



# The NDIS and Culturally and Linguistically Diverse Communities:

Aiming high for equitable access in Queensland





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Our appreciation goes to the Community Resource Unit, Queenslanders with Disability Network and Mamre Association for their foresight and significant support in providing AMPARO Advocacy with funding to undertake CALD focussed NDIS participant readiness activities from December 2014- June 2016, this work has greatly helped inform this report.

We would also like to thank the Queensland University of Technology (QUT) and research participants for the valuable information, and contribution made by joint research undertaken with AMPARO Advocacy.



## Executive Summary

It is clear from AMPARO's work and that of others, that longstanding disadvantage and additional barriers have contributed to 'decades' of low levels of access and participation in mainstream and specialist disability services for people from culturally and linguistically diverse (CALD) backgrounds with disability<sup>1</sup>. Systems in place for many years, including National and State Standards for Human Services and Disability Services, have failed to address these barriers.

AMPARO Advocacy considers the implementation of the National Disability Insurance Scheme (NDIS) across Australia to have enormous potential to improve the lives of people with disability. However to ensure all Australians with disability can equitably access and participate in the NDIS it is imperative that the NDIA develops and implements a robust Cultural Diversity Strategy with targeted access and equity measures.

Whilst it is estimated that nationally, approximately 21.9% of NDIS participants should come from a CALD background, the NDIA has acknowledged all sites have lower than expected CALD participants with only 4% with approved plans as of the 30 June 2016<sup>2</sup>.

Whilst the NDIS only commenced in Queensland on the 1 April 2016, figures for the June 2016 Quarter show lower than expected participation rates by people from CALD background at 2.5%.

***The lower levels of participation by people from CALD backgrounds at a National and State level in the NDIS, reflects a system that has been designed and developed with policy, processes, and communication and engagement strategies that so far are struggling to meet the needs of CALD communities.***

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<sup>1</sup> Robertson, H., Travaglia, J. (March 2105). Cultural Diversity Framework.

<sup>2</sup> National Disability Insurance Agency (JUNE 2016). Quarterly Report to COAG Disability Reform Council 30 June 2016.

The report speaks to the underlying causes of disparity, and the need to build a culturally competent and responsive NDIS system that will also work to strengthen the capacity of individuals, families and communities from CALD backgrounds to understand their rights, to know what a 'good life' looks like and to be able to fully participate in the NDIS. It highlights the additional vulnerabilities and challenges facing those from new and emerging communities and humanitarian entrants with disability, and their need for intensive support and independent advocacy.

AMPARO Advocacy's NDIS Participant Readiness Initiative (PRI) activities and multicultural engagement with CALD communities in Queensland has identified a number of factors that if addressed would support greater access to the NDIS. Lessons learnt from this work are also consistent with similar work undertaken in other states and influence the final recommendations of the report. This preparatory work with CALD communities in Queensland has demonstrated that a community development approach with the support of trained bicultural workers and interpreters, is an effective means to provide information and to identify people who are not connected to disability support services and have not heard about the NDIS.

Recommendations in the report are largely aimed at the NDIS, with priorities for strategies and actions that need to be incorporated in the National CALD Strategy. The report stresses the requirement to improve information that is being collected by the NDIA, so that meaningful and accurate data can be used to monitor participation rates and to inform targeted strategies, policy development and planning by the NDIS. The central role of Local Area Coordinators (LACs) in identifying difficult to reach and isolated individuals with disability is also discussed, with a recommendation to employ and resource LACs in each region, to work specifically with people from CALD communities.

We know that the NDIS is committed to a listen, learn and build approach to deliver a system that meets the needs of all stakeholders, we hope that this report will add to their understanding of what is necessary to achieve a system that addresses longstanding disadvantage and is fair and equitable for people from CALD background with disability.

The challenge now for the NDIS is to incorporate well-resourced access and equity measures into the core business of the NDIS as a matter of priority.



## Introduction

AMPARO Advocacy is a non-profit community based organisation that undertakes independent individual and systemic advocacy with and on behalf of vulnerable people from culturally and linguistically diverse (CALD) backgrounds, particularly those who do not speak English as their first language (NESB), with disability. For the purposes of this report the term CALD will be primarily used, and NESB will be used in relation to issues around language.

AMPARO Advocacy (AMPARO) is governed by a voluntary management committee the majority of whom are themselves people from a NESB with disability.

AMPARO assists vulnerable migrants and refugees with disability to understand important information and navigate services and systems so that they have equitable access to essential mainstream and disability specific supports and programs that they otherwise would not receive. AMPARO works in ways that respects and meets the language, cultural and religious needs of people with disability and is guided by a strong commitment to the principles of human rights, social justice and inclusive living. It is through this work that AMPARO has developed a deep understanding of the real life experiences and additional concerns of this highly disadvantaged group.



## Purpose of the Report

The implementation of the National Disability Insurance Scheme across Australia has enormous potential to improve the lives of people from CALD backgrounds with disability. To ensure that inequities in the current specialist disability service system are not replicated in policy and practice and in the delivery of supports under the NDIS, important access and equity issues must be addressed.

All government agencies have an obligation to incorporate “access and equity considerations into all relevant policies, programmes and services as a central element, not just as an add-on”, as outlined in the Australia’s Multicultural Access and Equity Policy. This policy also promotes the right of all Australians to communicate and engage with the Australian government and funded agencies, irrespective of their first language preference and cultural, ethnic, linguistic and religious backgrounds<sup>3</sup>.

However, there are concerns held by many across the disability and multicultural sectors that not enough is being done by governments and the NDIA to give effect to this commitment.

This purpose of this position paper is:

- To highlight longstanding disadvantage that has contributed to low levels of access and participation in mainstream and specialist disability services for people from CALD backgrounds with disability.
- Inform the ongoing development of social policy, strategies and practices that will support people from CALD backgrounds with disability to equitable access and participation in the National Disability Insurance Scheme, with a particular focus on Queensland.

***This paper will make recommendations that are particularly relevant to the National Disability Insurance Scheme, Queensland State Government and specialist disability service providers.***

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<sup>3</sup> Commonwealth of Australia (Department of Social Services). (2015). Multicultural Access and Equity Policy Guidelines. Commonwealth of Australia.

# Recommendations

## Recommendations for the National Disability Insurance Scheme

### Strong Leadership and the NDIA CALD Strategy

- 1. Develop strong leadership and a dedicated well-resourced team** within the NDIA to take responsibility and oversee the effective implementation, and regular review of the CALD Strategy to ensure access and equity measures are imbedded into NDIA core policies, programmes and services. Without this commitment it is unlikely that measures will be effectively implemented.
- 2. Develop and implement a robust CALD Strategy** with targeted access and equity measures that will address longstanding issues of disparity and ensure all Australians can equitably access and participate in the NDIS. It is imperative that the NDIS CALD Strategy is developed and implemented as a matter of urgency.
- 3. Ensure the CALD Strategy demonstrates a strong commitment to human rights,** inclusion and meaningful engagement in order to meet the needs of people from CALD backgrounds with disability.
- 4. Implement CALD strategies in Queensland now** to increase CALD participation in the NDIS as a matter of priority, rather than wait for the national CALD Strategy to be finalised.

### Effective Evaluation and Quality Assurance

- 5. Monitor and evaluate the performance of the NDIA and service providers:**
  - Develop clear benchmarks and key performance measures based on best practice to determine if access and equity initiatives are effective.
  - Ensure effective feedback and complaints mechanisms that are appropriate and accessible to CALD communities.
- 6. Develop and incorporate quality assurance indicators** that address access and equity barriers for people from CALD backgrounds into the NDIS National Quality and Safeguards Framework. e.g. Require services develop a language service policy that provides clear guidelines for staff regarding how to effectively engage and work with interpreters and translators.
- 7. Establish clear targets for participation rates** of people from a CALD background and undertake specific strategies to reach these figures.
- 8. Review the NDIS system,** including all current policies, processes and information to ensure they meet the access and equity needs of CALD communities.

### Effective CALD Communication and Engagement Strategy

- 9. Undertake targeted communication and engagement,** including outreach programs to:
  - Understand the needs of CALD communities
  - Ensure the cultural diversity of the NDIS participants is reflective of local communities and regions
  - Guide the delivery of sensitive and complex information to ensure accurate understanding

and expectations of the NDIS

- Move beyond a reliance on web-based information and the NDIS 1800 number as the main means to assist CALD community members.
  - Develop an NDIA language services policy to provide clear guidance on how to engage and work with interpreters and translators, including at the pre-access stage.
  - Guide capacity building activities.
- 10. Promote key aspects of this new system to CALD communities** using a range of mechanisms: including ethnic media, ethnic communities' newsletters, translated and video information via the internet and face to face information, with the support of trained bicultural workers and credentialed interpreters.
  - 11. Invest the resources required for an effective CALD communication strategy** including designated and skilled personnel, and a long term and flexible approach.
  - 12. Value the skills, expertise and connections** that community leaders, bicultural workers and multicultural organisation can offer as partners and connections to CALD communities. Ensure they are part of the process in Queensland.
  - 13. Establish local CALD NDIS working groups in regional areas** to provide advice on targeted engagement locally.

### Cultural Competency

- 14. Build cultural competence throughout all levels of the NDIS**, with policies, programs and practices reflecting best practice and the skills of staff reflecting high levels of culturally competence.
- 15. Include training in how to engage** credentialed interpreters, translators, and bicultural workers.
- 16. Undertake strategies to build the cultural competence** of the broader mainstream and specialist disability sector.
- 17. Develop linguistic and culturally responsive person centred tools**, and provide training for staff to build their skills and knowledge in this area.<sup>4</sup>

### Information, Linking and Capacity Building

- 18. Undertake targeted Information, Linking and Capacity Building activities with CALD communities to:**
  - Increase understanding of potential participants, their families and diverse communities, about the NDIS, how to access and take advantage of the opportunities to participate in this scheme.
  - Understand the needs and rights of people with disability and to address cultural perceptions of disability that may be stigmatizing and discriminatory.
  - Raise expectations for what is a 'good life' and what that could look like for people with disability and help them to understand what choice and control could look like for them and their families.

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<sup>4</sup> Winter, B. & Katrivesis, M, M. (May,2015). *Supporting Interpreters to work effectively in the Disability Sector*. National Disability Services. NSW.

## Local Area Co-coordinators (LACs)

19. **Employ and adequately resource CALD focussed LACs** in each region to work specifically with people with disability and their families from CALD backgrounds. Allow time to effectively liaise and develop relationships with local CALD communities.
20. **Ensure targeted strategies are in place to identify** those who are isolated and hard to reach.
21. **Ensure all LACs undergo ongoing training** to be able to work effectively with CALD communities.

## Support to Access the NDIS

22. **Develop alternative NDIS access strategies** that are appropriate and suitable for CALD communities. Recognise the limitations and dangers of requiring people who have low levels of English proficiency to rely on family, friends or services to provide information and complete Access Request forms.
23. **Provide intensive preplanning and case management support** for individuals with disability and their families from CALD backgrounds to ensure they understand and can effectively access the NDIS, including support for any assessments or diagnosis if needed, and to collect important information and complete the necessary forms.
24. **Investigate, consult and develop specific targeted strategies in regional and remote areas** to overcome barriers associated with remoteness for people from CALD backgrounds.

## Data Collection

25. **Develop improved data collection systems to monitor participation rates** and to ensure effective planning, policy development and strategies, including workforce development strategies. The following information should be collected:
  - the main language spoken at home
  - proficiency of spoken English for individual and key family members
  - preferred spoken language for individual and key family members
  - country of origin and
  - country of birth<sup>5</sup>

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5 Department of Immigration and Multicultural Affairs (2001). The Guide: Implementing the Standards for Statistics on Cultural and Language Diversity Commonwealth of Australia.

## Recommendations for the Department of Social Services

### The National Disability Advocacy Program must strengthen its commitment to protect and defend the rights and interests of people with disability by:

1. **Increasing its funding commitment for independent advocacy** in various forms across Australia for the effective implementation of the NDIS.
2. **Supporting the development of cultural competence** within organisations delivering advocacy, including the effective engagement of credentialed interpreters, translators and bicultural workers.
3. **Funding specialist independent advocacy for people from CALD backgrounds** with disability, until such time as advocacy agencies can build their capacity to be culturally competent and responsive to the needs of all people with disability, and this is reflected in participations rates and outcomes for people from CALD backgrounds.
4. **Maintaining a commitment to fund independent advocacy** that is separate from the delivery of services, to minimise potential or actual conflicts of interests.

## Recommendations for Queensland's transition to the NDIS

### These recommendations need a collaborative approach between the Department of Communities, Child Safety and Disability Services and the NDIA:

1. **Develop and implement a comprehensive plan of engagement for CALD communities** that supports their inclusion in the NDIS as it transitions throughout Queensland.
2. **Develop local strategies and solutions** that suit the unique diversity of Queensland's CALD communities as they transition into the NDIS.
3. **Ensure that appropriate culturally responsive strategies are in place** to inform current clients of Disability Services from CALD backgrounds of the processes to transition into the NDIS.
4. **Fund long-term capacity building initiatives** to increase the social inclusion of people from CALD backgrounds with disability and their families in their ethnic and local communities.
5. **Undertake joint workforce strategies** to ensure people with disability from CALD backgrounds and their families have access to a workforce that can apply culturally competent person centred approaches to delivery support<sup>6</sup>.
6. **Implement workforce development strategies** to increase the availability of National Accreditation Authority for Translators and Interpreters (NAATI) accredited interpreters and translators, including in new and emerging languages.
7. **Implement training programs** for interpreters, translators and bicultural workers to increase their knowledge skills and awareness of disability and relevant terminology.

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6 Travaglia, J. & Roberston, H. (March 2015) Cultural Diversity Competency Framework.

# Human Rights, Legislative and Policy Frameworks

## Supporting Access and Equity Measures

### The Convention on the Rights of Persons with Disabilities 2006

Article 5: Equality and non-discrimination, requires State parties, like Australia, to prohibit discrimination on the basis of disability and guarantees persons with disability equal and effective legal protection against discrimination on all grounds including: on disability or any status such as gender, age, race, ethnicity, religion or sexuality.<sup>7</sup>

### The Racial Discrimination Act 1975 (CWLTH)

The Commonwealth Racial Discrimination Act gives effect to Australia's obligations under the United Nations International *Convention on the Elimination of All Forms of Racial Discrimination* (1965) and provides that it is discriminatory and unlawful to treat a person unfavourably on the basis of: *race, colour, descent or national or ethnic origin*.<sup>8</sup>

### National Disability Strategy 2010-2020

Acknowledges the significant barriers that people from a CALD background with disability experience – *"In particular newly arrived migrants such as refugees and special humanitarian entrants can be particularly vulnerable and those with disability are likely to experience multiple disadvantages, lack of accessible information, communication difficulties or cultural sensitivities and differences can create barriers to services and supports."*<sup>9</sup>

### The Australian Multicultural Access and Equity Policy

Promotes the right of all Australians to communicate and engage with the Australian government and funded agencies, irrespective of their first language preference and cultural, ethnic, linguistic and religious backgrounds.

Australia's Multicultural Access and Equity Policy aims to *'harness the economic and social benefits of Australia's diversity'*. This policy is very consistent with a key guiding principle of the NDIS, which states that *"people with disability should be supported to participate in and contribute to social and economic life to the extent of their ability"*<sup>10</sup>.

### Multicultural Language Services Guidelines

The Australian Government Multicultural Language Service Guidelines provides clear recommendations to assist those for whom language and culture may present barriers to effective participation in the Australian community<sup>11</sup>.

### NDIA's Cultural Diversity Strategy and Action Plan (Draft)

This strategy is currently being written by the NDIA. AMPARO is a member of the CALD Stakeholder Advisory Group and has provided feedback on the development of this strategy.

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7 Queensland Advocacy Incorporated. (2008). Human Rights Indicators for People with Disability. Phillip French Disability Studies and Research Institute for Queensland Advocacy Incorporated. Brisbane.

8 Australian Human Rights Commission. (2012). *Racial Discrimination, Know Your Rights*. Australian Human Rights Commission. Canberra.

9 Commonwealth of Australia (2011). National Disability Strategy 2010-2020. Commonwealth of Australia.

10 Commonwealth of Australia (2013). National Disability Insurance Scheme Act 2013. An Act to establish the NDIS and for related purposes. Commonwealth of Australia.

11 Commonwealth of Australia (2013). Multicultural Language Service Guidelines. Commonwealth of Australia

## About AMPARO Advocacy

**AMPARO Advocacy's vision:** People from a non-English speaking background (NESB) with disability to be accepted and respected as part of the diversity of Australian society, with access to information, services and benefits, so that they can be included, participate and contribute in family and community life.

**AMPARO Advocacy believes:** People from a NESB with disability have a rightful place in community where they are welcomed, respected and valued with opportunities and support to live a life that has meaning for them.

**Our Mandate:** AMPARO Advocacy takes our mandate from important United Nation declarations, Federal and State anti-discrimination laws and principles which promote the rights of all people as well as expectations for the lives of people from a non-English speaking background with disability.

**Advocacy Principles:** AMPARO's independent advocacy and engagement with people from a NESB with disability is undertaken in a way that respects and meets the language, cultural and religious needs of the person and group and is guided by a strong commitment to the principles of human rights, social justice and inclusive living.

**Individual Advocacy:** Independent individual advocacy aims to ensure migrants and refugees with disability, particularly those with limited English proficiency, have their fundamental needs met, so they can actively participate, and fully engage in family and community life. The individuals who receive advocacy are most likely to be at risk and are least able to represent or defend their own rights and interests. They often do not have a voice or close family or friends who can support their aspirations, or speak on their behalf.

**Engaging with Diverse Communities:** Engaging with diverse communities assists us to better understand the specific challenges and issues that people with disability and their families from culturally and linguistically diverse communities experience and informs all aspects of our work. This work also increases community understanding of disability within particular communities and reduces cultural barriers for people with disability and is undertaken in partnership with multicultural and disability organisations, utilising interpreters and bicultural workers.

**Systemic Advocacy:** AMPARO Advocacy's independent systemic advocacy aims to influence positive sustainable changes to attitudes, policies, practices and resources within governments and communities. This work is informed by our individual work with migrants and refugees with disability and their families and an understanding of the real life experiences and additional concerns of this highly disadvantaged group. This means that systemic issues that are taken up by AMPARO are those most relevant to the individuals we assist.

AMPARO Advocacy's systemic advocacy responsibly challenges systems, approaches and values that can impact negatively on the lives of people with disability and questions the coherency between what human services and governments say and what they do in practice. AMPARO provides advice to government and community organisations, responds to strategies, participates in consultations or working groups, and addresses forums, so that the needs of Queenslanders from a CALD backgrounds with disability are represented and so the issues they experience are well understood.

## This report and recommendations are informed by AMPARO Advocacy's work and learnings from:

- Many years of providing independent individual and systemic advocacy to address issues of disadvantage and discrimination, on behalf of and with vulnerable people from CALD backgrounds with disability.
- Targeted capacity building with Burundi, Afghan, Iraqi and Karen communities to increase community members' knowledge and understanding of disability, the rights of people with disability and the availability of services, supports and advocacy.
- Eighteen months' work delivering Participant Readiness Initiative (PRI) activities to assist people with disability and their families from CALD communities to prepare for the introduction of the NDIS in Queensland. This work was undertaken in partnership with the Community Resource Unit (CRU), Queenslanders with Disability (QDN) and Mamre Association. The Participant Readiness Initiative (PRI) has been funded by the Department of Communities, Child Safety and Disability Services to prepare Queenslanders for the introduction of the NDIS. The department now funds AMPARO directly to undertake this work for a further 12 months.
- Work undertaken by Griffith University with AMPARO and our PRI partners: CRU, Mamre Association, and QDN, to improve responses to people from CALD backgrounds under the PRI, with the final report, *NDIS Participant Readiness Initiative: A culturally competent response to people from cultural and linguistically diverse (CALD) backgrounds*.
- Joint research with Queensland University of Technology (QUT), exploring the barriers to services and inclusion for refugees living with disability, *Disadvantage and disability: Experiences of people from refugee backgrounds with disability living in Australia*<sup>12</sup>.
- Current capacity building work with four distinct communities, the South Sudanese in Toowoomba, Congolese and Rwandan in Townsville, and Burmese and Somali communities living in Brisbane. This work aims to build the capacity of communities to understand the rights and needs of people with disability and their families and to be more inclusive of people with disability in their communities. This work is being undertaken with the paid support of bicultural workers in those communities and is funded by Multicultural Affairs Queensland.
- Recommendations from a Key Stakeholder Workshop with 9 community organisations from across Queensland, to discuss shared concerns about the participation of people from CALD backgrounds in the NDIS. The workshop was held in March 2016 with the support of Queensland Survivors of Torture and Trauma (QPASTT) and Queensland Council of Social Service (QCOSS) and brought perspectives from a diversity of organisations who work with people with disability and mental health issues and CALD communities. State-wide peak bodies and regionally based agencies were also represented.
- Important learnings from similarly focused CALD NDIS engagement projects in NSW and Victoria, including work undertaken by Diversitat and Ethnic Community Services Co-operative.

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12 King, J., Edwards, N., Correa-Velez, I., Hair, S., and Fordyce, M. (2016). Disadvantage and disability: Experiences of people from refugee backgrounds with disability living in Australia. *Disability and the Global South (DGS)*.



## Evidence of Under Representation in Accessing Disability Services

**There is strong evidence that issues of disparity, discrimination and neglect are nationwide and longstanding.**

People from CALD backgrounds with disability and their families experience multiple and complex layers of disadvantage and low levels of participation in mainstream and disability specialist services. Many reports have highlighted serious issues of disadvantage and referred to “*multiple layers of discrimination*” leading to the “*exclusion, isolation and alienation of people from a NESB with disability*”, including in 2000, the then Human Rights and Equal Opportunity Commission.<sup>13</sup>

According to recent Australian research, there continues to be a “*substantial accessibility gap in specialist disability service between people from CALD backgrounds and the broader community in Australia.*”<sup>14</sup> Zhou like many others argues that bridging this gap requires understanding the underlying causes of disparity. Zhou also believes that “*promoting the awareness of the services and developing appropriate and effective services to respond to the need of people with disability from CALD backgrounds*”<sup>15</sup> is required.

### **National Figures – people from CALD backgrounds with disability.**

According to the COAG Reform Council report on social and economic participation, rates of service use for people from a NESB background was 11.7%, less than half of the national rate of 34.9%<sup>16</sup>. The report states that, “*These inequalities are even more acutely experienced by people with disability who are Indigenous or who were born in non-English speaking countries.*”

Examining the most recent data on people who have used disability support services under the National Disability Agreement (NDA) shows the numbers of people born in non-English speaking countries has remained relatively steady at 10% over the 5 years to 2014–15<sup>17</sup>. The most telling aspect of this data is that there has been no increase in participation levels for the past 5 years.

13 Human Rights and Equal Opportunity Commission (HREOC) (2000) *On the Sidelines: Disability and People from Non-English Speaking Background Communities*. HREOC.

14 Zhou, Q. (2015). Accessing disability service by people from culturally and linguistically diverse backgrounds in Australia. *Disability and Rehabilitation*

15 *Ibid.*, p. 1

16 COAG Reform Council Report Disability 2011-2012: Comparing performance across Australia.

17 Australian Institute of Health and Welfare (June 2015) *Disability Support services: Services provided under the National Disability Agreement 2014-2015*. Bulletin no.134. Canberra. Australian Government

## CALD participation in the NDIS

The National Ethnic Disability Alliance more accurately estimates that 21.9% of NDIS participants should come from a CALD background<sup>18</sup>. However, the NDIS Quarterly Report 30 June 2016, showed that only 4% of participants classified as CALD had approved plans, a drop from 4.2 % in the previous March Report. The report acknowledges that all sites have lower than expected CALD participants<sup>19</sup>.

## Queensland's Figures – people from CALD backgrounds with disability

Queensland is a state of significant diversity with 21% of the population being born overseas, 9.8% speaking a language other than English and 220 languages spoken. The size and geography of Queensland and the remoteness of many rural communities presents a number of challenges to accessing services including transport, aged care and disability support, medical treatment and so on.

Whilst the south-east corner has the largest population of people born overseas, others settle in smaller numbers throughout the state in rural towns and remote areas. This means providing information and engaging with people from migrant and refugee communities with disability across the state is a complex process. On site language interpreters are often not available in many rural and remote communities. Recent engagement by AMPARO with a number of individuals with disability and their families from CALD backgrounds in Toowoomba, meant that interpreters had to travel from Brisbane.

In Queensland 9.8% speak a language other than English at home and 10% of people with severe and profound disability between 0-65years, come from homes where English is not spoken.<sup>20</sup>

## Queensland CALD participation in the NDIS

More recent data from the National Ethnic Disability Alliance estimates that approximately 13.7% of participants of the NDIS in Queensland should be from a CALD background<sup>21</sup>.

However Queensland's figures for the first NDIS June 2016 Quarter shows that only 2.5% of participants classified as CALD have approved plans.

It is understandable that figures are lower than expected for the very first Quarter of the operation of the NDIS in Queensland, however CALD focused engagement strategies need to be adopted to ensure future figures accurately reflect the diversity of the community.

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18 National Ethnic Disability Alliance (NEDA) (March 2016). Unpublished data. NEDA

19 National Disability Insurance Agency (JUNE 2016). Quarterly Report to COAG Disability Reform Council 30 June 2016.

20 Australian Bureau of Statistics (2011) Census 2011. Commonwealth Australia.

21 National Ethnic Disability Alliance (NEDA) (March 2016). Unpublished data. NEDA



## Longstanding Disadvantage and Additional Barriers

**Systems in place for many years, including National and State Standards for Human Services and Disability Services, have not addressed longstanding issues of disparity and people from CALD backgrounds with disability continue to be significantly underrepresented in accessing specialist disability services, including independent advocacy.**

AMPARO knows from our work and that of others, that longstanding disadvantage and additional barriers have contributed to low levels of access and participation in mainstream and specialist disability services for people from CALD backgrounds with disability.

Australia's Multicultural Access and Equity policy articulates a strong commitment to ensure that Australian Government programs and services and those services delivered on behalf of government *"be accessible by all eligible Australians, responsive to their needs, and deliver equitable outcomes for them regardless of cultural and linguistic backgrounds."*<sup>22</sup>

In considering the specific needs of people from CALD backgrounds with disability and their families it is important to understand factors that increase vulnerability and contribute to low levels of participation.

### Pre-migration trauma and the challenges of early settlement

There has been a welcomed increase in the numbers of people with disabilities receiving visas under the Refugee and Humanitarian Program since the Australian Government implemented changes to the visa health requirements, as a result of the Joint Standing Committee Migration Report.<sup>23</sup> AMPARO and others argued the unfairness of a Migration Act that meant people seeking protection from persecution, war and trauma were refused entry because they had a disability, despite this putting them at even greater risk of human rights abuses<sup>24</sup>.

AMPARO has found that people with disability and their families, from new and emerging communities or those who have settled under Australia's Refugee and Humanitarian Program, face particular challenges and require more intensive support and advocacy to ensure their needs are met.

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22 Commonwealth of Australia (Department of Social Services). (2015). Multicultural Access and Equity Policy Guidelines. Commonwealth of Australia.

23 Refugee Council of Australia retrieved 16 September 2016 from <http://www.refugeecouncil.org.au/wp-content/uploads/>

24 AMPARO Advocacy (October 2009). Submission to Joint Standing Committee Inquiry into Immigration Treatment of Disability.

## These challenges include but are not limited to the following:

**Having been forced to flee their homes to escape war and violence** people are “working to restore a sense of safety and control over their lives, and often processing grief about the loss of self and country.”<sup>25</sup>

**The ongoing effects of trauma or torture**, and the impact of being forced to flee their homes and the loss of family members. As a result there is often a need for culturally appropriate trauma counselling, with the added complexity and need to engage accredited interpreters for this to be effective.

**Complex unmet health needs**, as a result of having spent many years in refugee camps or countries with little capacity to provide good or even basic health care and treatment.

**Learning a new language**, or two, if they have a child or family member that is deaf it is important they also learn Auslan. Our work with two families with deaf children from CALD backgrounds showed that learning Auslan in a large class where an understanding of English is assumed is not useful and that at home sessions with families learning Auslan relevant to their life circumstances works best.

**Unable to attend English classes** as they do not meet their needs in relation to their disability, or their family have no support for their family member with disability to enable them to attend classes. One example of this is people who are blind and living in Brisbane are forced to travel to Logan Campus to attend Adult Migrant English Classes as this is the only campus with appropriate equipment to support their learning.

**Experiencing high levels of unemployment** despite working hard to better their education and find work to support their families.

**Limited appropriate and affordable housing.** Locating suitable accessible housing for newly arrived refugees with disability is extremely difficult. Accessible housing is limited generally and very expensive in the private market. Making modifications to private rental accommodation can be prohibitive because of the high cost and the lack of support by some landlords.

AMPARO routinely works with refugees with disability and their families who are living in housing that places them at risk physically or keeps them trapped inside because they are unable to negotiate stairs. Securing accessible public housing in Queensland is extremely difficult with a wait list of many years and little hope of an allocation unless the person is listed on the very high priority list. Furthermore, some individuals with disability live in large families where their combined income levels make them ineligible for public housing, so they are forced to live in inaccessible, and expensive private rentals. Limited understanding of public housing processes and tenancy rights further impacts on their housing options.

**Working towards family reunion.** AMPARO has worked with many families who must financially support other family members who remain in their countries of origin or dislocated in other countries or refugee camps. They are often saving or working towards family reunion with husbands or children they have been able to reconnect with, often after many years of not knowing they were alive.

**May have an impairment, but lack understanding about the cause of their impairment, and lack a diagnosis.** Accessing medical specialists and receiving a diagnosis can take considerable time and people often require significant case management support or advocacy to do this in a timelier manner. This lack of diagnosis can mean they miss out on important benefits and services, including early intervention support for children.

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25 Refugee Council of Australia, op. cit., 2016 from <http://www.refugeecouncil.org.au/wp-content/uploads/>

**Difficulties negotiating the public transport system** and the high cost associated with this was shown to be a significant barrier to accessing services, including employment, education, health, and connecting with other family members and friends<sup>26</sup>.

**Limited settlement support:** Understanding and effectively responding to these issues is crucial to supporting people with disability to settle and establish new lives in Australia. However responses to the additional needs of people with disability and their families can be inadequate as resources for the Humanitarian Settlement Services (HSS) and in particular complex Case Management Support (CCS) are limited. Case workers often have high numbers of clients to work with, lack knowledge of the disability service system and understanding of the needs of people with disability generally. As a consequence they can fail to make appropriate referral and provide adequate support for their clients with disability.

## **Misconceptions of disability, stigma and isolation.**

Misunderstandings and beliefs about the causes of disability can determine whether individuals with disability and their families are welcomed and included in their diverse communities and the broader community.

Through listening to the people's stories we know that prior to resettlement in Australia many people with disability and their families from refugee backgrounds have experienced stigma, isolation and discrimination, both in their countries of origin and refugee camps, with few opportunities and limited access to education and health services.<sup>27</sup>

Targeted engagement with the Burundi, Afghan, Iraqi and Karen communities similarly identified stigma and isolation were commonly associated with issues of mental health and disability within their communities.

### **These experiences are reflected in the research participants' comments:**

*"The majority of people with a disability, they see them as a burden...someone who is useless. You have to be healthy."<sup>28</sup>*

*"... also the parent's karma...also scolded in the village that you are cursed, you are idiot"<sup>29</sup>.*

*"In the culture it's shame to have a child with disability like that...people hide it, when I was a kid at school they asked me do you have any brother or sister, I say no, I am an only child."<sup>30</sup>*

*".....bad karma, they are sinners in the past and that is why they are still suffering nowadays."<sup>31</sup>*

*" Some people say very cruel. Cruel to me, and I got very upset".<sup>32</sup>*

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26 King, J., Edwards, N., Correa-Velez, I., Hair, S., and Fordyce, M. (2016). Disadvantage and disability: Experiences of people from refugee backgrounds with disability living in Australia. *Disability and the Global South (DGS)*.

27 King, J., Edwards, N., Correa-Velez, I., Hair, S., and Fordyce, M. (2016). Disadvantage and disability: Experiences of people from refugee backgrounds with disability living in Australia. *Disability and the Global South (DGS)*.

28 *ibid.*, p. 849

29 *ibid.*, p.848

30 King J, Edwards N, Correa-Velez I, Fordyce M. An exploration of the barriers to service and inclusion of refugees living with disability. School of Public Health and Social Work (QUT) and AMPARO Advocacy Inc. Brisbane, 2014.

31 *ibid.*

32 King J, Edwards N, Correa-Velez I, Fordyce M. An exploration of the barriers to service and inclusion of refugees living with disability. School of Public Health and Social Work (QUT) and AMPARO Advocacy Inc. Brisbane, 2014.

According to discussions with many individuals and families whilst stigma and discrimination occurs less in Australia, “these experiences continued to negatively affect their relationships with their families, communities, and access to services.”<sup>33</sup>

Two families recently expressed concerns that mental illness and cerebral palsy were contagious, and that other family members could be affected.

### **As a result of these experiences people from CALD backgrounds with disability and their families may:**

- Be reluctant or more cautious about seeking help outside of immediate family.
- Feel intense shame, guilt and stigma.
- Be more isolated than most new settlers and miss out on the ‘*sharing of information*’ that happens within new communities<sup>34</sup>
- Feel unsupported by their own communities and the broader Australian community.
- Have limited or no connections with other individuals with disability or families from their own cultural background.
- Are unsure of what a ‘good life’ for a person with disability can look like and limited experiences of the opportunities or ‘choices’ that may be available.

These experiences highlight the need to build understanding of the causality of impairment, knowledge of the rights of people with disability, the importance of promoting positive roles and the contributions that all people with disability can make to family and the broader community.

## **Lack of effective engagement and communication**

The Australian legal and social systems and their requirements are extremely complex and understanding and negotiating these systems is difficult for anyone. However, language and cultural barriers, including a lack of awareness of services and the rights of people with disability, the failure of services to provide culturally competent responses and a mistrust of authority can make accessing them a much more difficult process.

## **Availability of services and understanding rights**

The concept of disability and the operation of Australian systems such as disability services, are often unfamiliar and little understood by people from CALD communities, particularly those from new and emerging communities.

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33 King, J., Edwards, N., Correa-Velez, I., Hair, S., and Fordyce, M. op. cit., p.859.

34 King, J., Edwards, N., Correa-Velez, I., Hair, S., and Fordyce, M. (2016). Disadvantage and disability: Experiences of people from refugee backgrounds with disability living in Australia. *Disability and the Global South (DGS)*.

Many people with disability from refugee backgrounds come from countries where their human rights have not been protected and where because of their disability they have been “*particularly vulnerable to neglect or abuse.*”<sup>35</sup> In addition, prior to coming to Australia they may have had limited experience of receiving services, or accessing formal education, and limited or no access to medical care or treatment. This lack of experience can lead to lowered expectations of assistance that can be provided once in Australia and being unaware of the difference good supports, both informal and formal, can make to the life of the person with disability.

*“...we didn’t have a right there. They didn’t have any human service and human protection.”*<sup>36</sup>

These issues are compounded by the failure of many community and government services to effectively promote their services or to undertake targeted communication and engagement with culturally and linguistically diverse communities.

Cultural factors can also contribute to people from CALD backgrounds being reluctant to challenge decisions or make complaints, as they may also feel they have to be grateful for what is offered to them and overwhelmed by the prospect of making a complaint.

Our recent Participant Readiness work helping people from CALD backgrounds with disability, their families and communities to understand the NDIS and prepare for the roll out of this new scheme, highlights that mainstream communication strategies in Queensland by the NDIS have largely not reached CALD communities.

## Language and communication

The provision of high quality language services (interpreting and translation services) that are supported by culturally competent and responsive service systems are necessary to fulfill the principles of equitable access, social justice and social inclusion for people from CALD backgrounds.

The Federal government recognises this and promotes the importance of facilitating accurate communication through language services to support access, “*to the necessary information, programs and services they need to fully participate in society.*”<sup>37</sup> These commitments are well articulated in both the Federal Government’s Access and Equity Policy<sup>38</sup> and Multicultural Language Service Guidelines. At a state level the Queensland Language Service Policy similarly acknowledges that a lack of English proficiency is a “*significant barrier to economic independence and participation within community*” and articulates a strong commitment to the provision of qualified interpreters.<sup>39</sup>

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35 Women’s Commission for Refugee Women and Children, (2008). *Disabilities among refugee and conflict-affected populations*, New York: Women’s Refugee Commission.

36 King J, Edwards N, Correa-Velez I, Fordyce M. *An exploration of the barriers to service and inclusion of refugees living with disability*. School of Public Health and Social Work (QUT) and AMPARO Advocacy Inc. Brisbane, 2014.

37 Commonwealth of Australia. (2013). *Multicultural Language Service Guidelines*. Commonwealth of Australia.

38 Commonwealth of Australia. (2013). *Multicultural Access and Equity Policy: Respecting diversity, Improving Responsiveness*. Commonwealth of Australia.

39 Department of Aboriginal and Torres Strait Islander and Multicultural Affairs. (2013) *Queensland Language Service Policy*. Queensland Government.

Through our work with CALD communities and in particular those who have limited English proficiency, we understand that access to credentialed interpreters and the provision of translated and easy English information is critical in ensuring they can:

- understand important information
- communicate their needs
- make informed decisions
- navigate complex systems of support
- access and fully participate at all levels in the NDIS.

AMPARO's recent research with Queensland University of Technology (QUT), shows that language barriers and the failure of services to provide access to professional interpreters continues to be a major barrier to finding and utilising services and the cause of much frustration<sup>40</sup>.

### The following comments by research participants highlight these difficulties

*"Actually she said she very sad, because she doesn't know the language, so she doesn't know how to find the service".<sup>41</sup>*

*"When in hospital the interpreter isn't available any time, so very hard to communicate with doctor"<sup>42</sup>*

*"My mum doesn't have the English skill to speak, it was extremely hard. So many times she just crying, she was very upset."<sup>43</sup>*

*"...do not know how to find out, how to contact, how to talk".<sup>44</sup>*

**Access to credentialed interpreters** under the NDIS will also be essential to enable people with disability from CALD backgrounds to influence the direction of their own lives or where they have limited capacity, for families to take on this role.

### Culturally competent and responsive approaches

AMPARO Advocacy's experience highlights the importance of implementing culturally competent, safe and responsive approaches when engaging with and providing services to people from CALD backgrounds with disability and their families. Unfortunately, it is still common that many mainstream and disability specialist services struggle to effectively engage, communicate and support this group.

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40 King, J., Edwards, N., Correa-Velez, I., Hair, S., and Fordyce, M. (2016). Disadvantage and disability: Experiences of people from refugee backgrounds with disability living in Australia. *Disability and the Global South (DGS) Vol.3, No.1*).

41 King J, Edwards N, Correa-Velez I, Fordyce M. An exploration of the barriers to service and inclusion of refugees living with disability. School of Public Health and Social Work (QUT) and AMPARO Advocacy Inc. Brisbane, 2014.

42 King J, Edwards N, Correa-Velez I, Fordyce M. An exploration of the barriers to service and inclusion of refugees living with disability. School of Public Health and Social Work (QUT) and AMPARO Advocacy Inc. Brisbane, 2014.

43 King, J., Edwards, N., Correa-Velez, I., Hair, S., and Fordyce, M. (2016). Disadvantage and disability: Experiences of people from refugee backgrounds with disability living in Australia. *Disability and the Global South (DGS) Vol. 3, No. 1*).

44 King J, Edwards N, Correa-Velez I, Fordyce M. op. cit.

Whilst the Multicultural Access and Equity Policy Guide clearly requires agency staff to be "equipped with cultural awareness and competency skills" and to "understand their multicultural access and equity responsibilities"<sup>45</sup>, this is all too often not the case. The following comment from a family member from a CALD background reveals an assumption by a service provider that the person had knowledge of the disability service system and related terminology.

*"They say oh what do you want? Has he had an assessment done to him?"*

*"Does he have a support package?" "You know, all these questions that I didn't know anything about."<sup>46</sup>*

The disability service system has generally failed to develop cultural competence at all levels of service delivery and to embrace the principle of substantive equality and non-discrimination. The following is one of many definitions of cultural competence:

*Cultural competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency or among professionals and enable that system, agency or those professions to work effectively in cross-cultural situations.<sup>47</sup> (Cross et al.,1989)*

Inadequate service responses that fail to consider the language and cultural needs of individuals can result in a failure to follow up on referrals to specialists to address serious health issues, or missed hospital outpatient's appointments. It often means that credentialed interpreters have not been engaged to provide accurate information to the person and to check their understanding or more intensive case management support is needed. The result is complex health needs continue to go unmet and a formal diagnosis of the person's disability may not be received. A family member with a child with disability having to attend hospital medical appointments speaks of the difficulties negotiating the transport system and finding her way.

*"I don't know how to get there, sometimes we are good, sometimes we miss the bus, miss the appointment , get there late... it was so hard for me"<sup>48</sup>.*

## **A culturally competent person centred approach**

Whilst a person centred approach is central to ensuring choice and control under the NDIS, a commonly expressed assumption by some service providers is that if you are working in a person centred way you will automatically meet the language and cultural needs of the person. These same services are often not engaging with professional interpreters and not working in other culturally responsive ways with their clients or making remarks like "we don't work with any of those people".

People with disability from CALD backgrounds and their families require organisations with a workforce that can apply culturally competent person centred approaches to delivery support<sup>49</sup>.

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45 Commonwealth of Australia (Department of Social Services) 2015. Multicultural Access and Equity Policy Guidelines. Commonwealth of Australia.

46 King J, Edwards N, Correa-Velez I, Fordyce M. An exploration of the barriers to service and inclusion of refugees living with disability. School of Public Health and Social Work (QUT) and AMPARO Advocacy Inc. Brisbane, 2014.

47 Cross et al. (1989). Retrieved September 2016 <http://www.ncccurricula.info/culturalcompetence.html>

48 King J, Edwards N, Correa-Velez I, Fordyce M. An exploration of the barriers to service and inclusion of refugees living with disability. School of Public Health and Social Work (QUT) and AMPARO Advocacy Inc. Brisbane, 2014.

49 Travaglia, J. & Roberston, H. (March 2015) Cultural Diversity Competency Framework.

## Improving Data Collection

The Multicultural Access and Equity Policy Guide clearly recommends effective CALD data collection is necessary to measure the *"effectiveness of multicultural access and equity initiatives"* and to understand the needs of this group.

AMPARO strongly supports the need to establish targets to increase the participation rates of people from CALD background with disability in the NDIS, however to monitor participation rates and ensure effective planning and policy development it will be necessary to develop appropriate data collection and analysis mechanisms.

Unfortunately, the Disability Services National Minimum Data Set (DS NMDS) which collates data of disability support services provided under the National Disability Agreement has been inadequate and limited to country of birth, to determine those born in predominately non-English speaking countries. In addition to this, we have been told by the state government that services have not always provided this basic information. Furthermore, quality service standard indicators have generally not encompassed specific measures to address access and equity issues for people from CALD backgrounds with disability.

As people transition to the NDIS, the NDIA will collect information about participants once they have an approved plan, and funding is available. Current data collected by the NDIS is limited to country of birth is not Australia, UK, USA, Canada or South Africa or primary language spoken at home is not English. Country of birth or language spoken does not accurately indicate the person's ethnicity, for example many refugees may be born in countries they have fled to.

There is a concern that this data is not adequate to:

- Monitor the participation rates of people from CALD background
- Inform targeted strategies with specific diverse communities
- Ensure effective policy development and planning, or
- Inform the development of workforce strategies to increase numbers of skilled bicultural workers, interpreters and translators with disability awareness.

The data that is collected by the NDIS could be used to inform strategies by governments to ensure an adequate workforce of credentialed interpreters and translators and bicultural workers in languages that are needed.

Data on the need for interpreters and the incidences of their engagement by services is currently not kept. Being able to measure demand and trends in the area of language services, to inform the development of workforce strategies is necessary to ensure the language and communication needs of people from CALD backgrounds can be met under the NDIS. This information could also be used to inform training around disability awareness for those providing language services.



## National Disability Insurance Scheme and Participant Readiness Work with CALD Communities

**The lower levels of participation by people from CALD backgrounds in the NDIS reflects a system that has been designed and developed with policy, processes and communication and engagement strategies that so far are struggling to meet the needs of CALD communities. The challenge now for the NDIS is to incorporate access and equity measures into the core business of the NDIS as a matter of priority.**

### How many people from CALD backgrounds in Queensland will be eligible for the NDIS?

This report has highlighted the need for accurate data to be collected regarding how many people from CALD backgrounds have disability in Queensland. AMPARO is often asked by peak bodies, and state and federal government departments if we can provide this data.

For this report we provide figures from unpublished data from National Ethnic Disability Association (NEDA), sourced from: 2011 Census and 2012 Survey of Disability, Ageing and Carers (SDAC).

AMPARO considers these figures to be conservative given that participation in ABS census is usually lower for “*many people born overseas, especially recent arrivals and refugees*”<sup>50</sup>. However it illustrates that in Queensland, a significant number people who are eligible for the NDIS should come from CALD backgrounds and this should be reflected in NDIS participant numbers, and well considered in the development of policy and strategies.

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50 Australian Bureau of Statistics (Retrieved 16 September 2016)  
<http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/2911.0.55.004Main%20Features42011?opendocument&tabname=Summary&prodno=2911.0.55.004&issue=2011&num=&view=>

Estimates of NDIS participants from CALD backgrounds across Queensland		
AREA	CALD NDIS estimates	CALD NDIS estimates % of total participants
<b>Australia</b>	<b>98,353</b>	<b>21.9%</b>
<b>Queensland</b>	<b>13,178</b>	<b>13.7%</b>
Brisbane	5295	22.0%
Cairns	599	14.2%
Toowoomba	283	9.5%
Darling Downs & Maranoa	178	5.3%
Central Queensland	296	6.5%
Gold Coast	1,436	13.9%
Ipswich	1,535	17.7%
Logan - Beaudesert	1,170	16.9%
Mackay	309	7.3%
Moreton Bay	667	8.7%
Queensland – other (rural and regional)	78	9.8%
Sunshine Coast	639	7.6%
Townsville	259	8.6%
Wide Bay	435	6.2%

## Learnings from AMPARO’s PRI work in Queensland

AMPARO Advocacy’s NDIS Participant Readiness Initiative (PRI) activities and multicultural engagement with CALD communities in Queensland has identified a number of factors that we believe need to be addressed to support better inclusion and access to the NDIS.

### Our approach

Culturally appropriate, participatory, and flexible processes that support the effective engagement of people from CALD backgrounds with disability and their families is central to our approach for this work.

### Components of this work

- Gathering information and undertaking research to determine what will best help CALD communities to learn about the NDIS
- Informing people with disability and families from CALD communities about the National Disability Insurance Scheme (NDIS)
- Creating resources and translated materials to assist CALD communities prepare for the NDIS
- Informing multicultural workers, settlement workers and community leaders in Queensland about the NDIS so they can spread the word
- Working in partnership with multicultural organisations, community leaders and disability services in order to hold information sessions, workshops and at home sessions for people with disability, their families, and CALD communities
- Encouraging disability services to work in ways that are inclusive of CALD individuals and their families
- Raising awareness within government and community agencies of the importance of developing culturally inclusive strategies and ways of working with CALD communities

- Helping CALD communities to learn about the rights of people with disability, and their right to a good life
- Recruiting and training bicultural workers.

### Limitations of this work

- Our state-wide work is undertaken with minimal funding, enough for a part-time project worker and some resource development.
- There is no culturally appropriate communication strategy in Queensland, on the scale that is necessary, to inform CALD communities about the NDIS.
- As our project is the only CALD focussed NDIS participant readiness work currently being undertaken in Queensland, our time and resources are spread very thin.

### Findings from PRI work in Queensland

#### 1. CALD individuals and families need more information about disability and the opportunities that will be available under the NDIS.

- People with disability from CALD backgrounds can be very isolated and difficult to reach. The lack of understanding about disability, stigma and isolation, low levels of English literacy, limited awareness of services and inadequate service delivery responses are common.
- Building the capacity of individuals, families and communities from CALD backgrounds to understand the needs and rights of people with disability and to explore what a 'good life' can look like is an important precursor to providing information about the NDIS. This work takes time and is resource intensive.

#### 2. A one-size-fits all approach to communication with CALD communities is not effective.

- Mainstream NDIS communication strategies have not reached many CALD community members.

#### 3. A range of approaches are needed to reach isolated CALD individuals and families.

- Developing ongoing relationships with multicultural workers, community leaders and others who are connected to isolated individuals with disability and their families is essential. In Townsville where the NDIS has commenced, several multicultural organisations report no contact or outreach from the NDIS or Local Area Coordinators to inform them about the scheme or how to assist people with disability to access it.
- Providing information to CALD communities about the NDIS including what it is and how people can prepare for it closer to the roll out time of the scheme in their area, and then for an extended period afterwards, is critical.
- Providing information too early without providing access to much needed support and advocacy is not helpful or appropriate. This is because many individuals with disability and their families have a number of serious and pressing needs and issues that require immediate attention.
- Addressing language barriers by holding individual face to face sessions with bicultural workers or with the assistance of credentialed interpreters is often needed. It can also allow individuals and families to speak more about their circumstances and help address gaps in understanding and concepts that are unfamiliar.
- Providing information to community leaders and multicultural workers and engaging bicultural workers is a useful strategy to disseminate information about the NDIS and to identify hard to reach individuals with disability.

- Explaining the PRI work and purpose and following up on referrals can be slow work, but a very effective process. On several occasions when AMPARO has met with a refugee family referred by a multicultural worker, the family will mention they know another family that has members with disability who receive no support or help.

#### **4. Support to complete NDIS access processes and ongoing case management is a critical component of increasing CALD participation within the scheme.**

- Access to case management support and independent advocacy to assist with accessing the NDIS is currently limited or non-existent, this is particularly the case for people from CALD backgrounds.
- Many people from CALD backgrounds do not have access to advocacy and are not connected to services. We have found that many people from CALD backgrounds do not have family or friends with the necessary English proficiency and knowledge to assist them to complete the Access Request Form, or to help them collect information that is needed by the NDIS.
- There is often an assumption that people from migrant and refugee backgrounds who are assisted by settlement services and multicultural organisations, will receive the intensive support they need to help with diagnosis, assessments and form filling. This is often not the case, as it may fall outside of the organisation's scope or capacity.
- Requiring people to rely on website information or ringing the NDIS 1800 number is not a culturally appropriate communication method. There seems confusion and a lack of consistency in information provided by the NDIA regarding the process for people who do not speak English well, to access support from the NDIS.
- Providing intensive case management support and independent advocacy to people from CALD backgrounds and families to access and navigate the NDIS.

#### **5.**

##### **Need for interpreters and translators.**

- Interpreters are often not being engaged by disability services who are working with families with no English proficiency and extremely high and complex needs.
- Interpreters and translators are not of a consistently high quality and their understanding of how to translate disability terminology, even the word "disability" which is seldom found in many languages, may not be clear.
- Training for interpreters and translators engaged by the disability sector is necessary as language changes over time, and we have found quite negative terms being used in translations to describe disability. We know that language is powerful and that positive language can help to reduce negative perceptions of disability.
- There is limited availability of interpreters in regional areas of Queensland, which does not reflect community need.

### **Learnings from interstate**

There has been considerable capacity building work undertaken with CALD communities in NSW and Victoria. This work has been undertaken by a number of multicultural organisations including settlement services and multicultural advocacy organisations. It appears that in these states there is a greater level of commitment and understanding of the need to support CALD communities' access to the NDIS than currently is the case for Queensland. This is reflected in the funding levels for CALD capacity building in Queensland and the limited NDIS readiness outreach work with multicultural organisations in order to reach CALD communities.

## Key learnings and issues identified from work with CALD communities in Barwon, Victoria and NSW are consistent with AMPARO's experience.

Diversitat, in Barwon, Victoria, have found through their work with CALD communities that the NDIS system assumes that people from CALD communities have an understanding of empowerment and the rights of people with disability in the Australian context, service systems and what they can provide and how to define and articulate their goals and aspirations.

Diversitat notes an assumption of adequate levels of English literacy, with a lack of translated information and a requirement to negotiate information through the internet. However limited English proficiency and confusion around the role of different services, stigma and negative perceptions of disability within communities and limited understanding about rights makes understanding the NDIS and opportunities within the system much more difficult.

Diversitat also makes clear that there is an opportunity to identify people with disability in the early stages of settlement to ensure access to early intervention and prevent them being "lost in the system". Learnings also stress the need for intensive case management support for new arrivals to Australia to negotiate the NDIS to determine eligibility, organise diagnosis and assist with preparing for the planning and assessment process<sup>51</sup>.

Ethnic Family Services Co-operative (ECSC) in New South Wales have also found that people with disability from CALD backgrounds are very isolated and difficult to reach due to a number of factors, and that advocacy support and follow up is often needed by individuals and families who attend their NDIS information sessions. From their work with CALD communities, ECSC found that "online and telephone supports" are not effective ways of communication but rather recommend face to face interaction.

## Some sound strategies that have been used and could be duplicated in Queensland include:

**In Regional areas- the establishment of local CALD NDIS working groups.** Local NDIS offices recognise the importance of connecting with local settlement services, multicultural services and multicultural advocacy organisations. In some areas, such as the Hunter region, regular network meetings held between local CALD stakeholders and the NDIS to see how CALD communities could be most effectively targeted. This led to targeted local strategies including project work with local CALD community leaders.

**Well-resourced and funded CALD NDIS community education and information strategy.** In NSW, Ethnic Community Services Co-operative receives state funding for a team of workers to undertake NDIS participant readiness. This team includes both trained bicultural workers to deliver information in their own language, and advocates to address the multiple, complex issues people with disability and families are dealing with.

**Local NDIS offices work closely with multicultural services and participation readiness programs.** This collaboration between organisations and the NDIS helps ensure greater participation of people from CALD backgrounds in the NDIS.

**Settlement services are well positioned to provide support to people with disability from refugee communities.** Diversitat has been very effective in identifying and supporting refugees to access the NDIS. They work closely with their local NDIS office and have written reports that highlight the issues and ways that refugee communities could be better supported.

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51 Diversitat Settlement (2014). Diversitat Disability Findings Report. [http://www.diversitat.org.au/documents/Settlement/Diversitat\\_Disability\\_Findings\\_Report.pdf](http://www.diversitat.org.au/documents/Settlement/Diversitat_Disability_Findings_Report.pdf)



## Other Important Considerations for the NDIS

### Local Area Co-ordinators (LACs)

LACs who have specialist skills and understanding of CALD communities are crucial to the effective participation of people from CALD backgrounds in the NDIS. There is some concern that with pressure to support large numbers of people with disability to access the NDIS in a short timeframe, that people with disability from CALD backgrounds will once again miss out. This is of particular concern for those that are not currently linked into the disability support system and the data would show that the majority of people from CALD backgrounds with disability are not.

### Access to interpreters under the NDIS

Since early 2013 AMPARO and others have argued that the obligation to provide access to free language services for NDIS participants should remain the responsibility of state and federal governments as mainstream language services and separate from 'disability supports' under the NDIS. However the decision was made, that is not reflected in the NDIA legislation, that the provision of language services for NDIS participants, should be allocated in a participant's plan. However there are legitimate concerns about this arrangement and only time will tell if they are well founded.

### Concerns regarding access to interpreters include the following:

- The onus on individuals with disability and their families to know they have a right to request that the engagement of interpreting or translating services, when communicating with the NDIS and services, and for this cost to be included in their plans.
- The difficulty of estimating the cost of language services to incorporate into a participant's plan.
- A question that hasn't been answered is will the cost of engaging an interpreter to communicate with family members by the NDIA and service provider be included in the participant's plan?

This is particularly relevant for parents of children with disability or family members who are involved in supporting or living with a participant with impaired capacity.

- The lack of NATTI accredited interpreters in new and emerging languages, particularly in many rural communities.
- The likely increase in the demand for interpreters given the expected increase in people from NESB accessing supports and services under the NDIS.
- The lack of interpreters with the knowledge, skills and awareness of disability and NDIS terminology.<sup>52</sup>
- Lack of incentives and career pathways to support the retention of credentialed interpreters.<sup>53</sup>
- The lack of cultural competence within organisations will mean staff will not have the knowledge, skills and confidence to effectively engage and work with credentialed interpreters.
- If credentialed interpreters are not engaged and instead family, friends or others, who are not qualified, are used this can result in important information being misinterpreted and service delivery seriously compromised.

## NDIS Eligibility Criteria and Residence Requirements

Queensland, particularly South East Queensland, has a large and increasing New Zealand-born population<sup>54</sup>, of which significant numbers are Pacific Islanders<sup>55</sup>. Currently New Zealand citizens can access some state-funded disability supports, however New Zealand citizens will only be eligible for the NDIS if they hold a protected Special Category Visa (SCV), and non-protected SCV holders (including their children) will not.

Queensland Council of Social Service has raised concerns that a lack of eligibility to the NDIS adds to a range of social supports that this group misses out on and that impact on their ability to participate socially and economically.

Missing out on access to the NDIS is likely to lead to significant hardship for people with disability and their families. QCROSS argues that a lack of adequate social safety nets *“leads to poverty, with well-documented consequences including crime, homelessness, and mental health issues. Family violence also increases when there is financial pressure.”*<sup>56</sup>

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52 Diverse Werks for National Disability Services. (May, 2015). Supporting interpreters to work effectively in the disability sector. Diverse Werks,

53 Queensland Accessing Interpreters Working Group (Oct, 2014). Blueprint for a Queensland Language Services Provider. Queensland Accessing Interpreters Working Group.

54 ABS. (2011). Australian Social Trends 2010: New Zealanders in Australia. Retrieved from [www.abs.gov.au/socialtrends](http://www.abs.gov.au/socialtrends).

55 Kearny, J. (2012). 'Unlucky in a lucky country: A commentary on policies and practices that restrict access to higher education in Australia'. *Journal of Social Inclusion* 3(1): 130-134.

56 QCROSS (2016) Indefinite Temporaries: Scoping the impact of Trans-Tasman Travel Arrangements on Queensland Communities. Retrieved from [www.qcross.org.au/report-indefinite-temporaries](http://www.qcross.org.au/report-indefinite-temporaries)



## NDIS and people with psychosocial disability

Many people from refugee and new and emerging communities will have experienced pre-migration trauma that is life changing and that will contribute to the development of serious mental health issues. Some will experience significant disability as a result, and make them potentially eligible for the NDIS. People with psychosocial disability from CALD communities, in particular those from a refugee background, will experience the same challenges of early settlement and disadvantages discussed earlier in this report. Stigma related to mental health issues in CALD communities is well documented and even when assistance is available, acknowledging that help is needed is extremely difficult, with fear of being alienated from their own families and communities a legitimate concern. A lack of knowledge about mental illness and how to help those with mental illness in diverse communities, fear and cultural perceptions of mental illness, are cited as key factors contributing to stigma, isolation, and are a major obstacle to early detection and intervention and accessing services<sup>57</sup>.

*A culturally competent, safe and responsive approach by those with specialist experience in this area is needed for this cohort, to build relationships based on trust as a very first step to engaging with diverse communities and highly vulnerable individuals and their families.*

57 Multicultural Mental Health Australia (2001) Stepping Out of the Shadows, Stigma Reduction Project-June 2010. Multicultural Mental Health Australia



## The Importance of Independent Advocacy

AMPARO has found that many individuals from CALD backgrounds are struggling with a myriad of complex issues and do not have a voice, or close family or friends to support their aspirations, or speak up on their behalf. Independent advocacy based on human rights, social justice and inclusion, which strengthens relationships in the lives of people with disability, is critical to safeguarding their rights and wellbeing.

All sides of government have recognised the importance of independent advocacy, and funded independent advocacy programs have existed since the 80's with the Federal Government establishing the *National Advocacy Program* in the same year as the Disability Services Act of 1986. The *National Disability Strategy* commits to and promotes the importance of independent advocacy, as does the *National Advocacy Framework* and the *General Principles Guiding the NDIS* also articulate a commitment to "support the role of advocates"<sup>58</sup>.

The **Convention on the Rights of Persons with Disabilities** in particular provides advocates with a mandate to assert the rights of people with disability to education, health, work, adequate living conditions, freedom of movement, and freedom from exploitation and equal recognition before the law.<sup>59</sup>

58 Commonwealth of Australia (2013). *National Disability Insurance Scheme Act 2013. An Act to establish the NDIS and for related purposes*. Commonwealth of Australia

59 United Nations Human Rights Office of the High Commissioner. *Convention on the Rights of Persons with Disabilities*. Retrieved from <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx> <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>

## Strong support from Queensland's Public Advocate

Queensland's Public Advocate has shown strong support for independent advocacy being adequately funded to represent the rights of people with impaired decision-making capacity, as can be seen in the following statement.

*Where advocacy and representation relates to Commonwealth programs, the Queensland Government should campaign for these accordingly. Further, funded advocacy and support services must remain independent and the value of upholding this independence must not be diminished<sup>60</sup>.*

The Public Advocate of Queensland also highlighted the importance of advocacy agencies being independent from other service systems to minimise potential or actual conflicts of interest and to safeguard people with impaired decision-making capacity and reduce risk and to strengthen "their voice".<sup>61</sup>

## The NDIS and the increased need for independent advocacy

Whilst it is expected that the NDIS will significantly improve the social and economic participation of people with disability across Australia, no system can be perfect, some will not be eligible for the NDIS and others will fall through the gaps. People with disability can struggle in many areas of life and as a result can require independent advocacy support to access timely and effective medical and hospital treatment, accessible housing, education and training, English language and Auslan classes and so on.

AMPARO expects there will be an increase in the need for independent advocacy if people from CALD backgrounds are to have equitable access to the NDIS. This is supported by the experiences of those in trial sites and early reports from advocacy agencies in NDIS sites. Agencies in Townsville and in Canberra report major increases in requests for advocacy from people with disability and their families wanting to access the NDIS or wanting to appeal decisions made by the NDIS. Deborah Wilson from an advocacy agency Independent Advocacy in the Tropics in Townsville (personal communication, September 22, 2016) reported a 30% increase in requests for independent advocacy since 1 July this year.

The *Diversitat Disability Findings Report* highlights the additional barriers to the NDIS experienced by new arrivals from a refugee background in the Barwon region and reported the need for intensive case management and advocacy support for people to determine eligibility, organise diagnosis, assist with preparing for the planning and assessment process and to query decisions made that deem a person ineligible for the NDIS<sup>62</sup>.

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60 Office of the Public Advocate (Qld), (April 2016). *Decision-making support and Queensland's guardianship system: A systemic advocacy report*. The State of Queensland (Department of Justice and Attorney-General) 2016.

61 Ibid.,p.22

62 Diversitat Settlement (2014). *Diversitat Disability Findings Report*. [http://www.diversitat.org.au/documents/Settlement/Diversitat\\_Disability\\_Findings\\_Report.pdf](http://www.diversitat.org.au/documents/Settlement/Diversitat_Disability_Findings_Report.pdf)

## The Role of Independent advocacy:

- Represents the rights and interests of the most vulnerable in our community.
- Supports the individual's decision making to the fullest extent to ensure people's aspirations and wishes are heard.
- Enables individuals to access important information, supports and assistance they need so they are able to actively participate, engage and contribute to family and the broader community, including access to early intervention to prevent an escalation of the person's issues and an increase in their vulnerability.
- Is a form of early intervention that can prevent an escalation of the person's issues and concerns and in the long terms saves government money in meeting people's needs.
- Supports timely access to essential mainstream and disability services.
- Builds the capacity of individuals with disability and their family members to understand their rights and to speak up about what is important to them.
- Seeks to build and repair close relationships around the person, an important safeguard.
- Encourages services to work in ways that are culturally responsive, and supports the engagement of professional interpreters to ensure services effectively engage with individuals and their families from CALD backgrounds.
- Sometimes advocacy is needed to save the lives of people with disability.

The National Disability Advocacy Program must consider increasing its funding commitment for independent advocacy in various forms across Australia for the effective implementation of the NDIS. Without access to independent advocacy there will be people from CALD backgrounds with disability and others, who though eligible for the NDIS, will miss out on the opportunities and essential supports that this scheme has to offer.



## Conclusion

The experience of AMPARO and that of others working towards the social and economic inclusion of people from CALD backgrounds with disability, is that additional measures are necessary to address decades of disadvantage and low participation levels, and to ensure equitable access to the NDIS. Strategies and actions recommended in this report, if well-resourced and implemented appropriately as part of a National NDIS CALD Strategy, will lead to greater understanding of the potential opportunities and benefits of the NDIS and to increased levels of participation of people from CALD backgrounds with disability.

AMPARO believes it is critical that mistakes of the past are avoided, and the NDIA incorporates, as a matter of priority, genuine and well-resourced access and equity measures into the core business of the NDIS.







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