

# AMPARO Advocacy Targeted Strategies for NDIS Participant Readiness Initiative

Final Project Review

June 2018

## Introduction

AMPARO Advocacy has consistently supported the potential for the NDIS to improve the lives of all Queenslanders with disability and advocated for the NDIS to be designed and delivered in a way that would meet the needs of people from culturally and linguistically diverse (CALD) backgrounds.

However, according to the latest figures from the NDIS Quarterly Report for March 2018:

- In Queensland has 2.5% of participants come from a CALD background in Queensland however ABS suggests this figure should be between 12-15%.
- Nationally 7.2% participants come from CALD background, however the NDIA suggests this should be at least 20%.

These low statistics are not surprising given AMPARO's experience through the Participant Readiness Initiative (PRI), where we found that many individuals from CALD backgrounds with disability and their families continue to experience many obstacles to equitable access and participation in the NDIS.

This report will highlight the benefits, outcomes and learnings from the Targeted Strategies Project and how some of these successful strategies can be used to assist similar cohorts in other areas of Australia, understanding and access the NDIS.

# **Project Model**

AMPARO Advocacy's CALD Targeted Strategies Participant Readiness Program's aim was to assist people from CALD backgrounds with disability and their families to access information about the NDIS in Queensland, including what it is, how it works, and the ways that they can prepare for it.

The central design of this program was to undertake culturally appropriate, responsive and flexible processes that would support the effective engagement and the provision of information to people from CALD backgrounds with disability and their families

This project has trained and supported a team of 18 Bicultural Community Educators (BCE's) to seek out isolated people with disability in their particular communities, to inform them about: disability, the rights of people with disability in the Australian context and the opportunities that the NDIS will provide.

AMPARO has provided information to CALD communities in a number of ways:

- Community workshops
- One on one individualised home visits
- Stalls at various venues, including, shopping centres, festivals, expos, and cultural celebrations

Through this work AMPARO has identified and met with over 222 individuals with disability and their families, a majority of whom are not connected with disability services, and have missed out on important supports such as early intervention. However most will be eligible to access support via the NDIS.

## **Benefits**

We believe the CALD communities have benefited greatly through use of the above model and that our reach has been extensive.

Firstly, individuals with disability and families have found comfort and safety in talking to a Bicultural Community Educator who has an understanding of how disability is seen in their own cultures and how to disseminate new and complex information in a culturally appropriate manner.

Community members felt comfortable talking to me because I was from the same cultural background. (Bicultural Community Educator).

For some cultures there is not a word for disability and it is necessary to have a much more detailed discussion about what disability generally means in Australia, more information about the particular disability the person has, and what supports and services are available.

Understanding disability within Burundian Community – Burundian Bicultural Community Educator

For many there is a lack of basic understanding of some types of disability especially non-physical disabilities. Some types of mental disability symptoms are not considered as signs of disability in our home countries (eg. Some autism disorders and intellectual disability). The stigma associated with disability prevents some people to accept the disability and/or to discuss with others. This prevents some people with disability or/and their families to see the need of discussing about their disability and/or NDIS.

The family will be worried that if others know about their family member with disability and then people will avoid them and the future opportunity for that person will be limited eg no one will marry them. This can also extend to the rest of the family members as it might be seen that the family has bad genetics.

Some religious people think that recognising some types of disability is lack of faith in God and/or accepting disability support other than prayer does not believe in God's power. They assume that a mental or intellectual disability is about bad spirits and this can be healed by prayer only. These people say for example:" I know I am fine/my child is fine because we are praying.

Secondly, the ability to visit people in their homes to deliver this information face to face in first language was very well received and has reduced many of the barriers associated with access for these communities

For many families attending information sessions outside the home was not possible due to:-

- Costs to attend the venue eg taxi, public transport
- The complexity of arranging for the individual with disability to attend the meeting or for a family member or friend to support the person if they could not attend
- Due to cultural understandings of disability there was a reluctance to discuss disability in a public space

The feedback from community members have consistently highlighted the appreciation by families of a home visit by a Bicultural Community Educator.

# Home visits Feedback - Vietnamese Bicultural Community Educator

This approach was greatly appreciated by all families as it was conducted in a place that the family felt more relaxed and comfortable environment. It allowed the family to have more time to be engaged in the session rather than travelling to the workshop, having to have someone to care for their disability person and rushing back home when caring time is up. Also, it allows us to see a small window of how their family is structured with caring for their disability person to help them later on.

The most benefit was no interruption of other attendees at the workshop with unrelated question to NDIS, or asking questions that we do not have any control over and become a political discussion. Some attendee have had negative experience with some other government agencies/school, therefore, their input to the workshop is discouraging to other families. The family will have more time to ask about their own individual circumstances. From this home visit, we learned that a few younger migrants' families do not have an understanding of how the Australian government agencies work. They rely on other to help them, however, the person who help them don't usually explain the whole process to the family.

# Home visits Feedback - Peruvian community member

The information was very relevant and quite useful for my circumstances. I appreciate the fact of having a home visit. Many thanks, God bless you.

Thirdly, an integral part of the delivery of information through this work has been the resources developed by AMPARO that are available on our website. Provision of information in language either written, digital or via video greatly has increased community members capacity to access and gain more knowledge about this complex information. Through this project these resources were used in our face to face sessions and then translated information was provided to the families to allow them to educate themselves further in their own time.

Having resources translated in my community language was very appreciated by my community members and made my job much easier. (Iraqi Bicultural Community Educator).

## **Outcomes**

The outcomes we wished to achieve through this project were as follow:-

- Raise awareness of the NDIS
- Build skills of the target group to engage with the NDIS and the planning process
- Increase understanding about the opportunities presented by the National Disability Insurance Scheme; and
- Build capacity of people from CALD background with disability and their families ability to apply these opportunities to their own circumstances before entering into the participant planning processes with the National Disability Insurance Agency

Through the targeted strategies Project AMPARO has successfully:

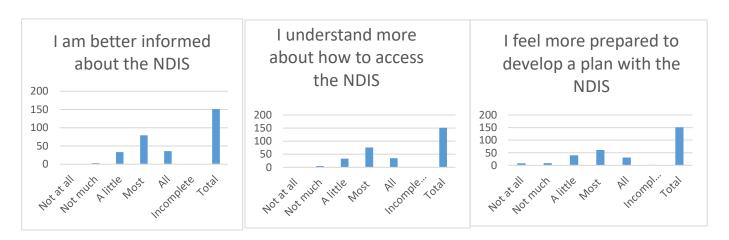
- Conducted over 39 workshops and presentations for CALD communities were held with 929 attendees, which includes people with disability, family members, community members and leaders, bicultural and multicultural workers
- Visited and provided 214 individuals with disability information about the NDIS in their homes
- 198 individuals have given their consent for AMPARO to provide their contact details to NDIA to ensure they are given the opportunity and support to apply for NDIS support. The reasons some families refused to give consent were around concerns about privacy and not wanting people to know about their disability and/or they feel it is their responsibility to take care of their child with disability.

Every individual with disability or a member of their family were provided the opportunity to complete an evaluation form on completion of the information session.

Evaluation forms were completed by 58 Individuals with disability and 96 family members and came from the following ethnicities:

| Afghanni           | Egyptian        | Lebanese  | Salvadorian |
|--------------------|-----------------|-----------|-------------|
| Dari (South Sudan) | El Salvadorian  | Liberian  | Sindhi      |
| Burmese            | Eritrean        | Ma"di     | Somalian    |
| Burundi            | Ethiopian Farsi | Pakistani | South       |
| Chinese            | Filipino        | Peruvian  | Sudanese    |
| Columbian          | Hazaragi        | Punjabi   | Syrian      |
| Congolese          | Indian          | Rwandese  | Tajik       |
|                    | Iraqi           |           | Tamil       |
|                    | Karen           |           | Vietnamese  |
|                    | Karenni         |           | Zomi Chin   |
|                    |                 |           |             |

The result of the evaluations show that individuals with disability and their families have increased awareness and understanding of the NDIS process:



- 76.2% stated that they understood all or most of the information provided about the NDIS
- 73.5% stated they understood all or most about the information on how to access the NDIS
- 60% stated they understood all or most of the information on how to prepare to develop a plan for the NDIS.

#### Feedback from individuals

We were really informed well about NDIS. This will go a long way to help us to have our son being given more support, to help him in his future life. (Indian family).

I understand that I have the rights to get support and I understood much better about NDIS. AMPARO supported me a lot and I would love more support from AMPARO. (Eritrean family).

More understanding about disability in Australia. It's our first time hearing about this kind of services. More clear. (Karen family).

I am thankful to know about the NDIS project. I am hoping to get help for my disability. I am feeling very hopeless for not being cared about (Burundian community member).

Due to this increased awareness these individuals with disability and their families from a CALD background have an increased understanding of disability in Australia and the rights of people with disability, NDIS and increased awareness of supports and services available to those who have disability.

## Feedback Burundi Bicultural Community Educator

- Some people are overcoming their old cultural beliefs about the possibility for people with disability to be successful and have a better life. Increase of confidence and self-esteem.
- More families have been connected to services and support.
- Social connections between people with disability and/or families of people with disability.
   Where culturally appropriate people meet through information sessions and found support from each other. In some cases friendships were established.
- There is hope that individual with disability may not be accepted by own community but more accepted by Australian community.

# Feedback Eritrean Bicultural Community Educator

- Not so much discrimination in own country about disability but most community members
  are not aware of rights or what is available. Back home there are no supports available so
  low expectations.
- This impacts the planning outcome. How support organisations frame interaction need to ask if services wanted vs expecting individual to request. Need to provide opportunities and offer access support rather than expect individual to approach. Takes time. Very tricky.

Through our collaboration work with a number of stakeholder providers across regions we have been able to inform and educate services on the needs of CALD communities. The verbal feedback received has been:

- Services are more informed about the needs of individuals with disability from a CALD background
- There has been more interest to work collaboratively on addressing the accessibility barriers for CALD families
- More acceptance that this cohort is also their cohort and they need to consider their accessibility barriers, cultural competence and interpreter use
- Appreciation of the resources AMPARO has developed through all of the participant readiness work

- Developing improved understanding regarding the absolute necessity to engage interpreters in all situations
- NDIA is now collaborating with AMPARO in holding joint stalls –previously it felt that AMPARO's work was seen as quite separate from theirs. (NDIA at Sunnybank and Inala TAFE workshops used our resources)
- Disappointment that the project is ceasing at a crucial point in the transition to NDIS.
   AMPARO has noted an increased number of inquiries from organisations and service providers who are looking for supports for individuals they are involved with. Most inquiries are about assistance for individuals and families to make access request and support to obtain evidence of disability and impact

# Learnings

AMPARO has extensive experience in understanding the additional barriers and challenges for individuals with disability and their families within the Disability sector. This project has provided further evidence of many of their barriers and additional understandings of how to work with this client group.

The main take away lesson is that this cohort continues to experience many complexities and all approaches need to be flexible, culturally appropriate and individualised to ensure best practice.

Some of the important learnings and issues for further consideration for work in this area:

## **Community Engagement**

- Workshops are often not appropriate for many cultures due to privacy and confidentiality concerns
- Whilst other members of the Australian community may be happy to approach information stalls in a public space, CALD community members can be very cautious due to cultural reasons
- Using cultural rituals as opportunities to engage with people in comfortable and relaxed space was successful
- Smaller intimate celebrations was another successful strategy to share information that is not specific to an individual
- Always recognising cultural difference and being flexible in your response
- Being aware that sometimes community leaders are not the most effective way to spread awareness and information due to leadership, gender and control issues
- Identifying key people in the community and using their connections and relationships to identify vulnerable and isolated people in the community.
- There was a great deal of support for workers/supports to come from own culture/CALD background
- Direct individual approaches through Bicultural Community Educators (BCE) networking and connections has proven a very successful strategy
- It takes time, persistence and patience to build relationships and trust to engage individuals who might benefit
- Remember the importance of confidentiality in building trust and not forcing issue was highlighted. Many families experience fear and concern that their private information will be shared with their community

- Families needed to feel the approach was sincere and there was a heartfelt desire to inform and help them using an much more informal approach
- Ensuring BCE's are well trained and supported to ensure mis-information is not provided putting people in vulnerable positions
- Providing clear and correct information so that there is no guessing and incorrect information is not spread across the communities

## <u>Individuals</u>

- Families do not want to be a burden, therefore sometimes hesitant to approach outsiders for assistance
- Families do not want anyone to know their business
- Inconsistent support, multiple services and case managers makes it very confusing
- It is stressful for families to go through intimate information over and over again
- Challenge to trust as so many people enter their lives on a temporary basis

# **Systems**

- Australian systems are very complex and more time is needed for each family to really understand the information
- Individuals new to Australia may have very little understanding of how systems work in Australia, therefore imparting such complex information without prior understanding of how structures work in Australia is an enormous task to accomplish, particularly through an interpreter
- It was difficult for individuals to understand the difference between health, disability and mental health and that in Australia which are different departments with different eligibility and processes
- Difficult to understand due to the complexities and the politics within systems and how they impact on the implementation
- Difficult for families to understand the limitations of the project. People had higher expectations on what AMPARO workers could actually do. What they want and need is support throughout the whole NDIS process
- More support is required to help families to become confident about choice and control.
   Choice is seen as positive within Australian culture however it is not always positive for people from CALD background. They may have had limited choice through life and choice is not a part of their culture

#### Interpreters

- There continues to be a significant lack of use of interpreters
- Many families may speak some English and it can be misconceived that they then understand all terminology.
- Telephone interpreting is problematic as the interpreter cannot see the paperwork being referred to. They miss context and non-verbal cues, such as facial expressions and gestures and therefore are danger of providing incorrect interpretation.
- Interpreters need more information on language gaps and need confidence to prompt service providers for further explanation if the terminology doesn't exist in first language.
- Requests for specific interpreters is part of best practice, however the process to access a specific interpreter via TIS is extremely arduous and therefore LACs and planners are reluctant to comply with requests for this.

- Many organisations are inappropriately using the person in the family with the most English
  to disseminate information rather than engaging a certified interpreter and providing the
  information to the person and close family members.
- Due to lack of translated information regarding disability many individuals and families feel isolated and not able to fully understand their disability

## Accessibility and Preplanning

- There are no organisations funded to provide the level of access and preplanning support that individuals and families from CALD backgrounds require
- Due to the complexities of this cohort they are often put in the "too hard basket" by service providers and government departments
- Families often do not have the understanding or knowledge to navigate the systems, such as the NDIS themselves

Through these learnings we have clearly identified and have been asked by families to provide the following supports:

- More information to understand their rights and to know what a 'good life' for people with disability can look like.
- Assistance to contact the NDIA to make an access request and complete documentation.
- Assistance to gather eligibility "evidence", including evidence of disability and impact
  of impairment on their functional capacity and to access to timely, affordable
  assessments if needed, such as cognitive assessments
- Help completing preplanning to understand and take advantage of the opportunities available to them under the NDIS
- Advocacy support to ensure interpreters and the most appropriate method of interpreting is provided to communicate with the NDIA.
- Help to respond to requests from the NDIA for additional information

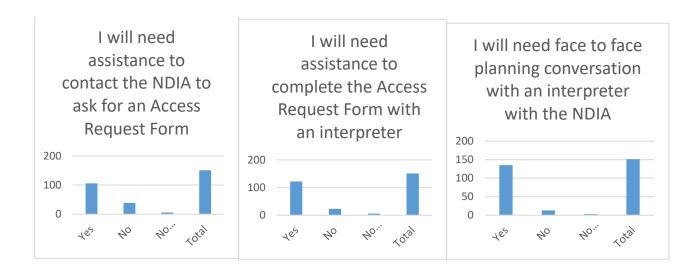
## Feedback from individuals

English barriers in speaking, writing, reading & understanding, had no ideas where to get help, no idea how things going in Australia/everything is hard for me (Karen family)

Limited English. Need help with referral, communication and connect with services (Vietnamese community member)

Don't know how to access the system. I don't know how to implement my plan. I don't know what services are out there so wont engage. Withdraw. Too overwhelmed

This is also reflect through the results from the evaluations we conducted with families about how they will continue to work through the process of registering and preparing themselves for the NDIS reflect these challenges.



- 70.2% stated they would need assistance to ask for an Access Request Form
- 89.4 % stated they would need a face to face planning conversation with an interpreter with the NDIA
- 80.8% stated they would need assistance to complete the Access Request Form with an interpreter

Clearly from the evaluation results we can see that although the families stated they understood more about NDIS and the processes, the vast majority of families still reported that they would need assistance to complete each stage of the application process and the development of an NDIS plan.

# **Strategies**

Through AMPARO previous extensive experience many of the strategies for engagement we included in our work plan have been successful. These were:

- Targeted engagement with bicultural community educators
- Conducting workshops and information sessions
- · Providing one on one Information sessions for individuals and families in first language
- Engaging community leaders, multicultural workers, disability services and government to assist with information dissemination
- Delivering information sessions at other community forums/ events
- Incorporating translated materials in our information kits
- Making use of audio visual translations and digital stories to provide information to families

# **Successful Strategies**

We found through this project the following strategies were effective:-

- Use of a strong community development approach, using culturally appropriate, responsive and flexible processes that support targeted communication and engagement with people from CALD backgrounds with disability, their families, and communities.
- 2) Recruitment of Bicultural Community Educators (BCE) who were well linked to their community either through their roles as community leaders present or in the past, informal leaders who already support the community in a number of ways and those who had lived experience themselves of disability or a family member. Many BCE naturally took a strong community development approach and their engagement strategies were about building relationships, developing trust, taking it slowly and not pushing the agenda
- 3) Training and initial one on one shadowing of BCE assisting them to feel confident to seek out isolated people with disability in their particular communities, to inform them about disability, the rights of people with disability in the Australian context and the opportunities that the NDIS will provide.
- 4) Conducting home visits. This approach has been well received and for many communities this was the best approach as there can be a reluctance to discuss issues related to disability in a public forum.
- 5) Working in partnership with organisations in the multicultural and disability sector to deliver information sessions regarding accessibility and participation barriers for people from CALD backgrounds with disability, their families and communities

# Through our learnings we would recommend:

- When educating communities be very flexible in the way you deliver that information
  ensuring at all times you consider the most culturally appropriate approach for that
  particular community eg individual visits, rather than workshops.
- Employing and training Bicultural Community Educators to guarantee information is provided in a culturally appropriate way which increases the ability to reach isolated community members.
- Intensively educate people about their disability and ensure they have a clear understanding of what it is and how it will affect them every day and into the future.
- Intensively educate people of what are the most appropriate supports that should be provided for that particular disability.
- Help link individuals and families to a support service that will provide culturally appropriate support.
- Ensure you and any service providers they are referred to use interpreters.
- Use of well-trained bicultural workers or interpreters (where appropriate) to ensure language support but also that information is provided in the most culturally appropriate and understandable way.
- Ensure relevant information resources are translated and provided in a number of modes eg written, digital, video

We thank the Department of Communities, Child Safety and Disability Services for the opportunity for AMPARO Advocacy to engage with CALD communities and help prepare them for the NDIS. AMPARO will continue to advocate strongly, that much more work needs to be done to ensure individuals with a disability and their families from a CALD background are provided with equality of opportunity.