

Inquiry into Better Support for Carers

The House of Representatives Standing Committee on Family, community, Housing and Youth

Submission attachment from

Ethnic Disability Advocacy Centre

Table of Carers experiences

Comments from Carers attending EDAC workshops

I am Vietnamese, far from my homeland
For me now the days and circumstances are foreign
I alone must care for my life long partner
Our children earn their living the hard way
There are no relatives, no neighbours here for us
Many times, difficulties arise from language barriers
I, the husband, work the household chores alone, settling thing in order,
Oh! A difficult life is like this.
I wish for someone to confide in
I must bear the rest of my life the same way.
(Carers: non-English speaking background Culturally and linguistically diverse- by EDAC)

Ethnic communities

- *“It is my job to look after her.”*
- *“In Burma there was no special school.”*
- *“In India rich families could get a maid. If you were poor you had parents and extended family, but no government support.”*
- *“In your own country you have more family support.*
- *“People [in my ethnic community] think you have probably done something wrong.”*

- *“The local church said confess your sins.”*
- *“There is a stigma about getting formal help.”*
- *“No-one wants to know about it.”*
- One person mentioned their concern about obtaining appropriate social support where they feel uncomfortable with the current social support systems available in the general Australian communities and want an environment within their own Muslim community, where people have better understanding of social requirements for Muslims
- One male carer mentioned his feeling of isolation because he had no other carers to relate to within his ethnic community and those in mainstream society don’t understand his cultural caring concerns
- One parent also mentioned that although she felt that mainstream service providers were respectful of her cultural and religious needs she still felt uncomfortable accessing these service for support; such as obtaining female carers for her daughter and culturally appropriate social support. She has found that the process of ensuring services are culturally appropriate has caused extra stress on herself and her family.
- It was also reported that religious leaders were refusing children with challenging behaviors to attend the Mosque during religious prayers, which was creating an environment that was reinforcing the perception that Muslims with disabilities don’t have the same value as other Muslims, which is a notion that other religious leaders dispute.
- Negative perceptions of disabilities within some communities is so devalued that one participant had reported how 2 brothers came to Australia because the other sibling in home country who had a disability had caused their marriage prospects to be reduced within their home country, it was viewed if they come to Australia where not many people from their home land knew them and were distanced from their brother they would have a better future.
- LAC reported that a mother who came to Australia as a refugee stated that her child’s down syndrome came from them coming to Australia. *“We don’t have those illnesses in my country” (Carers: non-English speaking background Culturally and linguistically diverse- by EDAC)*

Mainstream service providers

- *“DSC has narrowed its definition of disability and turned away people who don’t fit in.”*

- A nurse thought a patient refused to speak to his own mother simply because she is a woman. However, though the patient was from the Middle East, he was brought up in Australia and strongly influenced by the Australian culture. His problem with his mother had not simply stemmed from her being a woman.
- One participant reported that hospital staff have racist tendencies and treat patients inappropriately. She has also been doubted at times because of her appearance. Some of her friends have also complained to her and recommended her not to go to certain hospitals. Our participant has had to use her own time to train staff individually on the needs of CaLD people
- Service providers are making assumptions regarding a person's appearance. These assumptions have deterred participants from using certain services as they have been made to feel misjudged and less credible.
- Mother of 28yr old high support need daughter has been waiting 8 years for accommodation support. She is tired, is depressed and has commented that when support workers come to her home they have difficulty with understanding her cultural practices.

Cald carers participating in management and/or making complaints

- One of the participants who said she was happy with the services she was receiving told the facilitator after the workshop about her experiences as a refugee, where she had to struggle to survive civil war in her country and found that obtaining services for the person she was caring for there was out of the question and when comparing her experiences of services from her country of origin to the service she is receiving now she feels bad about making any complaints, even though she isn't obtaining suitable services according to her needs. She felt that providing feedback or making a complaint is equivalent to her showing ingratitude for what she is receiving, that receiving something, even though not suitable is better than receiving nothing.

Obtaining information

- One participant said that she was aware of many services but could not access them to gain a good understanding of what they do because she cannot speak English well
- Most participants reported to have approached a service provider who has not used an interpreter and some were not even aware of the Telephone Interpreter Service. The bigger organizations use the service but small agencies and private companies are very reluctant to use it, even though some are aware of it
- One mother of a 5-year-old child has been finding difficulty obtaining disability service support for her son. She has now been on disability support waiting for 7 months and didn't think anyone cared. No interpreters were provided to explain to her about the waiting list.

- One mother commented that she didn't know she had the right to request interpreter assistance when accessing services.
- Another participant mentioned they have been assisting the care of their grandchild and the child's mother hasn't been informed [by interpreters/translated information] of the different types of services they could obtain to assist with the care of the child, so the family has struggled on their own for a number of years without suitable support.
- Other participants mentioned they are interested to find out about services, events and workshops like this within their local area, but they are missing out on this information due to agencies not advertising within their local resources such as ethnic community newspapers/newsletters or providing suitable translations of information. The participants also mentioned that they would like to access information about services from ethnic radio programs such as EthnicAbility

Leadership needs of carers

- *"It's an eye opening experience, learning to have less expectations."*
- *"I have learnt to be more patient and self reliant."*
- *"It makes you more imaginative and innovative."*
- One women voiced their sense of isolation and lack of confidence that has resulted from the minimal opportunities that they are given to network and practice their social skills such as English within Australian society
- One woman also said she felt very afraid and vulnerable. While very tempting, returning to their country of origin was not an option as they would not be receiving the services there that they are entitled to and the knowledge of disability is very limited.

Temporary resident / migration issues

- *"At home you could have a servant, trained to look after someone 24hrs a day. We should be allowed to bring someone in from overseas on contract."*
- One of the participants has mentioned the cause of their feeling of isolation have been because they are not able to access appropriate support and care that is appropriate to their cultural needs and have felt depressed and lonely due to family members who have applied to migrate to Australia to provide that support being denied access into Australia, where the role as a carer isn't recognized as a viable reason to migrate to Australia.
- One mother is in Australia on a Student Visa, she has a 6 year old daughter who was diagnosed with an intellectual disability. Her daughter has been denied access to disability services due to her residence status. The daughter has also been

denied entrance to the school system as they need to provide a teachers aid for the daughter, which the mother cannot afford to pay. Without the opportunity to provide early intervention and accessing education for her daughter she is concerned about the future prospects of her daughters later in life.

Employment/respite issues for Carers

- *“In Australia there is a severe shortage of nurses, it is a problem as we age.”*
- *“Looking after a person who won’t get better is physically, emotionally, spiritually and financially difficult.”*
- *“I can’t get sick, I can’t get sick, I can’t get sick.”*
- *“She has a problem in her head, high blood pressure, headaches at night with worry, and she takes panadol every night.”*
- *“I have been crying every day with stress, because I don’t know how to manage my life and see her everyday... I tried bringing her into the business, but it was impossible, she isn’t safe to be left alone.”*
- *“We haven’t even had time for a cup of coffee alone.”* (Since the birth of their child with a disability).
- *“I can’t leave a burden on someone else, they (my other children) have their own family. The life of the other children is already spoilt, they have lost their childhood.”*
- *“The only care we can expect from siblings is to oversee (paid) carers and finances - not daily care.”*
- *“Two of my sons are protesting and moved out. They don’t want to do it. One said it is not his responsibility, he has a life of his own.”*
- One mother said that she has six children including one who has a disability. She has been invited to take respite with assurances that her son with the disability will be looked after, but has had to decline as there was no one available to care for her other children.
- One male person with a disability talked about his concern regarding not having male support worker in accordance to cultural requirements, requiring him to maintain his reliance on his family carers.
- Difficulty with accessing accommodation support had caused one participant to try and obtain a carer, who is a close family friend from her country of origin. She was advised that the current migration laws don’t allow people to migrate as a carer

unless they are a direct family member, but this participant didn't have any direct family members who would be able to take on the caring role.

- It was found by one participant that they were appreciative of how the accommodation service provider was trying to make adjustments to meet their individual cultural needs by providing religiously appropriate food, but this food wasn't fresh (pre-cooked meals), while other residents good fresh food. This caused the carer to feel guilt and stress to go to the accommodation centre most days to deliver fresh culturally appropriate food.
- Migrants have the problem that we don't have, the extended family support" – *(Carers: non-English speaking background Culturally and linguistically diverse- by EDAC)*

