



AMPARO Advocacy's Response
To the *Review of the
National Disability Advocacy Program*

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About AMPARO Advocacy

AMPARO Advocacy is a small non-profit community based organisation that provides independent individual and systemic advocacy with and on behalf of vulnerable people from a non-English speaking backgrounds (NESB) with disability. Advocacy is provided to adults and children between the ages of 0-65.

AMPARO is governed by a voluntary management committee the majority of whom are themselves people from a NESB with disability and is funded by the Queensland State Government Department of Communities, Child Safety and Disability Service.

AMPARO Advocacy's vision is for people from a 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 that people from a non-English speaking background (NESB) with disability have the same right to valued lives that are comparable to other citizens. We believe that societal responses to vulnerable people can be extremely inadequate and independent social advocacy on their behalf is often needed.

We know that even when rights exist, something more is needed when those rights are not respected, honoured and protected, that something is independent advocacy. (Advocacy Development Network, 1997)

AMPARO Advocacy believes:

People from a non-English speaking background with disability have a rightful place in community where they:

- are respected and valued;
- can experience valued relationships with friends and family;
- have access to interpreters and information in their preferred language;
- have supports and services provided in a culturally sensitive and responsive way;
- have their gifts and strengths recognised;
- have natural authority to influence the direction of their own lives, or where they have limited capacity, that their family if possible retains this authority;
- are welcomed and have opportunities to live an ordinary life;
- are participating and contributing members in the social, economic and political life of broader Australian society.

Our Mandate

AMPARO Advocacy takes our mandate from important United Nation declarations, Federal and State antidiscrimination laws and principles which promote the rights of all people as well as expectations for the lives of people from a NDIS with disability.

*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, freedom from exportation and equal recognitions before the law.*

Advocacy Principles

Independent advocacy is provided 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 following principles of:

- Human rights
- Social justice and
- Inclusive Living

Advocacy is based on the following elements of social advocacy:

- Taking positive, ethical action
- Being on the side of someone who is vulnerable
- Understanding the position and vulnerability of the person
- Remaining loyal and accountable over time
- Being independent with minimised conflicts of interest
- Focusing on the fundamental needs, welfare and best interests of the person
- Doing advocacy with vigour and a sense of urgency.

AMPARO Advocacy undertakes independent individual and systemic advocacy

The **National Disability Strategy** (2010-2020) acknowledges the significant barriers that people from a CALD background with disability experience in the following statement:

People from culturally and linguistically diverse backgrounds – 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.

Individual Advocacy

The social reality for many people with disability is that they can experience discrimination, rejection, loss of power and control, segregation, abuse and neglect with high levels of unemployment, poverty and an absence of close personal relationships.

Independent individual advocacy aims to ensure people from culturally and linguistically diverse backgrounds with disability have their fundamental needs met, so they and their families can actively participate, engage and contribute to the broader community.

The people we advocate for are most likely to be at risk and are least able to represent or defend their own rights and interests.

AMPARO directly represents the rights and interests of vulnerable people from a NESB with disability who do not have a voice, or close family or friends who can support their aspirations, or speak on their behalf.

The advocacy efforts address issues of **social and economic isolation, unfair treatment and discrimination** by: getting to know the person with disability and their family, understanding their situation, and identifying culturally appropriate ways to assist them.

AMPARO Advocacy's work with migrants and refugees with disability and their families has shown that they often have limited understanding or awareness of their rights or entitlements in Australian society. Being new to Australia means they are often unaware of the specialist disability and mainstream services and supports that may be available.

We have found that:

- Language and cultural differences make it much more difficult for people from CALD backgrounds with disability to access and navigate complex systems of support.
- Particularly when those systems are **NOT** responsive to their needs, and **do not** deliver equitable outcomes for them regardless of their cultural and linguistic backgrounds.

➤ *Working closely with families*

Whilst the rights and interests of the person with a disability are paramount in our individual advocacy efforts, AMPARO works closely with the families of people with disability where appropriate. We know many families are struggling with serious and complex issues that require assistance to access support, such as culturally appropriate counselling, without this assistance and their involvement, the person with disability can be placed at a greater risk.

- **AMPARO'S Individual advocacy** provides important accessible information to individuals and their families, often with the assistance of accredited interpreters, so they are able to:
- understand information
 - communicate their needs and
 - make informed decisions that set the direction for how they live their lives.

This includes providing accessible information on the availability of services and supports, the rights of people with disability and what a 'good life' can look like for people with disability.

Building the capacity of individuals and families to understand the needs and rights of people with disability is an important element of our work. This is particularly important for those families who have children with disability or family members who because of capacity issues, require them to make decisions their behalf.

- **Independent advocacy support is a crucial form of early intervention that:**
- Represents the rights and interests of the most vulnerable in our community
 - Enables the 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.
 - Prevents an escalation of the person's issues and concerns and in the long terms saves government money in meeting people 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 for people with disability.
 - 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 following nomination to the service, **A Place to Belong**, is testament to this.

"I would like to nominate AMPARO advocacy organisation for the Inclusion Awards. They do an extraordinary job in ensuring marginalised people can access services and support they are entitled to. Their advocacy work is life changing and often lifesaving. The staff headed by Maureen Fordyce are brilliant role models demonstrating on a daily basis their genuine commitment to the principles of compassion respect and inclusiveness".

Mandy Cox, Communify Qld

- ***Our assistance enables individuals to access*** the information, supports and assistance they need so they are able to actively participate, engage and contribute to family and the broader community.

- ***As a result of the individual advocacy migrants and refugees with disability have access to:***
 - credentialed interpreters for effective communication
 - culturally responsive disability and mainstream support
 - timely medical treatment
 - legal representation
 - review of guardianship orders
 - review of restrictive practices orders
 - appropriate mental health support
 - inclusive education
 - safe, accessible and affordable housing
 - necessary aids and equipment
 - English language classes
 - appropriate income support

- ***AMPARO Advocacy receives referrals from*** hospital social workers, the Office of the Public Guardian, Police, Department of Community Services, Child Safety and Disability Service, Settlement services, child safety, mental health services, disability specialist services, other advocacy agencies, special education units, schools, families and individuals themselves.

Systemic Advocacy

AMPARO Advocacy's state wide systemic advocacy work is informed by our individual advocacy work with migrants and refugees with disability and their families. This works aims to influence positive sustainable changes to attitudes, policies, practices and resources within governments and communities.

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.

Over the past ten years we have assisted people with disability and their families from a broad range of cultural and linguistic backgrounds to address issues of disadvantage and discrimination. **It is through this work we have developed a deep understanding of the significant concerns of this highly marginalised group.**

Over the years AMPARO Advocacy has worked closely with allies to bring about access to fee free interpreting services in Queensland, through the Queensland Accessing Interpreters Working Group.

We have participated in many public hearings and responded to Joint Standing Parliamentary Inquires, including the Inquiry into Queensland's preparedness for the NDIS.

Because of AMPARO Advocacy experience, the organisation is often called upon by the State Government to provide advice, respond to strategies, participate in consultations or working groups, and address forums, so that the needs of Queenslanders from a NESB with disability are represented and so the issues they experience are understood.

To this end AMPARO Advocacy is an active member of the QLD NDIS Transition Advisory Group and previous member of the QLD NDIS Working Group, providing feedback and advice on the challenges and questions encountered throughout the transition to the NDIS in Queensland.

AMPARO Advocacy is also the only Queensland organisation that is a member of the CALD Stakeholder Advisory Group for the NDIS, charged with developing a **National CALD Strategy for the NDIS**.

Questions

1.1 How do people with disability, their families and carers benefit when agencies are funded to provide only one or two models of support?

Most advocacy agencies specialise in a particular model of independent advocacy such as formal individual advocacy, family advocacy, systems advocacy or citizen advocacy. All forms of independent advocacy are valuable and a healthy democratic society should fund, support and encourage all forms of advocacy. Agencies that specialise in one model of advocacy usually have high levels of expertise in this area and this is to the benefit of the person with disability.

Some agencies do undertake more than one form of advocacy. AMPARO Advocacy is one of such agencies which undertakes both independent individual and systems advocacy. There are definitely benefits in providing more than one model of advocacy, where the agency is aware of and manages the tensions that can arise.

Providing both individual and systems advocacy to migrants and refugees with disability means that the systemic work is well informed by a deep understanding of the real life experiences and additional concerns of this highly marginalised group. This also means that systemic issues that are taken up by AMPARO are those most relevant to the individuals we assist.

AMPARO Advocacy's staff are also highly skilled and experienced at providing culturally competent, safe and responsive advocacy and understanding the particular needs of this disadvantaged group.

This includes understanding that many of the people with disability and their families we assist have been:

- Forced to leave their homes to escape war and violence
- Are experiencing the ongoing effects of trauma or torture and require access to culturally appropriate counselling, with the added complexity that many require access to professional interpreting to access this counselling.
- Many have 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
- Struggling with settlement issues, learning a new language, or two if they have a child that is deaf and they need to also learn Auslan.
- Experiencing high levels of unemployment but working hard to better their education and find work
- Looking for stable appropriate and affordable housing which is difficult to access.
- Working towards family reunion.
- Experiencing significant discrimination, isolation and socio-economic disadvantage

Focusing on this particular disadvantaged group has meant that we understand the importance of developing and sustaining strong relationships with diverse communities and multicultural organisations that support our work.

1.2 What are the drawbacks?

Expecting every advocacy agency to provide all forms of independent advocacy to each individual with disability would not be reasonable or in the best interests of people with disability. Every model of formal advocacy requires different specialist skills, knowledge, experience, training, policy, processes and accountability measures.

Nevertheless independent advocacy agencies are usually highly collaborative with other models of advocacy in their location or region and referral and support between the different agencies is common practice.

This is particularly evident in Queensland through the **Combined Advocacy Groups of Queensland (CAGQ)** which is a statewide network of both Federal and State funded independent advocacy agencies. CAGQ provides an important function of supporting strong collaboration between over 13 agencies across Queensland.

This network links up on a 4-6 weekly basis to share important information on key issues people with disability are experiencing, changes in legislation and policy that impact on people with disability, reforms being undertaken by government, and areas where collaboration will improve outcomes for people with disability. Referrals between advocacy agencies throughout Queensland are made more easily because of the strong collaborative relationships that have been built over many years.

Queensland is the most underfunded State when it comes to independent advocacy for people with disability, yet we have strong links that could be further built upon to strengthen access to independent advocacy.

1.3 How do we value and support the various models of advocacy while ensuring equitable access to individualised, fit-for-purpose advocacy, regardless of location?

➤ The Importance Of Independent Advocacy

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***. Article 4 of the ***Convention of the Rights of Persons with Disabilities*** states that '*advocacy organisations have an important role to play in the implementation of the CRPD*' and the ***General Principles guiding the NDIS*** also articulate a commitment to "*support the role of advocacy in representing the interests of people with disability.*"

Whilst the NDIS will go a long way in addressing the inequities of the current disability service system it will not be a perfect system, as no system can be. Inevitably some people will fall through the gaps and many will not be entitled to access the scheme. 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 treatment, quality educational support, personal care support and so.

AMPARO Advocacy would like to see a stronger commitment from the Federal Government to increase the availability of independent advocacy in its various forms, as a means of safeguarding the rights and interests of vulnerable people with disability, including those from non-English speaking backgrounds.

If the Federal Government is serious about ensuring equitable access to individualised advocacy across the Nation, an increase in the funding for all forms of advocacy will be necessary.

Advocacy agencies could also benefit from support to increase their capacity to cooperate, share information and even partner with other advocacy agencies where appropriate, to ensure the particular needs of all people with disability for independent advocacy are met.

2.1 How do we improve access for

- people with disability from culturally and linguistically diverse communities and their families;
- people with disability in rural, regional and remote locations and
- people who are very socially isolated including those with communication difficulties.

Barriers to Equitable Access

People with disability from CALD backgrounds experience multilayered and additional barriers that generally have not been taken up by mainstream systemic advocacy agencies.

*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**¹.*

*However the National Ethnic Disability Alliance estimates that between **18-24%** of NDIS participants should come from a CALD background².*

*Despite this the most recent Quarterly Report by the NDIA to COAG for March 2016 shows that **ONLY 4.2% of participants classified as CALD have approved plans**. The report also acknowledges that all sites have lower than expected CALD participants³.*

Clearly systems currently in place have not addressed this disparity over many years and people from CALD backgrounds with disability continue to be significantly underrepresented in accessing specialist disability services, including independent advocacy.

The ongoing disparity of access continues largely because disability service systems, including advocacy agencies, have often failed to develop cultural competence at all levels of their organisations and to embrace the principles of substantive equality and non-discrimination.

Unfortunately **National and State Standards for Human Services and Disability Services** have had little impact on improving access to services generally, including disability advocacy services for people with disability from CALD backgrounds.

➤ **Access to Cultural Competent Responses**

To improve access to independent advocacy for people with disability from CALD backgrounds, including those with communication difficulties, advocacy agencies need to develop cultural competence at the level of the individual worker and throughout all organisational systems.

¹ 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

² National Ethnic Disability Alliance (NEDA) (March 2016). Unpublished data. NEDA

³ National Disability Alliance (March 2016). Quarterly Report to COAG Disability Reform Council 31 March 2016.

Cultural competence requires at a minimum that agencies:

- Develop knowledge and understanding about a person's specific culture, values, beliefs and life experiences
- Know how to engage and work effectively with credentialed interpreters and have language services policy and procedures in place to guide best practice. This includes providing interpreters for people who are deaf or require facilitated communication.
- Recognise the need to allocate additional time to work with people who may need access to interpreters and who have many complex unmet needs
- Promote their services by undertaking outreach programs to ensure the cultural diversity of service users is reflective of the community in which they operate.
- Include a cultural competency audit as part of an annual organisational self-assessment.

➤ ***Access to Credentialed Interpreters***

The majority of individuals AMPARO Advocacy works with and or their family members, require access to credentialed interpreters to understand information, make informed decisions and communicate their need.

AMPARO Advocacy recognises the right of people with disability and their family members who have low levels of English proficiency, who first language is Auslan or who require a communication facilitator, to have access to credentialed interpreters to ensure effective communication.

Unfortunately however this right is often not recognised by both government and nongovernment services and is an impediment to people having equitable access to services.

Other strategies that could be implemented to improve access to independent advocacy, is for funding bodies to:

- (i) Support the development of cultural competence within organisations delivering advocacy, including the effective engagement of credentialed interpreters, translators and bicultural workers.
- (ii) Establish targets for participation rates of people from CALD backgrounds with disability in accessing independent advocacy, and require agencies to undertake specific measureable strategies to reach these figures.
- (iii) Undertake research and evaluation of the mechanisms to increase participation rates of people with disability from CALD backgrounds in accessing advocacy.
- (iv) Investigate, consult and develop specific targeted strategies in regional and remote areas to overcome barriers associated with remoteness for people from CALD backgrounds with disability.

2.2 What are the strategies or models that have worked?

- **AMPARO Advocacy is well respected in the multicultural and disability sector in Queensland for providing specialist culturally competent, safe and responsive independent advocacy.**

We do this by having skilled staff who are experienced in working with migrants and refugees with disability and who seek to understand the:

- Person's vulnerability, life experiences, values, beliefs and current situation.
- The impact of the person's impairment
- The impact of culture, language and religion
- Where the person and their family are at in their settlement process, and what issues they are still needing assistance with. They may have many other issues that need addressing to enable them to focus on the needs of their family member with disability.
- The potential impact of advocacy efforts, so as not to increase the vulnerability of the person
- The broader social, legislative, policy and systems that impact on the person and their family.

Through our work with refugees and their families and our ongoing research with the Queensland University of Technology, language barriers are identified as a major barrier to finding and utilising services. **AMPARO Advocacy recognises** this and routinely engages credentialed interpreters and provides translated material to ensure effective communication so that people with disability and their families who are not proficient in English are able to:

- understand information
- communicate their needs
- make informed decisions

Access to credentialed interpreters is 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.

Through our work with individuals and their families from CALD backgrounds we know we must be respectful of the following:

- Building relationships based on mutual trust with the person with disability and their families can be a slow process, because of people's life experiences of trauma, discrimination, and stigma.
- Gaining people's trust takes time and without trust advocates can't fully understand the needs of the individual or support them to be open to new opportunities.
- Where a person with a disability is a member of a family, their needs may be considered in the context of what is best for the family as a whole.
- Concepts and value of independence may be viewed very differently
- Some may be reluctant to accept support and consider it a duty to care for their family member until a point of crisis.
- Some may be fearful that people are intruding on family matters or wanting to remove their family member from their home.

Independent advocacy can then be provided in a way that respects and meets the language, cultural and religious needs of the person.

2.2 What are the strategies that do not work?

Expecting people with disability and their families from a NESB to phone an 1800 numbers to access individual advocacy does not support effective or equitable access to independent advocacy. Face to face discussions, with the assistance of onsite credentialed interpreters, is necessary to know whether the advocacy agency is able to offer assistance and to understand the person's vulnerability, life experiences, values, beliefs and current situation.

Determining whether advocacy is needed is extremely difficult over the phone when the person has limited English language and a credentialed interpreter is required. Often a face to face meeting is necessary to determine whether advocacy is the appropriate response or a referral to an alternative agency is necessary.

The majority of AMPARO's referrals come through other agencies or trusted relationships that the person has and we are given permission to contact the person, often with an interpreter. We have developed strong links and relationships with many culturally diverse communities and workers over the years and our membership and governance structures reflect the diversity of the communities in which we work.

Substantive equality requires additional measures to be implemented by government, services and advocacy agencies to ensure equitable access to services and independent advocacy.

However until advocacy agencies build their capacity to be culturally competent and responsive to the needs of all people with disability, and this change is reflected in participations rates matching expected figures, specialist disability advocacy will be needed.

To enable people with disability from CALD communities to access independent advocacy AMPARO Advocacy could train and support an individual advocacy worker in each region, and have them situated in advocacy agencies that we currently have strong relationships with across the state.

If appropriately funded AMPARO Advocacy could also resource other advocacy agencies in Queensland to develop more culturally practices and responses.

3.1 What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?

AMPARO Advocacy is speaking with other advocacy agencies across the state that are members of the Combined Advocacy Groups of Queensland (CAGQ) about the benefits of forming partnerships or stronger more formal alliances in the near future.

Potential benefits of this strategy would be more formal structures for sharing information of systemic issues and collaborating on the development of joint reports that could be provided to peak bodies, governments, independent state and federal statutory bodies such as Queensland's Anti-Discrimination Commission and the Office of the Public Advocate, and the Australian Human Rights Commission.

3.2 How can we help disability advocacy organisations work with a wide range of other organisations with similar aims?

The Disability Advocacy Network Association (DANA) is a network of organisations throughout Australia that undertakes individual advocacy, systemic advocacy, self-advocacy, citizen advocacy, legal advocacy or family advocacy. DANA as a national peak had an important role in supporting and strengthening independent disability advocacy organisations in their work.

The Department of Social Services could reinstate funding for DANA to support the collaborative efforts of this large network of advocacy agencies through the:

- Sharing of information and advice on a range of issues
- Provision of professional development opportunities
- Development of best practice protocols for the provision of different models of advocacy
- Cohesive voice for independent advocacy for vulnerable people with disability

➤ **AMPARO Advocacy has history of maintaining strong collaborative relationships with a range of agencies that promote and protect the rights and interests of people with disability.**

AMPARO routinely provides information about the lived experiences of people from CALD backgrounds with disability to inform the work of these agencies and undertakes joint systemic advocacy when this is appropriate. Examples of this work include, but not limited to the following:

- **Partnered with Queenslanders with Disability Network (QDN)** a DPO, over the past 18 months to help prepare Queenslanders with disability from CALD backgrounds for the NDIS.
- **Inform peak bodies** such as Queensland Council of Social Services, Ethnic Communities Council of Qld and the National Ethnic Disability Alliances of the issues and concerns that are relevant to people from CALD backgrounds with disability
- **Undertaken joint systemic advocacy** with allies on relevant issues eg. The **Accessing Interpreters Working Group** that AMPARO has been a member of since its inception, is chaired by QCOSS, which aims to improve access to credentialed interpreters that are supported by a culturally competent service system.
- **Collaborated with Welfare Rights** Anti-discrimination lawyer in taking a case to the Australia Human Rights Commission for a young child who is blind and was being discriminated against by the Queensland Department of Education.

- **Routinely refer individuals to other federally and state funded advocacy agencies** across Queensland and at times to advocacy agencies in other states.
- **Undertaken joint research** with Queensland University of Technology and Griffith University.

4.1 What steps or organisational structures should be put in place to ensure conflicts of interest do not arise, or are minimised?

In a recent report the **Public Advocate of Queensland** highlighted the importance of advocacy agencies being independent from other service systems as a necessary safeguard for people with impaired decision-making capacity.

- **The importance of independence and the need to minimise potential or actual conflicts of interests is evident in the Public Advocates following statement:**

It is essential that funded individual advocacy and support services remain independent and that the value of upholding this independence is not diminished. Individual advocacy can help ensure that systems and programs are transparent and accountable. Further facilitating access to advocacy can reduce risk for vulnerable people and strengthen 'their voice'.⁴

Other strategies to minimise conflicts of interest would include:

- NDAP should only fund advocacy agencies that are independent of other services systems, particularly direct service provision.
- Ensure advocacy agencies have a strong commitment to the principles of human rights, social justice and inclusion.
- Prevent boards of management from having members who have obvious conflicts of interests, such as direct links to their funding bodies.
- Require agencies to have a **conflict of interest policy and register** in place that requires staff and members of boards of management, to identify and list any **actual, perceived or potential conflicts of interests** and clearly outline how the agency will respond to conflicts of interests as they arise.
- Ensure staff and members of boards of management have in their code of conduct an obligation to report any actual, perceived or potential conflicts of interest.

See Appendix A – The story of a vulnerable young woman highlights the need for independent advocacy to be autonomous and independent of other service systems and why independence is necessary to minimise conflicts of interest and to protect the rights of vulnerable people with disability.

⁴ 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. http://www.justice.qld.gov.au/__data/assets/pdf_file/0010/470458/OPA_DMS_Systemic-Avocado-Report_FINAL.pdf

4.2 How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP?

AMPARO Advocacy expects that if people from CALD backgrounds with disability are to have equitable access to the NDIS they will require significant support and independent advocacy. This is backed up by the experiences of those in trial sites.

The Diversitat, a CALD organisation in the Barwon region, highlights the additional barriers to accessing the NDIS experienced by new arrivals from a refugee background.

This report supports the need for intensive case management and advocacy support for new arrivals to Australia to negotiate with the NDIS to determine eligibility, organise diagnosis, assist with preparing for the planning and assessment process and to query decisions made to that deem a person ineligible⁵.

Diversitat cites an example of a settlement worker providing 50 hrs of support for a refugee with disability to successfully access the NDIS.

The National Disability Advocacy Program must increase 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.

4.3 What policies and strategies do we need to protect the rights of people with disability?

In promoting the need for supported decision-making for Queenslanders with impaired decision-making capacity, within both the guardianship system and the legal and human service system, the Public Advocate made a total of 26 Recommendations.

- **Recommendation 24 is particularly relevant to the need for governments to adequately fund independent advocacy to represent the rights of people with disability with impaired decision- making capacity:**

The Queensland Government should ensure that there is adequate funding for independent advocacy (including legal advocacy) and representation services to meet future demand. 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 diminished⁶.

⁵ Diversitat Settlement (2014). *Diversitat Disability Findings Report*.

http://www.diversitat.org.au/documents/Settlement/Diversitat_Disability_Findings_Report.pdf

⁶ 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.

All advocacy agencies should have strategies and policies in place that respect, protect and promotes the human rights articulated in the ***Convention on the Rights of Persons with Disability***.

5.1 What forms of legal review and representation do people with disability need most?

AMPARO Advocacy recognises that there are other advocacy agencies that specialise in the provision of legal representation for people with disability, such as Queensland Advocacy Inc. in Queensland, that are better able to respond to these questions.

AMPARO Advocacy provides independent social advocacy and when individuals require legal representation our role is to advocate for access to this, via organisations like QAI, legal aid, or pro bono legal representation. We have established strong relationships to support our capacity to do this on behalf of individuals and families when necessary.

5.2 What barriers prevent people with disability from accessing justice?

The additional barriers that make it difficult for people from CALD backgrounds to access services generally also prevent them from accessing justice.

AMPARO is often involved in supporting individuals with disability and their families to understand and negotiate statutory bodies, such as the Queensland Civil and Administrative Tribunal, Office of the Public Advocate, the Office of the Public Guardian and the Public Trustee. In supporting people to access justice AMPARO Advocacy's experience is that it is not uncommon for police to fail to engage credentialed interpreters when communicating with people from CALD backgrounds with disability.

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 the availability of legal services and the rights of people with disability, the failure of services to provide culturally competent responses, including access to credentialed interpreters, and a mistrust of authority can make accessing justice a much more difficult process. Furthermore challenging decisions or making complaints is often an overwhelming prospect.

In 2015 the report, *Not now, not ever: Putting an End to Domestic and Family Violence in Queensland*⁷, cited a lack of suitable interpreters as a major barrier for women from culturally and linguistically diverse backgrounds to access justice and the right to be heard. This includes women with disability from CALD backgrounds.

⁷ Special Taskforce on Domestic and Family Violence in Queensland (February 2015). *Not now, not ever: Putting an End to Domestic and Family Violence in Queensland*
<https://www.qld.gov.au/community/documents/getting-support-health-social-issue/dfv-report-vol-one.pdf>

The Taskforce made the following recommendations to strengthen the engagement of interpreters by police and the criminal and civil courts.

(113) The Queensland Police Service strengthens policy and guideline documents to ensure the use of interpreters for victims of domestic and family violence and their families, where required.

(114) The Queensland Police Service and the Department of Justice and Attorney-General ensure that applicants, including police and private, for a protection order or a variation of a protection order, have indicated either “yes” or “no” to interpreter requirements on each application filed.

(115) The Chief Magistrate issues a practice direction to require the court to engage an interpreter, where a party has difficulty communicating in English, at the first mention for all domestic and family violence civil proceedings before the Magistrates Court.

(116) The Department of Justice and Attorney-General identifies opportunities to streamline systems for engagement of interpreters for civil domestic and family violence court proceedings to ensure best practice.

Independent social and legal advocacy in Queensland is underfunded generally, consequently people from CALD backgrounds with disability are often not always able to access the support they need to receive justice or to have their voices heard.

Appendix A

The following true story highlights why independent advocacy strives to be autonomous and independent of other systems and to minimise conflicts of interest and why this is such an important principle to protect all vulnerable people with disability.

A young woman in her late twenties had been in and out of hospital for the past 2 years, diagnosed with depression and eating disorder at different times, and whose mental health had been deteriorating significantly during this time.

AMPARO received emails about this person seeking advocacy in which the following 2 comments were made by 2 service workers that had been involved for some time trying to assist the family to get the support they desperately wanted for their daughter.

First worker: *“This case requires urgent action, as this person’s time is possibly limited”*

Second worker: *“The Case manager (from the hospital) told me that she has been restricted to contact the person’s family or organizations involved as this case was sent to Complex Case Review Meeting, happening this afternoon”*

The case manager then stated in her email that the: *“hospital made that decision after identifying that the woman is in very serious situation and can die at any time.”*

Despite the obvious seriousness of this young women’s situation, both workers suggested meeting with AMPARO Advocacy and family members in one week’s time, as their schedules were busy.

AMPARO Advocacy responded in an email highlighting the seriousness of their comments and asking to meet the following day, as it was clear that this person was highly vulnerable and at serious risk.

In the meeting the following day there were representatives from 3 of the 5 services that had been involved, and the young woman’s parents. **During that meeting the following was clear:**

- The young women’s parents were distraught and overwhelmed with how the medical treatment team had been responding to their efforts to get their daughter committed to hospital for more than just a few days for appropriate mental health treatment.
- 3 of the services involved reported that hospital staff had been very uncooperative with them and the hospital appointed case manager, who was sympathetic to the families concerns, had recently been removed from working with this family and the individual.
- The family strongly believed their daughter lacked the capacity to make informed decisions and her mental health had been steadily declining over the past 2 years.
- The parents were of the opinion that unless their daughter was immediately hospitalised and treated she was at imminent risk of dying. They said their daughter was dangerously underweight, seriously depressed and continued to refuse food and drink.

During this meeting the family received a telephone call from the hospital requesting that they attend a meeting with the treating psychiatrist that day.

The advocate from AMPARO and 2 of the mental health service providers, one a funded Partners in Recovery service provider, agreed to attend this appointment with the family.

Prior to walking into this meeting both service providers advised the advocate from AMPARO that they had to tread carefully in this situation as they had members of their boards of management who were also senior staff of the state government Department of Health.

- ***One worker stated to the advocate that if the doctors deemed that the young women had capacity they would not be able to be involved or to challenge that decision.***
- ***The other worker stated that in previous meetings with hospital staff when supporting the family, she did not identify herself as a worker from a mental health service, but allowed doctors to think she was a family member. This was to minimise any negative impact on the service she worked for.***

At this meeting the family were informed by the treating psychiatrist that a special meeting had been held the night before with several senior psychiatrists and other medical staff from the hospital to discuss their daughter's condition and the hospital's response.

The Psychiatrist from the mental health treating team informed the family and those present of the following:

- Over the previous ten days the young women had been brought into the hospital under an Involuntary Treatment Order three times a week to receive 30% of her nutritional requirements, because of serious concerns for her physical condition.
- Prior to the meeting he stated that he had conducted an assessment of the young women's capacity and determined that **she did have capacity to refuse treatment.**
- This this young women was seriously underweight with a low BMI of 16.
- That their daughter was **'choosing'** not to eat or drink and this was **not due** to serious mental illness that could be treated.
- Recent blood tests showed that their daughter's sugar levels were extremely low and her salt levels very high and should she continuing not to eat or drink **that over the next 10 days or so her blood chemistry would continue to deteriorate and ultimately she would fall into unconsciousness and could die.**
- That once she went into unconsciousness she would then be deemed not to have capacity and the family could call an ambulance and have her admitted to hospital.

- However the psychiatrist also stated that doctors would not be compelled to provide mental health treatment should she be admitted to hospital.
- He informed the family that their daughter had been sent home in an ambulance prior to this meeting and would not be readmitted into hospital under an ITO as she had been deemed her to have capacity to refuse treatment.

The family begged the psychiatrist to reconsider his decision and reminded him that their daughter was refusing anyone entry into her home, so that when she did fall into unconsciousness it was likely no one would be there to call an ambulance.

AMPARO raised a number of concerns including the fact that the women's current physical condition alone would at the very least be impacting on her capacity to make clear informed decisions and to understand the consequences of refusing medical treatment. The doctor disagreed with this suggestion and after much discussion and pleading by the family to admit this young woman for treatment the hospital refused to do so.

When asked by the advocate whether their decision to deny lifesaving treatment to this young woman would stand up if legally challenged, the psychiatrist advised that the hospital had sought legal advice regarding their decision the night before and they were confident it would.

After this very distressing meeting the PIR service provider stated that they would not challenge the hospital's decision that this woman had the capacity to refuse lifesaving treatment and could no longer be involved.

Initially because of limited capacity, AMPARO thought that we could provide advice and support for the 3 services that were involved without needing to provide independent advocacy.

After the meeting at the hospital it was clear that vigorous, independent advocacy was needed on behalf of this extremely vulnerable young woman as the entire mental health system, including a large publically funded hospital, specialist psychiatrists and mental health team and funded community mental health services were failing her and her family.

Briefly, the outcomes for this young woman was that with vigorous independent advocacy:

- An independent psychiatric assessment was undertaken by a psychiatrist from another public hospital
- Her brother was appointed as guardian for health matters, service provision and as financial administrator
- She was finally hospitalised, treated vigorously to stabilise her physical condition which was life threatening and then moved to a ward to receive intensive mental health treatment and is alive and well today.

The advocacy efforts were extensive and at the Ministerial level and met with strong opposition from the hospital who fought, with the help of a legal team, to prevent her admission.

The person and family are from a culturally and linguistically diverse background and freely acknowledge that without AMPARO Advocacy's efforts their daughter would not be alive today.