

SUBMISSION

to the

**REVIEW OF THE CARERS RECOGNITION ACT
2004**

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REVIEW OF THE CARERS REGOGNITION ACT 2004

Thank you for the opportunity to provide a response to the Review of the Carers' Recognition Act 2004.

We are pleased to do so on behalf of families and carers from culturally and linguistically diverse (CaLD) backgrounds who are caring for someone with disability.

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/carers. It is the WA member of the National Ethnic Disability Association (NEDA).

OUR RESPONSE: WITHIN THE TERMS OF REFERENCE OF THE REVIEW

1) On the operation and effectiveness of the Carers Recognition Act 2004 with regard to its objectives of:

a) recognising the role of carers in the community

Family carers are an extremely valuable resource to the Australian society as they play a very important role in providing support to people with disability in their homes and communities. They also take on many 'professional' roles such as health care nursing, life coaches/counsellors and educators, social facilitators, negotiators and advocates, care managers, futures planners, etc. They frequently take on the caring role with cultural understanding, with minimal complaint and attend to the needs of the individual with love and compassion, qualities that are understandably rarer among non-family paid carers.

They are the main care givers and the 'providers of choice' especially so in CaLD communities. As well as assisting with disability-related communication difficulties, CaLD carers may be required to be interpreters for a person with limited English skills, such as during appointments. They also need to be translators to help assist the CaLD person with disability to access information, fill out forms and write letters. They also need to continually monitor all types of care assistance the CaLD person with a disability obtains, to ensure that it is of a nature that is consistent with their specific cultural or religious practices.

But it is our concern that the role of CaLD family carers are not sufficiently recognized in their own cultural communities as well as in the general community. They are under represented and not adequately included or supported within the carer service system at State and National levels.

We acknowledge many CaLD carers would feel reticent to engage with the sector due to cultural and language reasons. But we believe that central to the ongoing nature of this problem is the lack of opportunity for leadership and meaningful engagement and input of CaLD family carers into carer matters at all levels.

EDAC recently made a submission to the ***Inquiry into Better Support for Carers*** conducted by The House of Representatives Standing Committee on Family, Community, Housing and Youth (FCHY) (July 2008). As indicated, there are about 2.6m carers in Australia and among them is considerable cultural diversity - 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 (formerly known as NESB - Non-English Speaking Background) (ABS 2003/4). This cultural diversity is reflective of carers in Australia across all sectors, ageing, mental health and disability.

Critical areas for recognition under the Act:

- **Firstly, there is not adequate explicit recognition of CaLD family carers** - not for all these and the many other duties that family carers provide in this multiple and skilled culturally appropriate care for a CaLD person with a disability.
- **Secondly, there is insufficient recognition of the culturally appropriate support that needs to be available specifically for CaLD family carers** - requiring that there be explicit recognition of their special roles and contribution in the first place.
- **Thirdly, there is inadequate recognition of the need for inclusion of CaLD family carers in services.** Whilst the Carers Recognition Act is commendable as a first step in articulating and recognizing the important role of carers it falls short of achieving the most critically necessary outcome for all carers, but especially for CaLD family carers - which is to change the organizational culture, policies and practices of service providers so that CaLD carers are **included** in assessment, planning, the design and delivery of services and in their evaluation and review.

We are concerned that CaLD carers are not adequately represented at all levels in service organizations and at government levels in matters that

affect their lives and effectiveness and wellbeing as CaLD carers of people with disability.

- **Fourthly, explicit formal procedural recognition of CaLD carer leadership in the affairs of CaLD disability care is an essential ethical and practical requirement to begin to achieve outcomes that address the wellbeing of CaLD carers.**
- **Finally, this must be accompanied by recognition of the special capacity building and support needs necessary to achieve both inclusion and leadership by CaLD family carers in CaLD disability care matters and substantive equality of care for CaLD people with disabilities.**

b) providing a mechanism for the involvement of carers in the provision of services that impact on carers and the role of carers;

As indicated above, 'involvement' of carers, and of CaLD carers of people with disability in particular, needs to explicitly include as mandatory:

- ✓ inclusion of CaLD family carers in all matters and all aspects of services that affect them and CaLD people with disabilities;
- ✓ that this inclusion also involve them in leadership in all such matters; and
- ✓ that provision be made for the necessary capacity-building and support to enable CaLD family carers to exercise well-informed and skilled contribution to the design, development, delivery and evaluation of all aspects of all services for CaLD family carers of people with disability, and also for them to provide quality leadership on all CaLD family disability care matters.

The first requirement then is for the need for involvement to be recognized explicitly within the Act.

The second requirement is for the nature of this involvement to be specified as above, in terms of inclusion and leadership.

The third requirement is for the Act to mandate resourcing the capacity to progressively achieve that involvement in those ways.

Finally, the Act requires the development of mechanisms that can facilitate the setting of explicit goals in regard to each of these requirements and to monitor demonstrable progressive achievement of key outcomes, linking this to funding

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contracts for the provision of carer services and to Quality service reviews (Continuous Quality Improvement: CQI) and regular Standards monitoring.

2) on the effectiveness of the operations of the Carers Advisory Council and the need for the continuation of the functions of the Council;

- ✓ There is an issue with the cost-neutral nature of the resources and initiatives to be administered by the Carer Advisory Council. It is recommended that the Act make provision for positive resourcing, such as
 - Information material such as pamphlets to be made available in translations suitable for CaLD carers,
 - hard copies be made available not just on websites and
 - research studies and pilot projects. For example, exploring the availability of bi lingual and bi cultural support worker for the sector.

2) other matters relevant to the operation and effectiveness of this Act, including but not limited to:

a) the issue of defining compliance

- ✓ Compliance, as suggested for the above initiatives (1b) and those below to be taken up by agencies, will need to be mandated within funding contracts and Quality and Standards reporting.

b) the development of a prescribed method of publication of reports from reporting organisations as required under Section 7 (4) of the Act;

- ✓ Reporting under the Act needs to identify carer services by categories such as disability, CaLD carers, Aboriginality, etc.
- ✓ This is necessary to enable progress to be reported within each of those specific target groups, such as CaLD carers of people with disabilities, in each of the areas for which explicit recommendations have been made above - culturally appropriate carer support, inclusion, leadership and capacity building.
- ✓ For this to be possible, all disability and health funded agencies would need to include culture and disability/health identifiers in their data bases and report using those categories. It will need to be specified within funding contracts and Quality and Standards reporting.

c) the need to develop any other Regulations; and

d) advancing the State Government's aim to change the culture of service

Producing real, equitable and sustainable outcomes for CaLD carers of people with disabilities: enabling diversity of carer needs to be adequately addressed under the direction, guidance and control of carers.

- ✓ This intention, requirement and expectation to improve the culture of service provision needs to be made quite explicit in the Act. As mentioned above (1a) for CaLD carers this is a key objective - constructive developmental shift in the culture of service provision is seen as absolutely necessary.
- ✓ For any cultural shift to occur we recommend:
 - A set of guiding **Principles** as precursor to specifying specific requirements. For CaLD family carers of people with disabilities, and others, we suggest that multiculturalism, diversity, substantive equality, inclusion, valued status and leadership are critical requirements.
 - The Act has to some extent linked **associated legislation** that it expects care service providers to operate within matters under this Act but the objectives for supporting carers are not explicitly stated. For CaLD carers of people with disability, we suggest that the Multicultural Charter and Substantive Equality Framework be included.
- ✓ The Act also needs to mandate explicit enabling mechanisms, resourcing and monitoring that will bring this cultural change into effect. Above we have mentioned those that are critical for the CaLD family carers of people with disability - culturally appropriate support services, inclusion and leadership. These follow from our research and extensive experience as being essential base requirements for changing organizational culture of services to enable the diversity of carer needs to be adequately addressed under the direction, guidance and control of those concerned.

Specifically, agencies themselves need to develop skills in,

- understanding consumer populations for those with special needs, such as CaLD family carers ;

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- creating culturally appropriate support networks and groups/activities for them;
 - developing and providing training for participation and inclusion - such as understanding, confidence and skills associated with meetings, workshops, input into service design, delivery and evaluation, informed and effective consumer input into service reviews, research, projects and initiatives;
 - leadership training in - developing familiarity with legislative, policy and practice frameworks; collaborative networking and partnership with stakeholders; working inclusively with consumer constituencies to provide needs analysis and strategic directions for planning programs and services; ongoing evaluation, and project management, etc.
- ✓ There is also a need to explicitly mention and target demonstrably improved outcomes for carer groups with special needs, such as specifying CaLD carers of people with disabilities, as being those for whom inclusion and leadership development is essential, - to break the mainstreaming hold that services have been encouraged to adopt, that continues to compromise satisfactory levels of service access, satisfaction and outcomes - so that diversity of needs is adequately addressed under the direction, guidance and control of those concerned.
- ✓ "Hidden CaLD carers" is a major factor and problem among carers' service agencies and support groups. We suggest greater encouragement, consultation and meaningful involvement with CaLD Carers and the ethnic communities to find a satisfactory solution.

It is our experience that the fundamental issue relates also to the poor service uptake of CaLD people with disabilities, which we have documented and previously made recommendations (e.g. EDAC submission to the *Sector Health Check: Disability Services Commission 2007*).

The key factor seems to be the cultural inappropriateness of mainstream services due to lack of inclusion and leadership of CaLD carers. The recommendations we make in this submission to the Review of the Carers Recognition Act follow from our consultations, research and experience as peak advocacy service provider to CaLD people with disabilities and their families/carers and communities. Consultations, engagement, valued inclusion and leadership needs to be resourced not only through training, as mentioned above, but also by:

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- Initiatives designed to reach CaLD carers of people with disabilities in their families, cultural communities and wider society; and
 - determining the types of culturally and community supported representation that CaLD carers need so as to be informed, confident and culturally accepted to speak on behalf of those they represent. Experience suggests an ongoing working committee is a desirable and necessary support mechanism for a CaLD representative in many instances. The administrators of the Act need to recognize these requirements, encourage their use and commit resources to enable agencies and their CaLD carer representatives to do so.
- ✓ Other issues that we would like to raise for the Review are:
- In implementing the provisions of the Act it is important to determine and measure the effectiveness of the provisions and initiatives for carers, especially for CaLD carers of people with disabilities.
 - Membership of the Carers Advisory Council - currently 10 members - we suggest that 2 be CaLD and 2 Aboriginal, or provision be made for an ongoing working committee to support each.
 - The Carers Charter:
 - is too abstract - it needs to be more user-friendly; and
 - for CaLD Carers it needs to be available in various community languages and reflective of our multicultural society.
 - Staffing – to provide the direction and support that the carers Recognition Act warrants to be effectively implemented in the population, consideration needs to be given to increasing the staffing of the Carers Advisory Council.
 - Budget - similarly, to realistically expect the Carers Recognition Act to make the differences in the carer services sector that are discussed, especially the landmark initiative to change the organizational culture of carer services, there is going to also need to be a significant funding commitment within the provisions of the Act this time around.

References:

Supporting CaLD Carers – addressing their service needs, EDAC 2003
www.edac.org.au.
Sector Health Check Submission EDAC 2007 www.edac.org.au
Inquiry into Better Support for Carers EDAC 2008 www.edac.org.au