SUBMISSION ON THE PLANNING OPTIONS AND SERVICES FOR PEOPLE AGEING WITH A DISABILITY

Exploring the issues of people with a disability from a CaLD background

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Introduction

The **Ethnic Disability Advocacy (EDAC)** EDAC is a peak disability advocacy service in WA which seeks to promote, protect and safeguard the rights and interests of culturally and linguistically diverse (CaLD) people with disabilities, their families and carers in order for them to achieve their full potential as Australian citizens.

We appreciate the opportunity to respond to the Senate Community Affairs References Committee. We understand that the inquiry refers to planning options and services for people with a disability to ensure their continued quality of life as they and their carers aged, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers.

Given the short time frame we can only provide a general overview of people ageing with a disability and their service options with special reference to people from cultural diverse backgrounds.

The Ageing and disability population

The Australian population will continue to age due to the inevitable result of declining mortality rates and low levels of fertility over a long period. As a result of the ageing population, people with a disability are also ageing since survival to old age is now a reality for some people with an early onset of disability. Advances in medical technology, medical treatment and rehabilitation have expanded the life expectancy of many people with disability so much so that within the last fifteen to twenty years there has been an identifiable group of ageing disabled adults.

The baby-boom generation is believed to have contributed to the current ageing population in Australia and among them are people with disabilities. However, immigration equally has played an important role in population growth after World War II. New immigrants and their children [1]accounted for over half of the population growth, even during the peak of the baby boom period.

Those migrants and their children who arrived after World War II are now ageing, and many had acquired disabilities much earlier on, due to the labor intensive and risky jobs they held that the general population was reluctant to take.

The number of ageing and disability in the ethnic community also included immigrants who arrived in the 70s and 80s. The experience of trauma from war and persecution had attributed to many disabled conditions and mental health illnesses among this group.

Are current aged care services appropriate for those who have ageing with a disability?

[1] Australian Institute of Health and Welfare (AIHW) 2000. Disability and ageing: Australian population patterns and implications. AIHW cat. no. DIS 19. Canberra: AIHW (Disability Series).

While there are similarities between the current disability and aged care service systems in broad service philosophies and policy directions, the two systems differ in their program focus, service types, main target groups and trained personnel. In particular:

- Aged care services are geared to the needs of frail older people and older people with a disability due to ageing, while disability services generally focus on people aged under aged 65.
- Aged care services focus more on health needs, broad personal care and self-maintenance, while disability support services also emphasize on non-health needs and address a broader range of life domains, including employment and community participation.

The AIHW report also refers to the 'grey areas' in service provision in the border territory between the disability and aged care service systems. They refer to four categories of potential grey areas that require consideration in planning service options. These categories are not necessarily mutually exclusive but may be of use in identifying particular issues for service planning:

- People ageing with an early onset disability often have fewer basic living skills and so need higher levels of assistance in some areas. The services they require may be different from those needed by their younger counterparts.
- People ageing with a disability acquired during adulthood usually have basic living skills. Their need for assistance generally arises from increasing physical frailty and diminishing levels of functional skills.
- Some people ageing with an intellectual disability may acquire dementia relatively early in life. They may become frail and need health and medical care more than help with other activities. These people might be more appropriately assisted by aged care services, because of their early ageing and deteriorating health.
- People retiring from Commonwealth-funded employment services may need replacement services. Those in disability funded accommodation may require more flexible ‘retirement’ services, enabling them to ‘age in place’ or to make a smooth transition to appropriate residential aged care.

The AIHW Report cautioned adopting or identifying a single factor (e.g. age, age at onset, disabling condition) as an indicator of need as people with a disability are not a homogenous group. It is therefore important for different service programs to assess individual needs and circumstances and be flexible in their service delivery.

Other studies also indicated that the existing services between different programs cannot accommodate the emerging needs of people with disability who are ageing, similar to the grey areas that are outlined above. Disability and age related service organizations currently appear to be providing services to two distinct populations, with little cross-over. Lack of flexibility in support provision obviously creates considerable practical difficulties for many disabled person as their needs changes especially relating to ageing.

Service options and considerations

It has been suggested that because of changing disability needs, and/or changes in eligibility for certain services, it may be appropriate or necessary for people ageing with a disability to transfer between service types—for instance, from employment support to day activity services, or from specialist disability to generic aged care services.

A broad framework for planning individual services, spanning and possibly mixing aged care and disability service programs, could be useful, as long as there are criteria for decision making. Day services may need to be restructured from full to part time, with more flexible arrangements for people ageing with a disability. In-home accommodation support and respite may be provided via flexible support packages, allowing people to modify their balance between these two service types. It is important to clarify the roles of disability and aged care services with respect to the individual needs of people ageing with a disability and with a greater degree of flexibility. There needs to be greater collaboration between aged and disability services, including the health system and cooperation between State and Commonwealth governments to address socioeconomic and jurisdictional problems posed by the population ageing with disability.

Despite ageing some people with disability could still be in the workforce. They should be encouraged to remain active in their work and leisure pursuits. To encourage people with disability who are ageing to remain in employment there should be some tax incentives and centrelink payments such as personal/disability allowance and pharmaceutical benefits, to offset the cost of disability.

From anecdotal reports, people with disability who are currently receiving support services from specific diagnostic organisations, (e.g. Cerebral Palsy, MS, Visually Impaired, Spinal Injury, Acquired Brain Damage) are reluctant to transfer to generic Aged Care facilities. Many will prefer to remain in familiar services for continual support even in aged care. The transition from disability services that they are familiar with and have spent most of their adult life in, to aged care services is a difficult concept and process for many people with disability. Similar resistance is encountered when transferring from a Disability Support Pension to an Aged Pension.

Health of Carers as the person with a disability is ageing

The support role of carers of people with disability who are ageing should not be overlooked especially in circumstances when family carers themselves are also ageing. These family carers can be siblings, parents and grandparents. The House of Representatives Standing Committee on Family, Community, Housing and Youth (STFCHY) recognizes that:

> Physical impacts of providing care are broad ranging and are likely to increase as the carer ages, as the care receiver grows to adulthood or as a consequence of providing care over a prolonged period of time or at a high intensity[2]

These ageing carers will not only need extra support and services due to their early onset of age-related disabilities, but their conditions could also result in the increasing number of people with disability entering disability services and aged care facility.

The Standing Committee acknowledges that the important role of carers needs better recognition from all government agencies and service providers to ensure they are supported to continue their role as much as possible throughout the life of the person with a disability.

Issues of disability and ageing in the multicultural community

As indicated earlier migrants and their children who arrived after World War II were now ageing as were those refugees and humanitarian entrants who arrived in the 70s and 80s and a significant proportion had early onset of disability. EDAC's annual report 2009 also demonstrated that 25% of clients with a disability were over the age of 56. NEDA's national research[3] also identified that impairment for 'first wave' non English speaking migrants, [is] up to 3 times that of the Australian born population".

Cultural diverse groups are not homogenous. However, considerations for those with disability and ageing from a multicultural background have to be included in the context of their cultural and language complexities and pre migration trauma experienced. It's about understanding the cultural and linguistic differences as well as barriers, attitudes and discrimination they encounter in our community when accessing services. Attitudes of stigma and shame can sometimes cause self-imposed concealment and isolation in some ethnic communities leading to social exclusion in addition to that experienced by others with disability in the general population.

The Equal Opportunity Commission (EOC) WA[3] has found that racial and impairment issues have the highest incidents of reports and complaints within the last 25 years with a dramatic rise over the last year for both these issues. This '***double discrimination' of people with a disability from a CaLD background is one of the major causes for low utilization of services*** for this client group and requires stronger policies and monitoring to ensure that people with a disability from CaLD backgrounds have more equitable access to services in their older years.

In 2004 the *Policy Framework for Substantive Equality* was endorsed as an official Government policy in WA. It is an expression of the principles in the Western Australian

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[2] STFCHY 2009, Who Cares: Report on the inquiry into better support for carers

[3] EOC; 2010, Discrimination Matters, January Edition, accessed 30th April, 2010; from: http://www.equalopportunity.wa.gov.au/pdf/Discrimination%20Matters%20newsletter%20-%20January%20%202010.pdf

Charter of Multiculturalism to ensure that all people have access to a public service that best meets the different needs of WA's diverse community. In WA the Substantive Equality Framework is administered and monitored by the WA Equal Opportunity Commission. Government agencies are expected to implement the framework to ensure that all people have access to a public service that best meets the needs of WA's diverse community. We believe this framework should be extended to all government funded services and established as a national framework to enable culturally responsive services and support for ageing people with disability from ethnic background.

Ethno-specific vs mainstream services

Ethno-specific agencies and multicultural services play an important role in care management for people from CaLD backgrounds. They often act as entry or referral points into the aged care system for many older people from CaLD backgrounds and their family carers. Many people ageing would opt for culture specific and/or multicultural aged care facilities because of familiarities of culture and language needs even though the disability care/support may not be ideal. At the same time aged migrants often regressed to their own native language and poses difficulty for the generalist aged care facility. They require culturally involved services – such as interpreting and translation and cultural care practices. The family members can be quite bewildered and lost in choosing the types of care and support required.

Mental Health and Disability

It is also important to acknowledge the long-term effects of social exclusion experienced by people of cultural and diverse backgrounds with early and mid-onset disabilities. We believed that people with long-term disabilities who are migrants and refugees are at higher risk of developing mental health conditions.

Refugees and Humanitarian entrants who experienced persecution, torture and trauma pre migration may already have mental health conditions or have a greater tendency of developing mental health especially in the ageing years. Settlement (migrant) services are beginning to develop disability and mental health awareness and facilitate early referral to specialist support agencies however there are some concerns about appropriate role separation between settlement support and specialized therapeutic services.

The mainstream agenda has seen the progressive disbandment of ethnic generalist and transcultural mental health services in WA. Although there have been some initiatives in addressing migrant mental health services and improvement of service access in mainstream agencies the specialized intersection of culture, disability and mental health has yet to be determined.

Mainstream service providers supporting older people with a disability need to be mindful of these issues and ensure they are *implementing services which are inclusive of a person's mental health condition.*

Disability services themselves will need to be much more supportive in retaining family and community care responsibilities and practices and also become more culturally safe for CaLD consumers and their families/carers and communities.

Family Carers from Overseas

People with a disability from CaLD backgrounds generally have fewer family members to turn to for care and support but when available is an integral factor in advocating for integrated cultural practices within mainstream services. They can be a primary source of maintaining and linking the person into their cultural community and enhancing the quality of life for the person with a disability.

Family carers who wish to maintain the care of the ageing person with disability at home should be assisted with all available support from the government and community services. In circumstances when the family carers themselves are ageing, they will need support and respite that are culturally and linguistically appropriate. Many families would prefer a family member from overseas to assist with the caring or respite roles because of culturally appropriate assistance and cost factors. Whilst the Migration Act 1958 has a visa provision for carer application there are major restrictions in eligibility and long delays. Not many carer applications have been successful.

Recommendations

The Senate Community Affairs References Committee should take on board the following recommendations when considering people with a disability in their ageing needs:

- Priority action in the area of the interface between ageing and disability.
- Commit government agencies at both levels of government to take a whole of government and cross-jurisdictional partnership approach.
- Promote and implement State and National policies which recognize the cultural and language needs of elders with a disability when accessing services.
- Ensure the role of the Carer is upheld throughout the life of a person with a disability, in particular providing better opportunities for extended families to access carer visas within the migration process.
- Enable ethnic communities to undertake more ownership of their community members with a disability through liaising and networking with disability and/or aged care service providers.
- Ensuring mental health services are readily available for people with a disability accessing aged care support, especially those who are refugees or humanitarian entrants.