of CALD participants. NDIA and LAC planners will not leave a message for a participant or family member if they don't answer the phone, unless the family has included their surname on their voicemail message. The individuals and families from CALD backgrounds we work

with usually have a generic voicemail as they may not know how to do create their own message or may not have adequate English proficiency. Therefore, they rarely have a message left by the NDIA to advise them of their planning meeting. Additionally planners will attempt to contact the person three times, so when they haven't been able to reach the person, the result is that people from CALD backgrounds with disability are falling through the cracks and without additional support, not accessing the NDIS.

8. NDIS Planning Issues

- **Planners not understanding the right to advocacy and benefits of this for Participants.**

Unfortunately, there have been many instances where planning meetings were held without the advocate from AMPARO being informed or invited to these meetings despite being listed on the Participants file with their consent, as a 'contact person' and someone to be invited to the planning meeting.

In situations where this happened participants did not receive a plan that met their needs, receiving less core support and either limited or no support coordination. Some planners are welcoming of the involvement of advocates when consent has been provided, however some appear to have little understanding of people's right to advocacy support and less appreciation of the value of the advocate's involvement for the person. When one advocate asked the LAC why they hadn't been informed of or invited to the participant's planning meeting, the LAC stated that: ***"they didn't need an advocate, the planning meeting went well"***, contrary to this the person's plan had inadequate core support and no support coordination.

- **Planning Meetings or Pre-planning meetings?**

A major confusion for many Participants has been the use of language by LAC's in referring to planning meetings as "pre-planning meetings". This meant some participants did not recognise the importance of this meeting and were not sufficiently prepared, as they believed it was not their official planning meeting.

- **Plan Decision Maker Not Present at Planning Meetings**

The planning process is undertaken by the NDIA Planner or a LAC and can take up to 2 hours of question and answers with those involved. When a LAC conducts the planning meeting, they see themselves as an information gatherer and report that unfortunately do not have the final say on whether their recommendations for support are approved. It is the planner from the NDIA who approves the participant's plan despite never having met the person with disability and or their family.

We see this as a significant flaw in the system, as they do not hear directly from individuals about their needs for support in the different areas of their life. Despite this they are charged with making powerful decisions about the types of supports the person with disability needs and often refusing requests for support coordination even though without this, participant's plans are not being implemented or implemented poorly.

8. Issues related to support coordination and plan implementation

▪ Limited culturally competent Support Coordinators

The availability of Support Coordinators who have the experience, knowledge, and capacity to provide culturally competent and person-centred support coordination is severely limited. Those providers that are doing good work in this area are often working at capacity and not taking new referrals.

▪ The expectation that levels of Support Coordination funding will decrease over time

Many Participants are having their levels of support coordination decreased in their second NDIS Plan, based on the assumption that they will have increased skills to implement their plan. This is unreasonable as many individuals will never have the necessary skills and capacity to manage their own supports, deal with ongoing service issues, and prepare for plan reviews without significant assistance, nor have family who are able to assist them. One NDIA Planner told the AMPARO advocate, that the support coordination for a young teenager who has Autism and significant support needs, would decrease over time, as they would be expected to develop their skills to manage their supports. Advocacy is also often needed to assist individuals and their families to change providers when they are unhappy with the support they are receiving. However, many are unaware of their rights to do this and need significant support to do so. The common experience of having support coordination levels reduced even when there is evidence of the need to maintain or increase these levels is a serious systemic barrier to plan implementation.

Of the 42 individuals who received advocacy over the past 6 months, 36 needed advocacy for issues related to the NDIS, and of those 17 required plan reviews, with 14 of these the result of Participants receiving inadequate or no support coordination in their plans.

▪ Lack of support coordination

Despite advocates providing significant background information regarding the participant's needs and their family situation, prior to planning meetings and when in attendance at these meetings, many CALD participants continue to receive insufficient or no funding for support coordination in their plans. This situation is causing unnecessary stress to individuals and their families, and the result is that many CALD participants are not implementing their plans and missing out on accessing the essential supports they are entitled to.

Many LACs are reluctant to argue for support coordination stating they can help the person to implement their plan It is possible that LACs have a conflict of interest in insisting they can do this work that should be examined more closely. It may be in the interests of the person with disability and their family to have good levels of support coordination and less need for LAC involvement.

AMPARO Advocacy has been advised by the NDIA State Manager that the Support Coordination Standard Operating Procedure (SoP) that guides LAC/ Planners decisions regarding the inclusion of support Coordination in Participants Plans, does not specifically highlight the need to consider CALD as an indicator of the potential importance or need for support coordination.

This must be rectified so that the additional barriers that this cohort often experience are seen as a legitimate consideration in the allocation of support coordination.

- **LACs generally not providing adequate support for plan implementation.**

Support by LACs is limited to one visit post plan development and then periodic follow up phone calls, many individuals report to AMPARO that these often do not happen. This level of support is inadequate for most and especially for those from a CALD background with limited English proficiency, little awareness of how to locate appropriate services and no capacity to access internet services to monitor expenditure and so on.

Unfortunately, AMPARO has not seen good evidence that LACs are providing the necessary time and culturally appropriate support that Participants require to effectively implement their plans, and find many people are disadvantaged by LACs limited capacity to do this work well.

- **Children from CALD backgrounds accessing Early Childhood and Early Intervention (ECEI) services** are generally not receiving support coordination to ensure their plans are being implemented. ECIE workers advise that they only receive 10 hours over 12 months, to meet with the child and their family, develop a plan and provide assistance to commence implementation. If you factor in working with an interpreter for all communication, this equates to a maximum of 5 hours per year. This is unfair and fails to recognise the additional language and cultural needs of these children.

AMPARO's previous experience with children accessing Better Start for Children with Disability and early intervention support through Commonwealth programs was that funding was often unspent by the time the child turned seven, and they missed out on important support, therapy and equipment. This was because they did not receive the case management support they required to understand what supports were important or how to access them. Similarly this is happening for children under the NDIS.

- **Experience and expertise of planners**

Questioning techniques vary considerably between planners, often with yes / no options, such as *'Do you have the ability to go to a festival?'* and *'Are you fine with reading and writing?'* Little understanding is gained by these questions as to how much support someone would need to attend a festival, or whether someone has a good understanding of a simple or complex text. There appears to be a vast difference in the competencies and expertise of planners, and this leads to the quality of plans varying greatly. There is often no consistency in approaches and assessments and clear that some planners have had little or no experience in working with people from CALD backgrounds with disability. Many planners have no experience or knowledge of how to engage and work effectively with qualified interpreters.

- **COVID 19 Impact on Planning meetings**

Unfortunately, because of COVID Planners have gone back to undertaking planning meetings over the phone. For those who require interpreters for these conversations, it is impossible to have such complex discussions over the phone. For others with disability who do not require interpreters, planning conversations over the phone result poorer outcomes and inadequate plans. Just recently a person with complex psychosocial disability had a planning meeting over the phone without the involvement of any other supports from family or services. On hearing she had been accepted for the NDIS, the advocate offered to meet to support her with preplanning and to attend her planning meeting. She was happy to accept the offer of support and met face to face with the advocate to prepare for her planning meeting. Within a few days of this we contacted her again to ask if she had heard when her planning meeting would take place. She advised AMPARO that she had received a

NDIS plan in the mail, she reported to the advocate that she was not aware that she had participated in a planning conversation.

This level of confusion when planning meetings occur over the phone is commonplace unfortunately. AMPARO is now having to ask for an urgent review of her plan which is has limited hours of core support and inadequate support coordination.

AMPARO Advocacy would like to thank the Queensland Productivity Commission for the opportunity to provide this submission to highlight key barriers preventing people from CALD background with disability accessing and participating in the NDIS. AMPARO would also like to submit the attached reports as part of this submission.

Yours sincerely

Maureen Fordyce
Manager



53 Prospect Road, Gaythorne, QLD 4051
PO Box 2065, Brookside Centre, QLD 4053
phone 07 3354 4900 fax 07 3355 0477
email info@amparo.org.au
web www.amparo.org.au
ABN 56 876 279 925

Mr Martin Hoffman
CEO NDIS
ceo.office@ndis.gov.au

Dear Mr Martin Hoffman

AMPARO Advocacy is a non-profit community organisation which provides independent, individual and systemic advocacy with and on behalf of vulnerable people from culturally and linguistically diverse (CALD) backgrounds with disability. The majority of individuals that AMPARO works with are from a refugee background experiencing multiple and complex layers of disadvantage and have generally missed out on accessing specialist disability services, including early intervention for their children. They are often marginalized, and isolated from their own communities and have fallen through the gaps.

Since January 2018 AMPARO has provided intensive support to Queenslanders from new and emerging communities and refugee backgrounds to access the NDIS in the Brisbane, Logan and Strathpine areas. AMPARO has witnessed the enormous difference the NDIS can make in people's lives when they are well supported to navigate this complex new system.

Our experience is that individuals and families require culturally appropriate support through each step of the process: from accessing affordable allied health or specialists assessments, to making access requests and undertaking preplanning, to effectively participating in the planning process and to connect with appropriate service providers.

However we are also aware of the many obstacles and barriers that people experience in accessing and participating in the NDIS, including the prohibitive cost of new assessments that are required by many for access. Without targeted culturally appropriate engagement and specialised assistance, many individuals from a CALD background with disability and their families have either:

- not submitted an access request to the NDIS
- had their NDIS access requests rejected, often due to lack of evidence
- received poor plans that cannot meet their needs, or
- not been able to implement their plans, due to receiving inadequate or no funding for support coordination.

AMPARO would like to draw your attention to why having access to preferred on-site interpreters is critical to facilitating accurate communication and effective access and participation in the NDIS for people from CALD backgrounds with disability.

The current NDIS information on accessing interpreters refers to the participant's right to request a specific interpreter when issues of confidentiality and continuity of care are a concern for them or their families. Due to issues of confidentiality and stigma attached to disability in some communities, many people with disability and/or their families prefer to use a specific interpreter they have had previous contact with and trust. However in practice this is difficult to do.

The memorandum of understanding developed between the NDIA and TIS National does not address the difficulties experienced when requesting a specific interpreter. This process is administratively time consuming and cumbersome, with TIS National often refusing applications for a specific interpreter or those making the booking giving up because the process is so difficult.

As the NDIS and NDIS service providers can only use TIS National for interpreting this is a highly significant and concerning issue for many for the following reasons.

The Importance of Having Access to Preferred On-Site Interpreters

- i) **A core tenet of the NDIS is 'choice and control'. The NDIA's website clearly states that '*participants control the support they receive, when they receive it, and who provides it*'. TIS National's policy of refusing to allow the majority of participant's choice when booking an interpreter conflicts directly with this guiding principle of the NDIS.**

This in itself should be sufficient grounds for participants to be able to choose their preferred interpreter, but there are also many other reasons why a participant's choice of interpreter should be respected.

- ii) **CALD communities are often very small with many in the community knowing each other well. For many from CALD communities there is considerable stigma around disability and mental illness which results in a real fear of their personal information being shared within their community. Participants may have real and or perceived concerns about breaches in confidentiality and wish to ensure that highly confidential information regarding themselves and family members is not shared within their community.**

AMPARO worked with one young man from a small community who had previous experience of working with untrustworthy interpreters who had shared information about him within his community. As a result of this he was not prepared to speak in front of people that he didn't fully trust. Fortunately we knew of three interpreters that he trusted and were able to request one of the three for each meeting.

For someone else who was highly fearful about having information shared within the community, and had previously refused to engage with interpreters despite having little English, AMPARO was able to recommend a highly respected and trusted interpreter who spoke the same language but who was from a different community.

- iii) **When people are not confident that their privacy and confidentiality will be protected, or they do not want to share their very personal information with yet another member of their often small community, significant and important information will not be shared. This is likely to result in poor planning, inadequate funding and inappropriate service provision.**

Following a recent planning meeting the advocate received a phone call from the participant informing her that he had been unable to share significant information regarding required supports with the planner, due to the interpreter being well known to the person, and to the interpreter having discussed his issues with community members in the past. Had he been able to use his preferred

interpreter this would not have happened, and the planner would have been given a much more accurate account of his support needs.

Often it is clear that the person is struggling and in need of significant support, however the advocate / worker is unable to establish the extent of the issues or the supports required without the assistance of an interpreter. Developing a relationship with the person based on respect and trust is often necessary before the individual will trust the interpreter that has been recommended by the advocate.

- iv) **During the pre-planning and planning meetings and at meetings with NDIS service providers, highly confidential information is shared again and again, often in the participant's home. It is much easier for people to have this information shared with one or two trusted interpreters rather than with a large number of different interpreters from within their community.**

AMPARO advocated for a Sudanese man with psycho-social disability who had no evidence of the impact of disability to help with access to the NDIS. As is the case with most individuals we assist, AMPARO needed to engage an interpreter to ensure accurate communication with the person and their family member and other professionals and through each step of the process.

This included following:

- For the OT to conduct a functional assessment
- With his psychiatrist to access a psychiatric report
- To complete his NDIS Access Request Form
- To write and lodge an NDIS Access Review
- To explain his NDIS Plan to him
- To meet with a potential Support Coordinator.

Much of the same material was revisited at each meeting. Working with one known and trustworthy interpreter over time, the man and his mother began to trust the advocate and interpreter and was gradually willing to provide more stressful and private information. This was critical to ensuring appropriate supports were provided in his NDIS Plan.

- v) **Interpreters who have worked with the person for some time, develop a good understanding of the context of the discussions, which makes the need for repeated clarification of points less likely. With new interpreters information usually has to be explained in more detail, and often clarified, to ensure the interpreter understands the point that is being made.**

This was certainly the case in the above example. Over several meetings the interpreter gained a good understanding of the issues involved and thereby sought less clarification and was able to interpret more accurately.

- vi) **On a practical level, using a preferred interpreter enables the worker to arrange a meeting with relevant parties at a time when an interpreter is known to be available, and willing to travel to the meeting location. If meetings are arranged and then an interpreter requested, frequently there can be no on-site interpreter available.**

This has been a particular problem for families living outside the central Brisbane region; with plenty of work available more centrally interpreters do not opt to pick up jobs further afield as they are not paid travel time or costs. When first working with a family in Redlands, three meetings had to be cancelled before the interpreting service was willing to offer to fund travel time and costs and provide an interpreter for a critical meeting. Now the advocate checks the availability of interpreters who

are known to be willing to travel to appointments prior to making the booking. Likewise, no interpreter was available to travel to a planning meeting at Browns Plains, despite several weeks' notice.

- vii) **There is a huge variation in quality of interpreters. For those with a disability who may have difficulty expressing their wishes and concerns, or find this process very stressful, it is vital that they have access to NAATI certified and experienced interpreters who provide a respectful and supportive service.**

Where AMPARO has worked with interpreters with individuals and family members, we have had feedback that information is not always interpreted correctly, that the interpreter may speak a different dialect or that people can feel rushed. It has been reported that some people have even felt denigrated by the interpreter. Recently during a two hour meeting we had thought that important information had been shared accurately, however at a follow-up meeting with a different interpreter it became clear that it hadn't and the material had to be revisited.

At an NDIS planning meeting for a young woman from Iraq, the phone interpreter from TIS was so poor the phone call had to be terminated, and a replacement interpreter requested.

At another NDIS planning meeting the interpreter spoke so softly the family member could not hear. On another occasion it was obvious that the phone interpreter was driving at the time of the call and not focused on the conversation. On another, the phone interpreter had only expected a short call and informed us after 10 minutes that her battery was low and that we'd have to call TIS for a replacement interpreter.

- viii) **The use of telephone interpreters at lengthy meetings such as planning meetings, makes open and detailed discussion of functional impairment and support needs impossible. Likewise, phone interpreters should not be used for functional and medical assessments, nor for occupational or speech therapy and counselling sessions, where discussions are complex and where body language and facial expression are crucial to understanding what is being said. If such appointments can be scheduled for when a good on-site interpreter is known to be available, such appointments do not need to be cancelled and rescheduled due to lack of interpreter availability, and inappropriate fill-in phone interpreters do not have to be relied upon.**
- ix) **In exceptional circumstances TIS has agreed to provide preferred interpreters where 'continuity of care' can be proven. While AMPARO welcomes the recognition of the need for preferred interpreters, often it is not possible for a participant to provide such evidence.**

People require interpreters in a variety of settings and may well not be able to get proof of continuity of care. For example, they may know of interpreters from hospital or GP appointments, or from meetings with services they no longer use.

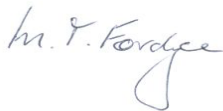
Also, participants may wish to use interpreters that come recommended as professional and trustworthy by a third party who they already trust. AMPARO's experienced advocates have worked with a wide range of interpreters over many years. While most are highly professional and trustworthy, unfortunately a significant number are not. Engaging those that are well respected ensures that people with limited English are able to share their wishes and concerns clearly and accurately in a safe environment and get the most out of their meetings with the NDIA, Carers QLD and service providers.

It is therefore crucial that participants are able to request their preferred interpreter should they wish to do so, and that on-site interpreters are engaged for all detailed and complex conversations.

Should TIS National continue to be unable to provide preferred interpreters except in all but the most exceptional of circumstances, it is essential that the NDIA, LACs and service providers are able to access interpreters through alternative interpreting services who acknowledge a participant's right to choice and control and are willing to book preferred interpreters as requested

AMPARO Advocacy and our allies whose logos are below, hopes that the detailed information presented here provides adequate justification for simplifying current processes for requesting specific interpreters under the NDIS. Should further clarification be needed please do not hesitate to contact me.

Yours sincerely

A handwritten signature in cursive script, appearing to read 'M. Fordyce'.

Maureen Fordyce

Manager

Two lines of blacked-out text, likely redacting contact details such as a phone number and email address.





**JOINT STANDING COMMITTEE ON THE
NATIONAL DISABILITY INSURANCE SCHEME**

6 September 2019

NDIS Planning

*53 Prospect Road, Gaythorne, QLD 4051
PO Box 2065, Brookside Centre, QLD 4053
phone 07 3354 4900 fax 07 3355 0477
email info@amparo.org.au
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ABN 56 876 279 925*

INTRODUCTION

AMPARO Advocacy is a small non-profit community based organisation which provides independent, individual and systemic advocacy with and on behalf of vulnerable people from culturally and linguistically diverse backgrounds (CALD) with disability. We welcome this opportunity to provide feedback to the Joint Standing Committee in relation to NDIS Planning.

AMPARO is governed by a voluntary management committee the majority of whom are themselves people from a CALD background with disability and is funded by the Queensland State Government Department of Communities, Disability Services and Seniors. AMPARO Advocacy's vision is for people from a CALD background with disability are accepted and respected as part of the diversity of Australian society, with access to information, services and benefits, so that they can be included, participate and contribute in family and community life.

AMPARO's advocacy addresses issues of social and economic isolation, unfair treatment and discrimination. We represent those who are least able to defend their own interests, and who may not have close family or friends who can support their aspirations or speak on their behalf.

The majority of individuals that AMPARO works with are from a refugee background experiencing multiple and complex layers of disadvantage and have generally missed out on accessing specialist disability services, including early intervention for their children. They are often marginalized, and isolated from their own communities and have fallen through the gaps.

Since January 2018 AMPARO has provided intensive support to Queenslanders from people new and emerging communities and refugee backgrounds to access the NDIS in the Brisbane, Logan and Strathpine areas. AMPARO has witnessed the enormous difference the NDIS can make in people's lives when they are well supported to undertake preplanning and to navigate this complex new system.

CALD PARTICIPATION RATES AND ADDITIONAL BARRIERS

However we are also well aware of the many obstacles and barriers that people experience in accessing and participating in the NDIS. The latest NDIS Quarterly Report for June 2019 shows a slow increase in the numbers of NDIS participants from a CALD background..

The NDIS estimates that nationally approximately **20%** of participants should be from a CALD background, and at the state level, **15%** of Queensland participants should come from a CALD background. In examining the most recent data, there is clearly a need f

However the active participation rates of people from CALD background as of the June 2019 Quarterly Report to CAOG are:

- Nationally – **8.4%**
- Queensland – **5%**

These rates are reflective of a number of issues, foremost is the failure of the NDIS to prioritise and adequately resource the implementation of the ***Cultural Linguistic Diversity Strategy 2018***. It is imperative that the NDIS develop and implement targeted access and equity measures to address current barriers in the system as a matter of priority, to increase participation levels.

Through our work we have identified several factors that impact on whether CALD Participants and their families are able to effectively participate in NDIS planning processes and whether as a result they receive a plan that is comprehensive with the appropriate supports to meet their needs.

1. Pre-Planning Issues

1.1 Lack of pre-planning support and information

Critical to a participant receiving a good NDIS plan is the pre-planning process, and for people and their families from CALD background this is often not available. Most people from a CALD background have not previously been accessing or connected to specialist disability services and have no access to preplanning support.

They usually will have no assistance to think through what their needs for support are and what supports and strategies will help them to achieve their goals. This means they often attend NDIS Planning sessions with little idea as to what supports, capacity building, therapy or equipment they would benefit from receiving.

Once a person receives access to the NDIS, they are sent NDIA documents that are intended to help them to plan for their planning meeting. The NDIA has translated this information into some languages, but there are few resources translated into languages of new and emerging and refugee communities. Furthermore many individuals have had limited or no access to education in their countries of origins and are not literate in their own language. Without direct support to explain information in these documents they are of little value.

However through our work AMPARO Advocacy has been able to meet participants from a CALD background with disability and/or their family and with the certified interpreters have face to face discussions to provide important information, answer their questions and assist with preplanning. All of the individuals and families we have worked with required significant support in the preplanning process to:

- Understand their rights
- Explore what a good life for a person with disability can look like
- Understand the opportunities available under the NDIS
- Identify their specific needs for support/ therapy/ equipment/ capacity building
- Understand complex terms and language of the NDIS.
- Document this information to take to their planning meeting

1.2 Processes to arrange planning meetings do not meet the needs of participants and their families from CALD backgrounds

Unfortunately process the NDIS and LACs are engaging in to arrange planning meetings is not meeting the needs of CALD participants. NDIA and LAC planners will not leave a message for a participant or family member if they don't answer the phone, unless the family has included their surname on their voicemail message. The individuals and families from CALD backgrounds we work with usually have a generic voicemail as they may not know how to do create their own message or may not have adequate English proficiency. Therefore they rarely have a message left by the NDIA to advise them of their planning meeting. Additionally planners will attempt to contact the person three times, so when they haven't been able to reach the person, the result is that people from CALD backgrounds with disability are falling through the cracks and without additional support, not accessing the NDIS.

2. NDIS Planning Issues

2.1 Planners not understanding the right to advocacy and benefits of their involvement.

Unfortunately, there were several instances where planning meetings were held without the advocate from AMPARO being informed or invited to these meetings despite being listed on the Participants file with their consent, as a 'contact person' and someone to be invited to the planning meeting.

In instances where this happened participants did not receive a plan that met their needs, receiving less core support and either limited or no support coordination. Some planners are welcoming of the involvement of advocates when consent has been provided, however some appear to have little understanding of people's right to advocacy support and less appreciation of the value of the advocate's involvement for the person. When the advocate asked the LAC why they hadn't been informed of or invited to the participant's planning meeting, the LAC stated that: "*they didn't need an advocate, the planning meeting went well*", contrary to this assertion the person's plan had inadequate core support and no support coordination.

2.2 Planning Meetings or Pre-planning meetings?

A major confusion for many Participants has been the use of language by LAC's in referring to planning meetings as "pre-planning meetings". This meant some participants did not recognise the importance of this meeting and were not sufficiently prepared, as they believed it was not their official planning meeting. AMPARO Advocacy has been in discussion with both the NDIA and Carers Queensland about this issue and understands that Local Area Coordinators (LACs) have been advised by the NDIA not to refer to planning meetings as pre-planning meetings, because of the confusion that this causes.

2.3 Accurate communication and the need to engage Interpreters

NDIS Planners and LAC's often have to be reminded by AMPARO of their obligation to book onsite NAATI certified interpreters for planning meetings when this is needed. Most individuals we work with require this language support for effective communication.

Prior to May this year, requesting a face to face interpreter for planning meetings was extremely difficult, however since the NDIS has updated their processes and information regarding participant's rights to access interpreters, AMPARO has found this has improved. Unfortunately however the NDIS has not widely promoted these improvements and new information, NDIA staff, LACs and Early Childhood Early Intervention (ECEI) services often require prompting to provide onsite interpreters. Staff have often not had any training in knowing how to engage and work effectively with interpreters and regularly provide inaccurate information on this process to participants, and their families. They are often unaware of their obligation to have plans translated into the person or their family's language if this is required, citing that this is "not possible".

New NDIS information on language services refers to the right of participant's to request specific interpreters when issues of confidentiality and continuity of care are a concern for them or their families. Due to issues of confidentiality and stigma attached to disability in some communities, many people with disability and/or their families prefer to use a specific interpreter who they have had previous contact with and trust. However in practice this is difficult to do.

The NDIS and TIS National have developed a memorandum of understanding to provide access to interpreters for NDIS participants, however the process to request a specific interpreter

through TIS is administratively time consuming and cumbersome. Because of this we have found LACs can be reluctant to do this, even when requested by the person, their family or advocate. This can make the planning meeting an even more stressful experience for the person with disability and/or their family member as they may be asked to share very personal information with a new interpreter that they lack confidence in.

2.4 Plan Decision Maker Not Present at Planning Meetings

The planning process is a question and answer session, conducted over a two hour period, by an LAC or NDIS Planner. When a LAC conducts the planning meeting, they see themselves as an information gatherer and report that unfortunately do not have the final say on whether or not their recommendations for support are approved. It is the planner from the NDIA who approves the participant's plan despite never having met the person with disability and or their family.

We see this as a significant flaw in the system, as they do not hear directly from individuals about their needs for support in the different areas of their life. Despite this they are charged with making powerful decisions about the types of supports the person with disability needs and often refusing requests for support coordination even though without this, participant's plans are not being implemented or implemented poorly.

2.5 Lack of support coordination in participant's plans

- It is AMPARO's experience that many LACs are reluctant to argue for support coordination in Participant's plans, as they may not have knowledge had experience in working with people from CALD or refugee backgrounds, to fully appreciate the needs of this cohort.

LACs regularly justify why the person doesn't need support coordination, stating that they can help the person /family to implement their plan. Unfortunately AMPARO has not seen good evidence of LACs providing the necessary time and culturally appropriate support that is required to effectively implement plans, and find many people are disadvantaged by LACs limited capacity to do this work well.

The NDIA are also allocating much less in core support than has been justified as necessary in planning meetings, that they have not participated in. Where the planning meeting is held with an NDIA Planner this seems to occur less and there it appears that support coordination is better understood as important and often necessary. However LACs seems to predominately undertake planning and often people receive inadequate or no support coordination and generally expending any that they may receive in their plans well be a review is due.

- **Children from CALD backgrounds** who are accessing **Early Childhood and Early Intervention (ECEI)** services are generally not receiving support coordination to ensure their plans are being implemented. AMPARO receives requests to assist families to implement plans for their children, however we do not have funding to support this work. ECIE workers advise that they only receive 10 hours over 12 months, to meet with the child and their family, develop a plan and provide assistance to commence implementation. If you factor in working with an interpreter for all communication, this equates to a maximum of 5 hours per year. This is unfair and fails to recognise the additional language and cultural needs of these children.

AMPARO's previous experience with children accessing Better Start for Children with Disability and early intervention support through Commonwealth programs was that funding was often unspent by the time the child turned seven, and they missed out on important support, therapy and equipment. This was because they did not receive the intensive support they required to understand what supports were important or how to access them. Similarly this is happening for children under the NDIS.

2.6 No opportunity to see the draft plan and provide feedback to the NDIA

Furthermore in the current planning process there is no opportunity for the participant or their family to examine a draft plan and provide feedback before it is finalised.

In AMPARO's experience it usually takes many visits to get to know a person well, and to gain a good understanding of their disability, support needs and aspirations for a good life. Advocacy goals are developed with individuals and their families over several meetings and produced in draft format, to be discussed and agreed at a follow up meeting, to ensure that the information that we have is accurate.

The NDIA should immediately adopt at a national level, the process of providing a draft plan to the persons and their family for comment and feedback, before the plan is finalised.

2.7 Experience and expertise of planners

Questioning techniques vary considerably between planners, often with yes / no options, such as '*Do you have the ability to go to a festival?*' and '*Are you fine with reading and writing?*' Little understanding is gained by these questions as to how much support someone would need to attend a festival, or whether someone has a good understanding of a simple or complex text. There appears to be a vast difference in the competencies and expertise of planners and this leads to the quality of plans varying greatly. There is often no consistency in approaches and assessments and it is clear that some planners have had little or no experience in working with people from CALD backgrounds with disability. Many planners have no experience or knowledge of how to engage and work effectively with qualified interpreters.

2.8 Planner Preparation

The NDIS often has information and reports already on file about the person with disability, but these have to be supplied again at the planning meeting. Many people would not know that they have to show these reports again, which may reduce the level of funding that they receive if they fail to provide the LAC or Planner with a hard copy.

2.9 Location of Planning Meetings

Many planning meetings have taken place in temporary offices, with little or no roadside or external signage to indicate where the offices are. Temporary computer networks had been established, which frequently dropped out throughout the assessment process. As the NDIA was not willing to conduct planning meetings in people's homes, some people with significant disabilities had to travel long distances by public transport to their planning meetings.

3. Review Process

3.1 NDIS Access Reviews and Reapplications

The system is very complex to navigate and difficult for people with disability and their families from a CALD backgrounds. AMPARO has assisted several people with disability from CALD backgrounds who had previously had their access requests rejected by the NDIA to reapply. In some circumstances this was despite evidence being submitted previously that demonstrated the person met all requirements for support from the NDIS, others required additional assessments and proof of the impact of impairment on their functional capacity.

On their own individuals and families would not have been able to pursue a review of the NDIA's decision, nor would they have completed a new access request, despite their significant unmet needs. They required intensive support to successfully complete a new access request, including support to access assessments with allied health, psychiatric or psychological assessments, collate reports and provide this evidence to the NDIS. An additional stumbling block for individuals was the justifications given by the NDIS for denying access, which were generally vague and confusing and difficult for a person to understand.

3.2 Lengthy wait times and risks of receiving less funding

Another difficulty that people from CALD backgrounds with disability and/or their families face is the length of time it takes to receive an outcome from a NDIS access review. If you submit an access review, the waiting time to receive a decision can be up to 10 months, which is an unacceptable delay.

AMPARO was advised by senior NDIA staff and our experience confirms, that it is easier to get an access request approved by gathering further supporting evidence and reapplying for access, than seeking a review. AMPARO has been successful with every individual we have supported to access the NDIS.

There is a risk that if you ask for a plan review because the amount of support a participant has received is not adequate, they may receive less funding than originally given. This is because a different planner looks at the plan and they may decide that the persons original funding does not meet their 'reasonable and necessary' criteria.

Many individuals did not receive the level of Support Coordination that was needed and in these situation it was better to contact the NDIS Planner or LAC and request a 'light-touch review' otherwise known as a 'soft-review'. This means that the whole plan is not reviewed, only the request for Support Coordination. Wait times for a decision after a formal plan review can be up to 10 months, which is an unacceptable delay.

Conclusion

The NDIS is a complex system that is largely designed and delivered to reflect mainstream practices and the NDIA has still not developed a pathway that can meet the needs of CALD participants and their families. Without targeted culturally appropriate engagement and specialised assistance, many individuals from a CALD background with disability and their families are falling through the gaps and either:

- not submitting an access request to the NDIS
- having their NDIS access requests rejected
- receiving poor plans, or
- not implementing their plans at all or effectively.

There is a need for funding to assist people from with a CALD background with disability access the NDIS and effectively navigate its pathway. Every individual and family that we assisted would have had extreme difficulty in accessing the NDIS without the added assistance of AMPARO Advocacy.

AMPARO Advocacy thanks the Joint Standing Committee for the opportunity to provide input into the inquiry into NDIS Planning and hopes the information in this submission is able to influence positive changes in areas where obvious improvements are necessary.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'M. Fordyce', with a stylized flourish at the end.

Maureen Fordyce
Manager
AMPARO Advocacy



TMSG

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