



DISABILITY SECTOR HEALTH CHECK

**Submission
by**

ETHNIC DISABILITY ADVOCACY CENTRE

October 2006

The Ethnic Disability Advocacy Centre (EDAC) is an established community based advocacy organisation representing the rights and interests of people with disabilities from culturally and linguistically diverse backgrounds (CaLD) and their families.

SUBMISSION TO THE DISABILITY SERVICES SECTOR HEALTH CHECK

EDAC appreciates the opportunity to provide an evaluative response to the Sector Health Check, to appraise the present situation and to guide current and future directions.

Since the Ethnic Disability Advocacy Centre (EDAC) is a community based advocacy organisation representing the rights and interests of people with disabilities from culturally and linguistically diverse backgrounds (CaLD) and their families - we take responsibility here particularly to consider the efficiency and effectiveness of both disability services and advocacy in meeting the needs and aspirations of CaLD people with disabilities and their families.

The main concerns and suggestions we make, within the survey framework, are that for people with disabilities from CaLD backgrounds, cultural/family roles require explicit, practical and informed inclusion in the overall approach to disability services and case-work. This differs to the individual independence and social roles model that currently operate. Mainstreaming as a services ideology is not effective and is contrary to fundamental human rights, including the inclusion of one's culture within all aspects of life.

This has been readily apparent from our considerable and successful experience of 10 years working to address difficulties in disability services and towards obtaining effective and substantive equality of outcomes for CaLD people. That is, that services require being culturally responsive in the sense of working with them *as CaLD people*, respecting and including centrally in all aspects of service design and delivery, their cultural values, ways and understanding. The cost of service access should not be one-way assimilation. Explicitly, if not implicitly, that is thankfully a rejected policy of an unfortunately racialised past.

Nor is the situation an either-or binary divide. Cultural relations are naturally dynamic and subject to a constantly ongoing process of flexibly negotiated change and influence both ways. This involves protecting core values and practices integral to preserving cultural identity and psychosocial wellbeing of all concerned.

The complexity of the many different cultural backgrounds and the wide range of changing cultural exchange and mutual adaptation and influence that makes up the valued richness of contemporary Australian multicultural society must be considered. Working effectively with this dual aspect of cultural diversity must be a key aspect of all services, including those for people with disabilities. It is known to affect readiness to access services, the effectiveness of outcomes, and consumer satisfaction.

The main problem in disability services for CaLD people is the identified serious and concerning gap between the 14% of people with disability who are of CaLD background and only 2.5% who access disability services. Incorporating cultural diversity in service design and delivery, from our consumer research and experience, is the solution.

It is argued that this is a necessary interpretation of the WA Charter of Multiculturalism and of the key objective of Inclusion in the WA Citizenship Strategy – both of which we have promoted as necessary policy frameworks to the Disability Service Standards to clarify the cultural rights aspect of its overall human rights approach. We have worked with CaLD consumers with disabilities and their carers to produce practical guidelines to assist disability services agencies to work with CaLD clients in these ways (*CaLD Perspectives on the Disability Services Standards 2006*).

1. A comparison of the Commission with other comparable government departments and other disability systems.

As a member of the Disability Coalition of WA, EDAC has contributed to a joint response on this item.

2. Examination of growth in funding since 2001 and its effectiveness of application to the Commission and also non government organisations.

Similarly, EDAC has contributed to the response by the Disability Coalition of WA on the effectiveness of growth funding to the Commission and NGOs. Here EDAC takes the opportunity to comment independently as an agency example.

Firstly, EDAC has had some increase in its funding since 2001 from DSC for individual advocacy. This has been limited, however in comparison to the significant and sustained increase of funding to DSC over the past 10 years. In this respect, EDAC is part of the general situation experienced by other disability service agencies in receiving only a small part of the overall increase to DSC. It appears that most of the increase has been retained for developments within DSC itself and has not flowed on to agencies. These agencies continue to struggle to meet service demand.

EDAC's core funding for example, is able to maintain executive, administrative and client service staff only on a part-time basis. Project funding is short-term and development activities rely to a significant degree on unfunded professional support. Funding levels affect continuity of NGO staffing and staff development. It also puts serious strain on the capacity of organisations such as EDAC to continuously play an active role in sector activities directly and in collaboration with other providers. Furthermore, it also limits EDAC's capacity to keep its own constituents (consumers, carers and stakeholders) active inclusively in all aspects of its organization. These factors are both vital for the sector to maintain healthy processes and quality status of operations and services. Overall the

imbalance of funding between DSC and service providers compromises the consumer-driven component of sector policy and practice.

The Health Check process itself is an example. The Health Check process may provide some initial indications that are valuable. The absence, however, of independent review compromises its effectiveness. A broader, independent panel is also believed to be more effective. Critical response can not be guaranteed from service provider agencies funded by DSC in this competitive subsistence funding environment.

Also, the response time and resourcing has not provided for non-government and community based agencies to:

- consult their constituents to provide input and validate agency comment, which is required due process and accepted best practice to represent consumer interests and views; and
- mobilise their always stretched agency resources to investigate the issues sufficiently so as to provide valid and useful responses based on collated and reviewed agency data;
- liaise effectively on the basis of both of the above, with other NGOs within the state and elsewhere, to provide substantive responses to the issues.

Secondly, on top of this general condition of NGO service providers in the disability sector, of which EDAC is one unique and vital component - there is a serious persistent gap in service uptake for CaLD people with disabilities. This was identified and reported to DSC some time ago (*EDAC Carers Project*). It is of concern that in addition to the current unmet need for people with disability in general, the participation rate in disability services of people with disability from CaLD backgrounds does not reflect that of the general population.

In terms of *substantive equality* there is therefore a *special need* for much improved resourcing in the CaLD disability sector to develop initiatives to bring the use of disability services by CaLD people into line with service use by the general population. Consequently, our conclusion must be that growth funding since 2001 has not been effective in improving service access for CaLD people with disabilities. This remains a priority concern that is still to be addressed.

EDAC is the only dedicated agency in WA providing individual advocacy for CaLD people with disabilities. As such it is part of the urgent need to address the service uptake gap by CaLD people with disabilities across all areas of disability services. Most importantly, however, EDAC is positioned as the most appropriate agency to provide the necessary leadership, experience and skills to assist the disability services sector as a whole to address this gap across all areas.

To achieve this there are three necessary interrelated components for EDAC:

- *individual advocacy,*
- *systemic advocacy,*

- *training.*

A significant commitment to funding of these components is essential to make any substantial inroads and to reduce the identified services gap.

To date, EDAC has continued to work to its current capacity on individual and systemic advocacy. EDAC has also taken the initiative to begin to help address the gap across the sector by strategic use of project funding. This has been used to develop practical tools and training available to all agencies in order to enhance their capacity to attract and work effectively with CaLD people with disabilities. EDAC has also worked with ethnic communities on disability awareness, service availability, and their inclusion in service design and delivery.

To achieve *substantive equality* in services for CaLD people with disabilities across the sector, consideration should be given to further resourcing EDAC. This would enable EDAC to significantly increase its capacity in all three aspects of its operations: individual advocacy, systemic advocacy and training.

3. Examination of new service improvements – efficiencies, changes in function and new initiatives since 2001.

The ability of EDAC to increasingly access specific project funding from a wide range of other sources and the availability of DSC Service Improvement Grants, has enabled the development of creative applications with CaLD consumers, carers, ethnic communities and service providers.

Examples of these (documented in EDAC Annual Reports and on the website for all others to access) include:

- ✓ CaLD Perspectives on the Disability Services Standards
- ✓ Establishing CaLD Carers groups from the EDAC Carers Report
- ✓ Self Advocacy for CaLD people with disabilities
- ✓ Developing a CaLD Consumers Group and capacity-building
- ✓ Ethnic Radio Program by/for CaLD people with disabilities.

Project funding has also enabled significant research and development. This has provided the beginnings of disability services innovations applicable across the sector for CaLD people and their families.

4. Examination of service improvements – effectiveness and changes in functions *still to be made.*

As indicated above, the CaLD disability sector urgently needs innovative development that will be effective in addressing the gap in services uptake for CaLD people with disabilities.

From its experience and research, EDAC and the CaLD disability sector have together strategically identified the barriers and developed the beginnings of initiatives to progress toward effective solutions.

This now requires commitment and resourcing in order to pursue these to full implementation. Specifically, for training to facilitate sector uptake and, importantly, for supported implementation to bridge the traditional gap between training and achieving actual demonstrable service improvements.

5. Examples of best practice since 2001 (both service and corporate).

EDAC is positioned and experienced as the lead agency in developing best practice initiatives for CaLD people with disabilities. The individual projects listed above are integral parts of a broader need to develop for the sector as a whole:

- an improved overall service model for CaLD people with disabilities, and also
- an improved model for advocacy.

To adequately, ethically and effectively engage and produce results for the CaLD population with disabilities, there is a need to incorporate and build on the significant contemporary developments in the cultural inclusion aspects of human rights, multicultural policy and citizenship. This is through developing guidelines for its practical implementation throughout all aspects of services to support the sector's disability services standards and quality processes. Similarly, there is a need to encourage and resource the promotion, prevention and early intervention principles of primary health care for disability services throughout the sector and to enable practice approaches that facilitate holistic health and wellbeing.

EDAC is the only advocacy agency suitable for CaLD people with disabilities, in terms of addressing the complexities of cultural responsiveness of information, access, service design and delivery, and producing holistic, effective and sustainable outcomes that meet with high levels of consumer satisfaction. In operation since 1995, EDAC has been and is the only multicultural disability agency in WA that provides an independent and quality advocacy service for this target population.

This gap highlights the priority need to sustain and enhance both the individual advocacy and systemic advocacy, and the training support provided by EDAC – with initiatives to bring together both the ethnic communities and service provider organizations to develop, provide and promote and access culturally responsive services.

That is, for EDAC

- to continue to provide individual advocacy,

- to continue to develop its systemic advocacy, in terms of direct systemic advocacy generally for CaLD people with disabilities,
- to continue its project development initiatives,
- to continue training, both working with ethnic communities on disability awareness toward improving their access to disability services, and, assisting agencies throughout the disability services sector to improve their cultural responsiveness capabilities.

EDAC's philosophy is that by working cohesively together, the CaLD disability services gap can be addressed. This can only be achieved, however, by introducing culturally appropriate ways through all aspects of services. EDAC, from its considerable experience, together with its consumers, carers and stakeholders, is convinced that this is the approach necessary to lead to service equity and effective and sustainable outcomes.

In terms of moving towards best practice for CaLD people with disabilities, there are issues in the sector that need to be addressed. Some of these are listed in brief below.

Complementing mainstreaming with culturally responsive services.

From EDAC's experience, mainstream disability agencies are generally not culturally responsive and many require extensive and intensive work in order to become more culturally competent. EDAC believes that greater emphasis needs to be placed on achieving cultural competence in mainstream disability agencies.

With appropriate increase in individual and systemic advocacy funding, supported by significant resourcing for project development and training, EDAC believes that it can build on its initial achievements and provide for the necessary leadership required to provide more culturally responsive services.

Improving the funding base for NGOs to provide CaLD client services.

Currently EDAC, for example, is only funded by DSC to provide individual advocacy services to 100 clients a year yet the number of people with disabilities from CaLD backgrounds in Western Australia is estimated to be considerable. Its systemic funding from the Commonwealth is seriously over-stretched and project and training funding is ad hoc.

Consumer choice of culturally responsive services for CaLD people with disabilities

EDAC believes that it is necessary for it to continue to be a specialized service of this nature. This allows choice by CaLD consumers of a culture-based disability advocacy service. In addition, EDAC can exercise leadership in developments for CaLD consumers in the disability sector. It believes that all agencies require capacity for cultural responsiveness through policy and procedures, CaLD staffing and training.

Research including CaLD people with disabilities

EDAC also believes that there is insufficient research funding allocated in the area of CaLD people with disabilities and that further research is necessary in order to determine how to best service CaLD people with disabilities.

Disability capability in Migrant Services

EDAC receives considerable client intake from other providers in the disability sector due to their incapacity to adequately manage services for CaLD people. EDAC considers that these instances provide indications of valuable possibilities for sector improvements. For example, as EDAC is currently the only advocacy agency in Western Australia that provides services for people with disabilities, and the scope of our work is quite extensive, the inability of the various migrant services to assist people with disabilities results in significant referral to EDAC. Migrant services could be enhanced by including services for people with disabilities within its culturally responsive approach.

Comparative funding for people with disabilities from CaLD backgrounds

EDAC is concerned that people with disabilities from CaLD backgrounds continue to be severely under-represented within State funded services. EDAC recommends that equitable funding target CaLD people with disabilities. EDAC would also like to seek clarification of how much of the \$300M state disability funding is allocated towards CaLD specific services.

Substantive equality for people with disabilities from CaLD backgrounds

EDAC believes that the Sector needs to place greater emphasis on achieving substantive equality for people with disabilities from CaLD backgrounds. The predominant issue for people from CaLD backgrounds with a disability is the lack of access to services that effectively meet their needs. As mentioned previously, there is the lack of cultural competence in “mainstream” disability services. This leads to a lack of ability and willingness to accommodate linguistic and cultural diversity in “mainstream” services. The rhetoric of *inclusion* is not translated into practice in service provision.

The current system has not adopted some of the most basic mechanisms to ensure access and equity for people from CaLD backgrounds, such as the use of interpreters or publication of material in languages other than English. This is a very concerning situation that must be addressed as a matter of priority. It should also be noted that this is in contradiction to the Equal Opportunity Act, the Commonwealth Disability Discrimination Act, Racial Discrimination Act, Disability Services Act (DSA) and the WA Multiculturalism Charter of the Public Service.

Increased emphasis on systemic advocacy

The 2003/2004 financial year saw the first recurrent funding increase to Advocacy in more than a decade. This funding was very welcome and ensured CaLD people with disabilities gained greater access to independent individual advocacy.

It remains of concern to EDAC that it is not funded for systemic advocacy by DSC and that there has been no increase to systemic advocacy services for more than 12 years in WA. This lack of funding prevents the addressing of long term systemic issues that impact negatively on people with disabilities and their families. Instead, it requires advocacy agencies to focus on addressing these broad systemic problems on an individual case by case basis. It is essential that any assessment of the effectiveness of advocacy acknowledges and addresses the unmet need for systemic advocacy.

Increased systemic advocacy for CaLD people in particular is important as many are not aware of services.

Need for an improved model of advocacy

Levels of advocacy funding have tended to reduce both individual and systemic advocacy services to operating on a reactive crisis model. As indicated earlier, more adequate resourcing is needed to allow more positive and pro-active promotion, prevention and early intervention function for advocating on the behalf of consumers. This is especially true in the case of CaLD people with disabilities and their families and communities. This has advantages not just ethically in terms of improved duty of care but in the medium to longer term to begin to reduce levels of service demand and costs.

Building self-advocacy capacity building into case-work approaches and consultation

Language support and facilitating cross-cultural information and understanding are key components of case-work with CaLD clients. Even more important is the capability to work with the strengths of the client's culture and care processes as central to service support. Within this, positioning the client as the chief decision maker, relative to capability, with negotiated support by others along lines of cultural care responsibilities, requires capacity building for self-advocacy with clients. Similarly, consumers and carers in the CaLD sector also require skills development in representation skills. EDAC has initiated and successfully completed projects on both of these issues and is keen to assist agencies across the sector to take advantage in employing these initiatives for CaLD people in their own operations and consumer groups.

Further services required for carers from CaLD backgrounds

EDAC also believes that an improvement in services is required for carers from CaLD backgrounds. Poor access to interpreters and lack of information in appropriate community languages has adverse effects on carers from CaLD backgrounds. Of particular concern is that CaLD carers can be prevented from accessing services that can help support the needs of the people they care for, including respite care. Carers therefore have less opportunity to develop their own, personal, social or professional capabilities. This then affects the quality of the support and advocacy they are able to provide, resulting in people from CaLD

backgrounds with disabilities, their families and carers, being isolated from decision-making processes.

Training for Local Area Coordinators (LACs)

EDAC has some concerns with the Social Role Valorisation (SRV) that is the foundation for training new LACs. EDAC is concerned that it appears that LACs are not exposed to SRV in the context of other theories and best practice, rather it is the only theory that forms their core training. EDAC is concerned that part of the training looks at what is valued and devalued by society and that some of the examples used are in respect to culture/ethnicity. We believe that SRV can thus perpetuate the exclusion of people from diverse backgrounds.

Furthermore, SRV asserts that it is more valued for a person with a disability to live independently. For many CaLD families it is not deemed to be culturally appropriate for their child to live on their own. The choice of the CaLD person with a disability should be respected in conjunction with input from the family so that the individual does not become socially isolated.

EDAC believes that there is a need for LACs and the disability sector to undertake training that is up to date. This should include SRV but it should be explored in the context of other current theories and with an examination of its weaknesses. Training on culturally appropriate responses to the disability standards is a further essential need for LACs.

Staffing of LAC district offices

EDAC believes that greater emphasis should be placed on analyzing the demographics of areas LACs are responsible for. In particular, assessment should be made to identify areas of high CaLD population and to ensure appropriate service is delivered. For example, information about DSC and LAC services should be provided in appropriate languages in these areas. EDAC is concerned that the majority of offices in areas of high CaLD populations have mostly Anglo staff. This can result in limited cultural competency and portray to the community that the skills and expertise of CaLD people are not as valued.

Staffing of DSC

EDAC is concerned that the staffing of DSC does not reflect the cultural diversity of people with disabilities. For example, there does not seem to be many Aboriginal staff employed by DSC yet it is estimated that the rates of disability in the Aboriginal community are double that of the rest of the population.

Of further concern is that DSC does not seem to employ many people with disabilities. EDAC believes that DSC should set an example to other government departments by increasing the quota of people with disabilities that they employ.

Contact Person for enquiries:

Tony Vardaro

President

Ethnic Disability Advocacy Centre

320 Rokeby Road

Subiaco WA 6008

Phone: 9388 7455

Fax: 9388 7433

Email: admin@edac.org.au

Website: www.edac.org.au