

DIVERSITAT DISABILITY FINDINGS REPORT

(updated January 2019)



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Diversitat is the peak regional body representing 70,000 residents through 50 affiliated and incorporated CALD associations, including all Refugee and Humanitarian communities in the Barwon Region. Building on our proud history of migrant services, Diversitat provides innovative and high-quality responses to the changing needs of a culturally diverse community. Diversitat’s vision is to empower individuals and communities to reach their full potential. Diversitat provides a full suite of health, education, employment, training, youth, aged services and community enterprises across the Barwon Region.

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1. INTRODUCTION

Culturally and Linguistically Diverse people with disability

Almost 20 per cent of Australians experience disability and about one in four Australians with a disability are from a culturally and linguistically diverse (CALD) background (FECCA, 2011), making people from a multicultural background the second largest group with disability, after women. However, people from non-English speaking backgrounds with disabilities face multiple barriers and are less likely to access government-funded disability support services than others with disabilities (Productivity Commission, 2009). These support systems can include community support, respite services, employment services and accommodation support.

About one in four Australians with a disability are from a culturally and linguistically diverse (CALD) background

Dwayne Cranfield, CEO of the National Ethnic Disability Alliance (NEDA), estimates “there are one million CALD people with disability in Australia and, if reached effectively, 20% of eligible National Disability Insurance Scheme (NDIS)¹ participants are likely to be of CALD background. However, current numbers do not represent these estimates as CALD are a cohort who does not traditionally put their hand up for assistance and they are not being intentionally targeted by the government.” The latest NDIS quarterly report (NDIS, June 2018) reports that only 7% of participants with an approved plan are from a CALD background.

People from non-English speaking backgrounds with disabilities face multiple barriers and are less likely to access government-funded disability support services than others with disabilities

The recent relaxation of the health requirements for humanitarian entrants being resettled from overseas, along with the 2011 change in policy from ‘life-time cost’ to ‘net benefit’ of accepting the person with disability and their family, has allowed greater numbers of people with disabilities to be resettled in Australia under the Refugee and Humanitarian Program.

If reached effectively, 20% of eligible National Disability Insurance Scheme participants are likely to be of CALD background

Diversitat, the peak CALD organization in the Barwon region, is finding clients from non-English speaking backgrounds face barriers to accessing the NDIS and other disability support services. Newly arrived migrants and refugees often face difficulties in navigating the Australian welfare system and support services. This places them in a vulnerable position with the potential risk of unemployment and poverty. Diversitat’s experience with regional CALD communities has taught us that emerging communities require a service system that is capable of providing information and support in a timely, relevant and contextualised manner. In particular, there is great need for early intervention and support available as a part of settlement on arrival to reduce the incidence of being lost in the system until a crisis evolves.

“CALD are a cohort who does not traditionally put their hand up for assistance and they are not being intentionally targeted by the government.”

1. The NDIS is an insurance scheme that funds reasonable and necessary supports for eligible participants. It also assists people with disability to access mainstream and community supports

2. BARRIERS TO CULTURALLY AND LINGUISTICALLY DIVERSE PEOPLE ACCESSING DISABILITY SUPPORT

CALD people with disability face barriers to receiving adequate and necessary disability supports, due to a lack of:

- Literacy (in mother tongue or English)
- Knowledge about disability entitlements and available support services
- Translated information about services
- Culturally and linguistically diverse appropriate services e.g. respite services
- Interpreters available with disability awareness
- Trust established with case workers to fully disclose disability
- Culturally appropriate assessment processes, as often assessment of a person's disability does not take into account cultural and/or lingual diversity
- Clear and early diagnosis
- Family and community support network.

Also, for children born in Australia, their family cultural background and how this impacts on their environment and supports is often overlooked.

CALD people with disability can face a delay in receiving disability services due to:

- Negative stereotypes about both ethnicity and disability in the general community.
- Discrimination, stigma, shame and bullying experienced from a person's own ethnic community.
- No diagnosis or an overseas diagnosis of new arrivals that is not accepted by Australian service providers. With no service history in Australia referrals are difficult to obtain.
- A delay in support in the time taken to receive a diagnosis.
- A lack of linking and collaboration along with access and equity issues between refugee settlement services and disability services.
- Traditional disability services being unfamiliar with specific needs of new arrivals from a refugee background.
- Fear from refugees to disclose information about a disability because of insecurity about their visa status and the confusion surrounding

visa entitlements. This can impact service providers who are unsure about a refugee's eligibility to receive disability services.

- A lack of necessary equipment for new arrivals from a refugee background with a disability, due to no prescribed aids or a need to leave equipment behind.
- Lack of relevant documents necessary for submission to the NDIS.
- Concern of gossip and confidentiality within the community, particularly with bilingual workers and translators.
- Impact of stress and trauma on the capacity of refugees to fully engage with a complex system on arrival in a new country.

The delay in service provision can also lead to families and carers of the person with disability becoming housebound, impacting on their settlement and integration into a new community.

Within the recent Diversability evaluation it was noted that participants who arrived on 204 visas spoke at length of the issues faced within their own community. They spoke of the many levels of discrimination they experience – ethnicity, gender and either having a disability or being the carer for a family member. A lack of trust and a real disappointment in the behavior of members of their own community is leading to social isolation for these participants and their families.

According to Carers Australia, between 25-30% of carers in Australia are from CALD backgrounds, with between 543,404-652,600 of carers being born outside Australia or migrating to Australia (ABS, 2009; ABS, 2011). Many carers from non-English speaking backgrounds do not access services until they are at crisis point. This is due to language barriers; a lack of awareness about available services, the complexity of navigating the disability supports system and the lack of availability of culturally appropriate care (FECCA,

According to Carers Australia, between 25- 30% of carers in Australia are from CALD backgrounds,

2011). In addition, guilt and denial about the

disability and the sense of duty to the person in their care can inhibit carers reaching out for help when needed.

In regards to the types of services and assistance available to better equip carers from CALD backgrounds, there needs to be improved links between settlement services and disability service providers. This will ensure the provision of resources and information can be provided to families upon arrival in Australia.

Many carers from non-English speaking backgrounds do not access services until they are at crisis point. This is due to language barriers; a lack of awareness about available services, the complexity of navigating the disability supports system and the lack of availability of culturally appropriate care

3. MENTAL HEALTH & PSYCHOLOGICAL DISABILITY

When accessing and navigating the NDIS, CALD participants are confronted with comparable barriers to those that are experienced by people with mental health / psychological disability. The recent evaluation of the NDIS (Flinders University, 2018) noted key concerns related to access to the system for people experiencing psychological disability:

“Concerns also persisted across the evaluation, that people with psychological disability were experiencing higher rates of ineligibility and consequently had lower levels of NDIS participation.”

(Flinders University, 2018, page 184)

Mainstream services also highlighted concerns over “The ability of the NDIS to be responsive to the needs of people with mental health issues and psychological disability was also questioned by mental health organisations.”

(Flinders University, 2018, page 205)

Whilst the majority of barriers experienced are similar to those noted earlier within this report, additionally people with a psychological disability are challenged by significantly more complex language, definitions and terminology, uncertainty around how the NDIS can provide “functional support”, along with the confusing role between mental health services and the NDIS.

A recent co-design process undertaken by

Diversitat sought to assist service providers to gain an understanding of the barriers refugees and asylum seekers have accessing mental health services in the Geelong region. Whilst looking at the broader mental health service system, key findings are relevant for understanding the barriers and enablers to CALD people accessing NDIS for support related to psychological disability. The research identified that mental health is a highly sensitive topic in many communities, noting that for effective engagement to occur an approach that builds trust is vital (Carroll, 2018). Additionally, it is not possible / reasonable for participants to be able to separate experiences that impact on their mental health. Priority issues identified through the research included:

- Language barriers and the need for greater opportunity and resources to communicate in their own language.
- Complex and slow referral process that can also contribute towards repeated trauma by telling and retelling their stories.
- Participants don't just want medication, they want to be provided with a range of supports that are culturally appropriate.
- Lack of information and knowledge of the supports and service available, and the need for greater cultural competency amongst services and improved connection across services.

From the service providers a number of key learnings were identified by undertaking this co-design process with people with lived experience. Most notable and relevant were:

“Hearing these experiences crystallized the challenges around the community’s cultural understandings and stigma surrounding the western model of ‘mental health’ and clearly identified that further work within communities is needed” (Carroll, 2018, page 26)

“At the client, service provider partnership level it would be good to have more training for the Service Providers on how to interact and work with clients from a CALD background.” (Carroll, 2018, page 27)

Whilst focused more broadly on the mental health system, the barriers and opportunities and learnings identified within the co-design process are highly relevant for meaningful engagement and participation of CALD people with psychological disability within the NDIS. The process itself also lends itself to more meaningful engagement and the building of a better understanding of the complex needs for people from a CALD background.

Additionally, a key concern for refugees and asylum seekers is the need to relive experiences

that are often traumatic in order to be able to seek assistance. Whilst this is not unique to refugees and asylum seekers, the long term impact of trauma and post-traumatic stress syndrome on a person’s ability to function on a day to day basis is evident. As noted by the NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors, these experiences can include, but are not limited to, Systematic State Terrorism, torture, bombings, killings, kidnappings, sexual assault, detention, disappearances, and harassment. Whilst it is recognized that trauma has long lasting effects on an individual’s biological, psychological and social wellbeing, little remains documented around the intersect between PTSS and eligibility for the NDIS. In order to be truly accessible for a high risk and vulnerable cohort, with specific and individualized needs, further identification and articulation of the opportunity for connection and engagement with the NDIS is needed.

Whilst considerable progress has been made to more clearly communicate the role of the NDIS within the broader mental health sector, this continues to be a highly complex and confusing space. And resources that have been developed, such as Reimagine, do not currently address the additional complexity of CALD communities.

NDIA - What is psychological disability?

Psychological disability is a term used to describe a disability that may arise from a mental health issue. Not everyone who has a mental health issue will have a psychological disability but for those that do, it can be severe and longstanding and impact on somebody’s recovery.

Accessing the NDIS

For a person with a psychological disability to access the Scheme, they need to have a permanent or likely-to-be permanent disability as a result of their mental health condition. The condition must have a significant impact on their day-to-day life and the person’s ability to participate in the community. It also needs to be likely that the person will need support for the rest of their life.

What supports will the NDIS fund?

For NDIS participants, the scheme will fund supports that assist you to live an ordinary life. This includes:

- Assistance with planning, decision making and household tasks
- Assistance to build skills to live independently and achieve their goals, such as building social relationships, as well as financial management and tenancy management skills

The NDIS will not fund supports provided by the health and mental health system. The terms ‘treatment’ in the mental health system and ‘ongoing functional support’ provided by the NDIS, assist us to define the respective roles.

4. AN EMERGING SERVICE MODEL

With the commencement of the NDIS trial in the Barwon region, Diversitat established a Disability Service Program (Diversability) to ensure that the needs of individuals with a disability from a CALD background, their carers and families were supported in a culturally responsive and timely manner to access the NDIS. Diversability aims to empower people from a CALD background with a disability to realize their human rights, to understand the NDIS, to articulate their needs and aspirations, to support the implementation of plans, and to advocate with and on behalf of individuals and communities. Diversability commenced in November 2014 with three clients, increasing to twenty one clients with plans over a twelve month period.

As at January 2019 Diversability is supporting 56 people with an approved NDIS plan with Support Coordination, 48 of these are from a CALD background (86%). 22 of those of a CALD background have a support worker from the same cultural background and/or speaks the same language assisting participants with household activities, community access and participation and skill development. That equates to almost half.

Despite this support, people from a migrant or refugee background in the Barwon Region continue to be underrepresented in the numbers accessing the NDIS.

In 2016 the Diversability program undertook an internal evaluation (Carrol, 2016) to understand what was working and what was not within this program, with key findings of this emerging service model documented below. What was evident from this report was the need for seamless integration across settlement services for new arrival refugees, right through to connection to the NDIS.

Arrival & Humanitarian Settlement Program

The length of time between date of arrival in

Australia and date of referral to the NDIS or Diversability varied considerably, and was significantly dependent upon diagnosis of a disability prior to arrival in Australia. One client within the program spoke of the shock when arriving at the airport and the vehicle sent to drive them to Geelong was not appropriate for wheelchairs so they were physically lifted into the vehicle. This is quite confronting for new arrivals not used to being touched or carried by strangers. Where Settlement Services are made aware that a person with a disability is arriving in the region appropriate supports need to be put in place before arrival, including liaising with the current transport contractor to use appropriate vehicles.

The report noted the importance of early identification, intervention and support in order to reduce the incidence of being lost in the system until crisis occurs. While all new arrivals within Diversitat now have the NDIS explained to them during orientation when they first arrive, this was not available to clients who arrived before 2016.

"I had to slide myself in and out of the car and that has damaged some tendons in my shoulders from all the work they did. For the first two weeks I was housebound because there was no ramp I had to stay in the house until somebody came to take me in and out of the house."

Settlement Services also need to be cognisant of the potential lack of retention of new information by clients during the initial settlement period, particularly given the impact of stress on forming memories and recalling new information (QPASST, 2013) and the overwhelming amount of information being provided on arrival. With this in mind, it is recommended that consideration be made for the sharing and communicating of information at multiple points, and from multiple sources, during the settlement process, to ensure that clients have increased knowledge and capacity to make informed decisions regarding

their care and support. Clients within the program suggested that Diversitat inform clients of the support they can receive for disability and how to access that support as soon as they arrive. They were of the opinion that many new arrivals will not ask for support due to a fear they will be 'sent back'.

"Different cultures might be too scared to voice what they need or what they require because they would be scared that they will be sent back if it is found out that they need these things, so it is important that these organisations tell them that it's alright to speak out and inform them."

Additionally, clients recommended that appropriate short term housing for people with a disability be secured on arrival. This includes housing with appropriate shower chairs, ramps, rails and a car slide so that people in a wheelchair are able to get in and out of a car.

"I had to slide myself in and out of the car and that has damaged some tendons in my shoulders from all the work they did. For the first two weeks I was housebound because there was no ramp I had to stay in the house until somebody came to take me in and out of the house."

Diversability

The report noted that Diversability clients and their carers were overall happy with the services and support they were receiving, and considered staff to be culturally responsive and always respectful. Clients were surprised at the level of support they were able to receive in Australia and all spoke of the positive impact this has had on their lives. However, the report also acknowledged that more work is required to give clients a better understanding of the system and of their rights within that system.

The clients who arrived before the NDIS pilot commenced in Geelong in 2013 were waiting longer periods of time to be linked to a disability service. Those arriving since 2013 were usually linked in a shorter timeframe, however it does depend on the type of disability and how the client presents. For example, a client in a wheelchair will be linked to a service immediately whereas a child with autism may take longer to be recognised and diagnosed.

There was not one singular pathway for clients being linked to the NDIS or Diversability, with referrals being made by GPs, refugee health nurses, complex caseworkers, Settlement Services and Community Development staff. Some clients were clear as to where the referral to Diversability came from, while others were a little confused about the pathway.

Most clients within the program were supported by Diversability to assess and diagnose a disability. Once there is a diagnosis clients were then supported to gather the evidence required to complete the NDIS' Access Request Form. Support included making appointments, transportation, accompanying to appointments, organising interpreters, assisting with paper work and gathering evidence.

"Physiotherapy appointment swimming pool everything. Also Diversitat provided the application for me. Diversitat put me through everything for NDIS."

While clients were very happy with the support they were receiving from Diversability the question around what advice would they would give to others with a disability was mixed. Some said they would tell people to go to Diversitat while others said they wouldn't discuss disability with their community. Clients spoke of experiencing discrimination both from the broader community and from within their own ethnic communities.

"Honestly I do not talk about the Disability Service to anyone."

However, other clients spoke of recommending Diversitat for assistance to others, including advising a friend living in another state that he would be better living in Geelong where he could get greater assistance for his disability. One carer, having been told many times by community members that having a child with a disability would impact the family's chances of resettlement and that they would get no support if settled, was adamant he would ensure all new arrivals with a disability understood they could get support and he would direct them to Diversitat. The misinformation the carer had received both in the country of asylum and after arriving in Australia had caused a great deal of stress and he wanted to

allay the fears of all new arrivals.

"Honestly I do not talk about the Disability Service to anyone."

The only real complaint of the NDIS and Diversability by clients was the length of time it was taking to receive supports once plans were in place.

Interpreters

Whilst Diversability consistently use interpreters when working with clients, barriers continue to exist with regard to the use of telephone interpreters and confidentiality issues and concerns.

Clients all stressed that they preferred face-to-face interpreters instead of telephone interpreters, as they found telephone interpreters difficult to understand. While not related to their NDIS plan or Diversability support, in one instance a client recalled life-threatening complications as a result of taking an incorrect dosage of medication after misunderstanding a telephone interpreter. Clients who had reasonable English comprehension spoke of understanding enough to know that an interpreter was not giving all information or was giving incorrect information and as a result have a real lack of confidence in the telephone service.

A number of clients did not always feel comfortable with the interpreters and bilingual staff. Some had experienced a breach of confidentiality and as a result lacked trust.

"Since the beginning I have had a lot of interpreters but I wasn't happy with most of them for two reasons. The first reason they wouldn't interpret everything and couldn't understand what is going on. My listening in English is getting better so I could understand that there was something missing here that they misinterpreted something because I knew what was going on so I wasn't happy with them. And the second thing I have heard some private things from different people that I have only told this information in front of an interpreter - they have breached confidentiality."

Whilst most clients were happy with the use of interpreters and considered the support they were

given was culturally appropriate and respectful, most considered that a caseworker who spoke their language would be an advantage.

"It would be very very helpful and easy because when you go at the time to see the case worker and the interpreter is not there so it is hard so if you had a case worker who had spoken your language then you could just go straight away and tell them and they start the conversation - would be very very easy."

Two clients however, were adamant that they did not want someone to support them who spoke their language and who might have links to the local community.

"No I don't want a caseworker that speaks my language. If they came from the same community I don't think they would support me very much and trust would be a problem."

Others said they would be happy to have someone who spoke their language but it would depend who it was.

"No I don't want a caseworker that speaks my language. If they came from the same community I don't think they would support me very much and trust would be a problem."

NDIS

The commencement of the NDIS pilot program in the Barwon Region in 2013 was considered an opportunity by many to increase the numbers of CALD clients accessing services (Qingsheng, Z, 2015). One of the NDIS design principles established by the Council of Australian Governments is to "ensure equity of access by addressing the needs of people in regional and remote Australia and people from Indigenous and CALD backgrounds" (COAG, 2016).

All clients understood the NDIS was a service for people with a disability but some were vague on detail. Only one client found the NDIS system easy to understand but still required support to coordinate their plan.

"I can see what they are doing for me I can see all of the supports and what is happening I just don't

understand how it works so if everybody could explain every step”.

The main complaint from all clients was the length of time it was taking for “NDIS” to put supports in place.

“I know my caseworker (from Diversability) has done what she needed to do but the main problem is with the NDIS.”

All clients needing supports had waited six months or more for them to arrive with some still waiting. One client waited six months for a bathroom rail to be replaced, another waited five months for a chair slide and a woman has been unable to access her shower for two months and is still waiting.

“Also I want to say about NDIS they help but when I want something it takes a very long time. For example, the rail in the bathroom was broken. I was injured when I fell. It took 4 or 5 months for them to fix the rail.”

There also seemed to be confusion for some around entitlements for transport by taxi, which had restricting their mobility.

“I can see what they are doing for me I can see all of the supports and what is happening I just don't understand how it works so if everybody could explain every step”.

One significant challenge related to the eligibility criteria, where a client must “be permanently living in the (NDIS) launch site before the 1st July 2013”. One client was originally rejected by the NDIS due to timing of arrival in Australia, however Diversability appealed the decision and advocated on their behalf. As a result the client was accepted and now has a plan in place. The ruling also set the precedent for the NDIS Nationally.

5. NATIONAL DISABILITY INSURANCE SCHEME

The Evaluation of the NDIS (Flinders University, 2018) noted that whilst the overall progress of the NDIS in establishing a new client driven system has been successful, some critical issues and delays were experienced. Of particular relevance were key concerns raised around equity and fairness of delivery and the identification of key cohorts with highly complex needs that continue to struggle to navigate a highly complex system.

The evaluation focused on a number of key elements of the system, including supply and demand, disability sector and its workforce, choice and control, reasonable and necessary supports, wellbeing, participation, fairness, equity and access, mainstream interface and older people with disability. The evaluation related to fairness, equity and access clearly identified CALD people as particularly struggling with the complexity of the system. Specific cohorts identified experiencing difficulty included people with psychological disability, those with literacy problems or cognitive impairment, and people from CALD or indigenous backgrounds. Key issues and challenges being experienced included (Flinders University, 2018, page 184):

- Difficulties encountered by those who could least 'fend for themselves';
- The eligibility process could be lengthy and complicated;
- The boundaries between the NDIS and mainstream services were often confused;
- Information about access to supports was often considered inadequate;
- The NDIS works best for those who can advocate for themselves, causing fairness concerns.

As was recommended within the original Diversitat Disability Findings Report, the need for individual advocacy is of critical importance for those with complex needs and additional barriers to accessing relevant supports and services. This was a consistent message and concern within the NDIS evaluation:

"People with disability who are unable to advocate for themselves or who struggle to navigate NDIS processes are at risk of receiving lower levels of services than previously and many have." (Flinders University, 2018, page xv)

"Participants with a mental / psychological disability and those unable to articulate their support needs or navigate the NDIS website, experienced lower levels of choice and control. Constraints to greater choice and control included a lack of service providers, long waiting list for services, limited information about provider options and inflexibility of service provision." (Flinders University, 2018, page xvi)

"Often it's the more articulate, confident people who actually have the confidence to access advocacy. Often really vulnerable people don't have the confidence... you actually have to be quite empowered to actually go through that process." (Flinders University, 2018, page 199).

Key findings within the evaluation included:

- Recognition that equity and fairness are a "fundamental ethical underpinning of the NDIS". Whilst it was acknowledged that this can be particularly challenging to implement (the provision of individualized support for people with diverse needs) within the context of creating a new system and way of working, it was identified as critical and requiring action.
- That people with complex needs, including those with psychological disability and those from CALD background, were at risk of receiving less support and lower levels of funding within this system.
- And whilst the need for advocacy was identified as critical in order to support those with highly complex needs and who may be less able to articulate the individualized support they require, the evaluation noted

concerns of a “lack of funding for formal advocacy support under the NDIS.” (Flinders University, 2018, page 185)

For new arrivals, it was additionally noted by mainstream services that:

“A family cannot be expected to sit down with a planner and talk about their goals and aspirations and dreams for their child, when they’ve just arrived here. They have no idea what services available, what their child even needs, what they’re entitled to. It’s just hugely problematic for CALD families.”

(Flinders University, 2018, Page 217)

In clear response to the growing gap in service delivery to people from a CALD background, the NDIA have developed a CALD Strategy (NDIA, 2018) that seeks to ensure that the NDIS is “delivered in a manner that respects and takes into account the language and cultural needs of individuals needed to achieve full participation in the NDIS.” (NDIA, 2018, page 3)

The strategy identifies key priorities ensuring greater equity in participation within the system, which include:

- Engaging with communities.
- Making information about the NDIS accessible.
- Increasing community capacity and broaden consumer choice.
- Improving our approach to monitoring and evaluation.
- Enhancing cultural competency within the NDIA and its Partners.

The strategy is also underpinned by commitments to working closely with CALD communities to ensure a deeper understanding of the interests and needs of CALD participants, embedding these learnings in to the design, planning and development of the system, and ensuring ongoing enhancement of the quality of the NDIS experience that supports cultural and language needs.

The strategy goes on to articulate key principles including human rights, dignity, meaningful engagement and that culture and community are central to engaging with people from the CALD community. The need for effective engagement

and a focus on building strong relationships that are genuinely based on mutual understanding, respect and equality is critical to ensure the best outcomes for people with disability from CALD backgrounds.

Whilst the formal identification of these gaps and needs, along with the articulation of a CALD strategy with clear direction to address previous inequities is welcome, the information provided is neither new, nor particularly ground breaking. The real test will be in the implementation of this strategy and the commitment to address critical short comings identified within the evaluation.

As was concluded within the evaluation:

“...in most of its aspects the NDIS is working well for the majority of the people it touches, which is a major achievement. However, the NDIS also leaves a large minority (about a third) as well off as they were before, and it makes a small minority (between 10 and 20 per cent) feel worse off. These proportions come up time and again in many of the evaluation findings. In most cases of a new policy, leaving a clear minority feeling worse off because of the policy would be a cause for concern. In the case of often highly vulnerable people with disability not clearly benefiting from the new system, such a finding points towards the need for closer monitoring and for more targeted and person-centered policy responses.”

(NDIA, 2018, page xxxiii)

6. FINDINGS

People with disability in the Barwon region

Diversitat identified more than 50 new arrival clients from non-English speaking backgrounds² with a range of physical and intellectual disabilities along with behavioral and mental health conditions in 2014. Identified disabilities included cerebral palsy, muscular dystrophy, hearing and vision impairments, schizophrenia, epilepsy, depression, post-traumatic stress disorder, intellectual disability and autism, in addition to a co-morbidity with other health issues including diabetes. While not all of these clients were deemed eligible for NDIS funding, only a few accessed the NDIS to determine their eligibility for the Scheme and were linked with disability service providers.

In addition, NEDA estimates the total number of people from non-English speaking backgrounds with a disability, under 65 years old and living in the Barwon region, to be between 4585 and 7980 people (NEDA, 2014).

Since the internal evaluation of Diversability undertaken in 2016, the working relationship and communication has been strengthened between the Diversitat settlement program case management staff supporting newly arrived clients and the Diversability team. Training has been provided to the case management staff regarding the NDIS and how to support clients to access it and case management staff are getting better at recognising disability and educating clients about accessing the NDIS. This is leading to more clients accessing the NDIS and accessing the NDIS sooner in their settlement journey.

In March 2018, 13 clients accessing Diversitat Settlement Services were identified as having a range of physical and intellectual disabilities along with mental and behavioural conditions. As of January 2019, seven of those clients have been approved by the NDIS, have an active NDIS plan and are linked in with disability support services.

Diversability worked in partnership with Ethnic Communities Council of Victoria on a 6 month project that has achieved an increased knowledge of ECCV member organisations of the NDIS and how to prepare for the roll out of the NDIS; increased number of the skilled CALD workforce in the disability sector working in partnership with Diversitat training to develop a pre accredited training course and; increased knowledge and understanding of clients and carers of complaints systems, independent advocacy and how to negotiate a plan review.

Another six-month project (July 2016 to January 2017) was funded through the Community Inclusion and Capacity Development (CICD) Grant from the National Disability Insurance Agency (NDIA). The project successfully developed and piloted an alternative approach to engaging 'hard to reach' communities and connecting them with the National Disability Insurance Scheme (NDIS). The 'hard to reach' groups included people experiencing homelessness and living in Supported Residential Services, people from Culturally and Linguistically Diverse backgrounds, Aboriginal people and people involved in the Criminal Justice System.

The Diversity Safe Place Project "Welcoming Ways" was a 12 month project (Oct 2017-Oct 2018) funded by the NDIS across three states - Victoria (Geelong), NSW (Sydney) and Queensland (Townsville). It aimed to address the low numbers of CaLD people with a disability accessing community programs and activities. Implementing a co design framework, barrier mapping workshops have been completed across the three states and an organizational audit has been developed by CaLD people with a disability in the Geelong Region. The 'Welcoming Ways' website (www.waystowelcome.org) features the co designed tools and products that have been developed across the three states to assist community organisations wishing to enhance their disability and cultural accessibility.

From September 2017 to June 2018, Diversitat Training in conjunction with the Diversitat Settlement and Community Programs, facilitated three ACFE pre-accredited Intro to Disability

Sector courses. The courses were attended by Diversitat bilingual support workers keen to support NDIS participants and members of the newly arrived CALD communities who wanted to work in the disability sector. The courses ran for ten weeks, at three hours per weeks. Topics included knowledge of the NDIS, professional boundaries, challenging behaviours, reporting, cultural awareness, strengths bases approach, professional communication, disabilities-cognitive, physical, sensory, manual handling and workplace health and safety.

The aim of the course was to provide employability knowledge and skill development in the disability field as well as give learners to pathway into further pre-accredited training or accredited training such as Certificate II in Community Services, Certificate II Individual Support (Disability and Home Care) and Certificate IV in Disability.

Of those that completed the course, eight learners went on to gain work in the disability sector and three learners went on to further study, completing their Certificate IV in Disability.

NDIS

NDIA has estimated that at full Scheme 20% of NDIS Participants will identify as being from a CALD background. Yet as of the last Quarterly report, only 8% of Participants identified as CALD.

The recent evaluation of the NDIS clearly identifies CALD people as significantly under-represented within the NDIS. Attempts to address this are being taken however are yet to be really tested and the impact understood. More specifically, Diversitat has found people from a non-English speaking background, who have arrived in the past five years, are not accessing the NDIS in expected numbers to determine their eligibility under the scheme, or to access the other services and support available to all people with disability.

CALD people with disability continue to be overlooked in regards to accessing the NDIS with numerous barriers and

challenges, as noted within this report.

Key reasons include:

- Many new arrivals with disability have not been linked with a disability service provider in the past so they will not automatically move to the NDIS, and in some cases may not be aware of the NDIS.
- There is no specific case-management or advocacy funding to support new arrivals with disability prior to NDIS eligibility determination and throughout the NDIS planning process, for example, to facilitate disability assessments. However, a Diversitat case-worker spent more than 50 hours providing support for just one client who was undertaking the NDIS planning process.
- There continues to be insufficient numbers of CALD disability support workers and interpreters with disability awareness.
- The NDIS model assumes empowerment and that people with disability from CALD backgrounds know what supports are on offer and how to define and articulate their goals. This is a foreign concept for many ethnic communities.
- There continues to be a lot of misinformation being given about disability entitlements for people from a refugee background. However, new arrivals from a refugee background and migrants with a permanent residency visa or citizenship – who satisfy other eligibility criteria – are able to access the NDIS as they have the same rights and responsibilities as others.

The NDIS needs to be culturally competent and accessible, with culturally appropriate support for people with disability from non-English speaking backgrounds. As noted within the NDIS evaluation, equity and fairness are a “fundamental ethical underpinning of the NDIS” and therefore need to be better reflected within the implementation of the Scheme.

After much lobbying from CALD advocacy agencies such as ECCV in October 2017 it was announced that TIS National was partnering with NDIA to provide interpreting services for NDIS participants from CALD backgrounds. The service supports participants when connecting with registered

service providers for funded supports in a participant's plan. However, TIS is not available for pre-planning or preparation of a plan review if it is related to a funded support that is not currently in the participant's plan.

The participant does not need to have interpreting supports listed as a funded support in their plan to access non-disability related interpreting services.

This has made such a difference for CALD participants and the NDIS registered providers they are accessing to provide support services. Previously interpreting services were provided in an adhoc fashion with no consistency in regards to who was funded interpreter services in their plan and how much. There was also a period of time when no interpreter services were funded in participant's plans as it was deemed by the NDIA that interpreter requirements were not directly related to the participant's disability therefore it was not their responsibility to provide funding for it.

A step towards removing information and language barriers for CALD people with a disability.

In January this year Settlement Services International (SSI) launched the National Multilingual Disability Hub, a multilingual hotline and website that provides relevant and easily accessible information on disability and the NDIS in 14 languages: Arabic, Assyrian, Bangla, Cantonese, Italian, Macedonian, Mandarin, Nepali, Spanish, Tamil, Urdu and Vietnamese. SSI developed the Hub through funding from an Information, Linkages and Capacity Building (ILC) grant and it is a well overdue resource for the sector.

Disability Service Providers

Diversitat met with various Disability Service Providers (DSPs) in the Barwon region within the original research for the Disability Findings Report. The issues and challenges previously reported continue to be experienced by DSPs, as noted within the NDIS evaluation. The key challenges include:

- The NDIS model assumes an understanding of needs, supports on offer, the disability system and English literacy.
- If there is no previous relationship with NDIS staff, and if the DSP is not included in the client's planning meetings, then not all needs may be disclosed. This leads to a package that is not reflective of an individual's complex needs as it only includes supports for disclosed needs.
- CALD clients' English literacy skills and lack of knowledge of the disability system is a barrier to liaising directly with the NDIS without DSP assistance.
- Pressure is put on families by the NDIS to gather the information to support their application – this is an issue for new arrival communities as they do not have the necessary documentation and generally have not undergone appropriate assessments.
- Working with an advocate is proving challenging as there is a lack of funding, lack of CALD competent advocates and advocates with experience working with CALD people with disability
- Visa status causes confusion in regard to NDIS eligibility and entitlements that DSPs can support.
- The need for strengthening and creating more formal referrals and links to the disability system, across service providers including Settlement Services, HSS and Ethnic Associations.

More work in this area is needed, evident in the low numbers of CALD people receiving disability services under the Scheme in the Barwon region

7. RECOMMENDATIONS

Understanding disability in an Australian context, including access and equity issues, is a challenge for new arrival communities. People with disability from a non-English speaking background need access to information about human rights, disability entitlements, essential services and available support. They require assistance to realize their human rights through self-empowerment and information on accessing individual advocacy.

Furthermore, there is a requirement for targeted practical support to assist CALD people with disability to engage with disability services. This can help them articulate goals to ensure relevant and necessary support to enable their social and economic participation. As newly emerging communities will continue to settle in the Barwon region, linking people with disability from non-English speaking backgrounds to disability services will be an ongoing need.

Recommendations for the NDIS

Whilst gaps in service delivery have been identified and the NDIS appears to be responding to this gap and need, it is unclear how this will be operationalized and what impact this will have on greater accessibility to supports for people from CALD backgrounds. For the NDIS to improve cultural accessibility, safety⁴ and security⁵, the following recommendations are made:

- Whilst participation and engagement is clearly identified within the NDIS CALD strategy as a critical approach to ensuring CALD needs are met, again it is unclear how this will occur and there is a risk that this will be tokenistic and not truly representative of engaging people with lived experience. This could be further strengthened by taking a strong human centered design approach to ensure their specific needs are met.

- Foster inclusion through addressing access and equity issues.
- Ensure there is CALD representation on NDIA advisory and reference committees.
- Improve data collection on CALD people with disability and their carers to help plan adequate and appropriate disability services and supports
- Make sure there is culturally accessible information, and culturally competent processes and support is available. This includes translated materials and budget for interpretation; cultural competency training for staff; increase multicultural staffing; KPIs regarding CALD service utilisation rates; and seeking advice from CALD communities and CALD peak organizations to improve services.
- Ensure the funding model supports services to provide the additional level of support needed for people with highly complex needs. This includes much needed funding to support advocacy and the need to provide pre-preparation support for CALD communities to understand the system and opportunities it may provide.
- Recognise the need for a single point of contact and focus, to support effective engagement and building of strong and trusted relationships.
- Further consideration is needed to ensure effective support for CALD people with psychological disability that aligns with the NDIA CALD Strategy, however is also cognizant of the specific needs of refugees and asylum seekers within this context.
- Promote the NDIS to CALD communities through ensuring key NDIS and disability system materials are made accessible through translation and promotion of information via ethnic media and making this information available in places regularly attended by CALD people.

4. Cultural safety - an environment where there is no attack, challenge or denial of an individual's cultural identity. An environment that fosters shared respect, meaning, knowledge, and learning about diverse cultural identities and needs

5. Cultural security – an obligation on those who work with CALD individuals to move beyond 'cultural awareness' to actively ensure cultural needs are met and included in policies and practices, so all CALD people have access, not only those who have engagement with culturally competent workers

- Widening the pathways into NDIS as it has for early childhood, for example, not only self-referral but nominating others who can either refer on behalf of, or in partnership with, the individual with disability.

Improve data collection on CALD people with disability and their carers to help plan adequate and appropriate disability services and supports

- Produce NDIS information and resources in all languages and in various accessible formats⁶
- Promote the awareness of rights and responsibilities of CALD people with disability, in particular eligibility regarding visas, for example, permanent residents and citizens can apply to be participants under the scheme.

Culturally accessible information, and culturally competent processes and support before a national roll out of the Scheme

- Raise awareness about personal advocate and disability complaints options and complaints mechanisms.
- Comprehensively map disability in established CALD communities.
- Ensure the NDIA considers workplace diversity in its workforce strategy for the NDIS. A key challenge in implementing the NDIS will be making sure the disability services sector is equipped to meet the individual and diverse needs of people with disability, particularly those from CALD communities. The National Workforce Strategy needs to ensure the complex and diverse needs of CALD communities are being met, and for the sector to be responsive to these communities.

Recommendations for Disability Service Providers

Disability Service Providers will need to improve cultural competency through:

- Undertaking a cultural audit to highlight gaps and areas in need of improvement.
- Procedures and policies to ensure access and equity.
- Providing cultural competency training for staff.
- Using interpreters when necessary.
- Translating resources and materials.
- Increasing multicultural staffing.
- Promoting opportunities for CALD people to work as paid carers.
- Disability Service Providers who are also Registered Training Organisations need to promote disability-related training courses to CALD communities to increase the CALD disability workforce.

In general, all parties involved in the disability system need to ensure disability advocacy pathways, including complaints mechanisms, are culturally and linguistically accessible.

Providing cultural competency training for staff. Using interpreters when necessary. Translating resources and materials. Increasing multicultural staffing.

⁶ Diversitat welcomes the recent translation of some NDIS materials in various languages but calls for additional language translations to be added to these resources

Recommendations for Settlement Services

Settlement Services have a key role in connecting new arrivals in to relevant mainstream services within Australia, including where relevant the NDIS. Key considerations for Settlements Services include:

- Accessible information about disability and the NDIS should be provided regularly, at multiple times and in multiple forms during the settlement process.
- Where possible, ensuring the relevant supports and facilities be in place prior to arrival, including coordination with other services as needed (eg arrival transport contractor).
- Ongoing community development support to assist in reducing stigma and discrimination both within ethnic communities, and more broadly within the local community.
- Ongoing and consistent communication that new arrivals will not be returned to their home country if they have a disability or health problems.
- Improved training and engagement of translators and bilingual workers to ensure confidentiality and greater understanding of medical / disability terminology.
- Advocacy with Department of Social Services for improved coordination and communication regarding people with a disability prior to arrival.

Measuring Success

A culturally competent disability service and support system will have:

- Increased utilization of disability supports from CALD people with disabilities.
- Culturally accessible information, in a range of formats, and culturally competent processes undertaken by disability service providers and the NDIS. This includes translated materials and a dedicated budget line for interpretation; cultural competency training for staff; KPIs regarding CALD service utilization rates; promotion of the NDIS and other disability supports and entitlements to CALD communities; seeking advice from CALD communities and CALD peak organizations to improve services.
- Registered Training Organizations promoting disability-related courses to CALD communities to build up a CALD disability work- force.

8. CONCLUSION

The disability sector needs to address barriers CALD people with disabilities face in accessing services. There is a short-term need for case management and bilingual support to link a backlog of CALD people with disability to disability services. In addition, there is longer-term support needed to ensure ongoing support to CALD communities and an improvement in the cultural competency of disability service providers and NDIS. Diversitat is advocating for processes that are inclusive of the specific needs of CALD people with disability; for cultural competency for staff and service providers, for cultural accessibility and for a CALD workforce strategy that considers the needs of a group that currently do not have access to disability services.

Support will enable increased opportunities and promote inclusion for CALD people with disability, enabling greater control, choice and independence.

Without support, vulnerable CALD people with disabilities and their families will continue to be underrepresented in receiving government funded disability support services and barriers to their inclusion will continue to restrict their access.

“When I came here and when I had the interview with NDIS and they said there was money for my child - to support my child for things like OT, speech therapy, interpreters, case worker. So after that when I came back home I was crying I was so happy. I was very happy and I knew I was in the right place and they would support my child. I was very happy and I was thinking it was a good day for me when I went to the UNHCR to register my family and myself”.

“The NDIS plan has taken all of my worries away for example shopping was a very big thing for me but now someone comes and does the shopping for me and home help comes and gardening so I don't have to worry about any of these things now.”

Diversability participants

9. DIVERSITAT CASE STUDIES

Andrew's Story*

Andrew is a 5 year old boy who was born in Australia, after his parents migrated from Afghanistan and Pakistan. Andrew is about to complete his first year of primary school. He loves playing with trucks, watching ABC for Kids, playing outside and going shopping. His favorite thing is Spiderman.

Andrew's parents are no longer together, and he now lives with his mother and siblings. Andrew has severe language delay. The family had been referred to the NDIS by their case worker at the Women's Refuge where Andrew's mother was living with her children.

Andrew and his family required a lot of support and guidance when they first commenced services with Gateways in 2014. Back in Pakistan, there were no supports at all for children with additional needs. Andrew's mother did not know about disability supports in Australia and did not know what to ask for or what types of supports were available.

Andrew needed support with his language development. This was addressed in his initial NDIS plan with fortnightly speech therapy. The family were also supported with fortnightly visits from a specialized teacher who visited him at kindergarten, and who also provided information and advice to the family which ensured Andrew had a smooth transition into Primary School at the beginning of 2015.

Andrew's mother shared with us that in her home land, it was not usual behavior to play with your children. This was something that the therapists had to show her and talk to her about – the benefits of play and how children learn through play. It was especially important for Andrew to develop speech and communication skills and build on his social interactions through play.

Andrew is now at school and continues to receive support for his ongoing speech needs. The NDIS are supportive of Andrew's therapy needs, however, the family no longer receive funded support to coordinate services through their NDIS Plan. The planning process presupposes that parents know what to ask for. This is very difficult for Andrew's mother who fears that she is not doing enough for her son.

Andrew's mother is still needing support to understand how her son's language delay impacts on his development and what will be helpful for her son. She needs support to explore options and feel confident about what to ask for at planning meetings and making decisions.

Andrew's mother has studied very hard to gain her qualifications to enable her to work full time in her chosen career. Because of her need to work, Andrew has received his therapy at school which his mother has greatly appreciated. She has also had her own health concerns to manage during this time.

*Names have been changed on clients' request.

Gateways ongoing support of Andrew and his family has been about supporting their family unit. Time was spent listening and gaining an understanding of their needs and exploring options that were suited to their cultural needs. The first priorities were securing a roof over their heads and providing food and a safe homely environment. Andrew's mother then progressed to gaining an understanding of the services available to support her and addressing the support needs of all her children.

Time was spent listening and gaining an understanding of their needs and exploring options that were suited to their cultural needs.

Staff also needed to support Andrew's mother to understand the importance of attending appointments, such as taking him to the Pediatrician, which staff supported the family to do.

Andrew's mother also greatly appreciated Gateways support in communicating with other agencies and service providers. Gateways staff ensured that they communicated with her on a regular basis so she always made informed and supported decisions about her son's care.

With the support of the services funded by the NDIS, Andrew's mother can see that he is happier and more confident, and he now has friends to play with. His mother also reports that she feels as though she has been heard. Staff do not just come in work only with her son, they support her and work together with her to achieve great things for her son.

Tom's Story*

Tom is the 4 year old only child of Alan and Tina. Tom was born in Australia. Tom has a diagnosis of Autism, Developmental Delay and Severe Language delay. Alan would say that Tom just doesn't speak good yet.

Alan was born in Vietnam but grew up in New Zealand and considers himself a New Zealander. He is not a Vietnamese citizen but has a Vietnamese birth certificate. Alan speaks Vietnamese, Cantonese and English. Tina was born in a small village in Vietnam and speaks mostly Vietnamese with only a very little English. Tina and Alan met through a family friend. Alan arrived in Australia in 1997 and Tina arrived in 2002.

Alan takes the lead role with all appointments and the provision of information.

Alan was supported by his GP to engage with a Pediatrician to provide support to Tom when there were some concerns raised about Tom's development. Alan went through the NDIS planning process and created a plan that was limited in its content due to the limitations on the information Alan could provide. Alan was asked if he wanted an interpreter for this meeting. Alan does speak English well, however, he has some difficulties comprehending spoken English which does create gaps in the information provided and miscommunication at times.

Alan did not understand that he had to pick up the plan and engage service providers to provide the services for his son. Alan waited for someone to call him.

Alan asks for information to be sent via SMS or email. The NDIS did this when Tom's plan was approved and ready to commence. Alan did not understand that he had to pick up the plan and engage service providers to provide the services for his son. Alan waited for someone to call him.

It was 4 months before services commenced.

The only reason service did commence was because Tom had a follow up appointment with his Pediatrician. The Pediatrician asked if Tom was receiving therapy services. When Alan responded no, the Pediatrician followed up with the NDIS and discovered that the funding was active but no support had been offered to the family to engage with service providers. The Pediatrician contacted service providers on behalf of the family and Tom commenced services with Gateways in November 2015.

*Names have been changed on clients' request.

The Key Worker needed to complete assessments with Tom to establish a baseline of development. These results were used to communicate Tom's needs to the NDIS to ensure that the funding clearly reflected his developmental needs. The Key Worker provides a lot of information about developmental milestones to help Alan and Tina understand what Tom needs to be doing for his age. Parent support and education is a key role in service delivery.

Parent support and education is a key role in service delivery

Recently, the Occupational Therapist needed to complete an assessment for Tom. This involved asking Alan a lot of specific questions about his development. Alan found these questions difficult to answer accurately and requested the support of an interpreter. The Key Worker went back to the NDIS to request the funding to be placed in Tom's plan so an interpreter could be organized to support this process. The NDIS quickly approved this request and the assessment was completed.

Alan reports that he is very happy with the support he is receiving through Gateways and the service he received from the NDIS.



Victoria Family Story*

Emma and Jason are the parents of Anne and Andrew. Anne commenced services with Gateways Early Intervention in 2009 and completed services when he transitioned to school in 2011. Andrew commenced services with Gateways in 2013 and is currently receiving Early Intervention supports.

Emma and Jason lived in neighboring villages close to Kosovo, near Albania. They met through their families, and both were poor so they could not afford a wedding celebration, just the wedding certificates. Their families were farmers and they did not have much money.

Emma was really sad that there was no high school in her village and no way to get to the nearest school, so her education finished at the end of primary school. Emma feels she is uneducated and yet she is a very smart and resourceful mother who has brought up 2 boys with autism, and works in great partnership with her early intervention workers.

Jason works many different shifts so Emma is the main carer for her boys, and she worries that her English is not so good, as she only did one year of the Gordon English course before becoming a mum to her first child. She has dreams of studying beauty therapy and working part time in the future. She is nervous and excited about Andrew starting school, and would never want to leave Australia because it is a good place for education and a good life for her boys.

There were no services in Kosovo for children with disabilities. If you had a child with a disability you were segregated. Because of this, Emma has no understanding of what services are available or what she should be asking for to support her children and her family.

Emma did not know what to ask for... and thought services would just continue under a few funding system

This was highlighted when Andrew's early intervention services was transitioned over to NDIS funding. Emma did not know what to ask for and did not inform current staff about the NDIS meeting and thought services would just continue under a new funding system. When Andrew's first NDIS plan was developed he only received a

package with respite funding and no funding for therapy services which he had previously been receiving on a weekly basis. The Gateways key worker and management had to work closely with the NDIS over an extended period of time to ensure funding for a transdisciplinary package was provided. Emma feels happy that Andrew has had regular services and accessed a group program.

*Names have been changed on clients' request.

The Key worker provides support with written forms and a lot of information about what services she can access and what her rights are as a parent with children with additional needs. The family would benefit from support coordination once Andrew transitions to school next year, to ensure that they have continued support with information and understanding of what they can access to support their children and family.



Vicki's Story*

Vicki, is a young woman who was born in Australia after her parents migrated from Turkey in the 1970's. Vicki lives with her mother, Dianne, and her father who are now both in their 70's. She has lots of contact with her brother and sister and their families.

Vicki has Down syndrome and requires high levels of support in the home and to access the community as she experiences severe anxiety connected to leaving home without her mother and going to places that are not familiar to her.

Before NDIS Vicki's supports were a mix of funding packages from Department of Human Services and Home and Community Care for respite and outreach services. The supports were provided by three service providers and enabled Vicki to engage in activities in the community and provided respite for her parents.

Until three years ago her mother looked after all her day to day needs. Vicki requires support during the night and when Dianne was experiencing a number of different health issues she had to rely on paid staff to manage Vicki's personal care needs. This was a difficult step for Dianne to take as it required her to trust strangers in her home with her daughter's personal needs. It is very important to her that a high standard of care is provided and she needs to oversee the support provision, particularly when new support workers are introduced. The funding for these extra supports was able to be provided by one of the three agencies involved.

The introduction of the NDIS has meant a personalized approach to funding, taking in the whole family story. Planning meetings have occurred in Vicki's home at the request of Dianne. After the initial plan was completed, the NDIS staff observed that Dianne found the implementation confusing. The NDIS staff became confused themselves by the different arrangements with service providers. As a result Support coordination was added to the plan and this was a great help to Dianne. She now has one point of contact for all services Vicki receives. Eventually Dianne decided that, given the choice, she would prefer only one service provider. This made it easier for her to manage and helped to maintain a consistent quality of care. Building trust is a significant factor for all families and cultural considerations are addressed with workers who develop relationships who respect individual family values and preferences.

The introduction of the NDIS has meant a personalized approach to funding, taking in the whole family story.

*Names have been changed on clients' request.

Dianne was told about the NDIS by one of her service providers before it was rolled out in the Barwon trial site. She admits that she is still confused about how the NDIS is funded and many of its processes. She relies on the support coordinator who works with her to implement Vicki's plan, to navigate the service sector and understand written documents.

However she does understand the ongoing nature of the funding and has reported that she feels more relaxed and doesn't have to panic about the future. She feels that her child will be well looked after.

Vicki's sister will take over responsibility for her care when Dianne is no longer able to, and Dianne understands that the NDIS funding will stay with Vicki through the stages of her life and will change with her as her needs change.



Sparey Family Story*

Jason and Katie are from Laos. They have two young boys both with a diagnosis of Autism. They have been clients with Gateways since 2010 with Alex receiving Early Intervention until he transitioned to school in 2012 and Ben who commenced with Gateways in 2013 and who is currently receiving support funded through the NDIS.

Jason and Katie feel they are very lucky to be married to each other and Jason says Katie is the best lady in the world. They are both from Laos and Jason is much older than Katie. He has an older son in the army in Queensland, and says the most important thing in the world is to have good family and friends.

They lived in small villages on the Mekong River, and were very poor. Jason says you have to be very smart and clever to be ok in Laos, and people will try to live the best they can. They love Australia and the good life they have here. They are also very thankful for the supports you can get here if you have children with additional needs like their boys. In Laos, they would have been segregated and shunned, and had no special education help. This also highlights that they have no history with support services and therefore do not what exists and do not know what to ask for.

The Key Worker has been a very important person to the Sparey family. She has had to support them with all decisions around service provision and service delivery. Support is needed to ensure paperwork is completed and also to ensure that the family has a clear understanding of the choices before them. Information provision is a key role of service provision. They require help with all written forms such as enrolments, reading government information, and ask for advocate support at medical meetings and NDIS planning.

They have felt well supported by their NDIS planner and ask that she confers with their trusted staff. This family do not ask for much as they do not seek respite in their culture. To ensure that the service provided reflects the changing needs of the family, the NDIS and Gateways have had to have a close working relationship. There has had to be the understanding that, for this family to have support and choice, the NDIS have had to respect and acknowledge the relationship the family have with their key worker.

Jason and Katie will benefit from Support Coordination when Ben moves into school to ensure that the family continue to receive the services and information they need to make informed decisions.

*Names have been changed on clients' request.

Jason and Katie have a wonderful veggie garden in their yard at their home in Bell Park, and they like to give their Gateways support workers special treats from their gardens like red chilies and lettuces. They also cook special treats like dumplings and special desserts to give to their helpers. It is an absolute honor to work with this family, who have so much respect and appreciation for any help they receive. They refer to their key workers as family and sometimes even fairy godmothers!

They refer to their key workers as family and sometimes even fairy godmothers!

Augustino

Augustino is a 50-year-old Karenni man from Burma. He has a degree in Mathematics and is the father of three children who were all born in a refugee camp in Thailand. Augustino lost his left hand in a landmine accident when he was 16 and now uses a split hook prosthesis. Augustino does not think he is eligible to participate in the NDIS as his support needs are not very high.

Augustino assists Diversitat and other local service providers to deliver important information to the Karenni community, and to help organizations understand Karenni culture and customs. He regularly helps organize traditional festivals and local events to create opportunities for the broader Geelong community to learn about Karenni culture, promoting mutual understanding and compassion. Augustino was an inductee into the Victorian Multicultural Commission's Refugee Recognition Record, in 2013, this award recognizes individuals of a refugee background for their outstanding work in the community.

When Augustino lived in a refugee camp in Thailand he "had a prosthetic device made in a camp workshop out of local material". Upon arriving in Corio in 2009, Augustino received a new prosthesis. "I visit the medical centre each year to check it and make adjustments. I'm not sure who would cover the cost of a new prosthesis – the NDIS or the health system," he said.

Augustino does not require much day-to-day assistance with his disability but "if a manual job requires two hands sometimes I need some modification to the activity or the equipment".

Augustino works and does not receive any disability support or pension. He is not sure if he is entitled to any assistance but doesn't believe he would qualify because of his employment.

He heard about the NDIS through Diversitat and said: "It is there to support people with disability and to do assessments. I went to the website to see if I was eligible, but I was not eligible because I didn't pass questions related to support needs."

While he was not able to access any supports himself, through his bilingual work supporting Diversitat clients to access the Scheme Augustino has since "helped two other Karenni families to access the NDIS and other services related to their disability and health".

Augustino found it interesting to "learn about the NDIS support that people with disabilities could receive if they couldn't take care of him/ herself, for day-to-day life skills and care, and the support to continue their education".

"Most new arrivals lack knowledge about the available services...more accessible information in many languages would be good so that others can access the information that is available"

Augustino is very active in his Karenni Community and he assists new Karenni arrivals from refugee backgrounds to settle in the Geelong region. He is always available for his community to assist others to attend medical and other appointments, advise and mentor the youth and support those in need, including the older members of his community, all on a volunteer basis.

Augustino's English language ability is very good but he reflected on potential barriers and

recommendations that he would make to improve disability system accessibility for culturally diverse people. “Many would not be able to access the information, many Karenni are illiterate in their own language and they need interpreters, they are illiterate as they never had the opportunity to go to school,” he said.

“Most new arrivals lack knowledge about the available services but young people have more literacy than their parents and if they know English they can search the internet and read the flyers in the medical clinics. More accessible information in many languages would be good so that others can access the information that is available and visible at the medical centres.”

He suggested the different circumstances of new arrivals from a refugee background will also need to be taken into account in the future. “The older Karenni refugees have had many years of hard labour and some injuries that restrict their work. Many of these people will face disability in the future because of their past labour experiences,” Augustino said.

Divine and Marielle*

Divine is a 17-year-old Congolese person from a refugee background with cerebral palsy. She lives with her mother and four siblings in Corio after arriving in Geelong in 2010. Divine meets the NDIS residency requirements as she has a permanent visa and she resides in Australia, she is eligible for the NDIS. Divine and her mother have been through the NDIS planning process but there has been no implementation of her plan since November 2013⁸.

“I don’t have good language ability and it is hard being new to Geelong, I don’t know many organisations who are delivering the service we need for my daughter,”

Divine attends a mainstream high school and is learning English. As her cerebral palsy affects her speech and movement she receives some assistance from a teacher’s aide and uses some specialized equipment. “I use the computer a lot because writing can be difficult,” Divine said.

Marielle, Divine’s mother and legal guardian, helps with Divine’s showering, dressing and other personal tasks. She is concerned about how she will manage supporting Divine in the future: “I am alone here (Marielle is a

widow) and I have a big family to look after so it is hard for me to cover all of Divine’s needs. Transport is not enough to cover the needs of Divine, support about her future is needed. She is growing up and needs special care as her support will be expensive in the future.”

While the Congolese community helps Marielle with general advice, she needs information about the disability system and the entitlements and services available to Divine. “I don’t have good language ability and it is hard being new to Geelong, I don’t know many organisations who are delivering the service we need for my daughter,” Marielle said.

Divine receives some direct support from the McKellar centre. Marielle explains: “I am worried about the future because Divine is in year 11, I don’t know if the McKellar program is connected to Divine being in school. I don’t know much about how to manage Divine’s disability in the future, her education, helping her to be independent and planning for her future. I would like to know what disability support is available after high school, especially to help her keep studying.”

Marielle has had some interaction with the NDIS. “I have had two appointments with the NDIS. Sally (case worker from Diversitat) helped us access the NDIS. The first appointment we answered questions and in the second appointment last November they told me there was a lady from the NDIS who would come and assist me, but up until now, nothing. Up until now we don’t know what is going on.”

* Names have been changed on clients’ request.

⁸ In June 2014 Divine’s plan was reviewed to find out why no implementation had occurred, some additional support items were added at this time and the new plan is now being implemented

“I was disappointed as I went there [to the NDIS] with much expectation but unfortunately after the assessment they said someone is coming around to help, but up to now it was a waste of time because no one came. I don’t know why they told me to go there,” Marielle said.

Marielle was not advised she could involve a personal advocate in her planning meetings. “No, I have never heard of this,” she said. She was also not made aware of the complaints procedure. Divine understands English fairly well, however Marielle requires an interpreter. While the NDIS will organize interpretation for clients, relying on this support has been problematic. “The first time I went there they said they would organize an interpreter but no one showed up, so they got a phone interpreter. I disagreed with something the phone interpreter said, we quarreled and they hung up. The second appointment they had someone on the phone organized and they gave me some assistance, however, none of the material was translated,” Marielle said.

There is a lot of misinformation about disability entitlements for culturally diverse people, especially those from a refugee background. “I was told because I am a refugee that I would not be assisted like mainstream people, I was told that it would be hard to get the same assistance if I am not a citizen. I would like to recommend that people with disability are assisted without discrimination,” Marielle said.

Marie Claire and Moses

Moses is six, he has albinism and low vision. Moses and his family arrived in Geelong in 2010 as refugees from the Democratic Republic of Congo. Moses meets the NDIS residency requirements as he has a permanent visa and he resides in Australia.

Marie Claire, Moses' mother, was eager for him to attend a mainstream school. He receives some assistance through a teacher's aide and specialized equipment. Moses and his family also receive assistance from Vision Australia. Vision Australia have organized medical checks, given Marie Claire information about how to manage Moses' vision impairment, and assisted the family with books, an iPad and stationary for Moses.

Marie Claire first heard of the NDIS through a letter she received. She is unsure of how they knew to contact her. "I didn't fill out the first forms I was sent because I didn't understand them. I put them aside and forgot. Then I met someone [from the NDIS] who could help me at the Our Choice expo [in Geelong] and they called later to organize a meeting time for me to bring in Moses." Marie Claire went to the meeting and Moses is eligible to be a NDIS participant.

Marie Claire was not made aware she could invite a personal advocate to her NDIS meetings but because of the strong relationship she had developed with Vision Australia she asked them to attend. "A person from Vision Australia came to my meetings, I invited them to come because they know Moses and the support he needs."

Marie Claire was very happy with the support she received from Vision Australia before and throughout the NDIS planning process. Vision Australia's Geraldine Ryan said: "Vision Australia hosted information sessions about the NDIS for parents and in these sessions it became clear who struggled with language difficulties so we then offered individual supports to these clients."

Geraldine said culturally diverse people face barriers navigating the disability system in Geelong as they are "working their way through the new maze of hospitals and specialists, while dealing with their day-to-day responsibilities, to find the information that is relevant for them".

Marie Claire didn't understand the initial information from the NDIS. "I didn't know how to use the services. I was confused. I didn't know the source for funding for Moses, where to get money to help him, I didn't know. The goals part was hard. Explaining the need and putting together the goals of my son."

Following the NDIS planning meetings, Marie Claire was happy to have clarified information about available disability support. "It was helpful to know what kind of services there were and how to get the services. I was happy because I became clear about the amount of funding and happy because I knew how to use the money," she said.

Geraldine agrees: "A difficulty that our CALD clients faced was understanding what was meant by 'goals and aspirations'. They didn't understand the NDIS paperwork and needed more discussion from a cultural perspective to turn the supports into what they want, as the concepts are very foreign."

“I have now had two meetings with the NDIS and we have a completed plan for Moses. For the first meeting an interpreter was arranged but they didn’t show up so I said don’t worry about it because it wasn’t completely necessary. The last contact was in February, we haven’t implemented the plan yet but I know the next steps and will follow up when we move to Adelaide in the next few months,” Marie Claire said.

“I find it hard to manage too many services, I will find out about what we can access as Moses’ needs change as he grows older, we will go step- by-step.”

When asked about her recommendations for how the NDIS can improve the services for culturally diverse people, Marie Claire said: “People from culturally diverse backgrounds will bring their NDIS letters to their Diversitat case workers if they don’t understand them. NDIS need to use interpreters and not just the letters alone as people won’t understand them. The initial phone call to organize an appointment could be with a phone interpreter but for the meetings they should use interpreters in person.

Tanha*

Tanha is a 19-year-old Afghani male with muscular dystrophy. He arrived in Australia in December 2013 through the Australian Government's refugee program and was settled in Geelong. Before coming to Australia Tanha assisted the International Organisation for Migration with English classes in Indonesia. Tanha would like to continue his education in Australia.

Since arriving in Australia Tanha has noticed a decline in his physical condition: "I have been getting worse since coming to Australia. I need help cooking and going places. It is hard to walk long distances. If I walk sometimes I fall down. Day by day my muscles are becoming worse. I don't use any equipment now but I will need help getting around soon. I am not currently using a wheelchair but I might need one in the future."

New arrivals from a refugee background with a permanent residency visa or citizenship – who satisfy eligibility criteria – are able to access the NDIS as they have the same rights and responsibilities as others

Due to the effects of muscular dystrophy he experiences, and with no family or carer support in Australia, Tanha requires external support to manage his disability and to access the community. With the help of a bilingual worker from Diversitat, Tanha visited the NDIS to see if he was eligible to receive disability supports under the scheme. However Tanha, who is a permanent resident of Australia, arrived after the NDIS Barwon's launch date so he was denied access to the NDIS and was not given any further information about how and where he could access other disability assistance.

"I know that there are things here to support me but I don't know how to access them. It is difficult as no-one has told me or shown me how I can access any information or support," Tanha said.

"I want to know how I can improve my life and my future here. I need lots of information, I am not aware of how I can get support as no information has been given to me. The NDIS didn't help me with any services or support. Diversitat has helped me with taxi vouchers and filling in applications but nothing else has happened except a small disability pension and some physiotherapy and occupational therapy, which will soon stop."

In addition to the lack of practical support for people with disability who are not able to participate in the Scheme, there is a lot of misinformation about refugee eligibility in the launch sites. "I was told by the NDIA that I was not eligible. I was told that I needed to be here for over one year before I could apply," Tanha said.

*Names have been changed on clients' request.

However, it was Tanha's date of arrival in the Barwon region, not whether he had lived in Geelong for a year or more, which determined his residency eligibility. In addition, refugees with a permanent residency visa or citizenship – who satisfy eligibility criteria – are able to access the NDIS as they have the same rights and responsibilities as others in the launch sites. Furthermore, in Diversitat's recent conversations with the NDIA (via their 1800 number listed on their website) there have been three occasions where NDIA call centre staff have incorrectly advised that new arrivals from a refugee background are ineligible to participate under the scheme.

Tanha was not advised he could appeal the NDIS eligibility decision through an exceptional circumstances clause; Diversitat is now supporting Tanha to pursue an appeal. In addition, Tanha was not provided with translated material about the NDIS and the disability system and community supports, he was not advised of the complaints procedure or that he could involve a personal advocate in his discussions with the NDIS and he was not made aware that he could appeal his eligibility decision. Without access to correct information, people with a disability from culturally and linguistically diverse backgrounds will continue to face barriers to reasonable and necessary disability support and assistance.

Ti Mo

Ti Mo is a 17-year-old Karenni refugee who, with her family, has been living in Geelong since 2010. Ti Mo has profound hearing loss and her speech is impaired. Ti Mo is not receiving necessary disability supports to communicate and feel safe in the community and this is increasing her social isolation.

Ti Mo is not receiving necessary disability supports to communicate and feel safe in the community and this is increasing her social isolation.

Despite living in the Barwon launch site for the NDIS, Ti Mo and her family have never heard of the NDIS, before being advised by Diversitat. Ti Mo's family has limited knowledge about the disability system in Australia and available supports. She and her family are not linked with a disability service provider and they are not receiving any disability supports (apart from Auslan assistance organized through Ti Mo's school). Ti Mo's eligibility for the NDIS has not been tested.

Ti Mo grew up in a refugee camp in Thailand and her family developed their own sign language to communicate with her. They have limited literacy in their local language of Karenni and a very limited understanding of the English language and Auslan. Since arriving in Geelong, Ti Mo has been learning English and Auslan at her mainstream high school however, as her parents are not learning English or Auslan, Ti Mo still experiences communication challenges and social isolation. Ti Mo's friends have some knowledge of the sign language her family developed but they too are not learning Auslan.

It is difficult for Ti Mo to engage with the community. Her father explains: "It is dangerous for her because she can't communicate. She was going to Melbourne for a cooking class at the hearing school but one night the train was delayed and we were calling her but she couldn't talk to us. Another time when she used the bus she just got on and walked down the back and the bus driver was yelling at her about her ticket but she wasn't aware because she can't hear. Because she can't communicate it is very hard and it makes us very worried when she is out in the community."

Despite living in the Barwon launch site for the NDIS, Ti Mo and her family have never heard of the NDIS... Ti Mo's family has limited knowledge about the disability system in Australia and available supports.

"Ti Mo is emotionally not strong because she can't communicate with people around her," he adds. He believes the difficulty in communicating and the lack of support is impacting her mental health and resilience, and he describes her as becoming increasingly "mentally weak". Due to Ti Mo's anxieties about being able to communicate effectively and remaining safe when out in the community she is spending more time at home, which increases her social isolation.

Like all new arrivals from a refugee background, Ti Mo's family received some settlement support through Diversitat when they first arrived in Geelong. The current support from Ti Mo's school (Auslan aid) will finish at the end of her secondary schooling (Ti Mo is completing VCAL over three years). Her family are concerned about her future in terms of her options for further study and employment and for ongoing Auslan support.

At this time there is no case-management funding for CALD organisations to support new arrivals with a disability to determine their eligibility for disability supports and services and to complete the necessary health referrals.

The access and equity issues that the family face in engaging with relevant services (in particular the

NDIS) include: language barriers (interpretation into Karenni and Auslan); a lack of knowledge about the disability system in Australia, disability entitlements and available support services; the complexity of navigating the disability support system; and the lack of availability of culturally appropriate care.

There is no case-management funding for CALD organisations to support new arrivals with a disability to determine their eligibility for disability supports and services and to complete the necessary health referrals

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Diversitat can work with your organisation to increase cultural inclusiveness and improve staff skills to support people from culturally and linguistically diverse backgrounds.

Cultural inclusiveness is achieved through the development, delivery and evaluation of:

- Cross cultural training for staff
- A cultural audit
- Cross cultural/diversity plan, including working with interpreters
- Access and Equity Plan

Diversitat has established an extensive network with ethnic communities and ethnic specific peak bodies within the Barwon South West region and state-wide.

For more information contact: Diversitat

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www.diversitat.org.au