



## **Queensland Program of Assistance to Survivors of Torture and Trauma (QPASTT) second submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.**

**April 2022**

Please note: This submission was initially made to the Commonwealth Joint Standing Committee on the NDIS Inquiry into Current Scheme Implementation and Forecasting of the NDIS (February 2022). QPASTT was invited to share this submission of our and our clients' experiences of engaging with NDIS, to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Royal Commission). QPASTT welcomes the opportunity to do so, recognising that the NDIS is a significant part of life for many people with disability. This submission compliments the initial submission QPASTT made to the Royal Commission in August 2020.

## About QPASTT

*We believe that to heal is a human right.*

The Queensland Program of Assistance to Survivors of Torture and Trauma (QPASTT) is a specialist, community-based, state-wide, not-for-profit organisation established in 1995 to support the recovery of refugee survivors of torture and trauma. Our purpose is to nurture meaningful futures by assisting people from refugee backgrounds to heal, belong and thrive in a just Australian community.

QPASTT strategic priorities are embedded in our logo:

- **Healing** the past – supporting survivors’ recovery across mind, body and spirit;
- Building **belonging** to people, place and culture so that survivors can feel safe – safety is vital for healing;
- Nurturing **thriving** futures by ensuring that individuals and families from refugee backgrounds experience positive social and economic conditions so that the risks of intergenerational trauma can be reduced; and
- Seeking **justice**, empowering services and local communities to overcome barriers to the aspirations of survivors of torture and trauma.

We work with survivors of all ages, with families and communities. Our services to support the recovery of survivors are evidence-based, trauma-informed and culturally appropriate. Our services include counselling, advocacy, group work, community development initiatives and sector development.

Last financial year, QPASTT supported 6207 clients from 82 countries of origin. Almost 30% of our clients are children and youth. Approximately 14% are people who are seeking asylum. We ran 188 group activities involving 2417 participants. We engaged in counselling and youth mentoring support with 1637 individuals. Jointly with Multicultural Australia, QPASTT facilitated quarterly gatherings for community leaders from Queensland’s refugee communities. We also conducted 98 training sessions with practitioners from agencies throughout Queensland to build their understanding of refugee trauma.

We currently employ 87 staff as well as casual bicultural workers with refugee lived experience. We operate throughout Queensland with offices in Brisbane, Logan, Toowoomba, Townsville and Cairns.

As a specialist agency, our primary focus is refugee trauma recovery. This means that all of our passion, energy and focus is invested in delivery responses that support people from refugee backgrounds to heal.

QPASTT is the Queensland member of the Forum of Australian Services for Survivors of Torture and Trauma (FASSTT).



## QPASTT Experience of Disability

QPASTT welcomes this opportunity to make a second written contribution to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. The quality of and equitable access to disability support services is a significant issue for many of the clients and communities we work with, as this has an enduring impact on quality of life, wellbeing and contextual factors contributing to recovery from trauma.

The report highlights the limited successful engagement of our clients with the NDIS. We also draw attention to the ineligibility of those in our community who are not permanent residents, such as people seeking asylum and those who have only been granted temporary protection visas, however may have already lived in Australia for 10 or more years. It is QPASTT's experience that the majority of people seeking asylum and those on temporary protection visas fear they will never be able to safely return to their country of origin. And yet they remain eligible for a number of social supports, such as NDIS, diminishing their wellbeing and quality of life.

The following summary illustrates our experience in working alongside people who are engaging in trauma recovery support and managing disability. Please note that this data reflects our counselling clients only, as we record detailed information of trauma symptoms, physical and psychological functioning for clients engaged in counselling programs.

- In December 2021, approximately 18% of current counselling clients have been assessed by their QPASTT counsellor as having an intellectual, cognitive, neurological, sensory or physical disability.
- As a trauma recovery agency, we do not assess presence or absence of psychosocial disability as is proscribed by the NDIS. However, as a trauma recovery service it is highly likely that the majority of our clients experience functional impairment due to mental illness/trauma. As a rough indicator, about 25% of current counselling clients have been engaged in counselling either continuously for at least 5 years or with a break and return to counselling in the past 5 years.
- Therefore the proportion of QPASTT counselling clients that are likely to have a disability as per NDIS definitions, including psychosocial disability, is likely to be far greater than 18%.
- Yet only approximately 3% of current counselling clients in total are known to be NDIS participants.

This data alone would indicate significant issues with equity of access to the NDIS regardless of experience once being deemed "access met" and receiving support. QPASTT does recognise that when people do get access to the NDIS and receive high quality support appropriate to their needs, this can have a profound and positive impact on quality life and wellbeing.

QPASTT has invested time and internal resourcing to understanding why access to the NDIS is so challenging or unavailable for our clients in the following ways:

- Staff completed a comprehensive internal survey to provide information of 69 individuals with a disability they are working with;
- Broad review of client data across our service interventions; and



- Deeper exploration of individual experiences through staff interviews of client experience.

We are sharing the feedback and issues raised by clients, community members and staff in the hope that this will contribute to improvements within the NDIS that will lead to people from refugee background enjoying the same equity of access as other members of the Australian community. The case studies in this submission have had identifying information modified to respect our clients' privacy.

# Responding to Inquiry into Current Scheme Implementation and Forecasting for the NDIS Terms of Reference

## Impact of boundaries of NDIS and non-NDIS service provision

Community based mental health and disability supports outside of the NDIS have been under significant demand, more so since COVID-19 pandemic commenced in 2020. This has also coincided with the transition out of supports available through final decommissioning of Partners in Recovery (PiR) and Personal Helpers and Mentors (PHaMs) which allowed a suite of flexible supports tailored to needs of individual without having to fit a fee for service model. While the support services offered may be similar, situating NDIA services within an insurance scheme with high front end administrative and screening in processes that results in a market based approach to service delivery has the following implications:

- Applicants are required to gather an extraordinary amount of “evidence” to prove their disability and impairment
- Once deemed “access met” NDIS participants need to master financial literacy of the fee for service system.

These two points will be explored in detail using data and client case studies from QPASTT service delivery experience.

## Gathering evidence of disability and functional impairment

Gathering of evidence, particularly diagnosis and functional assessment reports is time consuming and frequently expensive. In some cases and locations across Queensland, a culturally competent and appropriately skilled professional who can complete the functional report, does not exist. QPASTT staff have reported that inability to get evidence of disability or obtain a functional assessment is the greatest barrier to applying for NDIS (see below).

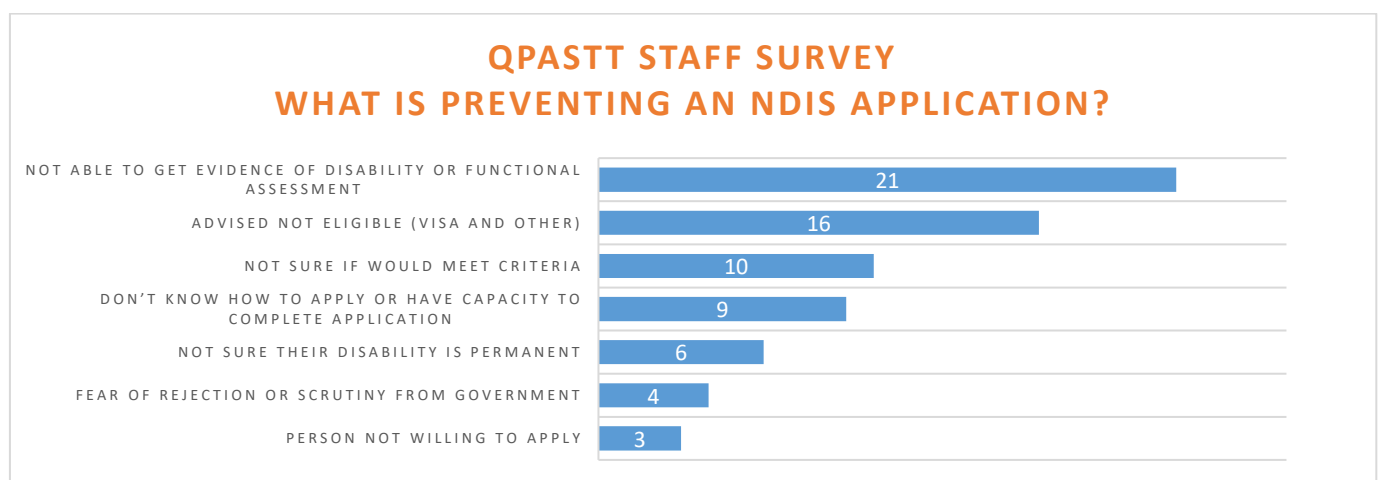


Figure one: What is preventing an NDIS application?

To gain appropriate evidence, individuals are generally reliant on bulk-billing or publicly funded practitioners. Where available, waitlists are long and in some cases people are waiting years to be able to complete necessary assessments for an NDIS application (see case study below).

*Case study - 40 year old single mother of 6 children from African descent who has been living in Australia for 20 years. She has a physical disability and intrusive symptoms of PTSD.*

*She has a chronic back condition which impacts on her mobility and her ability to complete daily living tasks to support herself and her family. In counselling sessions, client tends to rock back and forth to ease the pain while sitting and has to schedule appointments which allow time to rest adequately in between walking and catching a bus. She is unable to get work because she cannot sit or stand for prolonged periods of time without moving/ lying down/ resting. Pain medication that manages the pain is so strong it causes client to become drowsy and so she does not feel able to take this when her children are awake and so only, rarely, takes it at night before sleep and even then worries she will not hear children if they need her, so mostly she avoids taking medication completely. The GP has assessed that surgery may temporarily ease the pain but that the back (disc) issue is permanent. Client would benefit from mobility aids/ physiotherapy/ support with care for children and home tasks.*

*Client is of the understanding her GP is aiming to apply to NDIS on her behalf but she reports the tests are taking a long time to get through and COVID has impacted this timeline significantly. As a secondary issue, the GP is hoping client can obtain a psychiatric report to assist the NDIS application by also highlighting the effects of torture and trauma as part of the clients refugee experiences. Due to the combination of pain and flashbacks/nightmares/ hypervigilance the client rarely sleeps for a full night. Client cannot afford a private psychiatric assessment and is reluctant to save for this for fear of taking money away from children (food/school resources) to potentially be rejected in her claim.*

In the case of evidence for a psychosocial disability, individuals are commonly reliant on primary and tertiary mental health supports, namely public hospital psychiatrists and mental health acute care teams to provide evidence for a psychosocial disability application. Registrars change frequently, are overworked and do not have the capacity to complete NDIS application forms. Access to ongoing bulk billed psychiatric care is exceptionally rare, yet meeting evidence thresholds requires evidence of unsuccessful treatment despite compliance to treatment plans.

Even after accessing emergency mental health treatment and ongoing acute care, people from refugee backgrounds can struggle to access services or receive service that responds to the complexity of trauma, disability, cultural and language differences. Notwithstanding the broader quality of life experience of people seeking help, the competence to respond to the complexity of factors that intersect in the experience of disability prevents gathering sufficient evidence for NDIS applications. It is not uncommon for people to become exhausted and disillusioned with the amount of individual advocacy required to be understood and have their needs met.



*Case study – 50 year old woman of Asian descent with schizophrenia, with torture and trauma symptoms of chronic pain from injuries sustained in country of origin. Lives with her husband who is her primary carer.*

*The client experienced a psychotic episode after GP failed to consider mental health concerns that she was disclosing. After 10 days of hospitalisation, the client was discharged back to the care of the GP with monthly injections to be administered by the hospital based acute care team. Both the client and the carer have limited English language skills and frequently requested an interpreter during appointments at hospital, however an interpreter was not used during interactions. Due to this, the client and her husband mistakenly believed she was dying because they were not provided with adequate information in their own language. The acute care team initially believed that the client was mute because she did not speak during appointments. Rather, her reluctance to speak was due to unmet language needs and what her QPASTT counsellor has assessed as being acute discomfort at hospital and anxiety. The hospital based acute care team have declined to provide NDIS report as they do not recognise her trauma symptoms and state that injections are effectively preventing psychosis, and that her family needs to attend to her pain management needs and daily care. Her QPASTT counsellor sought guidance from LAC and despite initial expectations that she would be provided with assistance to complete NDIS application and gather evidence, this was later withdrawn. The client and her family are no longer willing to pursue an NDIS application as they are confused and very disappointed with their experience to date which has been extremely stressful.*

In addition to the issues raised in the above case study about the appropriateness of service response, QPASTT staff have also received queries from clients about the validity of GPs charging additional gap fees for the provision of NDIS letters or completing NDIS forms. A client has provided their counsellor with a photograph of the statement of fees that is displayed in the reception of their GP clinic which clearly states that insurance and NDIS paperwork requires payment of a fee in addition to the standard consultation fee. For people on limited incomes this is a further barrier or deterrent to pursuing an NDIS application.

Currently, there is a strong and rigid perception of thresholds to indicate permanent disability. While a degree of rigour is required in determining appropriate disbursement of public funds, people have the right to make decisions of informed consent or dissent to treatment. However, being deemed “non-compliant” to treatment is used as an indicator that the disability is not permanent, as treatment options have not been exhausted. Outside of the NDIS there is simply not the same quantity and quality of service supports for people with disabilities. If choosing not to consent with treatment effectively leaves vulnerable people without adequate supports in the community, this is a significant systemic failure. The case study below illustrates this issue.

*Case study: 60 year old woman of Middle Eastern descent who arrived to Australia in 2019. Physical disability with chronic osteoarthritis through her body. Lives with her husband who is her fulltime carer*

*The client is immobile - can barely move around house without assistance, cannot stand to cook or shower and requires assistance getting up and down, and with all personal hygiene. She lives in a second floor apartment and finds it very difficult to get down the stairs to attend appointments etc. She reported sometimes it is over two months between leaving the house.*



*She lives with an elevated state of emotional distress: she cries frequently about being separated from her children and weeps through every counselling session.*

*Her GP has recommended knee surgery which she is not willing to do because of the increased immobilisation after surgery and fears about the recovery period. She has subsequently been informed she is not eligible for NDIS because she is refusing treatment. She lives without disability aids and no daily support which is significantly impacting her husband's ability to attend English classes or look for work as he cannot leave her alone at home.*

Similarly, another QPASTT client has made two NDIS applications on the basis of psychosocial disability. Both applications were declined because the client is choosing not to take psychotropic medication for reasons of religious and cultural belief. This has created two barriers: firstly, the client is deemed as “treatment non-compliant” and secondly, there is no psychiatric report to accompany the application as bulk billing services are prioritised for individuals requiring medication.

QPASTT has also been advised that there are quite rigid criteria for evidencing permanent psychosocial disability of PTSD such as persistent symptoms after a complete treatment of EMDR, CBT or DBT. These three treatment approaches have performed well in clinical trials with mainstream population or military personnel, however have not been proven to be universally effective treatment programs to survivors of complex refugee trauma. As Queensland's specialist refugee trauma recovery service, QPASTT does not provide proscriptive treatment programs, rather our clinical work is determined in collaboration with our clients and driven by an assessment of their unique needs, experiences and understanding of their history and identity. Additionally, QPASTT staff have been advised by NDIS workers that trauma is “treatable” whereas psychosis is much harder to treat, therefore the evidence requirements for trauma based psychosocial disability are higher.

Similar to the reasons preventing an NDIS application, our staff report that the reasons NDIS applications are declined are based on failure to meet criteria and provide sufficient evidence (figure two below).

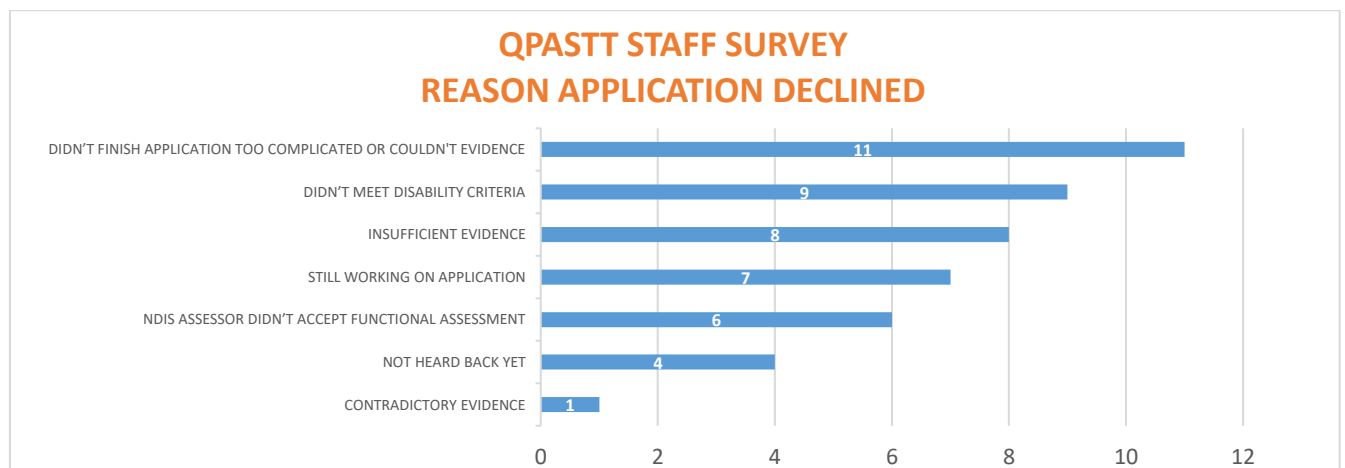


Figure two: Reason application declined

It is important to note that a large proportion of clients reportedly did not complete their application because it was too complicated or they couldn't get a functional assessment or other required evidence.



### *Assumed financial and service literacy*

The second issue identified in relation the boundaries between NDIS and non-NDIS service provision is the assumption that once someone has been deemed to be access met, they will have financial, service, or plan literacy. QPASTT has two examples of clients who, as NDIS participants, found themselves overwhelmed when it was assumed they would understand their package and how to use it. Both of these clients had funded support coordinators, however it was the support coordinators who failed to recognise the need to build a shared understanding with their NDIS client about their plan or how to use it.

The first client waited for several months for their support coordinator to obtain hearing aids believing that this was part of their package. However it became evident when their QPASTT counsellor made inquiries on their behalf, that the hearing aids were not part of the NDIS plan and needed to be obtained elsewhere. The clients NDIS support coordinator refused to arrange for the hearing aids as this was outside of the NDIS package, despite the fact hearing impairment was a disability recognised in the client's plan and the hearing aids would be an essential and life-changing device for the client. While waiting for the hearing aids, the client dropped out of TAFE due to anxiety and inability to hear in class. There has been no attempt by their NDIS support coordinator to identify alternative language education options despite learning English and/or AUSLAN being one of the client's plan goals.

Another client found their NDIS support coordinator to be very unhelpful throughout the process, and stated that "she [support coordinator] never got back to me", "was too rough" and used NDIS funds to buy equipment they did not want or use. When the QPASTT counsellor spoke with the support coordinator to clarify their contact with their mutual client, the support coordinator stated that the client "did not play the game". This comment was in reference to the client's understanding of the reimbursement system of NDIS funds, and indicates the support coordinator's frustration with the client's capacity to self-manage funds.

Overall, there is a high level of concern that if an NDIS participant does not fully utilise their plan, at point of review it will be assumed that they do not require the level of support budgeted and will experience a reduction in supports. However there are a multitude of reasons why a plan may be under-utilised.

While there can be periods of confusion, and QPASTT staff have shared anecdotal experience of client's NDIS plans changing without explanation. The following case study highlights how variable assessment of need and implementation of an NDIS plan can be.

*Case study – 35 year old single mother of four with an extensive trauma history, who experiences somatic pain, intrusive trauma symptoms and physical disability as a result of her refugee experience.*

*In September 2019 the client was receiving 5 hours of NDIS funded support per day. In December 2019, she reported that her support hours had been significantly reduced and she no longer had any support to attend appointments or to go grocery shopping. The client did not know why her hours had been reduced and expressed confusion regarding this. She was subsequently advised by her NDIS service provider in January 2020 that she had "used up" all her hours and would "need to reapply". The client was very distressed at this point and asked her QPASTT counsellor to intervene. After a series of phone calls and emails it became evident that there was a significant miscommunication between the client, the service provider and*




*possibly the NDIA. The service provider reported they repeatedly requested a review of the client's package and received no response from NDIA and through further investigation, there was no record of requests for review. Considerable time and effort was put into completing and submitting new OT functional assessment and an additional psychological report from QPASTT counsellor. As a result, the client's NDIS package has been increased significantly – she is now receiving 6 hours of support, 5 days per week. She has employed a female carer from the same cultural background who is very active in the ethnic community and has been supporting her to reduce her social isolation. The client reported improved mood, reduced fatigue, better sleep and less pain as she is also now receiving weekly physio home visits via NDIS.*

## **Variations between NDIS participants with similar needs**

### ***Barriers of language and stigma***

NDIA available data indicates that rates of CALD participation are low and slow, and CALD participants receive lower than average support packages. There are likely to be many reasons for these variations, including shame and stigma of identifying as a person with a disability and perceptions of family obligation to provide all care requirements for family members. Inconsistent use of interpreters when engaging in non-NDIS and NDIS services is a barrier to comprehensively understanding systems (for CALD community members) or for services and practitioners to comprehensively understand the experience and needs of individuals seeking assistance. QPASTT acknowledges that although there have been efforts made to make information and resources available in different media and different languages, there is significant variation in technical skill, literacy, and language spoken within the CALD community. As stated in the introduction of this submission, in the last financial year QPASTT has worked with people from 82 different countries of origin, many of whom speak languages that are not commonly provided in translated materials available. The table below lists the top ten countries of origin of our clients at three points in time in the past 25 years to indicate the changing nature of our client cohort over time.

## 📍 QPASTT client numbers and countries of origin

1996	2010	2021
 <b>110 counselling clients</b> from 18+ countries of origin 🌐	 <b>2675* clients</b> from 59 countries of origin 🌐	 <b>6207* clients</b> from 82+ countries of origin 🌐
<b>Top 10 countries of origin:</b> <ul style="list-style-type: none"> <li>• Bosnia/Herzegovina</li> <li>• Iraq</li> <li>• Iran</li> <li>• El Salvador</li> <li>• Somalia</li> <li>• Ethiopia</li> <li>• Croatia</li> <li>• Serbia</li> <li>• Laos</li> <li>• Cambodia</li> </ul>	<b>Top 10 countries of origin:</b> <ul style="list-style-type: none"> <li>• Burma (Myanmar)</li> <li>• Sudan</li> <li>• Afghanistan</li> <li>• Somalia</li> <li>• Iraq</li> <li>• Burundi</li> <li>• Sri Lanka</li> <li>• Congo (DRC)</li> <li>• Liberia</li> <li>• Ethiopia</li> </ul>	<b>Top 10 countries of origin:</b> <ul style="list-style-type: none"> <li>• Iraq</li> <li>• Iran</li> <li>• Congo (DRC)</li> <li>• Afghanistan</li> <li>• Eritrea</li> <li>• Sri Lanka</li> <li>• Syria</li> <li>• Burma (Myanmar)</li> <li>• Somalia</li> <li>• Ethiopia</li> </ul>

Source: QPASTT Annual Reports. \*Individual counselling clients and participants across group and youth programs.

We recognise that there translated resources in a 13 languages on the NDIS website<sup>1</sup>. The only common to the majority of our clients is Arabic. We also recognise that individuals can access TIS for verbal interpreting while communicating with the NDIS or service providers and that this is invaluable. Given the at times high levels of stigma in the community regarding disability, it would be extremely beneficial for interpreters to have access to resources that guide use of language that is factual and non-discriminatory. Such resources have been developed by sexual health services and are extremely beneficial to enabling clients to have respectful conversations about their needs and experiences (see TRUE Relationships and Reproductive Health interpreter training and resources for example <https://www.true.org.au/for-interpreters-translators>).

Stigma and shame can also be deeply personal and create barriers for people participating in NDIS application, planning and review processes. For survivors of refugee trauma a very common reaction is to have low levels of trust and disclose personal information slowly over time, once trust has been built with the practitioner. For many refugee trauma survivors, what they have experienced and the impact of those experiences on their lives, is deeply personal. It may take an extended period of time for someone to disclose the full nature of their needs. The brief assessment interview and planning meetings can be exceptionally intimidating.

*Case study – 45 year old man of Middle Eastern descent who arrived in Australia with his wife in 2011. He is vision impaired, suffers from epilepsy and has a diagnosis of PTSD and depression. He shares care of their two daughters with his wife and remains highly dependent on his wife for his own care.*

*He is an NDIS participant with vision impairment and epilepsy as recognised disability. Despite the supports provided by his NDIS package, he remains highly dependent on his wife to provide him with care and support as his plan is not adequate to meet his needs. He did not disclose details of his mental health needs during the NDIS assessment process, namely around the*

<sup>1</sup> Auslan, Arabic, Chinese (Simplified), Chinese (Traditional), Filipino (Tagalog), French, Greek, Hindi, Italian, Macedonian, Samoan, Spanish and Vietnamese.

*extent of his refugee related torture and trauma. As a result of torture, he has scarring on his body, and it is very difficult for him to accept personal care support from a carer. He was also sexually assaulted by male guards in the shower during his imprisonment, so it is particularly challenging for him to accept assistance with showering, have a male support worker or to participate in group activities with other men. Due to his epilepsy he suffers from urinary incontinence around three times per week during the night, which he stated he did not disclose during his NDIS assessment due to embarrassment.*

For another QPASTT client, the planning meeting has been triggering as NDIS staff involved were unfamiliar and the planning process was very focussed on finding goals. The client found this to be very similar to interrogation experiences and was so intimidating and caused such anxiety that they could not speak. While it was requested, their QPASTT counsellor was not informed of the planning meeting and would have attended to support the client to participate.

### ***Exclusion of people without permanent residence***

Returning to the QPASTT client data presented in the introduction to this submission, of the clients we know to have an intellectual, cognitive, neurological, sensory or physical disability (note not including psychiatric disability), approximately 35% do not hold permanent residence visas or citizenship and therefore are not eligible for NDIS regardless. This remains the most prevalent barrier to our clients accessing the NDIS. Following is a case study of a young man who is ineligible for NDIS because he is an asylum seeker, despite residing in Australia for 12 years.

*Case study – The client is a 19 year old young man who arrived in Australia from a Middle Eastern country in 2011. He has been diagnosed with a pervasive developmental disorder, has intellectual and neurological disabilities, and has limited speech.*

*In 2020, the client graduated from high school (special school). At this time he lost access to the speech therapy and occupational therapy supports provided during school. As a result, the client's QPASTT counsellor has observed that his verbal and sign language communication skills have notably declined. He is also no longer able to participate in meaningful social supports and activities as all services available and suitable require NDIS funding. Loss of access to supports as well as loss of meaningful activity was observed to have significantly impacted his mental health – he is bored, without meaningful activities and his social isolation is increasing as his communication skills decline.*

*He has also now lived in Australia for more than half his life. The country of his birth remains unsafe and is subject to a “do not travel” warning from the Department of Foreign Affairs and Trade due to “volatile security situation and very high risk of violence, armed conflict, kidnapping and terrorist attack”. Despite these pervasive risks, this young man and his family have not been found to be refugees through the protection claim process that the Australian Government modified in 2013 to deter people seeking asylum. Due to arriving in Australia by boat without a valid visa, this young man and his family are not able to apply for a permanent visa.*



The following case study is an example of a person who has sought asylum in Australia and while being found to be a refugee and owed protection, has only been granted a temporary protection visa and therefore is not eligible for NDIS.

*Case study – 50 year old single man of Middle Eastern descent who is paraplegic after contracting polio as a child and was unable to access appropriate treatment. He has type II diabetes, experiences chronic pain, experiences depression and traumatic stress and is extremely isolated.*

*The client arrived in Australia in 2013 and, after prolonged delays in processing of claims, in 2017 was found to be requiring protection from persecution and was granted a temporary protection visa. He lives alone and has limited support for daily needs. He has an extremely low income, frequently skipping meals because he cannot afford to eat. He is dependent on donations of charity for his wheelchair and cannot access regular pain management treatment. His physical disability in addition to his poor mental health are significant barriers to trauma recovery. He aspires to engage in education and employment, and to be able to have a richer social engagement with others.*

*Similarly to the case study above, his country of origin remains unsafe and he has no desire to return.*

### ***Inadequate NDIS service response and engagement – lack of cultural competence and understanding of complex disability***

When NDIS participants are found to be access met, the quality of engagement with NDIS service providers and staff can be poor, resulting in diminished outcomes for clients. These tend to be the result of one (or a combination) of three different issues:

1. Failure to use interpreters or provide appropriate language support;
2. Lack of cultural competence;
3. Lack of understanding of complex disability.

Failure to use interpreters is an issue experienced across a range of sectors, including health and disability. This is generally as a result of not knowing how to access and communicate with an interpreter, despite TIS being a funded support for anyone engaging with NDIS. However there is at times an unwillingness to use interpreters as it makes communication more complex or simply could be an expression of racism. At times, the failure to understand the significance of clear, mutually comprehensible communication is concerning: A QPASTT staff member with strong experience in disability and functional assessments was attempting to seek advice from a NDIS staff member regarding client presentations and needs, and was abruptly informed that “just because they don’t speak English, doesn’t mean they have a disability.”

The issue of lack of cultural competence is also pervasive, however is improved through training and organisational cultural shifts. In engaging with hard to reach communities, it is imperative for practitioners to understand core components of the NDIS being the experience of disability,



understanding of health systems, expectations of family and community, and perceptions of money is highly culturally influenced. And each individual has their own preferences, world view and identity which means that generalisations on the basis of ethnicity is also unhelpful. While cultural competence training has been mandatory for NDIA and NDIS contracted staff, it is not required for service providers who are engaging with people with a disability every day.

The following case study highlights a more concerning issue being lack of competence at understanding complex disability, which should be a requirement of NDIS staff and service providers.

*Case study - 45 year old woman of African descent, has significant intellectual disability, hearing impairment and is non-verbal. Her primary carer is her father.*

*The quality of this person's care and engagement with NDIS support coordinator is very poor. During her recent review, reviewer did not speak to her at all (only speaking to her carer/father). Her request for more support hours to cover weekends and the middle of the day was denied, despite her carer being elderly and increasingly struggles to provide informal supports. It is exceptionally difficult to find supports for this client due to her low developmental age. Paediatric services are required but many won't see her as she is an adult and/or say they don't use interpreters. Funded services are taking an extensive period of time to commence: Occupational Therapy (months) and Speech Therapy (waiting for over 12 months). There have been no attempts to engage client in social activities to the point she rarely leaves the house, except to go to the supermarket or the GP. Furthermore this family is living in a one bedroom property and the elderly carer sleeps on the living room floor.*

*As a result, despite being an NDIS participant, the client is very socially isolated and has not been able to learn social skills or gain confidence in speaking/ communicating. Her elderly carer is experiencing carer's fatigue: he does all of the cooking and cleaning, manages and takes her to appointments. He has no respite and had hoped extra support hours would be granted so she could be accompanied to social activities during the day and allow him some rest. All parties are very concerned about what will happen as he ages and is less able to care for his daughter.*

Limited understanding of psycho-social disability is also pervasive and concerning: A QPASTT staff member was discussing a mutual client with a support coordinator and was told that "she [the client] is a psychopath". The support coordinator went further to say "she is lying to us, she is so mean". Holding this derogatory opinion of an NDIS participant is undoubtedly going to influence the quality of the interaction between the client and the service provider.

Another client with a mood disorder/chronic mental illness has repeatedly reported to their QPASTT counsellor that they find it very difficult to contact their support coordinator and they frequently don't return calls. The client shared with their QPASTT worker that NDIS workers "don't care", "want to get rid of me", and "never call me back". The client has had multiple changes of staff in the past 7 months. The QPASTT counsellor's engagement with their client's NDIS providers over this time has, at times, been positive, but overall impression is that a number of NDIS workers found it hard to engage with the client, would blame the "difficulty and disengagement" on the client, and give up. Over these extended periods of contact, the QPASTT counsellor observed a lack of understanding of the impact of mood disorder and requirement for staff to be calm, consistent and patient. This has led the client to believe that nobody wants to care for them or make enough effort to stick around.



QPASTT also recognises that the above experiences are not universal across all NDIS participants and we remain optimistic that the recently released NDIS Psychosocial Disability Recovery Oriented Framework (2021) will influence a wider cultural change, and in particular, improve accessibility and quality of support. We are eager to see the principles within the framework being implemented at the front end of service delivery.

### **Measures to ensure transparency of data and information about the NDIS**

The volume of publicly accessible data on the NDIS is positive and allows a level of public transparency. While there is data available on the whole CALD participant cohort, it is not possible to explore what proportion of participants may be from refugee background as compared to migrants who are more likely to be part of well established, health literate and systems literate communities. In the case of CALD participants, a more detailed breakdown of demographics is required to inform which members of the CALD community are participating and who are not. The CALD community is broad in experience and in particular the experience of migrants as compared to people of refugee background is quite different. QPASTT has submitted an external research request to the NDIA to receive data that identifies the nationality, language spoken at home and entry details (if stated) and country of birth of participants. We are hopeful that this request will be granted in a timely manner, however would prefer that the NDIA take a proactive role in analysing this data nationwide and that it is made publicly accessible to inform the CALD Engagement Strategy. Given the continued low rates of CALD participation in the NDIS, QPASTT believes this would be a highly beneficial activity.





## Recommendations

### 1. Expand and extend the Community Connectors programs to vulnerable, underrepresented community cohorts

NDIS concepts and language are not always easily integrated into established models of recovery across allied health professionals and services, including QPASTT. This is despite most practitioners being trained to consider intersectionality of issues that impact on individuals' holistic social and emotional wellbeing, ability to lead a meaningful socially and economically engaging life. NDIS concepts, eligibility and requirements can be extremely complex for people from refugee background to understand and navigate.

QPASTT staff and clients have had very positive experiences with programs such as the Community Connectors pilot program. Such a program utilising to allow bi-cultural workers to provide culturally informed explanations of disability and NDIS has been highly beneficial. Community Connectors explored needs and experience with individuals from CALD backgrounds and most importantly, assisted in the gathering of evidence to support an application.

Gathering evidence requires health and systems literacy, and a strong understanding of NDIS framework, language and requirements. It is a time consuming process that also requires guidance to allied health professionals, including to services such as QPASTT, to ensure that the material provided meets NDIS evidence needs. To ensure equity of access to NDIS, Community Connector style programs need to be funded in a long term, if not permanent manner with sufficient time for organisations to recruit and train staff from a diverse range of cultural and linguistic communities.

### 2. Fund capacity building programs to increase financial literacy

There are limited numbers of participants from refugee background in the NDIS, however learning from the experience of First Nations Peoples, it can be expected that there will be reduced rates of plan utilisation compared to mainstream population. The small experience of QPASTT clients to date would indicate that this may be an increasing concern as more people from refugee background gain access to the NDIS. It is strongly recommended that community capacity building opportunities be made available to people from similar cultural and language groups to come together to increase their NDIS financial literacy skills to assist them to make best use of their NDIS plans. It is important to recognise that the use of money is highly culturally influenced, and peer learning is often much more effective in supporting people to learn about systems. Such a program could be delivered by services that may also run Community Connector programs.

### 3. Improve cultural and disability complexity competence

The case studies used in this submission strongly indicate the need for improved competency of service providers to provide culturally sensitive and disability complexity sensitive services, as well as competency in use of interpreters. Training of NDIA staff and NDIS contractors is a good start, however it is the service providers that NDIS participants interact with every day. Such training needs to be expanded to all service providers. Additionally, an operational plan of how the NDIS Psychosocial





Disability Recovery Oriented Framework will be implemented is required to ensure that the principles in the framework result in improved rates of access and quality of service for participants.

#### **4. Provide more detailed data on CALD participation in NDIS**

We believe that understanding who from within the CALD community is not accessing NDIS is essential information for the realisation of equitable participation of the NDIS in the future. More detailed breakdown of who is CALD (namely: nationality, language spoken at home, country of birth and visa details), rates of participation across states/territories, disability type and budget will give a more nuanced picture of which members of the CALD community are currently able to access the NDIS and the variation in funded supports. Release of this data will enable analysis of equity of access across the breadth of the CALD community.