

Supporting CALD Carers

**The service needs of culturally and linguistically
diverse carers of people with disabilities**

February 2003

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ACKNOWLEDGEMENT

The Ethnic Disability Advocacy Centre wishes to express its gratitude to the many people and organisations who contributed their invaluable information, skills and expertise to this project. It would also like to acknowledge the Disability Services Commission for providing the funding which enabled this report to be undertaken.

The paper was researched and written by Eversely Ruth and Harry Pickett with support from the staff of EDAC: Jenny Au Yeong, Fiona Pui San Whittaker, Luba MacMaugh, Jasbir Mann and Veronica Fitzgerald. Their contributions were very much appreciated. Duc Dau kindly read and commented on drafts.

Members of the Steering Committee met at regular intervals to provide guidance and input. They included Dr Anne Atkinson (Chair), Jenny Au Yeong (EO, EDAC), Thankam Abraham (Carer) and David Colvin (LAC, DSC).

The Multicultural Carer's Support Group gave freely of their personal experiences and advice which helped to shape the report. The contributions of bi-cultural workers who worked alongside the researchers are also very much appreciated. These workers included Raqiya Hassan Ali (Somali Community), Maimunah Mosli (Muslim Women's Support Group), Anna Harrison (Polish Centre) and Sister Thai (Buddhist Temple). EDAC also wishes to thank Sophie Jasinski who interpreted and participated in community sessions.

EDAC is particularly grateful to all those carers and service providers who participated in the project and shared their stories. Without them, this report would not exist.

Thank you.

ACRONYMS

ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
ADEC	Action on Disability within Ethnic Communities, Victoria
AIHW	Australian Institute of Health and Welfare
CALD	Culturally and Linguistically Diverse
CSDA	Commonwealth/State Disability Agreement
DIMIA	Department of Immigration, Multicultural and Indigenous Affairs
DSC	Disability Services Commission
EDAC	Ethnic Disability Advocacy Centre
ECDN	Ethnic Communities Disability Network, Queensland
ESB	English Speaking Background
HACC	Home and Community Care
HREOC	Human Rights and Equal Opportunity Commission
MALSSA	Multicultural Advocacy and Liaison Service of SA
MDAA	Multicultural Disability Advocacy Association, NSW
NESB	Non-English Speaking Background
NEDA	National Ethnic Disability Alliance (members are MALSSA, MDAA, EDAC and ECDN)
OMI	Office of Multicultural Interests
OSB	Overseas Born
TIS	Translation and Interpreting Service

ABSTRACT

This research was funded by the Disability Services Commission (DSC), and was conducted by the Ethnic Disability Advocacy Centre (EDAC), Perth, WA, an independent non-government organisation. Its data was collected between July and December 2002 in metropolitan Perth as well as selected regional centres in the state.

By means of focus groups and individual interviews, the project consulted culturally and linguistically diverse (CALD) carers of people with disabilities. The project provides an insight into their views regarding barriers to service access and presents their suggestions on overcoming them. Their insights and suggestions were supplemented with those of service providers.

Carers consistently conceptualised their concerns and suggestions within a critique of the current service model for CALD people with disabilities. Outcomes suggest the need to revise disability and aged care policies, practices and priorities to make more explicit the service needs of CALD carers. Moreover, there is a need for more effective data collection to enable better planning of programs and allocation of resources. Outcomes also called for greater prioritisation of resources to ethnic communities to address issues for CALD carers and the people they are caring for.

Areas for collaborative development include appropriate information for CALD carers and communities on disability benefits and services, as well as a holistic and coordinated approach to services for consumers. This development relies on the enhanced flexibility of services, as well as networking between CALD community agencies, the Disability Services Commission and other service providers.

The recommendations of the project should assist a revision of government and non-government policies to implement more culturally appropriate strategies in disability services. The project should also assist in establishing disability support for CALD communities in consultation with carers.

EXECUTIVE SUMMARY

This report provides an overview of the experiences and suggestions of culturally and linguistically diverse (CALD) carers of people with disabilities regarding their access to health, aged care and disability services in WA. It also provides secondary viewpoints of service providers on the issues and difficulties faced by CALD consumers. Sixty-six (66) CALD Carers and thirty-seven (37) service providers took part in this study, in the form of focus groups and personal interviews.

The report is divided into 4 chapters: introduction, methodology, findings and discussion, recommendations and conclusion. In addition there are several tables exploring quantitative data and frameworks for integrated, culturally appropriate service provision.

Chapter 1 presents the introduction and outlines the objectives of the project. The literature review examines national and state research on needs of CALD carers and people with disabilities in the areas of health, childcare, respite, day-care and training. Papers on the multiple disadvantages of ethnicity and disability, and social stigma are reviewed. A range of legislation, policies and practices relating to disability and multiculturalism is also examined.

Chapter 2 explains the methodology guiding this qualitative research project. Existing statistical data was assessed and found problematic as agencies do not collect data that cross-references disability, ethnicity, language and locality. It was therefore difficult to accurately determine the true demand for services and evaluate the ability of agencies to address the needs of CALD carers adequately.

Numerous group consultations and one-to-one interviews with CALD carers and service providers were conducted in Perth, Kalgoorlie and Broome. CALD carers were consulted from a cross-section of established and emerging ethnic communities including Vietnamese, Polish, Indian, Chinese speaking and Muslim groups. The interviews targeted carers of children/adults with disabilities, carers of aged people with disabilities and relevant service providers.

Chapter 3 explores the findings of interviews with CALD carers of people with disabilities and associated service providers. CALD carers faced additional difficulties in caring compared to the mainstream community, including the lack of awareness and understanding of services; isolation; stigma; language barriers and loss of extended family support for secondary caring. Agencies also asserted that CALD communities understood caring for family members as a natural responsibility and were therefore less likely to seek external assistance or support.

The complexity of responding appropriately to the differences of various CALD carers with mainstream community and ethnic communities highlighted the need for a community development approach to planning, implementing and evaluating programs. CALD carers expressed a keen interest in developing support groups and initiatives to address their issues and the needs of family members with a disability.

Key issues identified by CALD carers:

- Families may be reluctant to acknowledge a disability exists, making them less likely to seek disability assessments and services;

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- Counselling and referral to appropriate disability support agencies are required to reduce anxiety and stress experienced by carers;
- Translated information and assistance is needed to understand and co-ordinate the range of services available;
- Development of care plans should include long-term issues, such as carers ageing and having to utilise increased external care;
- Carer support groups are important to enhance carers' knowledge of community resources and information;
- Professional interpreters are essential when working with NESB consumers; and
- The scarcity of services in regional centres does not allow carers to establish ongoing personalised service relationships.

Key findings from service providers:

- Ethnicity, language, disability and locality data are essential to identify those needing services;
- Stronger networks should be developed between agencies and ethnic communities, particularly in regional areas;
- Bicultural support workers and culturally appropriate care services should be allocated additional funding;
- Community education programs should be provided to ethnic communities on disability issues and services;
- Agencies require cultural awareness training to enable them to deliver sensitive and appropriate services; and
- The limited options in respite care were insufficient for CALD people with disabilities.

The last section provides a summary of recommendations that are developed from issues and concerns of CALD carers and service providers. They have the potential to address the cultural and linguistic needs of the target group as well as providing a good foundation for the establishment of quality management plans for service providers. More importantly, they address the access and equity commitment of current disability legislative obligation and policies of both government and non-government sectors for the disability and multicultural sectors.

RECOMMENDATION 1: TO IMPROVE DATA COLLECTION OF CALD CARERS AND PEOPLE WITH DISABILITIES

RECOMMENDATION 2: TO EXPLICITLY INCLUDE CALD PEOPLE WITH DISABILITIES AND THEIR CARERS IN POLICIES AND PRACTICES

RECOMMENDATION 3: TO INCREASE CALD ACCESS AND OUTCOMES IN DISABILITY SERVICES.

RECOMMENDATION 4: TO DEVELOP CULTURALLY APPROPRIATE PROJECTS WHICH ARE INITIATED AND DIRECTED BY CALD CARERS AND COMMUNITIES.

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- RECOMMENDATION 5: TO REVIEW THE PROVISION AND COORDINATION OF SERVICES AND INFORMATION
- RECOMMENDATION 6: TO ENHANCE THE PROVISION OF APPROPRIATE INFORMATION
- RECOMMENDATION 7: TO DEVELOP HOLISTIC, COORDINATED APPROACHES TO CALD DISABILITY AND CARER SERVICES

CHAPTER 1 PROJECT OVERVIEW

Background

This research was funded by the Disability Services Commission (DSC), and was conducted by the Ethnic Disability Advocacy Centre (EDAC) WA, an independent non-government organisation. Its data was collected between July and December 2002 in metropolitan Perth as well as selected regional centres in the state.

Project funding was received on July 2002.

Project time frame 2002 - 2003

July	Appointment of research officer and formation of reference group
August	Literature review and planning focus groups
September	Focus groups with metropolitan Perth and Vietnamese community
October	Focus group with Polish community
November	Kalgoorlie and Broome focus groups
December	Individual interviews with the Muslim community
December to February	Analysis and finalisation of report

Project Objectives

The main objective was to determine how existing service providers of health, disability and aged care sectors can better respond to the special needs of CALD carers.

The scope of the project is to:

- provide an opportunity for CALD Carers to inform the funding bodies and service providers about their experiences and needs in their caring roles;
- identify special needs, potential or existing barriers faced by primary CALD carers in accessing existing services;
- increase awareness and understanding of the experiences of carers in their caring role;
- identify and evaluate the adequacy of service provider responses to the needs of carers;
- provide recommendations to enhance disability, health and aged care programs, including the responsiveness to the needs of carers; and
- provide a basis for informing further funding from the ‘carers package’ for service enhancement initiatives that would address the issues and recommendations made, such as in those areas broadly pre-identified; respite, training, family initiatives, counselling services, professional and therapy services, aids and equipment.

Literature Review

Major Australian studies conducted over the last decade on the needs of CALD carers of people with disabilities identify the many disadvantages they face. Such disadvantages include language barriers; isolation; lack of culturally appropriate services and translated information; loss of extended family support and networks through migration; stigma; as well as feelings of trauma or stress.

In general, the ABS *Survey of Disability, Ageing and Carers* in 1993 and 1998 showed that approximately 17.5% of households in Australia were involved in care-giving, with about a quarter of these 4.8% involving principal carers taking the main responsibility for frail aged and/or a person with a disability.

The subsequent *Toward a National Agenda for Carers* Workshop Papers, such as those of Howe and Schofield (1995) and Shaver and Fine (1995) indicated that few carers had any training or education in preparation or support for this role, few received any counselling support, and problems with employment were identified.

The national series of research papers for the CSDA Evaluation, such as the *Demand Study* by Madden et al (1996) identified problems with accommodation, accommodation support, respite and day/recreation services. These issues were incorporated into the recommendations of the *Final Report of the Review of the CSDA Agreement* (Yeatman 1996). Recommendation 15 specifically called for a study of the demand for services for people with disabilities from non-English speaking backgrounds.

A report on the childcare needs of ethnic families who have children with disabilities had shown that mothers who were primary carers felt isolated from their own communities and, along with these children, were often unwelcome at community and family gatherings. Some of the carers reported that they were not consulted by service providers on the best care options for their children. Others experienced stereotyping by disability services because of their particular ethnic background (Evert, 1995).

The Multicultural Advocacy and Liaison Service of South Australia (MALSSA) undertook a study to determine the needs of culturally appropriate day options for CALD families caring for their disabled members. They claimed they were often not consulted or included in the decision making process. The study raised the importance of culturally sensitive respite care, consultation with CALD consumers about their needs and preferences, and culturally appropriate information for carers. The study also found insufficient availability of interpreters in rural and remote areas, inadequate promotion of the Translation and Interpreting Services (TIS), and a reliance on family and friends as interpreters by service providers (Velotti, 1997).

Research on CALD carers using health and support services also reported their susceptibility to chronic health problems, such as diabetes, asthma, insomnia, hypertension and fatigue (Plunkett and Quine, 1997).

The Carers Association of Australia consulted with carers from ten ethnic communities in a study and found that services and support were lacking in the areas of respite care, transport, support groups and counselling (Fisher, 1996).

Uncertainty remains over the number of CALD people with disabilities accessing services especially those who are looked after at home by 'hidden carers'. Action on Disability within Ethnic Communities (ADEC) in Victoria reviewed the social support needs of Arabic-speaking carers and found that disability is stigmatised, thus rendering the person with a disability and their family invisible in the community (Wositzky, 1996). This may be relevant to the data analysis of the Australian Institute of Health and Welfare which revealed intellectual disability to be the primary disability for 68% of Australian born consumers and only 44% for CALD consumers. However, they speculated this was due to stringent medical screenings of potential migrants by the Department of Immigration and Multicultural Affairs (Black and Maples 1998).

A recent report by the Human Rights and Equal Opportunity Commission examined the attitudes and perceptions of disability within various non-English speaking background (NESB) communities. Although the 'constructions' of concepts of disability within these communities generally reflected those of the broader community, multiple disadvantages on the basis of disability, lower socio-economic status, ethnicity, gender and sexuality were also evident. HREOC suggested that culturally appropriate services are integral in enhancing the quality of life of both NESB people with disabilities as well as their carers (HREOC 2000).

Western Australian Research

Since 1995 several studies have been undertaken in Western Australia on CALD people with disabilities and the needs of primary carers. These studies emphasised that the existence of culturally specific stigma was an impediment to carers seeking out services. The studies emphasised the need to increase disability awareness among the CALD communities through appropriate information and the development of culturally effective service models.

The Ethnic Disability Advocacy Centre undertook a study on the needs of Muslim people with disabilities in Perth (EDAC, 2000). It identified specific elements of stigma and shame associated with disability, and identified significant barriers faced by the Muslim community. Another study investigating the needs of CALD people with disabilities in both the South West and in the Pilbara developed a model for country and remote area service delivery (EDAC, 2001).

The needs of CALD carers of people with mental health problems were canvassed in a recent detailed study (Kokanovic et al 2001). Although psychiatric disability does not form part of the current CALD carers study, the Kokanovic et al report was informative. It found that simple definitions like 'burden' or 'duty of care' concealed a multi-dimensional message. Foremost of the issues raised was the stigma experienced by families, which strongly influenced the carers' possible 'unworthiness' to seek external assistance. Therefore many participants stressed to health practitioners the need for support services to be available to CALD carers and people with mental health problems.

Rural and regional areas

The inadequacy of service provision and the isolation faced by carers in remote and regional Australia was acknowledged in the 1990 Home and Community Care 'user characteristics' survey, the Commonwealth/State Disability Agreement (CSDA) Report in 1996, and again in the National Advocacy Program Review Report (1999). These reports concluded that State and Commonwealth departments and community-based agencies failed to include rural issues in

program planning and delivery of services. Services need to be innovative and to work collaboratively with people with disabilities and their carers in regional and rural areas.

The more recent study by EDAC (2001), indicated that CALD Carers who lived in rural and regional areas were more likely to be even more under-represented in respite and carer services than their metropolitan counterparts. From their research consultations, EDAC believed that CALD carers from regional and rural areas and the people that they were caring for would remain peripheral consumers of government and non-government service and programs unless appropriate support and services were established.

Disability Statistics and utilisation of services

It was reported that 19% of the population in Australia has a disability (ABS *Survey of Disability, Ageing and Carers* 1998), but the number from NESB communities was not available. At present, there are no accurate statistics available on the occurrence of disability within CALD communities. As HREOC pointed out,

"the available statistical information on disability among NESB peoples is at best patchy and at worst a hindrance to the development of policy initiatives for the effective planning and targeted delivery of disability services." (HREOC 2000:24)

Many statistical reports on people with disabilities from CALD communities are categorised according to their countries of birth, not their ethnic origin or by language spoken at home. Unfortunately this is not always the most reliable indicator of ethnicity. The 1998 ABS *Survey of Disability, Ageing and Carers* listed the number of all persons with disabilities according to their birthplace. It indicated that over 900,000 or approximately 25% of all people with a disability were born outside Australia (ABS 1998). Although the 2001 Population Census presented by the Office of Multicultural Interests (refer to Appendix 1) did not refer to disability, it showed that Western Australia had the highest proportion of people born overseas of all States and Territories (28%). The majority of the overseas born were from the United Kingdom (40 percent), New Zealand (9 percent) and Italy (5 percent). These countries together with Malaysia, South Africa, India, Netherlands, Singapore, Vietnam and German born persons constituted the top ten countries of birth for the overseas born population.

The 1996 CSDA Report *Supporting Paper 2* (Madden et al *The Demand Study*) cited from the 1993 ABS Survey that 15.4% of people with disabilities were from non-English speaking background countries (Yeatman 1996:46). The 1994 data in the CSDA Report by AIHW (Black and Madden 1995) cited in the *Addressing the Needs of Ethnic People with Disabilities* Project Report (1999:11) also indicated that people with disabilities from NESB were not utilising services at the same rate as their counterparts. A participation rate of 4.3% for people with disabilities from NESB was indicated. It was further suggested that this group was less likely to report unmet needs or seek assistance.

The concern of low utilisation of services by CALD people with disabilities was indicated by NEDA in their response to the Commonwealth government (FaCS) on disabilities in families. They claimed that three out of four people from a NESB with a disability missed out on receiving Commonwealth funded services. NEDA claimed that disability families/carers from a NESB, even more so than their Anglo-Australian counterparts, tended to have a 'grin and bear it'

attitude. Asking for support was seen as a failing, not only in one's caring role, but also failing the family, the community and, most importantly, the person with disability. They also referred to instances where the lack of support and services led to family members (usually the mother) suffering extreme burnout and being admitted to hospital whilst the family member with disability ended up in institutional care.

“Family members from a NESB can end up incurring a disability themselves – commonly physical and mental health problems – as a result of the pressures involved with caring for a person with disability whilst juggling a range of other responsibilities.” (NEDA 2002: 3)

Western Australian Data

According to DSC (*Annual Report: 2001-2002*) most of the assistance needed by Western Australians with a disability was provided by family and friends, although the proportion of aid provided formally through agencies was increasing. It was reported that,

- 70% of all support was provided informally through family and friends;
- 24% of all assistance was provided formally through Government, or Non-Government or commercial agencies;
- no-one provided support in 6% of cases where it was needed; and
- some people accessed help from a number of different sources.

Of the 19,178 service users of their services, 8% were born overseas (approximately 2% were from non-English speaking background countries and 26% were unspecified). Given that 14.7% of the people in Australia with disabilities were from NESB (ABS 1998) there appeared to be a very serious gap in servicing even though not all people with disabilities would use DSC funded services. As these data only referred to DSC service users, it could not be ascertained accurately the proportion of usage in the whole of disability and aged care area by the CALD disability population or their carers. As mentioned in the CSDA Report (1996), the inconsistency of state and federal data collection, and the absence of cross-referencing between ethnicity, country of birth, disability and locality, currently limits the use of disability and disability services information for effective program evaluation and planning.

Centrelink benefits

	Carer Allowance			Disability Support Pension		
	NESB	ESB	Total	NESB	ESB	Total
Western Australia	4,327 17.7%	20,161 82.3%	24,488	9,383 16.8%	46,365 83.2%	55,748
Broome	<20 <15.4%	110 84.6%		<20 <4.2%	453 95.8%	
Kalgoorlie	26 11.9%	192 88.1%	218	34 7.7%	408 92.3%	442

TABLE 1: Recipients of Centrelink Carer Allowance and Disability Support Pension in Western Australia overall and in Broome and Kalgoorlie.

In the Centrelink WA client population as at 16.06.2002 (Table 2), there were 24,488 recipients of Carer Allowance in Western Australia who were born overseas, of whom 17.7% were from non-English speaking background countries; and of the 55,748 recipients of the Disability Support Pension born overseas, 16.8% were born overseas in NESB countries (Centrelink 2002: Qtr. 4, 06.12.02). Although recipients of Carer payments were not provided, these figures could be useful as a guide to determine the number of CALD Carers who may be potential service users. Again there needs to be improved data consistency developed between Centrelink, ABS disability identifiers, DSC and Health and Aged Care service statistics.

Legislative obligation, Policy and Practice

Multicultural Policy and Government Services

The legislative and procedural context for the implementation of services to all sectors in WA, including health, disability and the aged, now requires recognition of the multicultural population and their rights for equity and access, and encourages them to be expressed in agency-based Service Charters. (*Responding to Diversity*, DIMA Annual Report 1998)

These issues were documented in,

- The *National Agenda for Multicultural Australia* (1989), and
- *'A Fair Go For All': Report on Migrant Access and Equity* (1996: the Human Rights and Equal Opportunity Commission).

Outcomes to date at Commonwealth and State levels were presented in the following reports:

- Commonwealth: the *Charter of Public Service in a Culturally Diverse Society* (1996/1998: DIMA)

- State (WA): *Valuing Diversity: Guidelines for Government Agencies for the Implementation of Western Australia's Multicultural Policy: 'WA ONE'* (1997: Office of Multicultural Interests).

Both strategies aim at ensuring the diverse needs of all Australians are met by culturally responsive services. They are based on the values of inclusiveness and participation, which recognise the importance of involving people of diverse backgrounds in advisory and decision making processes. They also ensure that clients from CALD backgrounds face no barriers to receiving government services; are treated fairly; are given clear information about their entitlements and obligations; as well as assist agencies and their staff to meet individual client needs.

One important development from this has been the Western Australian Government's *Language Services Policy* aimed at enabling fair and equitable access to government services for clients less proficient in English than other Western Australians, through the provision of appropriate language services. Under this policy, government agencies are expected to budget for the provision of language services to agency clients.

Disability Services and People with disabilities of CALD backgrounds

The operations of the Disability Services Commission (DSC) and related disability services in WA are governed by the *Disabilities Services Act* 1993. Based on the Legislative Principles, eight *Disability Service Standards* (DSC 2002) provide a generic customer-focused framework for service provision and for the Purchasing Agreements with funded external service providers. The Disability services standards include service access; individual needs; decision making and choice; privacy, dignity and confidentiality; participation and integration; valued status; complaints and disputes; and service management. The rights to culturally appropriate access for people with disabilities of CALD backgrounds are implicit within these service standards.

However, in 1999 DSC undertook an internal study, *Addressing the Needs of Ethnic People with Disabilities*, (with the involvement of EDAC) which proposed recommendations and strategies of improved practice and services to ethnic people with disabilities. The report identified that DSC services were not accessed and utilised by CALD people with disabilities at anywhere near the levels of the general disability population. Key issues identified as needing to be addressed were – a lack of culturally appropriate and translated information; cultural factors such as stigma and different attitudes towards disability; language barriers; lack of culturally responsive services and staff; inconsistent data collection; and insufficient resource allocation for CALD families. As this is an internal document the stages of implementation and commitment is unclear. There is a concern that the current policy framework is as yet inadequate to enable CALD issues to be addressed effectively.

As equity and social justice are proclaimed across government policies it is important that multicultural principles are incorporated into all disability services, not only in terms of policy statements but also translate into service delivery and access. Each of the key provisions in policy, service provision, funding and accountability, equal access, community education and advocacy should incorporate an explicit CALD focus to ensure the inclusion of CALD people with disabilities and their families/carers. There should be a requirement for an independent evaluation against these provisions, and that this be reported in all Annual Reports and Reviews across the health, disability and aged care sectors.

CHAPTER 2 METHODOLOGY

Introduction

The main focus of this study was to provide an overview of the barriers faced by CALD carers in Western Australia when accessing existing disability services, and by doing so, to provide suggestions for improvement. The funding proposal and agreement between the Disability Services Commission and the Ethnic Disability Advocacy Centre determined the boundaries of this study and the focus of investigation.

Participating communities and process

Primary participants of this study included carers from CALD backgrounds residing in the Perth region as well as in Broome and Kalgoorlie. Four specific groups of carers were targeted in the Perth region: members of the Multicultural Family Support Group, Polish, Vietnamese and Muslim groups. Although they were not considered the total representation of CALD Carers, they represented carers from both the older and the more recent migrants.

Secondary participants were service providers from the disability and aged sectors, in metropolitan Perth as well as in Broome and Kalgoorlie. They contributed additional knowledge of carers' needs and to the analysis of the cultural appropriateness of existing programs.

The main consideration was to design an approach for the selection of participants which would enable a combination of breadth and depth of issues including the development of an overall framework or model for effective access and use of services for CALD carers. It was decided that a qualitative approach would be most appropriate given the investigative nature of the study and its potential to gather insights into the personal experiences of CALD Carers.

A "purposive" selection approach was used to ensure that there was an equivalent representation of Carers of the elderly (30) and Carers of child/adult (36). There was no attempt to balance the overall participant group by type of disability except for the exclusion of psychiatric disability. (A very comprehensive study on CALD Carers of people with mental health conditions in WA was undertaken in 2001 *Care-giving and the Social Construction of Mental Illness in Immigrant Communities*). The process included written invitations and phone contacts to disability service organisations and associated agencies within the selected metropolitan and regional localities to canvass possible candidates for focus group and personal interviews. Key leaders in specific ethnic communities were also invited to assist with identifying potential participants (carers). Progressive identification of carers was achieved through participants who attended focus groups or had been interviewed. Attempts were made to access "hidden carers" (i.e. carers who were not linked to services and therefore difficult to identify) by seeking contacts from CALD carers and raising awareness within ethnic communities.

In this study, focus groups were chosen as the key research technique as it was more expedient and suited the collection of general problems, feelings and significance attached to certain issues. However in some situations, personal interviews were conducted with Carers and service providers who were unable to attend focus group meetings but wished to be involved in the study, especially with Muslim carers. Professional interpreters were used in some instances when CALD carers were not bilingual.

To provide consistency, structure and reliability to the study, an interview schedule in the form of broad issues and questions was developed and trialled with a small group of CALD carers. It was then adapted to suit both focus groups and individual interviews and both carers and service providers (Appendix 4).

Confidentiality

At the commencement of each focus group and interview with carers, an assurance was given that no identifying information would be used in the report. Aggregation of data from all discussions and the suppression of personal details have safeguarded this agreement with carers. However, where numbers were small, some descriptive details were modified to minimise the possibility of identification.

Definitions adopted for this study

Disability

This study used the definition employed by the Disability Services Commission (DSC) in Western Australia, which incorporates the Australian Bureau of Statistics definition that:

"Disability is a condition:

- a) which is attributable to an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment or a combination of these impairments.
- b) which is permanent or likely to be permanent
- c) which may or may not be of chronic or episodic nature and which results in
 - i) substantially reduced capacity of the person for communication, social interaction, learning or mobility and
 - ii) a need for continuing support services"

(Disability Services Act 1993:No 36)

CALD (Culturally and Linguistically Diverse) Carers

At the time of this study, CALD or 'culturally and linguistically diverse' was a conventional term used by WA agencies to describe migrants or their descendants whose first language was not English and whose cultures are other than Anglo-Celtic. The previous term used was NESB or non-English speaking background. The current term represents an improvement on the single or primary focus on language as the determinant of ethnicity. It became obvious during the course of this and other studies that non-language aspects of culture were sometimes even more critical in influencing the carers' access to services and needs.

Limitation of this study

The main objective of this study has the potential to involve many issues and a wide range of service providers in the areas of health, disability and the aged care sectors. Given the time frame of five months and the limited resources to undertake this study, clear boundaries had to be established. For example, specific ethnic groups and two regional centres were selected. Focus groups were used to uncover issues and needs rather than only personal interviews. Whilst individual interviews were more time consuming and costly they had the potential of providing greater and richer qualitative data than those obtained from focus groups.

CHAPTER 3 FINDINGS AND DISCUSSION

Profile of CALD Carers

Location	Ethnic backgrounds		
Metropolitan – Perth	Singaporean/Malaysian	9	30
	Indonesian	3	
	Indian	3	
	Burmese	1	
	Khmer	1	
	Vietnamese	13	
	Ukrainian	3	18
	Croatian	1	
	Polish	14	
	Somalian	5	8
	Iraqi	2	
	Egyptian	1	
Total Metro			56
Regional/Rural Broome	Aboriginal/Malaysian	1	5
	Aboriginal/Indonesian	1	
	Filipino/Italian	1	
	French	1	
	Chinese	1	
Kalgoorlie	Italian	2	5
	Polish/German	1	
	Maori	1	
	Dutch	1	
Total participants			66

TABLE 2: Carers by regions and ethnic backgrounds

This study adopted two distinct groups of carers: carers (usually children or spouses) of the elderly; and carers (usually parents) of children with disabilities. Both groups had very different service and support needs.

A total of four focus groups and 18 personal interviews were held with fifty-six (56) carers from the Perth region and ten (10) carers from Broome and Kalgoorlie a total of 66.

CALD Carers of elderly persons with disabilities

Of the 66 carers who participated, 30 were carers of the elderly and 36 carers of children with disabilities. In this study, carers of the elderly tended to be females, either elderly spouses or

Supporting CALD Carers

middle-aged daughters. Only on 4 occasions were males the primary carers for their parent(s) or spouses. There were seven mutual carers where both spouses had some level of disability.

Often carers had assistance and support from adult children. This finding emphasizes the importance of recognising shared family support and care. A care roster within the family system was common among some participants, including siblings and grandchildren. The elderly persons being cared for were affected by Alzheimer's and other unspecified aged-related disabilities.

CALD carers of children with disabilities

Of the 36 carers of children with disabilities interviewed all were parents, with the majority between the ages of 20 to 45. Regarding types of disability, 6 were caring for children with Downs syndrome, 2 with cerebral palsy, 2 with epilepsy, and the remainder with developmental disorders at various degrees of severity. Some parents appeared to be unclear about the diagnosis of their children.

While the mother was usually the primary carer, in five cases the fathers shared this role. In several cases, both parents were unemployed, creating additional financial and emotional stress on them and other family members. They believed that their economic capacity to pay and the nature/level of support should be considered by service providers.

About half of the carers of children with disabilities who participated in the research were single parents. In some situations refugees were sole parents prior to migration, with complex and diverse settlement, parenting issues and needs. Therefore, in assessing their care needs, service providers should consider their situation in a holistic manner. Further research in identifying the effects of caring for children with disabilities in relation to spousal relationship and single parenting would be useful.

Cultural perspectives of caring

In presenting the cultural perspectives of caring there is always a danger in over generalising or stereotyping family values and beliefs. Cultural and social values, apart from differing between cultural groups and families, also differ between generations and genders. Culture determines our everyday expectations and behaviour, including family roles, kin relationships, parenting and attitudes towards caring for the aged, ill or disabled. These cultural expectations and practices are commonly retained through personal upheaval, including migration. It may take years, even a generation or more, for a family to become bicultural and able to adapt to the 'Australian' way of life. Younger family members may adapt to cultural transitions more easily, while older members tend to adhere more to familiar cultural traditions. This was particularly apparent in discussions on issues relating to families and carers with cultural values and practices being identified as significant determinants of accessing services and expression of needs.

CALD carers reported problems with understanding the unfamiliar western notions of disability and care as promoted by generic services. Most participants regarded the term 'carer' as foreign to them. The role of caring was most commonly regarded as a 'natural duty', as of a mother caring for her children, children caring for their parents, brother or sister caring for their siblings, and so on.

As one carer stated,

“It is my job to look after her.”

Most participants believed the term ‘carer’ involved the acceptance of the term ‘disability,’ a diagnosis that some still grappled with. It was felt that identifying as a carer and the family member as having a disability might open the child and family to public stigma and rejection. Those reluctant to identify problems as a disability were therefore less likely to seek disability assessments and access appropriate services.

There were different expectations of caring across different ethnic communities, language groups and both carers of the elderly and children with disabilities. CALD participants were asked to discuss their experiences of caring in their countries of origin and how this relate to their roles as carers

“In Burma there was no special school.”

“In India rich families could get a maid. If you were poor you had parents and extended family, but no government support.”

“In your own country you have more family support.”

“At home you could have a servant, trained to look after someone 24hrs a day. We should be allowed to bring someone in from overseas on contract.”

“In Australia there is a severe shortage of nurses, it is a problem as we age.”

Religious values and beliefs were raised as an important issue for many CALD carers. Rituals and ceremonies surrounding death were of great concern to the older communities. In particular, the need to return to their country of origin to die was emphasized, even though some had lived in Australia for many decades. Some families took their children back to their home country to be ‘cured’ of a disability or ‘sickness’ through traditional religious and cultural rituals. This may in part be due to a lack of knowledge about services and alternative treatments available in Perth.

Additional factors that affect cultural perspectives include education and employment opportunities; modes of migration, that is whether one has entered Australia as a refugee or as a migrant; the size of the migrating family; the community’s ability to lend support; and the availability and accessibility of settlement services.

Emotional responses to caring

With such cultural diversity in Australia and differences between communities and families, there can be no universal set of values and attitudes towards disability or responses to caring for someone with a disability. However, some carers were open in discussing their feelings about caring.

Vulnerability

Many participants in the study stressed negative culturally determined attitudes, such as stigma, guilt, denial, concealment, duty, fatalism and isolation. While these feelings were not exclusive to CALD carers, the frequency with which they were mentioned indicated a possible barrier to them accessing community services and facilities.

In particular, CALD carers reported that cultural stigma towards disability further isolated them not only from the general community but also from their ethnic communities. Some recent migrants/carers felt particularly vulnerable because they were single parents, with reduced family support and were unfamiliar with carer support networks and disability services in Australia. Some CALD carers were also refugees with limited command of the English language. Instead of services reaching out to them they were expected to seek out community services but they were often unaware of where to start. With their anxiety of settlement and the demanding role of caring they tended not to seek help until a crisis occurred.

Some carers indicated that they would appreciate some information to be provided to them on their arrival to Australia which could be kept for later use.

Stress

While many of the stress factors raised were also common for non-CALD carers, the emotional effects were exacerbated by the migration experience, as well as cultural and language barriers. This was particularly true for refugees who had experienced trauma and arrived with few personal belongings and no established networks. Some refugees emigrated with children with disabilities.

The need to be on constant alert was felt to be the most difficult aspect about the role of caring. The constant demands of caring produced feelings of depletion, exhaustion and being at wits end.

“Looking after a person who won’t get better is physically, emotionally, spiritually and financially difficult.”

“I can’t get sick, I can’t get sick, I can’t get sick.”

“She has a problem in her head, high blood pressure, headaches at night with worry, and she takes panadol every night.”

The priority of caring often resulted in paid work taking a secondary place – either given up or reduced. The common result was additional financial stress, reduced career aspirations, relationship problems, and sacrificed social and recreational pursuits.

“I have been crying every day with stress, because I don’t know how to manage my life and see her everyday... I tried bringing her into the business, but it was impossible, she isn’t safe to be left alone.”

“We haven’t even had time for a cup of coffee alone.” (Since the birth of their child with a disability).

Supporting CALD Carers

Several CALD carers had large families with up to six children. Some siblings provided secondary care to family members with a disability. However, the pressures of caring for siblings was often experienced as stressful and a burden, particularly in the long-term. There were concerns, however, as to how caring duties might negatively impact on their children's education, relationships and social development.

"I can't leave a burden on someone else, they (my other children) have their own family. The life of the other children is already spoilt, they have lost their childhood."

"The only care we can expect from siblings is to oversee (paid) carers and finances - not daily care."

"Two of my sons are protesting and moved out. They don't want to do it. One said it is not his responsibility, he has a life of his own."

In some families, there were not enough family members to share the caring. Some carers said that the caring roles were already assigned by the persons with the disability who were often elderly parents. Some carers said it was often the daughter who would be left to care for the elderly parent with disability.

"I feel obliged to look after my mum, and it has been worse than caring for a child."

The type and severity of the disability determined the level of responsibility for carers. Some care demands were very high and generated a significant level of stress for the carer unless effective support was available. Looking after people with disabilities who had challenging behaviour for an extended period and with little support would result in extreme stress and exhaustion for any carers.

Carers expressed a high level of uncertainty and concern about the co-ordination of effective and long-term care for their disabled adult children.

"I would like to know until what time I have to do it (care-giving) – I fear I would die before my child."

Stigma

Stigma was experienced by CALD carers in the form of blame, constant denigration and a lack of respect and consideration which made the caring role more difficult. Persistent feelings of exclusion and rejection -- which resulted in anger and resentment -- could have a debilitating effect over time.

The stigma -- often of religious basis -- associated with having a child with disability would sometimes extend to the whole family. Some in the community believed the disability to be 'God's punishment', 'the will of Allah' or 'bad luck'.

"People think you have probably done something wrong."

“The local church said confess your sins.”

Nonetheless, the disability was usually accepted in silence and as a duty by the carer.

The stigma and shame involved in having a child with disability seemed particularly strong in Asian communities. Participants reported reduced hopes, aspirations and expectations for the child’s education, employment and lifetime achievements. This sometimes led to reluctance in admitting the child’s disability, thus leading to delays in seeking early intervention.

“There is a stigma about getting formal help.”

Isolation

A sense of isolation was expressed as a serious concern among CALD carers.

One source was the all consuming demands of the carer role, which hampers the development and maintenance of personal and social friendships.

“He needs constant watching.”

“It can be very lonely.”

Another aspect, reported by carers and service providers, was the low level of community support for CALD carers.

“No-one wants to know about it.”

Some carers also felt service guidelines were too restrictive.

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

Support for carers from within their various ethnic communities varied greatly. Of those interviewed, only the Polish and other central European communities received structured support from the cultural group with which they identified and felt comfortable.

The Vietnamese, Maori and Muslim carers reported an absence of carer support from their own cultural groups. These ethnic groups therefore accessed only mainstream services, but this could lead to further isolation if there was inadequate cultural understanding.

Carers from CALD backgrounds in Kalgoorlie and Broome experienced the added factor of geographical isolation. As one carer said,

“When you have no family here you need more services than in the city.”

There were however some positive measures being taken. The Vietnamese group utilised informal social networks among carers and expressed the desire to establish a community-based cultural support service. Some mainstream disability services were also beginning to recruit staff from different cultural groups.

Positive experience of caring

Despite the difficulties faced by carers, many felt their role was rewarding. Caring challenged them to develop new strengths and learn more about themselves.

“It’s an eye opening experience, learning to have less expectations.”

“I have learnt to be more patient and self reliant.”

“It makes you more imaginative and innovative.”

Carer support groups were considered particularly useful in helping carers to realise the positive aspects of caring, foster mutually beneficial friendships and learn new skills. This was evident among some of the South-east and South-west Asian families.

Different expectations of gender, marriage and family responsibilities were evident across various cultural and religious groups.

“It’s more likely the man won’t want more children, but women feel having normal children would help them cope better.”

“Marriage is for life – that is how we are conditioned by society. But it depends on your culture, background and the environment.”

Service provision and access

CALD participants raised important concerns regarding the limitations of service provision, asserting the primacy of cultural sensitivity and awareness. Substantial improvements in disability services had occurred over the past decade, which created greater choice of care support and assistance in the community. Nonetheless, the advent of generic servicing and mainstreaming had resulted in unfortunately low levels of access to disability services by cultural minorities. Some service providers thought this continued trend had led to a reduction of ethnic specific services and neglect in cultural awareness and sensitivity among mainstream service providers. The researcher believed that the low levels of access had already been widely reported in statistics and literature (see chapter 2). There was little dispute that the barriers to access were attributed to various factors, one of which was the lack of recognition, sensitivity and accommodation to cultural diversity by mainstream service providers.

A recurrent theme was the carers’ lack of understanding the nature of disability and how to access appropriate services. For example, some of the cultural reservations prevented the acceptance of disability and made enquiries into services difficult.

Hospitals usually identified and assisted children with intellectual disabilities from the time of birth. Many participants were appreciative of the support they received both at the time of diagnosis and in an ongoing way from the Princess Margaret Hospital.

However, mothers who had little or no medical understanding of the condition which affected their children, tended not to seek further assistance. This was because they had not previously encountered the condition or they held a different cultural perception of the condition.

Supporting CALD Carers

Service providers suggested that existing child care units could accommodate the needs of children with disabilities. Services, such as the Ethnic Child Care and Resource Unit and the Resource Unit for Children with Special Needs could provide staff support of bilingual disability-trained workers. However, some carers had not sought help until the child was at school age, and therefore missed out on early intervention programs. Whilst some schools were able to detect disabilities in children, several families reported that schools offered inadequate support.

Families who were associated with ethnic agencies were more readily linked to a range of services. For example, those who were aware of the Polish agency seemed to benefit from quick and effective services appropriate to their needs.

The scarcity of services in regional centres, accompanied by the effects of frequent staff turnover, did not allow carers to establish ongoing personalised service relationships. The most effective point of access appeared to be Social Workers within the hospital.

The difficulty in accessing services, in addition to the associated anxiety and sadness experienced by the detection and confirmation of the disability, could be assisted by the provision of initial counselling and referral to an appropriate disability support agency.

Language

It was considered essential to use professional interpreters when working with people who have limited English comprehension. Carers provided examples of when the absence of interpreters resulted in the difficult comprehension of the diagnosis and treatment, led to a sense of diminished control in the decision-making process.

In the regional centres visited, the idea of using interpreters, even by phone, was rarely considered. There was a reliance on family and friends as interpreters. This information suggests a lack of familiarity with the TIS service, its cost and confidentiality, and/or displays a preference for family and friends.

The language barrier was not sufficiently understood by many service providers interviewed except CALD-specific agencies. One example was the institutional care of an elderly Asian women who was placed in a hostel where English was the only spoken language, which increased her loneliness and bewilderment. The possibility of a cluster system, that is, the same language group living close together, perhaps in a village for the elderly, was suggested as a means to prevent loneliness. However, this would be difficult in regional areas where services are limited and specific ethnic communities are small.

Information

There was a lack of information booklets and sheets that were responsive to the needs of CALD carers. Carers often find the information available difficult to understand, because general information is not collated around their specific needs. Without personalised assistance, most information in its current form was unlikely to be useful.

Apart from the need for information to be available in a more coordinated, relevant and understandable format, translation into a range of community languages would be a necessity. A

successful initiative in Kalgoorlie was a communication booklet, developed by a group of paid carers, which outlined services in the town for carers of children with disabilities.

Specific information needs raised by CALD carers included DSC distributing federal and state disability policies to all carers; a booklet on disability issues and services for parents whose child is diagnosed with a disability; and DSC Local Area Co-ordinators providing details on accessing funding for equipment, respite and programs such as speech therapy.

Individualised co-ordination of ongoing support

Many CALD carers from different ethnic groups emphasised the need for individualised and ongoing support. Carers expressed their confusion over the complexities of the existing service system, and require assistance to co-ordinate their access to what is available. For example, they may be required to select a range of disability services from different agencies, such as medical, educational services, and child development centres. Carers regarded the Local Area Co-ordination (LAC) service as a primary point of co-ordination, but were often disappointed by its inability to adequately meet their support needs.

As a result of the limited role of the LAC service and the fact that it no longer provide co-ordinated case management, carers wanted to develop the skills to manage and integrate their own care needs. The need for better support for this role was emphasised.

Often the need for care plans should include the long-term care needs of children, with personalised case co-ordination after the carers' death or when they are unable to advocate for their adult children with disabilities. The co-ordination of care plans should also consider a progressive change in the culture of caring in terms of families having to accept increased care outside the family system, such as nursing home care.

“Some people in my culture think it is my job to look after my husband, but we can learn to do it as Australians now.”

Carers mentioned that carer support services should include counselling through the initial stages of grief and anxiety upon discovery of the need for caring and also be included as part of a co-ordinated care package for carers; ideally counsellors should be culturally and linguistically competent.

Carer support groups

CALD carers expressed the value some had experienced of getting together to support each other and share resource information.

“You learn to open up, share problems and talk with others.”

“I get to meet wonderful mums and friends.”

Many informal carer groups were based around language and culture. New arrivals, especially refugee groups and ‘hidden carers’, felt more comfortable participating in these informal and familiar settings. In addition, participants often shared common interests and cared for people

with similar disabilities. These groups provide a culturally appropriate springboard for further community based service delivery and education.

Carers support groups not only enhanced carer knowledge of community resources and information, they also represented other CALD carers by representing their views to government. As a collective voice they acted as a point of consultation and asserted their rights as carers.

Flexibility of services

In the context of cultural diversity and disability, tailored carer support to individual needs requires both flexibility and choice. For example, participants expressed a preference for a variety of care arrangements and flexible options. Some multicultural day care services cater to specific language groups only on a weekly basis and aged persons from CALD backgrounds could attend the particular day centre only once a week.

Some participants were dissatisfied with the fact that they could not sponsor family members from their home countries to assist in the caring. Some, however, had brought in grandparents for up to 3 months. They felt there should be special concessions within the immigration system to allow for extensions of visas.

There was a mixed attitude towards the hours of caring as some carers expressed the need to go out occasionally in the evening for social activities. They felt that services like care centres ought to have flexible work times, such as after hour care.

Crisis care management was an issue of concern for carers. Relevant information on crisis care for people with disabilities was the least accessible. While carers could seek assistance from service providers in crisis situations, these services, particularly after hours, were not always immediately available. Contingency plans were necessary to cater for such situations. With one exception, none of the participants knew who to ring in emergency situations. Crisis accommodation, for emergencies involving CALD people with disabilities and their carers, was raised in this regard.

Respite Care

Some participants did not have a concept of alternative care options like respite. Those caring for the elderly were more likely to use respite once it was made known to them, but this often required acceptance by the person of disability. The majority believed in the need for “time off”, but were ambivalent about the types of respite available to them. Those caring for their children and adults with disabilities were less likely to accept respite care unless it was from someone whom they trusted. Several carers interviewed later insisted that the child must have them present at all times.

The need for the paid carer to be ‘known’ by the family carer was mentioned several times and, like other care arrangements, would be more acceptable if the person was one of the ‘extended family and friends’. Family members were often used as secondary support, especially in large families, this sometimes placed considerable burden especially on children co-opted into family shared-care arrangements as previously mentioned.

Out-of-home respite for younger persons with disabilities stirred strong views and emotions. While some carers emphatically refused assistance unless they could supervise the care, others preferred the respite care for the disabled child to be taken outside the home so they would ‘be away from hassles and noise’ for a while.

Service Providers’ Issues

The service providers interviewed and others consulted acknowledge that CALD carers did face barriers in accessing existing services. They also raised a number of additional issues from their perspectives as service providers.

The range of service providers working with people with disabilities was broad, and covered areas of disability, aged care, medical, education, employment, financial support, home and community care, respite and carer services. Of the 125 metropolitan and regional service providers canvassed, 20 responded and attended focus groups or personal interviews and a number of others were consulted by phone. The number of responses in the regional areas was generally poor but this could be related to the reduced number of disability and aged care related services.

Location	Service Providers
Metropolitan Perth	18
Broome	9
Kalgoorlie	10
Total	37

TABLE 3: Total number of Service Providers by region

A total of 37 service providers participated. They were represented by disability, migrant health and aged care agencies. Two focus groups and individual interviews were held in Perth and Kalgoorlie but service providers in Broome were consulted individually.

Policy

The general comment was that current disability policies and practices failed to meet the needs of CALD carers of people with disabilities. Special provision to address the cultural and linguistic needs of CALD consumers and carers were rarely stated or made explicit in policy guidelines. Some service providers indicated a lack of direction and training to effectively manage the cultural issues and needs of their disabled consumers.

Service providers suggested that generic disability agencies establish greater networks and partnerships with ethnic agencies in order that service access for CALD Carers and consumers could be improved. Considerable success was achieved by agencies that had sound multicultural policy and practice. EDAC, as an ethnic/disability advocacy service, could play a key role in assisting with establishing networks and dissemination of information. Funding for outreach workers to undertake this work would also be beneficial.

Difficulties faced by Service providers

Service providers had difficulty in accommodating all the needs of CALD carers due to rigid funding criteria and limited budgets. This resulted in fragmentation of services and confusion for consumers who sought a holistic and integrated service, co-ordinated around their range of support needs.

Another fundamental problem was the difficulty in identifying CALD carers because of the lack of ethnicity, disability and locality data. Without relevant and accurate data it has been difficult to plan and provide appropriate programs to CALD people with disability and their carers.

Service providers were also quick to point out that culturally many CALD carers would not normally identify themselves as 'carers'. Some felt that carers were not accessing services and community support because of a lack of information, isolation, cultural attitudes towards disability and the inappropriateness of some generic services.

The main problem in regional centres was the lack of disability and migrant support services. There was also a need for stronger networks and coordination between ethnic communities and disability agencies.

Respite services and institutional care

It was reported that the availability of respite care did not sufficiently meet carers' needs. Some carers were reluctant to use respite services due to cost. Language-specific respite services were considered important for aged NESB people, some of whom tended to revert to their original language due to age and disability.

Service providers reported that some NESB people experienced alienation or isolation in some hostels and nursing homes because of language barriers. Several larger nursing homes had 'clustered' people of the same language; however this was not viable in regional areas with smaller ethnic population. .

Cultural and disability awareness

Service providers who were unfamiliar with cultural and language factors tended to use English language competency as a basis to determine whether the person required cultural support. Hence in some situations service providers would unknowingly claim an absence of CALD people with disabilities and carers within their service provision or dismissed their cultural needs because they were able to communicate in English adequately.

Organisational practice seemed to relate to language only, with little provision for recognition of other cultural factors. It was also claimed that the use of interpreting was not a normal practice unless it was specifically requested. As often these non-government agencies had restricted funding, and were naturally concerned about the cost associated with interpreting and translation.

Mainstream service providers identified the need for further cultural awareness training to enable them to provide comprehensive culturally appropriate support but preferably, the government should provide the funding. Service providers also suggested the need for greater community education on disability issues and services within ethnic communities.

CHAPTER 4 RECOMMENDATIONS AND CONCLUSION

These recommendations were developed from the issues and concerns raised by CALD carers and service providers. They have the potential to address the cultural and linguistic needs of the target group as well as providing a good foundation for the establishment of culturally competent, quality management plans for service providers. They address the access and equity commitment of current disability legislative obligation and policies of both government and non-government sectors for the disability and multicultural sectors.

RECOMMENDATION 1: TO IMPROVE DATA COLLECTION OF CALD CARERS AND PEOPLE WITH DISABILITIES

Current data-bases concerning ethnicity and disability are inadequate for service planning and management purposes. Data definition and collection requires consistency between Government sectors such as ABS, Health, Aged Care and Disability Services.

Strategic collection of data on ethnicity, disability and locality is necessary to:

- ensure more effective identification of the CALD population who have disabilities and their carers;
- enable more informed planning, implementation and evaluation of services;
- provide accurate and comprehensive data for research; and
- create a strategic base for inclusion and participation by CALD carers at all levels.

RECOMMENDATION 2: TO EXPLICITLY INCLUDE CALD PEOPLE WITH DISABILITIES AND THEIR CARERS IN POLICIES AND PRACTICES

Multicultural policy and guidelines need to be incorporated into disability policy and service standards especially current disability related policies, practices and quality management in particular should make explicit the rights of CALD people with disabilities and their carers to access appropriate services. The development of policies and strategies for inclusion should be in consultation with CALD communities to ensure language, religious and cultural issues are appropriately addressed.

RECOMMENDATION 3: TO INCREASE CALD ACCESS AND OUTCOMES IN DISABILITY SERVICES

To enable CALD access to appropriate services, agencies should work with CALD Communities to:

- provide both translated information on procedures for service provision and interpreters;
- regularly measure outcomes to evaluate the cultural appropriateness and effectiveness of the procedures/ practices;
- review policy and practices to accommodate cultural needs;
- increase CALD staffing at all levels and in all areas of disability services;
- strengthen networks between disability, CALD groups and ethno-specific services to develop collaborative partnerships; and

- develop and deliver cross-cultural training for service providers working with CALD people with disabilities, their families, carers and communities.

This should apply to all areas, especially regional services.

RECOMMENDATION 4: TO DEVELOP CULTURALLY APPROPRIATE PROJECTS WHICH ARE INITIATED AND DIRECTED BY CALD CARERS AND COMMUNITIES

Funding should be reallocated, informed by community development principles, to resource the participation of CALD people with disabilities, their carers and communities in the development of CALD services and support. In addition, mainstream agencies should engage CALD stakeholders to develop culturally appropriate strategies to improve the access and relevancy of services.

These initiatives should include:

- ongoing consultation with CALD communities to address cultural concepts, values and processes regarding disability and care;
- community education that provides information on generic disability and other services;
- individual and systemic advocacy; and
- cultural awareness and competency training for mainstream service providers.

RECOMMENDATION 5: TO REVIEW THE PROVISION AND COORDINATION OF DISABILITY SERVICES

In relation to the current review of the Local Area Co-ordination model of disability service provision that:

- this be considered in the context of an examination of the wider overall complexity of disability services experienced by CALD clients, their families and communities;
- alternative or complementary models be considered and progress made toward providing more effective single access, referral and co-ordination point in each locality for all disability-related services; and
- there be engagement of a CALD disability professional at each of these points.

RECOMMENDATION 6: TO ENHANCE THE PROVISION OF APPROPRIATE INFORMATION

A series of new strategies to enhance the shared usability of current information be discussed with CALD carers, consumers and service providers, and implemented as appropriate.

These would include but not be limited to:

- co-ordination of current information on all disability services into one format, such that carers, clients and their families, and service providers, can navigate quickly and effectively the avenues of importance to their individual circumstance and needs.
- increasing the numbers of bilingual workers to meet equity targets generally, and strategically for each CALD group (especially per Rec. 3 and 4).

- promoting and extending the use of Translating and Interpreting Services and disability training (per Rec. 5).
- Developing new forms of information sessions and media.

RECOMMENDATION 7: TO DEVELOP HOLISTIC, COORDINATED APPROACHES TO CALD DISABILITY AND CARER SERVICES

Recognising the diversity within and between CALD cultures requires integrated, comprehensive and flexible service delivery it is recommended, that:

- a community development approach be utilised to develop and manage disability programs with CALD clients, their carers/families and communities;
- casework models, managed health care and other options be explored (per Rec.5);
- sufficient resources be allocated to CALD services to promote cultural awareness and values regarding disability and care, and the rights of consumers;
- opportunities be created to improve the cultural appropriateness and flexibility of services such as:
 - paid family carers and part/shared care
 - care facilities and family members sharing care
 - respite facilities for working carers
 - respite programs

(see Figure 1: Approach to Service Provision for CALD Carers.)

Holistic Approach to Service Provision for CALD Carers

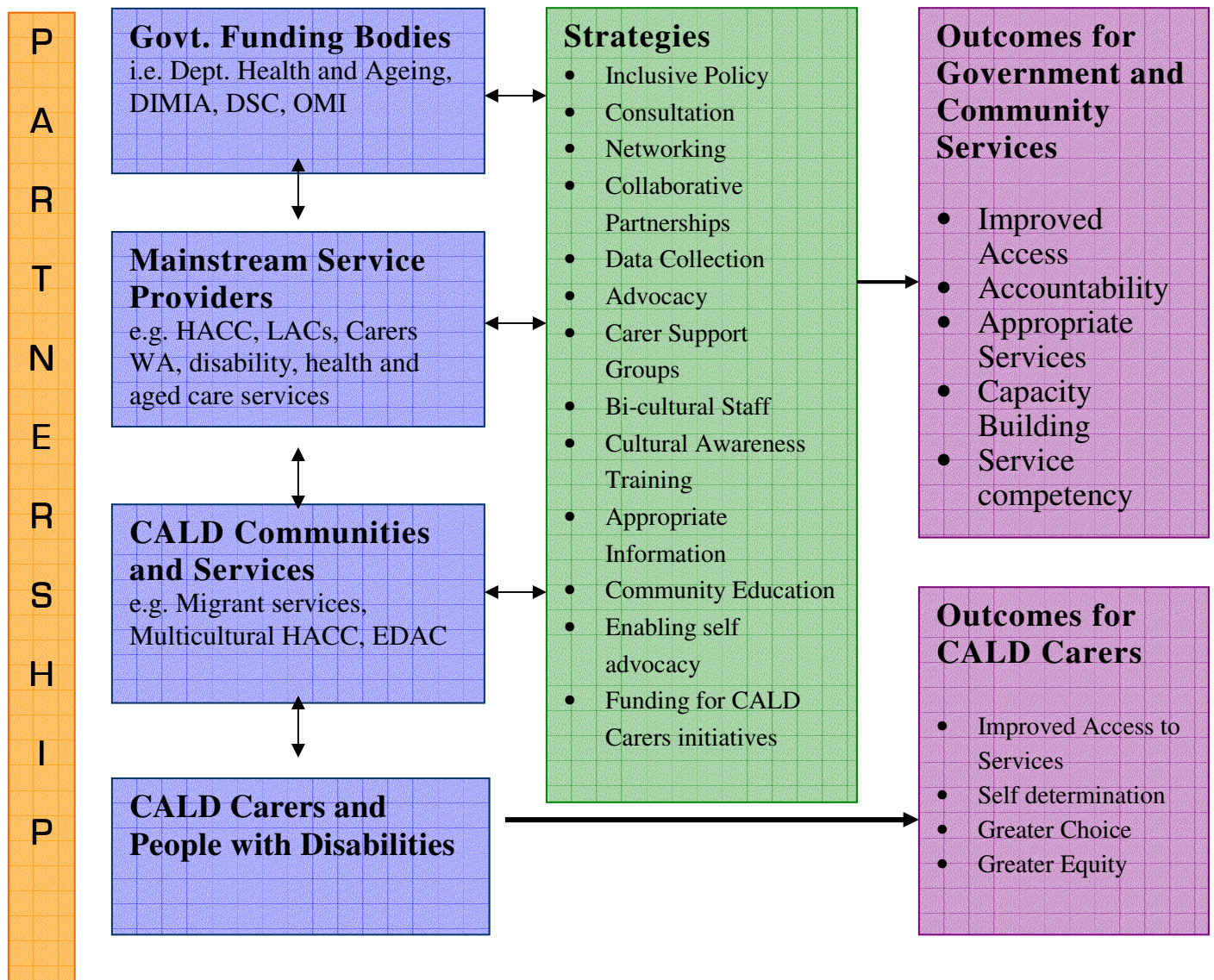


Figure 1 : Approach to Service Provision for CALD Carers

CONCLUSION

This report specifically set out to provide a basis to guide the development of improved service support to carers from CALD backgrounds.

Many examples of excellent responses to the needs of CALD carers by professional workers in both government and non-government agencies were found. In particular, Princess Margaret Hospital was singled out by many carers of children with disabilities for their service, not just at the time of diagnosis, but throughout their child's life. The other program singled out as specially meeting needs was that of the Polish Centre, where carers of the elderly felt welcome and able to access the services they needed.

However, on the whole, there was widespread misinformation on the part of carers about what was available to them, sifting through the range of options was often confusing. The culture and language would present difficulties in gain access to services. Newly arrived migrants and those arriving as refugees often had more trouble communicating their needs.

The multiplicity of services, and their lack of coordination became a central theme in almost all interviews and focus groups, pointing not only for the need for better dissemination of information, but for better personalised and planned configurations of service delivery within the disability and aged care sectors. With an ageing population, disability services will have difficulty coping with the increasing demand, unless some consideration is given to a more integrated and co-ordinated service approach. Otherwise CALD carers and their family members will continue to remain as peripheral consumers of services.

As a beginning it has been suggested that increased regional networking of service provider agencies occur, so duplication of and competition between services are eliminated and referral sources are clarified. Ultimately, it would require funding policy changes at State and Federal levels to provide better integration and collaboration.

CALD carers viewed the range of services with anxiety. Often they were seen as a place of last resort accessed only when a crisis occurred for their family member with a disability, or themselves as carers. The need for a case management approach which provides counselling and ongoing support was clear. The development of carers' support groups for various cultural groups as a means of providing mutual support and information was also strongly desired in Perth, where large groups of one language group can be found.

The strong need of many to be the sole carer of their family member, and their reluctance to take time out through respite, arise from both a lack of trust of services, from cultural responses to caring responsibilities, and from their perception of the stigma involved.

There was a need expressed for funded agencies and programs to develop principles, values and policies which demonstrate recognition and valuing of cultural diversity.

To assist in breaking down this barrier, cross-cultural training was recommended to enable service providers to explore the nature of multiple disadvantages experienced by CALD carers. This would facilitate ongoing involvement of CALD carers as services are developed.

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APPENDIX 1:

Table 1: People born overseas

Table 1 provides a comparison of the proportions of Australian and overseas born persons for Western Australia and Australia between 1991 and 2001.

	1991		1996		2001	
	Western Australia	Australia	Western Australia	Australia	Western Australia	Australia
Australian born	1,098,286 (69%)	12,719,726 (75%)	1,178,341 (68%)	13,227,996 (74%)	1,241,786 (67%)	13,629,685 (72%)
Overseas born	450,566 (28%)	3,688,385 (22%)	475,847 (28%)	3,907,993 (22%)	495,240 (27%)	4,105,444 (22%)
Not Stated, inadequately described and Overseas Visitors	37,973 (3%)	442,223 (3%)	71,907 (4%)	756,434 (4%)	114,226 (6%)	1,237,221 (6%)
	1,586,825	16,850,334	1,726,095	17,892,423	1,851,252	18,972,350

All Percentages are based on proportion of total population

People born Overseas: Countries of Birth

For the past decade, the majority of the overseas born were from the United Kingdom (40 percent), New Zealand (9 percent) and Italy (5 percent). These countries together with Malaysia, South Africa, India, Netherlands, Singapore, Vietnam and German born persons constituted the top ten countries of birth for the overseas born population.

Obtained from (www.omi.wa.gov.au)

Useful multicultural contacts

The following list is not meant to be exhaustive however the information is current as of February 2003.

State government

Office of Multicultural Interests
81 St Georges Terrace
Perth WA 6000
Ph: 9426 8690

Federal government

Department of Multicultural and Indigenous Affairs (DIMIA)
411 Wellington Street, Perth WA 6000
Ph: 13 1881

Community Settlement Services Agencies

Regional areas

Carnarvon Family Support Service
Community Information Centre, Lotteries
House
1 Carmel Lane
Carnarvon WA 6701
Postal Address: P O Box 898
Ph: 9941 1811

Geraldton Regional Community Education
Centre
24-28 Gregory Street
Geraldton WA 6530
Ph: 9921 4477

South West Migration Service
3/23 Spencer Street
Bunbury WA 6230
Ph: 9791 5271

Uniting Church Frontier Services
Newman Community Centre
Newman Drive
Newman WA 6753
Ph: 9177 8706

Uniting Church Frontier Services
South Hedland Community Health Centre
Colebatch Way
South Hedland WA 6722
Ph: 9172 1639

Uniting Church Frontier Services
72 Padbury Way, Karratha WA 6714
Ph: 9185 1856

Unity Church Frontier Services
Nintirri Centre
Central Road
Tom Price WA 6751
Ph: 9188 1928

Metropolitan WA

Afrikan Community in WA
Claisebrook Lotteries House
33 Moore Street
East Perth WA 6004
Ph: 9325 1623

Australian Asian Association
275 Stirling Street
Perth WA 6000
Ph. 9328 1160

Australian Asian Association
Suite 10, Joondalup Lotteries House
70 Davidson Terrace
Joondalup WA 6027
Ph. 9300 2720

Catholic Migrant Centre
25 Victoria Square
Perth WA 6000
Ph: 9221 1727

Communicare
29 Cecil Avenue
Cannington WA 6107
Ph: 9451 0777

Greek Orthodox Welfare Association of WA
390 Charles Street
North Perth WA 6008
Ph: 9201 9655

Italo-Australian Welfare & Cultural Centre
209 Fitzgerald Street
Perth WA 6000
Ph: 9228 2220

Lockridge Community Group
39 Diana Crescent
Lockridge WA 6054
Ph. 9378 4930

Multicultural Services Centre of WA
20 View Street
North Perth WA 6906
Ph: 9328 2699

Muslim Women Support Centre
c/- Australian Islamic College
139 President Street
Kewdale WA 6105
Ph: 9361 0539

Muslim Women Support Centre
Boogurlarri Community House (outreach
centre)
82 Langford Avenue
Ph: 9350 6236

Northern Suburbs Migrant Resource Centre
1/14 Chesterfield Road
Mirrabooka WA 6061
Ph: 9345 7577

South Metropolitan Migrant Resource
Centre
241 243 High Street
Fremantle WA 6160
Ph: 9335 9588

South Metropolitan Migrant Resource
Centre
Gosnells Community Legal Centre
1/2209 Albany Highway
Gosnells WA 6110
Ph: 9398 1455

The Gowrie
213 A Belmont Avenue
Belmont WA 6104
Ph: 9477 5222

Unity of Ethiopians in WA
Australia Asian House
275 Stirling Street
Perth WA 6000
Ph: 9209 1145

Languages – Translation and interpreting 131 450

Multicultural Women's Health

ISHAR Multicultural Women's Health
Centre
8 Sudbury Place
Mirrabooka WA 6061
Ph: 9345 5335

Multicultural Women's Health Centre
114 South Street
Fremantle WA 6160
Ph: 9430 4545

Child Health

Ethnic Child Care Resource Unit
384 Oxford Street
Mt. Hawthorn WA 6016
Ph. 9443 4323

Mental Health

WA Transcultural Mental Health Centre
WASON Building
Royal Perth Hospital
151 Wellington Street
Perth WA 6000
Ph: 9224 1760

Assoc. for Services to Torture and Trauma
Survivors
3rd Floor, Bon Marche Arcade
80 Barrack Street, Perth WA 6000
Ph. 9325 6272

Mental Health Access Service
South Metropolitan Migrant Resource Centre
241 243 High Street
Fremantle WA 6160
Ph: 9335 9588

Ethnic Aged and HACC Services

Multicultural Aged Care Service WA
Restorative Unit, Osborne Park Hospital,
Osborne Place, Stirling WA 6021
Ph: 93468149

'Rainbow'
c/- Polish Multicultural Aged Centre
33 Eighth Avenue, Maylands WA 6051
Ph. 9271 203

'Panda' The Asian Aged Care Program
The Chung Wah Association
128 James Street
Northbridge WA
Ph: 9328 2243

Multicultural Community Options
(Perth Home Care Service)
440 Vincent Street West
West Leederville WA 6007
Ph. 9388 6993

Multicultural Services Multicultural Day
Care
10 Farmer Street
North Perth WA 6006
Ph. 94448283/94439144

Disability Advocacy

Ethnic Disability Advocacy Centre
320 Rokeby Road
Subiaco WA 6008
Ph: 9388 7455

Domestic Violence

Manager
Multicultural Women's Advocacy Service (MWAS)
P.O. Box 32
Northbridge WA 6865
Tel: 08-9328 1200/9227 8122

APPENDIX 3: SERVICE PROVIDERS INVOLVED IN CONSULTATIONS

NB: Around 120 agencies were invited to participate in focus groups, face to face or phone interviews, but the following agencies accepted the invitation.

Perth

Carers' WA
Polish Centre: Umbrella and Rainbow
Ishar
Dar al Sharif
Muslim Women's Support Centre
Vietnamese Buddhist temple, Victoria Park
Multicultural Aged Care, Osborne Park
Multicultural Aged Care, Canning ton
Several Local Area Coordinators, Disability Services Commission
Home and Community Care, Subiaco
HeadWest
Southern Metropolitan Migrant Resource Centre
Multicultural Services of WA
Community Health
Red Cross Carers' Respite Centre, Fremantle
ACROD
Ethnic Child Care Resource Unit
Resource Unit for Children with Special Needs

Kalgoorlie-Boulder

Disability Services Commission
Goldfields Individual and Family Support Agency
Centrelink Disability Officer
Red Cross Carers Respite Centre
Alzheimer's Association, Mobile Respite Dementia Team
Home and Community Care
RUCSN Children's Inclusion Unit
Commonwealth Carelink
Social worker, Eastern Goldfields Regional Hospital
Activ Foundation

Broome

West Kimberley Family Support Association
Disability Officer Centrelink/Commonwealth Carelink
Broome Aged and Disabled service, HACC
Kimberley Aged Care Services, Carer Respite Centre
Disability Services Commission, LAC
Broome Lotteries House
Kimberley Personnel Inc
Broome District Office, Special Education, Education Department
Broome Multicultural Association

APPENDIX 4: CALD CARER INTERVIEW QUESTIONS

1. WHAT WOULD NORMALLY HAPPEN IN YOUR HOME COUNTRY WHEN SOMEONE HAS A SPECIAL NEED? WHO WOULD CARE FOR THEM? DO YOU HAVE A NAME FOR THE PERSON WHO DOES THAT CARING?
2. WHAT WAS YOUR REACTION WHEN YOU FOUND OUT YOUR FAMILY MEMBER HAD A SPECIAL NEED/DISABILITY? WHO DID YOU TURN TO?

FOCUS QUESTIONS

3. WHAT KIND OF HELP ARE YOU RECEIVING AT PRESENT?
4. HAVE YOU RECEIVED HELP FROM YOUR OWN COMMUNITY?
5. HAVE YOU EVER NEEDED TO TAKE TIME OUT FROM CARING?
WHAT WOULD BE GOOD FOR YOU?
6. WHAT HAS BEEN THE HARDEST THING FOR YOU AS A CARER?
7. WHAT HAS HAPPENED FOR YOUR FAMILY SINCE YOUR FAMILY MEMBER NEEDED CARE?
8. HAVE THERE BEEN ANY OTHER PROBLEMS FOR YOU AS A CARER? HOW COULD THEY BE IMPROVED?
9. DO YOU KNOW IF YOU CAN RECEIVE FINANCIAL HELP?
DO YOU USE (OR WOULD USE):
HOME HELP: COOKING, CLEANING, WASHING, IRONING, BANKING.
TRANSPORT
FOOD: MEALS AND SHOPPING
PERSONAL CARE – BATHING AND DRESSING
HEALTH SERVICES – NURSING, DOCTOR, DENTIST, PHYSIOTHERAPY, PODIATRY
OTHER
10. DO YOU NEED ANY OTHER INFORMATION/ASSISTANCE NOW?

ENDING QUESTIONS

11. DO YOU KNOW ANY “HIDDEN CARERS” (NOT LINKED TO SERVICES) AND HOW THEY ARE COPING?
COULD WE CONTACT THEM AND TALK WITH THEM?
12. WHAT HAS WORKED WELL FOR YOU AS A CARER? (AS IF APPROPRIATE)

NB: THESE QUESTIONS WOULD PROVIDE AN INITIAL FRAMEWORK, BUT THE CONVERSATIONS MAY FLOW AROUND PARTICIPANTS’ OWN NEEDS.