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Inquiry into Better Support for Carers

The House of Representatives Standing Committee

on

Family, Community, Housing and Youth (FCHY)

**SUPPORT NEEDS OF CARERS
FOR
PEOPLE WITH DISABILITY
WHO ARE FROM
CULTURALLY AND LINGUISTICALLY DIVERSE
BACKGROUNDS (CALD)
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Thank you for the opportunity to provide a response to the Inquiry into Better Support for Carers.

We are pleased to do so on behalf of people with disabilities who are from culturally and linguistically diverse (CaLD) backgrounds and their families/carers.

1. INTRODUCTION

EDAC - Ethnic Disability Advocacy Centre - is the community based advocacy organisation in Western Australia that represents the rights and interests of people with disabilities from culturally and linguistically diverse backgrounds (CaLD) and their families. It is the WA member of the National Ethnic Disability Association (NEDA).

CALD - culturally and linguistically diverse - is often used to describe the complex multicultural nature of Australian society. It applies to people who identify as having particular cultural or linguistic affiliations due to their place of birth, ancestry/ethnic origin, religion, preferred language or languages spoken at home. CaLD communities are not homogenous, but consist of micro-communities with disparate practices and beliefs. They include independent migrants, refugees and humanitarian entrants, with the latter frequently drawn from areas of serious conflict.

Background

For more than a decade now EDAC has been active in providing both individual and systemic advocacy for people with disabilities who are from CaLD backgrounds and their families/carers. During this time the Australian government embarked on implementing a deinstitutionalisation policy across all service domains, including health, aged care, mental health and disability services. It became apparent that carers, throughout Australia, would play a very important role in providing support services to people in their homes and communities. More recently family carers have become recognised as particularly crucial, especially in the diverse ethnic communities.

On funding from the Disability Services Commission (WA) EDAC conducted an extensive personalised interview survey throughout WA of carers of people with disabilities who are from CaLD background. This is available on the EDAC website - *Supporting CaLD Carers* EDAC 2003 www.edac.org.au. This included carers of CaLD people across the full range of types and levels of disability, from across the multicultural diversity of ethnic communities, and from both urban and rural areas of WA.

The 2003 recommendations:

1. Improve data collection (identification) of CaLD carers and people with disabilities.
2. Explicitly include CaLD people with disabilities and their carers in policies and practices.
3. Increase CaLD access and outcomes in disability services.
4. Develop culturally appropriate projects which are initiated and directed by CaLD carers and communities.
5. Review the provision and coordination of disability services.
6. Enhance the provision of appropriate information.
7. Develop holistic, coordinated approaches to CaLD disability and carer services.

Since then EDAC has been actively involved with the CaLD carers, certain ethnic communities and the Disability Services Commission (DSC) in progressing the implementation of the recommendations.

However, it is our concern that family carers of CaLD people with disabilities still continue to be impacted by wider carer support issues at State and National levels and by their lack of opportunity for leadership and meaningful engagement and input into matters relating to disability.

2. THE ROLE AND CONTRIBUTION OF CARERS IN SOCIETY AND HOW THIS SHOULD BE RECOGNISED

There are about 2.6m carers in Australia and among them is considerable cultural diversity, with 660,000 (25%) being born overseas, and 337,000 over half (51%) i.e. 13% of the total number of carers in Australia come from a CaLD background (NESB - Non-English Speaking Background) (ABS 2003/4). This includes carers in Australia across all sectors, ageing, mental health and disability.

Family carers are the main providers, of these, in CaLD communities, and are an extremely valuable resource to Australian society. They frequently take on the caring role with cultural understanding and minimal complaint and attend to the needs of the individual with love and compassion, qualities that are understandably rarer among non-family paid carers.

Yet, family carers generally find themselves taking on this role 24/7 with little preparation, knowledge or support for the task at hand. They are expected to do it with professionalism and frequently need to juggle the numerous other roles within their usual daily routine. Family carers take on many of the skills of 'professional'

roles such as health care nursing, life coaches/counsellors and educators, social facilitators, negotiators and advocates, care managers, futures planners, etc.

Recognition of the Carer role as employment in its own right. The Australian government has taken some steps to begin to recognise the role of carers through the carer payment and carer allowance, with the inclusion of the non-recurrent carers bonus. However, it must be recognised that these strategies, even for general Australian carers, fall short of adequately recognising the true value of carers.

Encouraging independent living by CaLD people with disabilities and others being cared for is most desirable. Care roles should incorporate this as a priority against creating any unnecessary levels of entrenched dependency. Effective care support can help people with disabilities into employment and active social life, it can also free the carer themselves to engage in other types of employment, social activity and care for the independent quality of their own life and wellbeing.

However it is crucial that these outward-looking priorities do not compromise the carer role being seen as vital and as quality employment in its own right and it being remunerated and supported as such. This approach is especially required in CaLD carer communities.

CaLD family carers in addition to the above are also required to also meet extra 'professional' roles for the person with a disability who is from a CaLD background. CaLD carers are also required to be interpreters for a person with limited English skills during appointments; to be translators to help an individual fill out forms and write letters; and be continual care monitors to ensure the individual with a disability obtains forms of assistance that are consistent with their specific cultural or religious practices.

Recognition and support of CaLD carers. CaLD carers feel there is not adequate recognition and support for all these skills and duties and the amount and hours of work they provide in care for a person with a disability. For example the stress of maintaining these and other extra and complex carer roles is rarely acknowledged by service providers and are frequently just taken for granted by them and often by family as the 'duty' expected of a CaLD carer.

This has tended to mask the serious need, for example, for culturally suitable respite care to relieve CaLD carers and enable them some participation in education, employment, social life and to care appropriately for their own wellbeing.

Many government agencies and service providers operate on the assumption that CaLD carers are recognised and valued by their own ethnic/religious communities, to whom they can readily turn for support and assistance when they need. EDAC has identified a number of ethnic/religious communities where the converse applies. Some see a person with a disability requiring special care in a negative fashion. The disability may be believed to be attributed to a past bad deed; is seen as evidence of

punishment for the person and/or the primary carer or family; and may see the disability as a reward or test - whereby the primary carer needs to persevere with tolerance and patience and without support. These negative perceptions can result in carers feeling devalued and excluded by their own ethnic community. In addition, these cultural/religious perceptions of the caring role, can be accompanied by disempowering guilt, shame and poor self esteem.

On top of this, CaLD carers tend also to believe that they are being devalued by the mainstream Australian society. These negative feelings and perceptions could result from the family not acknowledging the disability of their family member and avoiding both their ethnic community and the public. This can result in them not knowing about and/or deciding not to access what resources and disability support may be available for that person and for themselves as 'carers'. When they do attempt to access mainstream disability services, CaLD carers and people with a disability report low levels of satisfaction with both process and outcomes, mainly in terms of inadequate understanding and consideration of cultural aspects of their support needs (*Supporting CaLD Carers* (EDAC 2003)).

CaLD carers tend to feel their caring role is further devalued as there are no provisions designed to assist them to know about and access these benefits and services, and then, the services themselves poorly reflect the nature of their circumstances and support needs as CaLD carers. Carers from non-English speaking backgrounds are frequently intimidated by the barrage of forms and paperwork, by the intrusive nature and extent of the questions they are required to file to obtain financial assistance. Many do not come from circumstances where personal matters can be divulged in trust. In particular, recipients of the carer allowance also find the minimal financial assistance doesn't adequately reflect the time, effort, skill and support required for them to pursue and maintain such benefits. The constant difficulties with this and the feeling of an unhelpful organisational culture of suspicion and threat are causing anxiety, stress, a sense of depreciation and alienation in their dealings with Centrelink. Many forego their meagre entitlements and endure unnecessary hardship and poverty to avoid such humiliation and sense of possibly serious unforeseen consequences.

Strategic priority to work with ethnic communities on disability and care. To enable CaLD carers to feel their caring role is adequately recognised in Australian society and in their own cultural communities, the government should as a strategic priority be working with ethnic communities to assist them in realising the value of their own people with disabilities and their family carers and the rights of both to participation and inclusion as full citizens in Australian society.

On the other side, with service providers, there needs to be active promotion of the rights of CaLD family carers and those they care for with a disability, to support and offer assistance appropriate to the cultural aspects of their needs and care practices.

In between here is the need to work with employers and community organisations to improve their receptivity to positive engagement with CaLD carers and CaLD people with disabilities.

Leadership by CaLD people with disability and their carers. All of this requires leadership, development, delivery and management of culturally safe services by CaLD carers themselves, not simply consultation with them by mainstream services and token inclusion. Cultural awareness training of mainstream service providers, while necessary and of value, has not proven, and is not regarded by CaLD/disability consumers as, an adequate solution to addressing the service uptake gap of CaLD people with disabilities and their families/carers.

The Disability Services Standards recognise *inclusion* and *valued status* as necessary priorities for disability services. This must involve inclusion of consumers not just in services but in leadership at all levels as well, related to those services, from policy to practices, if the design and delivery of those services are going to meet the needs of, and thereby improve access by, CaLD people with disabilities and their carers.

CaLD/disability leadership in CaLD/disability affairs must be engaged as a necessary initiative under the State government Substantive Equality Policy for it to achieve demonstrable outcomes in the disability sector for CaLD people with disabilities and their carers.

Similarly, under the provisions of the Disability Access and Inclusion Plan, Disability Employment Policy and Carers' Recognition Act, intersectoral provision of support to CaLD people with disabilities and their carers is essential in their gaining and being effective in employment, especially in leadership positions in the disability services sector.

Finally, this will need to be accompanied by active promotions and leadership development training of CaLD carers (including people with disabilities) to overcome the effects of the multi-generational history and cultural influence of relegating people with disabilities to passive and dependent roles, resulting in 'learned dependency', and inculcating 'internalised oppression.' It can be most disempowering to say the least.

EDAC has developed self-advocacy training and inclusion programs with and for CaLD people with disabilities and their carers, but needs ongoing funding to engage the CaLD/disability population to develop confidence in asserting their citizenship rights and have leadership aspirations in managing their own affairs.

The active promotions of CaLD/disability leadership of both carers and consumers will also need to include positive acceptance and support within the disability sector at all levels.

3. THE BARRIERS TO SOCIAL AND ECONOMIC PARTICIPATION FOR CARERS, WITH A PARTICULAR FOCUS ON HELPING CARERS TO FIND AND/OR RETAIN EMPLOYMENT

Current services are continuing to fail to meet the needs of CaLD people with disabilities and their families/carers

Research by EDAC identified a persistent shortfall in CaLD consumers accessing services (*Supporting CaLD Carers* EDAC 2003 www.edac.org.au). In brief, of the 15% of people with disabilities who are of CaLD background only around 2-3% actually avail themselves of disability services (Australian Bureau of Statistics; DSC Annual Reports). Statistics on CaLD Carers service usage is not available.

Despite the good work conducted by some Carers organisations there appears to be an absence of quantitative and qualitative data on supporting CaLD carers needs. There is clearly a need to support leadership by CaLD people with disability and Carers in disability matters, including allocation of funds to update the research on CaLD carers' real needs and service use.

Implementation gap

From our experience we have attributed this shortfall in service uptake by CaLD people with disability and their carers in large measure to an 'implementation gap'. Each of the State governments through their Carer Recognition Acts and policies is demonstrating a desire to support carers. However there is still a need for a national carers legislation with targeted strategies and action plans for supporting carers – especially with integration of shared responsibilities between state and commonwealth governments, families and communities. There are the beginnings of recognition of the special needs and consideration of culturally responsive services and outcomes to CaLD people with disabilities - such as in the long overdue *Substantive Equality* program promoted by the WA government and being adopted by DSC to increase the input and participation of people with disabilities from CaLD backgrounds.

Without specific legislative and policy support, the identified gap in service uptake will not be effective in the design, development and delivery of culturally appropriate services. There is also a need to allocate sufficient resources so that practical measures can be developed to support and guide services in an integrated way across a broad front, such as in implementing the legislated principles and policies to produce demonstrable improvement in outcomes. In addition to helping agencies to be accountable for the outcomes of their services there also needs to be some level of enforceability in terms of requirements written into funding contracts such as in Disability Services Standards monitoring and Quality reporting.

Unless measures are taken to rectify this current implementation gap many CaLD carers, their communities and advocates will continue to perceive this inaction as systemic discrimination – in fact a double discrimination affecting services to CaLD/disability carers, one of both 'race' and disability.

EDAC recognises the dedication, determination and resilience of many carers in Australian society, protecting and supporting the needs of the individuals they are responsible for, and especially recognises the extra qualities needed for those caring for persons with disabilities who are from a CaLD background. Carers from a CaLD background frequently find themselves isolated from extended family network, from which, they could call upon for support and respite in their countries of origin. They feel Australian society isn't acknowledging their needs when caring for an individual with a disability, and are also finding too that their value as a carer isn't appropriately acknowledged or respected in their ethnic communities, a double alienation that can further alienate and cause enormous stress for CaLD carers.

EDAC's submission is not only based on the survey of CaLD carers in 2003, but is also based on years of individual and systemic advocacy, other research studies, projects and training, and on support provided to the Multicultural Carers Group that meets monthly at the agency. From its research report on the needs of Muslim people with disabilities and their carers/families in Perth metropolitan area, EDAC has also more recently established a Muslim Carers' Support Group in partnership with the Muslim Women's Support Centre of WA.

EDAC requests that the House of Representatives Standing Committee consider the extra difficulties experienced by CaLD carers of people with disabilities and support the implementation of appropriate measures at all levels to ensure CaLD carers are provided with opportunities equitable with other Australians. [Personal accounts of the experiences of CaLD/disability carers are detailed in *Supporting CaLD Carers* (EDAC 2003), available on our website www.edac.org.au].

Role containment of CaLD carers, especially in new and emerging refugee and humanitarian communities (e.g. Bosnian, Sudanese, Somali and West African) are particularly disadvantaged as they came from countries with relatively small numbers of people from a common ethnic group and have yet to establish infrastructure within their communities. They often have limited command of the English language and are unaware of the types of disability services and support networks that are available to help them in their carer role and for the person they caring for. Instead of services reaching out to them they are expected to seek out community services but they are often unaware of where to start.

With the demanding role of caring and added anxiety of settling in a new country they are not likely to seek help until a crisis occurs or their children with disabilities may be detected in the schooling system after difficulties become apparent.

Consequently they tend to be occupied full-time in their family and disability care role, leaving little time and energy to pursue possibilities of other employment. In many CaLD communities this is seen as a 'sacrificial' role and duty, requiring that the carer forego all personal ambitions and ideas of their own development and involvement in the wider sphere of life and community - marriage, employment, social life, etc. Where there are shared care arrangements within a family these disadvantages impact all participating members.

Some recent migrants/carers feel particularly vulnerable because they are single parents, with reduced family support and are fully engaged alone in their family and care role and unfamiliar with carer support networks and disability services in Australia.

Consequently the priority of family and disability caring often results in paid outside work taking a secondary place, often not considered or given up on as a practical option. With most migrants, the lack of extended family support means carers, often the mother/wife, have to take sole responsibility of caring for the person with a disability, which leaves little time to work or undertake training. Some refugee families have many children under their care.

This unfortunately also leaves most CaLD carers as they age with high levels of uncertainty, anxiety and concern about the future care of their family member who has a disability. This is especially so as those families frequently have little in the way of accumulated finances and assets to provide for transition to fully paid and probably institutional care. CaLD families suffer from chronic underemployment that limits their financial capacity to provide for continuation of family-based care or transition to institutional care as they themselves age, become no longer employed, and begin themselves to need care.

EDAC has initiated the beginnings of improvement of disability awareness and access for new arrivals through its CRIO Project and the Disability First Stop service, including making contact with family carers and linking them with appropriate services and support such as its Multicultural Carers Group initiative.

Isolation due to cultural attitudes toward disability. A significant part of this role preoccupation of CaLD carers and their isolation and non-engagement in social and economic aspects of the wider society can also be due to the cultural attitudes toward disability and the expected carer role that they bring with them. As mentioned earlier, such attitudes as family stigma, shame and guilt 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.

EDAC currently has a disability awareness promotions program active in the different cultural communities and seeks to maintain funded projects of this nature whenever successful grant applications make this possible. It is an issue as there is no ongoing funding to continually promote positive attitudes toward disability, carer roles and access to disability services in the multicultural ethnic communities.

Additional problems of refugees. Refugees experience greater disadvantage due to additional burdens – such as the mental health effects of torture and trauma that add to the more considerable settlement issues and extensiveness of support needed. This is usually compounded by language differences and difficulty in accessing support information and services.

Reluctance to access mainstream disability services. The development of effective cultural support in disability services for CaLD carers and consumers has been compromised by mainstreaming service policies. This has resulted in CaLD carers taking on the full burden of care and effectively locks them into unsupported full-time total care.

Newly arriving groups and those from specific religious backgrounds in particular tend to find that they have no comfortable access to mainstream services. They are special needs groups that warrant specially targeted funding, at least during their settlement years. Some will continue to need ethnic-specific carer support.

The advent of the policy of tendering that prioritises generic mainstreaming of services to large corporatised agencies, has precluded the development of ethnic-specific and multicultural disability services. Many of these disability carer support services are considered as not culturally sensitive to the needs and feelings of CaLD carers and those for whom they provide care and their families. Effectiveness is poor and satisfaction is low, resulting in reluctance to utilise mainstream disability and carer support services.

Although there have substantial improvements in generic disability services over the past decade, which have created greater choice of care support and assistance in the community, statistics have shown continuing significant under-representation of CaLD/disability consumer usage in service uptake.

Cultural awareness and sensitivity training among mainstream service providers, while necessary, cannot and has not satisfactorily addressed the continuing unacceptably low levels of access to disability services by CaLD groups.

Until the development of effective culture-based disability services is practised CaLD carers will tend to remain imprisoned within their care roles, in continuing poor economic circumstances, and be unable to engage in wider social activities and

employment or the fullness of citizenship to which they are entitled and for them to also fulfil their responsibility to the wider society.

4. THE PRACTICAL MEASURES REQUIRED TO BETTER SUPPORT CARERS, INCLUDING KEY PRIORITIES FOR ACTION

Key areas for practical action

1. Supporting the implementation of a National Carer's Recognition Policy and the development of an Australian Multicultural policy.
2. Supporting the development of National initiatives for carers, such as information and carer education.
3. Ensuring culture and disability is also explicitly included in State and future National carer legislation, policy and practices.
4. Providing strategies, incorporating CaLD/disability leadership and multicultural services funding, to overcome the service uptake gap for CaLD people with disabilities - i.e. to develop, deliver, and to monitor and support how agencies uphold the cultural/religious needs and the rights of persons with disabilities and their families/ carers in service provision.
5. Effectively promoting this legislation, policies and practical strategies throughout the ethnic communities, to inform and engage CaLD carers, so at the very least, they feel included and protected when they endeavour to access various social support systems, engage service providers and approach employers.
6. Developing improved financial assistance for low income groups toward the costs of caring, and its accessibility, recognising that the CaLD population is at particular risk and will need special CaLD-directed promotions and assistance with financial service support.
7. Integration of all aspects of carer support, including assessment, care support planning and care service delivery, including cultural care aspects for CaLD carers.
8. Strengthening community care systems, with special consideration to multicultural and culture-specific care for CaLD people with disabilities.
9. Developing new models of alternative care and accommodation that provide CaLD people with disabilities with real and suitable choices that provide for equitable quality of life for all ages, and both relieve and open out the range of possibilities for engagement of CaLD disability carers.

Specific barrier reduction targets

1. Recognising and supporting family carer roles as employment.

While a number of CaLD carers would like the opportunity to access general social and employment opportunities, the first priority must be to recognise and properly support the work of carers in its own right as a valued role and job in society.

There should not be the assumption that carers seeking paid employment are feasible for some or culturally suitable for all CaLD carers. For many their carer role is one of valued priority to them, their family and in their culture.

Many carers from diverse cultures are highly cautious and apprehensive in allowing their family and community care roles to be taken over by impersonal government funded formal services. On the other hand, some CaLD carers will accept some outside care and support which could enable them some opportunity for part time employment and social engagement. Depending on the severity of the disability, care demands and religious or cultural beliefs the current situation for many CaLD carers particularly women is, maintaining ongoing disability care in the home as well as the daily care of all family members while the husband provides the income for the family.

CaLD carers, especially women, need to have 'real' practical choices and flexibility regarding how they wish to uphold their caring role. Their cultural values and requirements need to be respected by the government, through provisions to enable opportunities for employment and social life to be negotiated and supported.

2. Workplace reforms - developing and promoting carer consideration guidelines in employment.

Working with DEEWR, FCHY could assist to develop employment policies to guide, encourage and support employers in engaging people effectively who have active care roles, especially those who care for a CaLD family with a disability. This is a necessary part of a National education campaign to employers regarding carers' needs in employment concerning flexibility of hours, etc.

Currently CaLD carers experience the fear of being discriminated against on both a racial and carer level if they dare to ask an employer for time off from work to take the individual they care for to appointments or cultural activity. They fear that employers will devalue their cultural beliefs and sense of work responsibility, and thereby their own value and standing as an employee and a human being.

On the other hand, working on the attitudes and values of ethnic communities is also required. Some CaLD carers fear that people in their own cultural community and others will be critical in the sense of seeing them as not fully and responsibly committed to their culturally assigned family carer role, should they seek to engage in employment or other social activities.

3. Income support.

On their low carer support income, and in a context of chronic migrant under employment as mentioned, CaLD family carers have considerable difficulty accumulating sufficient financial assets to purchase equipment, home modification, etc. to adequately cater for the family member they care for, especially when faced with the prospects of their own ageing. Apart from adequate carer remuneration, CaLD carer income support could help alleviate their poverty and concern.

The last thing anyone wants is for CaLD carers to be forced out or into paid employment to an extent that compromises the quality of care they provide and puts the person under their care at risk of neglect (Refer: the new National Standard 9 of the Disability Services Standards WA 'Human Rights: Freedom from Abuse and Neglect').

4. Getting carer support information out into ethnic communities.

On many occasions CaLD carers have also reported that they are not obtaining appropriate information regarding available support services, social activities or employment support, so they cannot make informed choices and decisions about possibilities of engaging in employment or other activities.

Carer support information available to the general Australian community needs to be disseminated among the usual resources utilized by CaLD communities such as ethnic radio, specific cultural organisations or ethnic specific businesses and newspapers.

Translated information that is disseminated amongst these communities would not only help CaLD carers learn about social options and services but would also enable their ethnic communities to learn how Australian society respects and values a person with a disability and the role of the CaLD disability carer.

5. Accessing English language classes.

CaLD carers who can't speak English have also reported that they would like to take classes to learn English. These carers have recognised the value of greater participate in the general Australian society and how English skills would open opportunities for them to access more employment and social activity options. However many find the constant demand of their caring role prevents them from accessing English lessons.

Others have also expressed the need for progressively higher levels of language development support while they are in employment, otherwise the basic survival level of migrant English support that is available effectively condemns them to the long-term under-employment status that is so much of an ongoing burden for the CaLD population. This is even more critical when it is recognised they have the need for income generation to effectively provide for quality care of their family member with a disability.

6. Expanding the range of support services to CaLD carers - apart from facilitating CaLD carers into social and economic participation, for their overall wellbeing they also need access to respite, support to engage in language and education programs, access to recreational activities, and support and incentives to maintain their health in what they experience frequently as a very demanding and all-consuming responsibility.

7. Providing carer respite through addressing the shortage of family and paid carers. Many CaLD migrants, particularly those coming on humanitarian visas as refugees, are not accompanied by their extended families who can share the care of a member with a disability. Also many women come (e.g. Somalian), with a number of children, whose husbands have been killed in the many conflicts they are fleeing. They have greater responsibility but also very limited resources of care support.

Currently there is also a shortage of paid carers. In particular it is difficult for CaLD families to find carers who have had any training to understand, value and respect others with diverse cultural/religious beliefs and practices.

Many of these carers have felt they have no options for respite, and no support, to pursue social or employment opportunities. Some of these carers have even tried to obtain visas for family members or close family friends to assist with this caring role but find that due to the strict limitations for carers to obtain visas that this strategy isn't a viable option, causing them to further feel this as systemic discrimination. If the Australian government was to reduce the criteria for carers to sponsor someone to migrate to Australia as a carer this would provide more CaLD carers with the opportunity to access social activities and pursue employment.

8. Disability transport.

Another major ongoing barrier for CaLD carers accessing employment and social opportunities is their inability to obtain suitable transport for themselves and the person they are caring for. Many CaLD carers are females who generally don't drive in their country of origin. This task was traditionally upheld by the males in the family, primarily the husband, father, brothers or sons. Generally these carers also would find that they could access their everyday needs outside the home within short walking distance. In metropolitan Australia many resources are not within walking distance and require public or private transportation to get there. Without a driving licence many carers need to rely on public transport that can be either expensive if taking a taxi or quite difficult when transporting a person with a disability on trains or buses, especially in an unfamiliar environment. Carers require better transport options and training on how to use the public transport system.

KEY PRIORITIES FOR ACTION

RECOMMENDATION 1

Engage in developing an improved legislative and policy framework for carers.

- a) Support the introduction of a National Carer Legislation. Link to the provisions of the Disability Services Act and promote the support of CaLD carers within the Disability Services Standards and the *CaLD Guidelines to the Disability Services Standards* developed by EDAC in 2006 (available at www.edac.org.au).
- b) Support the development of a National contemporary multicultural policy and a review of the WA Multiculturalism Charter, and link likewise to the Carer Recognition Act (WA).
- c) Implement and extend the Substantive Equity Policy of the WA government as currently pursued within the Disability Services Commission to CaLD carers.

RECOMMENDATION 2

Promote and support CaLD disability leadership in care.

- a) Develop strategies for progressively developing effective leadership by CaLD people with disabilities and their families/carers in all FCHY CaLD/disability care employment and program initiatives at all levels.
- b) Ensure these and CaLD disability carer representatives on FCHY consultation committees are persons actively engaged and broadly accepted in representation of CaLD disability care from various ethnic backgrounds.
- c) Utilizing a community development framework, financially supporting CaLD communities to take care initiatives such as setting up their culture-specific respite centres i.e. provide government support for community leadership initiative projects that enable small and large CaLD communities to obtain set-up and sustainable funding to support their carers.
- d) Develop strategically planned initiatives to reduce the systemic discrimination causing the serious implementation gap in the access of services by CaLD people with disabilities and their families/carers - by resourcing user designed, delivered, managed and monitored CaLD carer support services.

RECOMMENDATION 3

Recognise, promote and support the valued status of CaLD family carers.

- a) Provide better remuneration for all carers (paid and family) with specific emphasis on family carers.

- b) Facilitate easier access for carers to benefits such as the carers allowance, tax exemption, and trustee services.
- c) Negotiate with Immigration to ease the criteria for family, community and other carers to migrate.
- d) Promote recognition of the important role of CaLD carers in the ethnic communities, recognising their skills and contribution, particularly in supporting the people they care for and assisting their independence and valued inclusion in their communities.
- e) Encourage the employment of bi-lingual/ bi-cultural carers in the disability carer industry as they bring to an organisation not only the advantages of their language skills but also cultural competency as well, integrated with their skills, knowledge and experience in the application of disability care in a cultural environment.

RECOMMENDATION 4

Provide for CaLD/disability training for all government and non-government agencies funded by FCHY, encouraging care services to include carers of CaLD people with disabilities and to demonstrably meet cultural aspects of care standards as part of their funding agreements, standards and quality monitoring.

On the basis of the necessary improvement in each of the above to enable CaLD carers to consider accessing employment and social activities -

RECOMMENDATION 5

Promote valued inclusion, opportunity, support and flexibility of choice for CaLD carers regarding engaging in employment and social activities, balanced with meeting their CaLD carer role responsibilities - both in the wider community, among employers, and within the multicultural ethnic communities themselves.

Include opportunities for support to develop planned shared care and transitional care arrangements for both themselves as carers and for those being cared for, to help carers plan to engage in increased opportunities for employment and community activity.

5. STRATEGIES TO ASSIST CARERS TO ACCESS THE SAME RANGE OF OPPORTUNITIES AND CHOICES AS THE WIDER COMMUNITY, INCLUDING STRATEGIES TO INCREASE THE CAPACITY FOR CARERS TO MAKE CHOICES WITHIN THEIR CARING ROLES, TRANSITION INTO AND OUT OF CARING, AND EFFECTIVELY PLAN FOR THE FUTURE.

Wider strategies to encompass the above recommendations and progress their integrated and effectively planned achievement:

STRATEGY 1. Care legislation initiatives

That FCHY initiate and support National Legislation and a Strategic Plan for Carers that explicitly recognises the special role and support needs of carers for people with disabilities and also mandates provision for cultural care. This would include necessary linkage of these aspects of the proposed legislation to the new UN Convention on the Rights of People with Disabilities, with Australia's Disability Services Legislation, and with proposed National recovery of multicultural policy - with provision for associated subsequent review by the States of their Carer Recognition legislation.

That FCHY proposes the review of the State Carer Recognition legislation in the meantime, to explicitly include disabilities and cultural care, and mutually supportively link to the Disability Services Act and the WA Charter of Multiculturalism (for revision, strengthening and upgrading to an effective contemporary multiculturalism policy).

STRATEGY 2. Disability and cultural leadership in care provision

That FCHY develops a strategy of disability and cultural leadership in all affairs at all levels affecting people with disability and those of CaLD background, including the provision of care.

That this strategy includes a range of leadership, capacity-building and information, promotion and support measures as suggested.

That FCHY promotes its leadership in this matter, across sectors, with a view to encouraging other government services to do likewise.

That FCHY explicitly identify disability and CaLD/disability care service needs and prioritise provision of funding in its tendering to support the development of independent culturally based care agencies and services.

STRATEGY 3. Integrated strategic planning of CaLD disability carer initiatives.

That FCHY recognise the range of specific recommendations made here on behalf of the CaLD disability sector and engage with them to facilitate the development of

significant improvements to finally begin to close the gap in CaLD/disability carer support uptake.

CONCLUSION

Including culture and disability explicitly in carer legislation is a necessary first step. Articulating the rights of CaLD/disability carers under the Carers Recognition Act with culturally responsive strategies will provide the basis for developing provisions of engagement and support for CaLD carers.

To be effective in producing these outcomes the legislation must be supported by linkage to broader **cultural and disability policies**.

Disability and culturally informed carer practices must then follow as the key ingredient to actually effectively engaging the CaLD/disability carer population. Targeted practical and accountable strategies can enable policy implementation beyond a non-active politically correct rhetoric that hides persisting neo-colonial mainstream control over the lives of people who make up much of the richness of our multicultural population.

Promoting CaLD/disability leadership in achieving each of these stages is essential to wind back the systemic discrimination of mainstreaming that is causing the persisting levels of service access inequity that have for far too long continued to entrench the disadvantage of CaLD people with disabilities and their families/carers.

REFERENCE

Supporting CaLD Carers EDAC 2003 www.edac.org.au.