

# **Diverse Strategies for Diverse Carers The Cultural Context of Family Carers in NSW**

**A report prepared by  
Ms Beatriz Cardona  
Dr Sharon Chalmers  
Dr Brett Neilson  
(Centre for Cultural Research, University of Western Sydney)**

**for  
The NSW Department of Ageing, Disability and Home Care**

**July 2006**

<b>1</b>	<b>Acknowledgments</b>	<b>4</b>
<b>2</b>	<b>Executive Summary</b>	<b>5</b>
<b>3</b>	<b>Introduction</b>	<b>7</b>
3.1	Background information	7
3.2	Aims of the Project	7
<b>4</b>	<b>Background to Community Support Programs</b>	<b>8</b>
<b>5</b>	<b>Social Policy</b>	<b>9</b>
<b>6</b>	<b>Overview of Current Research on Carers in Australia</b>	<b>11</b>
<b>7</b>	<b>Cultural Research on Carers and Community Care</b>	<b>13</b>
7.1	Cultural dimensions of family responsibility towards the elderly	13
7.2	Factors influencing service use and non-use	17
7.3	Caregiver burden	18
7.4	Cultural Research on Carers and Community Care: Conclusions	20
<b>8</b>	<b>Methodology</b>	<b>21</b>
8.1	Cultural research	21
8.2	Definition of a Carer	22
8.3	Strategies to reach carers	22
8.4	Cultural research on caring issues	22
8.5	Carer participants	23
8.6	Profile of the carer participants	23
8.6.1	Anglo-Australian carers:	23
8.6.2	CALD carers:	23
8.7	Issues affecting the interview process	26
8.8	Use of interpreters	26
8.9	Volunteering information	27
8.10	Conclusion: Methodology	27
8.10.1	Cultural research:	27
8.10.2	Definition of a Carer:	27
8.10.3	Carer participants:	28
8.10.4	The interview process:	28
8.10.5	Interpreters:	28
<b>9</b>	<b>Research Findings</b>	<b>29</b>
9.1	More than a carer: Labels and relationships	29
9.2	Carers and culture – Cultural notions of caring	32
9.3	Diverse carers need diverse strategies	34
9.3.1	Cultural attitudes on caring	34
9.3.2	Anglo-Australian and CALD carers: similarities and differences	34
9.3.3	Personal care	35
9.4	Workforce development issues	36
9.5	Under-utilization of services	36

9.6	Language barriers .....	38
9.7	Dealing with disability issues .....	40
9.8	Carers and mental health issues .....	42
9.9	Notions of entitlements and citizenship rights.....	43
9.10	Carers in a global and cross-cultural context.....	44
9.11	Research Findings: Conclusion .....	46
<b>10</b>	<b>Discussion.....</b>	<b>50</b>
10.1	Tailoring needs to fit models.....	50
10.2	Cultural competence: Negotiating a complex system .....	52
10.3	Discussion: Conclusion .....	53
<b>11</b>	<b>Conclusions and Recommendations .....</b>	<b>55</b>
<b>12</b>	<b>Future Research.....</b>	<b>58</b>
<b>13</b>	<b>Appendix.....</b>	<b>59</b>
<b>14</b>	<b>References.....</b>	<b>62</b>

# 1 Acknowledgments

The authors gratefully acknowledge the support of Dr Peter Wejbora, Research Manager (UWS), and the expert advice provided to the study by members of the project's advisory group: Alberto Castillo, Nancy Butterfield, Helen McFarlane and Mary Kerr from the Department of Ageing Disability and Home Care, Vivian from NSW Community Options, Kathy Wood and Grace Chan from Carers NSW, and the community representative and carer Despina Papiolos. We would also like to thank Branca Vulojevic from the HACC interpreter service at South Western Sydney Area Health Service for facilitating the use of interpreters and all the community organizations that assisted us in gaining access to the carer participants involved in the research.

The act of academic research writing creates limitations particularly when attempting to communicate and capture the interconnected emotions of despair, love and moments of joy the participants share with their loved ones. Out of respect for the privilege of having been allowed to share these moments, we endeavour in presenting this research to remind ourselves and the reader that beyond the analysis of culture, ethnicity and institutions are the lives of individuals who hoped that their contribution would assist in the creation of new and innovative strategies to address their needs. We thank all the carer participants for their time and contribution. Due to issues of confidentiality all the names and references to specific services or organisations have been changed.

This research has been undertaken with assistance from the NSW Department of Ageing, Disability and Home Care. However the information and views contained in this study do not necessarily, or at all, reflect the views or information held by the Department, the NSW Government, the Minister for Ageing or the Minister for Disability Services.

Ms Beatriz Cardona  
Dr Sharon Chalmers  
Dr Brett Neilson  
(March 2006)

## 2 Executive Summary

*Diverse Strategies for Diverse Carers* presents the findings of cultural research into the everyday experiences of carers from culturally and linguistically diverse (CALD) and Anglo-Australian backgrounds. The research was conducted by the Centre for Cultural Research at the University of Western Sydney and funded by the NSW Department of Ageing Disability and Home Care. The purpose of the study was to increase awareness and understanding of the diversity of caring experiences and the inter-relationship of cultural, socio-economic and gender issues in shaping these experiences.

The project explored the everyday caring experiences of 34 carers from CALD backgrounds and 8 from Anglo-Australian backgrounds through a process of cultural research. This approach allowed for an explorative inquiry into the varying and complex cultural contexts in which values, practices and understandings of caring occur. Rather than pursuing a comparative approach that assumes definitive boundaries between Anglo-Australians and CALD communities, our methods call for the crossing of boundaries and a questioning of monolithic and universal concepts of culture. This approach is unique in its incorporation of broader concepts of culture and ethnicity and its attempt to shift the focus from individual and/or group pathologies to the broader social, physical and imaginary landscape defining and containing difference.

A qualitative method, using individual, semi-structured interviews was employed. The purpose of interviewing carers from both CALD and Anglo-Australian backgrounds was to explore the broader cultural context in which the care relation takes shape. The interpretation of the interviews was informed by an international literature review of studies concerning carers, caring and the care relationship.

The report identifies the following issues as significant in the everyday experiences of carers:

- Identification as a 'carer' in diverse cultural contexts
- The relation between everyday practices, cultural values and socio-economic forces in shaping the caring experience
- The impact of notions of entitlements and citizenship rights upon service usage
- The global and cross-cultural context of caring
- The models of service delivery and their limited capacity to accommodate flexible approaches to diversity
- The cultural competence required to navigate and negotiate a complex care system.

The research findings demonstrate that ethnicity, while a significant factor in the caring experience, does not alone account for the complex positioning of carers with respect to care recipients and the wider social and institutional context. This confirms the notion that culture is not reducible to ethnicity and highlights the need to understand the cultural context of caring as a dynamic

set of inter-relationships in which cultural identities and practices are constantly renegotiated.

The report makes a number of recommendations with particular emphasis on models of service delivery, the framing of discourses on disability, the process of identifying and assisting carers, and the way in which difference and cultural diversity can be understood and incorporated into the policy frameworks that inform service provision.

## **3. Introduction**

### **3.1 Background information**

The Centre for Cultural Research (CCR) at the University of Western Sydney was commissioned by the NSW Department of Ageing Disability and Home Care to conduct a pilot research project into home-based community care with a focus on carers. The study, employing techniques of cultural analysis, seeks to document and understand the everyday experiences of people who care for frail elderly and people with a disability from culturally and linguistically diverse (CALD) and Anglo-Australian backgrounds. This research focuses on carers who fall outside or have limited usage of the mainstream mechanisms of government support. By exploring the everyday experiences of such carers, the study aims to understand how diverse socio-cultural factors impact on everyday interactions.

A total of 42 carers (8 from Anglo-Australian background and 34 carers from CALD backgrounds), who had limited or no usage of Home and Community Care (HACC) funded services, were interviewed. The overall objective was to explore how the broad cultural contexts in which caring takes place informs structural aspects as well as the choices carers make in relation to the care of a family member.

### **3.2 Aims of the Project**

1. To undertake a comprehensive international literature review detailing the breadth of literature and existing models of care-giving by families for frail elderly and people with a disability from CALD and Anglo-Australian backgrounds with an emphasis on access and equity.
2. To explore the everyday experiences of family carers from CALD and Anglo-Australian backgrounds.
3. To understand the way diverse cultural factors impact on the psycho-social and emotional interactions of a variety of care arrangements.
4. To compare how socio-cultural factors impact on family carers from CALD and Anglo-Australian communities.
5. To produce relevant evidence-based research to inform long-term policy and planning to assist CALD carers in the Australian community.

## 4 Background to Community Support Programs

The provision of community support in Australia through the Home and Community Care (HACC) Program was introduced in the mid-1980s by the Australian Government. This intensified a trend away from the use of nursing homes and an increase of formal assistance for people at home. It also meant the introduction of a broader range of types of support to people living in the community. Greater priority was also given to those who lived outside the family settings and those who lived alone, as well as programs to support informal caregivers such as respite care and carers' payments.

The HACC Program provides services to older people, people with a disability and carers. People with a disability and their families also receive support through a range of services (including day programs, attendant care, group homes, early childhood intervention, respite, therapy and behaviour support services). There are services which are specifically designed for people with dementia and their carers. The NSW Carers Program funds a range of supports and research specifically for carers.

The Australian Government introduced the Home and Community Care Act in 1985. This consolidated four community care funding bodies into a single program. The HACC program, which is both state and federally funded, expanded the range of services to include transport, home modifications, domestic assistance, personal and respite care. In addition to the HACC programs, the Community Aged Care Packages (CACPs) were introduced by the Australian Government to provide a low-level category of care in an older person's home.

The capacity and willingness of extended family members to provide effective and quality care has been the subject of numerous national (de Vaus 1996, Batrouney & Stone 1998, Millward 1998, Shaver & Fine 1995, Saunders 1996, Ethnic Disability Advocacy Centre 2003, Schofield 1998, Thomas 2003, AIHW 2004) and international research studies (Wolfson et al. 1993, Litwin 2004, Dilworth-Anderson et al. 2002, Gillies 2000, Hinton et al. 1999, Neysmith 2000).

The social, financial and emotional impact of greater reliance on family resources has become evident through several documented studies on informal care-giving. This emphasis on informal care-giving has led researchers to examine the conditions that sustain family and community-based care. These include cultural perceptions of family duty and filial piety, the social and financial costs of care, and the physical and emotional impact of the caring role on the health of carers (AIHW 2004, Shaver & Fine 1995, Millward 1998, Ethnic Disability Advocacy Centre 2003, Plunkett & Quine 1996, Thomas 2003). Other studies have explored the strengths and weaknesses of HACC programs and the impact these factors have on the lives of people who need access to these services (Saunders 1996, Fine et al. 1991, McCallum et al. 2001).



## 5 Social Policy

Social policy interventions in family dynamics have recognised the importance of the role of carers. Until recently this role was taken as a given, couched in terms of the responsibilities and duties of family members towards each other, most often with the concomitant assumption that a woman's 'natural' place is in the home and that she is responsible for providing informal care (Shaver & Fine 1995).

The formal term 'carer' emerged around 30 years ago, attempting to redefine what was previously understood as a private family relationship into a distinctive set of roles, responsibilities and rights: a social contract between the carer, the care recipient and health and community care agencies. Once the family member identifies herself (himself) as the primary 'carer' she is entitled to complementary assistance to relieve her temporarily of care giving responsibilities. This is to allow her to financially support herself and her family, pursue a career or engage in other interests (Shaver & Fine 1995:8). This 'social contract' is permeated with contradictions and inconsistencies regarding rights and the allocation of assistance. Carers may be unable to access sufficient or appropriate support, with many services refusing to intervene and instead priority is given to clients without caregivers (Shaver and Fine 1995:22). These factors point to the need for further examination of the diverse daily roles assumed by carers, as well as the financial, social, cultural and spiritual needs of carers themselves.

On a more fundamental level, attention has also been drawn to the fact that although families do not want to evade their responsibilities towards their elderly and those with disabilities, some people are not in position to give assistance to or receive assistance from their family (Millward 1998). This is particularly the case for recent migrants with limited social and family networks, refugees facing psychological and emotional traumas, people with chronic health problems, and those on low incomes. As Millward points out, female relatives are significantly over-represented as carers and often find themselves under more pressure to give up caring responsibilities in order to prepare for their own independence in later life. The notion of an intergenerational contract of mutual obligation may also become more difficult to fulfil given the financial stresses and the dominant cultural emphasis on self reliance in retirement (1998).

The Western-based construction and definition of the role of 'carer' amongst ethnic minorities also demands attention. For example, research has demonstrated, and this study confirms, that the notion of 'carer' is a difficult concept to 'translate' (Ethnic Disability Advocacy Centre 2003). The term 'carer' evokes different cultural meanings and can conflict with a range of cultural understandings in relation to family dynamics, filial piety, and responsibility towards the sick and frail. It is important to understand that carers may also have other family roles such as mother, daughter, or breadwinner. Contrary to conventional expectations, these roles do not necessarily substitute for each other. Alternative cultural values understand caring as a continuing and multifaceted relationship, an 'action verb' rather than a descriptive noun.

Research into the care of adults suggests that a sizeable part of the population of people providing care do not recognise themselves as carers, while others experience difficulty accepting that they have adopted a caring role (Bittman et al. 2004). This difficulty is attributed to the tendency of the term 'carer' to focus on the physical tasks associated with providing assistance, the 'caring for', obscuring the emotional 'caring about' relationship that exists between the carer and the care recipient (Parker 2000).

The carer identification grants certain rights and responsibilities to the individual (Shaver & Fine 1995). Thus the absence of alternative culturally appropriate tags renders some individuals invisible to assistance and assistance invisible to them. The common associations of care with burden and dependency, in contrast to understandings that emphasise interdependency and mutual support, are not only very demeaning for care recipients and care givers alike but also reflect an ageist discourse dominant in most Western countries (Wilson 1998).

A shift in roles and family dynamics also creates a new understanding of concepts such as respite, burden, and coping that resonate differently in diverse cultural and socio-economic contexts. As pointed out by Neysmith (2000), 'respite' is one word used to describe services that might address this need but at the same time its use can insinuate a certain weakness on the part of the users; it raises the question of their ability to cope. Neysmith goes on to argue that:

It is all too easy to blame the victim if the analytic gaze focuses too strongly on individuals struggling to survive under conditions over which they have very limited control. Thus, context, social conditions and an appreciation of the social location of the parties are not so much denied as they become part of the backdrop rather than the primary focus for research and policy making. (5)

The way in which factors such as class, gender and ethnicity interlace to shape experiences of caring requires an analysis of the manner in which recent discourses of care have been framed.

## 6 Overview of Current Research on Carers in Australia

The most recent research concerning carers who do not access services (Bittman et al. 2004) and the factors contributing to low service usage by CALD people with disabilities (St George Migrant Resource Centre 2004) supports previous findings in relation to the impact cultural values and perceptions have in the way illness, disability and caring roles are assumed. Bittman et al.'s (2004) analysis of the Survey of Disability, Ageing and Carers by the ABS in 1998 and the ABS 1997 Time Use Survey found that services are more likely to be used when there is a high level of need or when the level of need is at a crisis point. The report also highlighted the fact that a major factor limiting the take-up of services is the failure of carers to identify themselves as carers and hence in need of assistance (Bittman et al. 2004: v).

According to the above research, most adult carers are older than 30, more likely to be women, to have a disability themselves and either to not work or work part-time. CALD carers were identified in the report as facing specific barriers such as culturally inappropriate services and previous negative experiences with services. Drawing on information from a previous report by Mistic (1996), Bittman et al. (2004) highlighted cultural issues acting as barriers to the access of services by CALD carers, including communication, feelings of failure for needing help, prejudice and misunderstanding of mental illness.

Mistic's (1996) research into CALD carers in Western Sydney identified structural barriers such as lack of appropriate information, dissatisfaction with previous service usage, lack of flexibility in service delivery and lack of cultural awareness by services as the main reasons for CALD carers limited usage of services. A recent consultation with CALD carers in the St George and Sutherland area provided comprehensive information regarding cultural and structural barriers to service usage which supports previous research findings (Plunkett & Quine 1996, Ethnic Disability Advocacy Centre 2003). These barriers include cultural values and beliefs about illness and disability, shortage of culturally appropriate support and services, lack of awareness of existing services, culturally inappropriate assessment, cost, and transport and counselling support issues. In addition, the non-identification of some CALD people with the term 'carer' was identified as a reason for not accessing services – an observation that reinforces previous findings regarding the complexity of individual identity in caring relationships.

Previous research (Payne & Ehrlich 1998) identified that CALD and Aboriginal carers tend to explain their caring relationship with reference to cultural beliefs. This can lead to a sense of social exclusion that influences their use or non-use of community services. By contrast, Anglo-Australian carers often overlook their own cultural backgrounds so their cultural assumptions about caring are 'taken for granted' and as a consequence rarely articulated.

Research on carers' needs (Payne & Ehrlich, 1998; St George Migrant Resource Centre, 2004) has called for increased funding to provide:

- culturally appropriate programs and assessment
- bilingual/bicultural case workers
- increased number of programs and counselling services
- personalized services
- staff training on carers issues
- education of carers and the wider community to give greater recognition to the role of carers and encourage use of services

Given the reluctance of most carers to seek help, Payne and Ehrlich (1998) also identified the importance of services being offered rather than requested. They also highlighted the importance of 'unpacking' some of the values and assumptions behind commonly made statements such as 'I can manage on my own', which can mask a number of issues and contradictions involved in the caring experience. Their report calls for personalized information, education and 'cultural acceptance of service use (which) can be included as components of information delivery' (66). They also recommended giving general practitioners a larger role in delivering information since their authority 'provides a strong message to carers about the acceptability of service usage' (66).

## **7 Cultural Research on Carers and Community Care**

The concept of culture, as conventionally understood, has frequently been taken to designate a relatively static set of unique behaviours and collective social practices that remain constant over time and space. With respect to ethnicity, in particular, such an understanding of culture leads to an approach that relies heavily, if not exclusively, on prescriptive models of cultural difference that have difficulty accounting for the way in which cultures change - for example, in the migration process or across generations. More recent approaches, influenced by interdisciplinary studies in areas such as gender, globalisation and self-reflexive methodologies, have reconceptualised culture as a dynamic and multifaceted process rather than as an embedded set of static rules and conventions.

As pointed out by Chalmers & Allon (2002), cultural research:

defines culture as a broad process whereby social meanings are created, and where our sense of who we are, how we want to be perceived and how others perceive us (identities and subjectivities) are produced. This is through complex social, economic, political, material and psycho-social actions, representations and interventions which are intimately linked to a diversity of factors such as class, ethnicity, race, gender, sexuality and age. How any of these inter-relationships occur need to be explored within specific historical contexts. (5)

By studying the complex relationships between social structures and individual lived experiences, cultural research acknowledges the multiple and diverse roles and the constant renegotiation of these roles by ourselves and others in everyday contexts.

The literature on carers and access to community care has paid some attention to culture in terms of personal and community identities and the challenges faced when negotiating these identities in new cultural contexts. Research on carers includes issues such as generational conflict, new family dynamics, and caring expectations that can not be met due to economic and time constraints (Thomas 2003). In this study we pay special attention to the cultural dimensions of family responsibility towards the elderly, factors influencing service use and non-use and notions of caregiver burden within a framework that acknowledges the diversity and complexity of experiences, cultural references and role negotiation between and among individuals and communities.

### ***7.1 Cultural dimensions of family responsibility towards the elderly***

Comparative research of Anglo-Australian and CALD carers by Thomas (2003) found that filial duties and forms of family responsibility are given more weight by some communities than others. This is in part due to the emphasis of some cultural groups on collective life and the traditional role of the elders as a source of experience and wisdom. Such traditional roles and expectations cannot always be easily met in the new country leading to loss of status and isolation. In some cases, this results in the emergence of mental health issues (Thomas 2003).

Other research findings (Payne and Ehrlich 1998) including this present study indicate that often values pertaining to family responsibility are articulated by CALD carers with specific reference to ethno-cultural attitudes. Anglo-Australian carers, on the other hand, tend to approach family responsibility as free from culturally specific values. This research found that family responsibility was a shared value among all carers, but differences emerged among carers in the strategies, resources and capacity to fulfil this perceived duty.

Different values and cultural understandings of institutional care may mean that the transfer of family members to out-of-home care may not be seen as an option – a situation that can create conflicting demands, financial stress and burden for carers. Thomas's study concludes that, given the range of care alternatives available in Australia, carers from CALD backgrounds should be given the choice of selecting the most appropriate care for their ageing family members rather than trying to live up to unrealistic social expectations (2003:7). Carers interviewed in our research however made references to the absence of choices and care alternatives available to ease their caring responsibilities. In other words, the 'choices' referred to by Thomas are almost non-existent for many CALD carers because of the limited ability of services (many of which lack flexible models of delivery) to accommodate cultural difference.

But when they say, 'We can't do this, you can't do this and you can't do that!' At one stage it was very bad. And flexibility. We want flexibility. They are not flexible enough. Because certain things are alright for you, but they are not alright for me, right? (Karina, from Macedonia, looks after adult daughter with disability)

What these professionals do, they let patients do whatever they want ... they just leave him alone to do whatever he wants ... they don't care ... I have tried everything. (Interpreter for Nicolas, from Greece, looks after adult son with disability)

Previous research has highlighted the tensions between social and cultural understandings of family responsibility and the capacity of families to fulfil these responsibilities due to financial constraints, limited support and available resources (Batrouney & Stone 1998, Thomas 2003, de Vaus 1996, Wolfson et al. 1993). Generally the relatively lower income of many families from CALD backgrounds (Batrouney & Stone 1998) as well as the introduction of changes to limit the range of social services and benefits available to new migrants has a significant impact upon the capacity of carers from CALD backgrounds to provide assistance to other family members (Batrouney & Stone 1998).

Comparative studies of carers from Anglo-Australian and CALD backgrounds have found no significant differences in their emotional well being, feelings about care giving, and the availability of informal support from other family members and friends (Batrouney & Stone 1998, Schofield 1998). The experiences of carers, it has been argued share more in common than they have differences, despite their cultural diversity (Bevan 1998). The challenges presented by the caring experience are however dealt with differently and determined by both cultural and structural factors. People from different

cultures vary in their beliefs about the causes of illness, in their behaviour when ill and in their expectations as to how illness should be treated (Legge & Westbrook 1994). Research from the US has found that, despite the widely held view that minority caregivers have extended families to call on for mutual assistance and support, the reality is that these families can sometimes add to the daily burden of the primary caregiver(s) (Fox et al. 1999, Dilworth-Anderson et al. 2002).

These findings were confirmed by our research. Contrary to common assumptions that CALD carers have additional networks of support or large families to assist them, many of the CALD carers in this research had, in common with Anglo-Australian carers, no social networks or extended families to support them, due to distance and/or the family removing themselves from the carer to avoid the caring responsibilities. Some CALD carers also removed themselves and their care-recipients from family networks to free themselves from the burden of further family expectations of childcare duties in addition to the caring responsibilities.

My friends will come here, we'll talk about certain things. They'd just get up and go. Big problem. Sometimes when they come here and you do say something, what you get in return is that they'll say something that will just hurt you more than necessary. I was the only one that could understand the problems that people are going through, but not many people can understand what I'm going through. (Komala, from Greece, looks after 2 young adult daughters with disabilities)

One of my daughters said to me if Dad didn't have this massive stroke probably they wouldn't live in Melbourne, so I felt my children left because it was too much for them to actually face the situation. It was too much for them to actually face it. (Emilia from Lebanon, looks after husband with disability)

When I go (to my son's) I don't have a rest. My son works as a truck driver and his wife works in the credit union. The children go to childcare, but if I am there they don't send them to childcare and we have to clean, cook ... it is too much. My daughter-in-law doesn't take into account our situation, so it is not convenient for us to be close to them. (Javier, from Argentina, looks after wife with disability)

He hasn't got any relatives ... since his wife died no one comes. No one knocks at the door, no one rings. (Interpreter for Nicolas from Greece, looks after adult son with disability)

The presumption that people from CALD backgrounds always have extended families to call on for help is highly debatable. Furthermore, care giving demands were also similar amongst carers from all groups in terms of duration of care, hours per week and the proportion of required assistance provided personally by the carer. Levels of burden and the impact on the health of the carer were also similar (Schofield 1998). In addition, Schofield found that despite the substantial satisfaction that flowed from care giving, all carers felt similar feelings of responsibility despite their cultural backgrounds, expressing marked anxiety and guilt at the possibility of relinquishing their role.

Studies highlighting the diversity of cultural behaviour within the same ethnic groups point to socio-economic determinants of specific values. For example, older Chinese people in Melbourne (Tsang et al. 2004) found that their expectations of being looked after by sons and daughters-in-laws had changed over time. This can partly be explained by their length of residence in Australia and subsequently their adaptation to new cultural and social environments. Economic constraints also played a role that often prevented families from following traditional norms (Tsang et al. 2004). At the same time, it was found that the loss of traditional roles have to some extent been compensated by a new pride in living independently, establishing their own networks of support (including the family) and not being seen as a physical or financial burden on their family. This finding is supported by other research (Schofield 1998:51) which found that contrary to the assumption of co-residency CALD carers were just as likely as Anglo carers to live apart from the recipient reflecting perhaps a greater accommodation to the dominant cultural norms.

A report on Dutch elderly (Kruijer 1990) and their networks of support in Australia, including usage of formal services, found that many people in their late 80s and early 90s still live alone with very little help from their families or the community. Kruijer (1990) suggests that their reluctance to utilize formal assistance even when family support was not available, related to issues of pride, not wanting to ask and fear of authority including the belief that if they accepted services they would be put on the waiting list for a nursing home. A deterioration in their ability to communicate in English with their own children and their migration experiences in the 1950s and 1960s when there was little support from the government, the report argues, has led to a marked sense of isolation, a loss of self-esteem and the perception that formal services are not for them.

Kruijer's findings are echoed in this study, although not specifically in relation to Dutch elderly. We found many elders from CALD backgrounds were reluctant to utilize formal care due to mistrust and the fear that it could lead to early institutionalization. The perception that services were not for them related to understandings of citizenship and entitlements, with some CALD carers feeling that enough had already been provided for them by being allowed into the country. Some Anglo-Australian carers also referred to how 'things were in the past' when formal help was not available but there was enough social capital to provide assistance to people in need. This affected their willingness to seek formal help and in some cases their perceptions of the service providers.

People used to look after each other always. Everybody is busy now. No time to care .... I think it's hard to come to terms with the idea that you need help ... The service for cleaning, they are very nice, but they also give you the feeling that you shouldn't be having this service. (Fiona, Anglo-Australian, looks after frail elderly husband)

A more nuanced theoretical framework, as suggested by Wilson (1998), allows for other (world) views and practices to be explored. Thus, the relationship between the carer and care recipient is not always an



uncontested power relationship and care can also be interpreted as control. Indeed, as Gibson points out (1998) many older people, particularly older women, fight a continuous battle to maintain their independence from well-meaning children who wish to streamline their input of care.

The provision of informal care at home by family members may not always be the care recipient's preferred choice but the family may be reluctant to relinquish their care giving role. Other research (Delgado et al. 2004) suggests that informal care giving at home may not stem as much from strong feelings towards a family-centred approach by the care recipient, as previously thought, but rather from a lack of knowledge about existing formal carer services. Reliance on a family member for personal assistance, as pointed out above, can result in distress and feelings of being a burden and beholden to those caring (Millward 1998; Chandraratna & Cummins 1988). This finding is also supported by some of the carers who participated in this research as the following comments illustrate:

I'll have to be independent and go to a retirement village, like my elder brother, who is 66 this year. His marriage broke up many years ago. He does have a daughter in another state and he's living in a self-reliant – you look after yourself, like a little unit or bed-sitter, and they take your pension. And he's got his meals there ... His daughter would take him in but he doesn't like living with his daughter and her husband and the grandchildren. He sees them, but ... he's like me. He is independent. There is nothing like being independent. You can get up yourself, make your own tea or coffee. (John, Anglo-Australian, 64, looks after mother)

Because my kids are working, and they won't be able – like, I don't want to put them through this. I have fear for them. I don't want to put them through all this because it is going to be hard. I don't want to ruin their lives ... I know their abilities. They can't handle... they don't have the ability to handle much. So that's why I told them, 'I don't want you to spend all your time with me. Just check everything's all right and leave me' ... I told them what I want and not to feel guilty because I wanted it like that. (Sonia, from Lebanon, looks after mother)

The above findings point to the great diversity of views, values, and cultural practices within and between different communities. A diversity of circumstances results in a diversity of experiences, including the positioning of individuals within both formal and informal socio-economic and socio-cultural structures. In this way, the choices (or perceived absence of choices) the individual makes in relation to care giving reflects the interconnectivity of structural forces working within and through cultural practices.

## **7.2 Factors influencing service use and non-use**

The above findings challenge commonly reported assumptions that CALD carers have greater access to support from extended family networks and the apparent perception that CALD carers (more so than Anglo-Australian carers) see their duty as looking after their elderly and family members with disabilities (Wilson 1998). However, significant differences do emerge in the utilization of formal services, despite the same levels of need. For example, CALD carers under-utilize respite care and other home and community based services due to lack of information, the refusal of services by care recipients,

and dissatisfaction with previous use (Schofield 1998). These findings reinforce comparable studies in the US (Fox et al. 1999) which point to the need to develop better communication and dissemination strategies and more appropriate and culturally relevant support services for use by different ethnic groups (Dilworth-Anderson et al. 2002).

Service under-utilization by CALD carers in this study reinforces these findings and highlights the need to reach CALD carers at different points of entry into health and community care services. Better communication and dissemination strategies such as personalized approaches to facilitate understanding and establish rapport could enhance access to services. Dissemination strategies should take into account the links between CALD carers and community services including religious organisations, ethno-specific centres, social groups and migrant resource centres.

We went to a HACC access (for CALD carers) – this is a blessing. It really is a blessing. They arranged a run around on the bus to all the services, showing us all the services, and we went around there for the day. (Lina, from Papua New Guinea, looks after frail elderly husband)

Armenians, they have good relationship with the church. She knew about services through the church. There was also an Armenian program on TV. (Interpreter for Sara, from Armenia, looks after husband with disability)

### **7.3 Caregiver burden**

Studies on African-American caregivers have found that they face deep frustration, trauma and alienation, which has not been adequately captured in comparative social gerontology research on caregiver burden (Fox et al. 1999). Similarly, the experiences of caregivers in Australia point to specific stress factors affecting CALD carers, including unfamiliarity with carer support networks and disability services, refugee experiences, limited command of the English language, reduced family support and stigma often attached to disability issues (Ethnic Disability Advocacy Centre 2003).

Despite high levels of stress and need for support, some carers in our study expressed guilt for wanting to have a break, feeling that it was theirs and no one else's responsibility to see their care recipients through the life journey. These feelings were expressed by some CALD women who have children with disabilities, pointing perhaps to a sense of personal accountability for the condition of their children and fears that government services will not look after them in a caring manner.

The government has helped me. I'm not complaining about that. But the problems are mine. I'm going to have to live with them. (Komala, from Greece, looks after 2 young adult daughters with disabilities)

Because it's too many organizations, but I don't trust, because we hear too many (things). I don't want my kids to be taken somewhere where they don't look after them. Because no one but I can look after them. Until my last day, I'm going to do whatever I can for my family. (Maria, from Greece, looks after young adult son and daughter with disabilities)

I am nearly eighty and just now she's with me on the weekends. I bring her to the doctor, but I am worried that this service, they're good people, but they could change. While I'm alive, maybe they'll be alright, but I don't know after. (Elena, from Poland, looks after adult daughter with disability)

Across numerous interviews in the present study, concerns about the substantial emotional impact of caring were repeatedly expressed. Yet, the impact was experienced differently by different carers, influenced by the level of support available, cultural values and relationship to the care recipient.<sup>1</sup>

Some days I don't want to talk to anybody, and I have taken anti-depressants sometimes, but I don't like to take that type of thing because that is not my personality ... And one time that I really, really felt that I want to pack my things – like it, what you call, triggers you. And then you feel it again. It's always there. And when I'm by myself I think, Why me? (Tina, from East Timor, looks after young son with disability)

Nobody tells me anything. Whatever I think is best, whether it's good or bad, nobody listens. I came twenty-one years ago to Australia, where am I going to go to, Greece? Nobody knows me there, nobody will care. (Interpreter for Nicolas, from Greece, looks after adult son with disability)

Look, I have depression. I don't like to talk to somebody. I don't like to go to somebody, I don't like somebody to come to my house. I am hopeless just now. (Elena, from Poland, looks after adult daughter with disability)

The physical impact of caring also needs attention given the risks of injury and, in some instances, violence that carers face when looking after people with mental health issues.

He said to his Dad: 'I'm going to break your head'. He didn't ring the police because they can't help. So he gave him the money. (Interpreter for Nicolas, from Greece, looks after adult son with disability)

Carers without access to a sustainable and caring environment, including culturally appropriate services and counselling, were dealing with deep emotional issues that often placed their mental and physical well being in jeopardy. This became evident through the interviews with numerous references by many carers to the emotional impact that caring has on their physical and mental health.

I've been suicidal and stuff like that. (Deborah, looks after adult daughter with disability)

Sometimes I'm very stressed out, so I swallow a tablet. Recently I also had cancer ... My husband gets scared, but I tell him it is OK but the reality is that I

---

<sup>1</sup> The researchers were extremely aware of the potential emotional ramifications for the interviewees during the interview process. As part of the formal ethics protocol counselling support was identified and these contacts were included in the information sheets distributed to all the interviewees prior to the interview. While no interviewees expressed the need for such support, the interviewer, an experienced community worker, had the background to assist any interviewee to gain such support and/or counselling if the situation arose.

am very sick, very stressed out. (Anna, from Poland, looks after husband with disability)

Their biggest fear and this is a very emotional issue as you can see, (crying) is what is going to happen to her when they are not around. (Interpreter for Mr. and Mrs. Zodakh, from Former Republic of Yugoslavia, look after granddaughter with disability)

She drives me mad ... I read in the paper about parents that kill their disabled children and I can understand why they do it. (Karina, from Macedonia, looks after adult daughter with disability)

Sometimes I want to run away ... I just cry and ask 'Why me?' (Tina, from East Timor, looks after son with disability)

While mental health considerations surrounding caring are not necessarily specific to CALD communities, they can acquire specific characteristics in these contexts. The different legal and cultural conventions with respect to domestic violence (emotional, economic and physical), elder abuse, and stigmas around mental health can inflect the experiences of both carers and care recipients from CALD communities. It is crucial that within the wider policy debate surrounding these issues, attention is given to the fact that carers as well as care recipients may need access to appropriate health services. CALD carers, particularly those at greater risk, should have access to culturally appropriate support services that are integrated across government departments and target the specific cultural needs of carers and their families.

#### **7.4 Cultural Research on Carers and Community Care: Conclusions**

This chapter has focused on the complex social, economic, psycho-social and cultural factors shaping caring. Major conclusions to be drawn:

1. Expectations differ according to diverse cultural values regarding the role of the family in the care of the elderly. For example, emphasis can be placed on collective life or the traditional role of elders as a source of wisdom and experience. These factors impact on how carers' perceive the suitability of services available to them.
2. CALD carers generally believed there was a lack of choices available to them. The ability of services to develop flexible models of care becomes paramount to maximise CALD carers' participation and usage of services.
3. CALD carers do not necessarily have extended families or community networks to assist them.
4. Factors influencing service use and non-use among CALD carers call for reflection on the cultural appropriateness and relevance of support services as well as the strategies used to disseminate information.
5. Despite high levels of stress among CALD carers, there is a reluctance to use services due to past negative experiences and anxiety regarding the standard and consistency of care provided.

## 8 Methodology

### 8.1 Cultural research

A cultural approach to health and community care seeks to reconceptualize issues of cultural diversity and community care in terms of cross-cultural interactions. Crucial to this approach is the recognition that all parties bring certain cultural viewpoints to their daily interactions. Rather than focusing on the barriers and strategies to enhance carers' usage of services we look at the cultural context in which interactions between providers and carers occur and the cultural specificities each of them brings to these interactions. Within this conceptual framework culture and ethnicity are understood as also concerning the varying values and attitudes institutions and providers of community care possess and the points at which they intersect with carers.

Most approaches to culture and ethnicity and the interactions between individuals and services, as pointed out by Chalmers (2004), tend to address the question of cultural diversity and community care in terms of the clients special needs while overlooking the culture(s) amongst providers. Issues of cultural diversity 'are often understood in terms of 'problems' or 'barriers' CALD communities face by focusing on 'their' unique characteristics or risk factor.' (Chalmers 2004). Just as it is frequently presumed that mainstream Anglo-Australian culture is neutral or 'culture-free' (Chalmers & Allon 2002; Kolar & Soriano 2000; Morrissey 1997), the values and assumptions underlying Western health and community care are uncritically understood by many as objective and value-free. Yet, health and community care services themselves are not neutral institutions but large, complex social organisations operating within cultural frameworks that may not always match those of the communities they service (Aldrich & Mooney 2001). The result is that health and community care workers often believe it is incumbent upon the client to fit in or assimilate into the mainstream Australian health and community services culture (MacIntyre 1994).

Understanding mainstream Anglo-Australian culture as one culture among many rather than as a neutral and culture-free set of social practices has important implications for the methodology of this study. Rather than comparing CALD carers to Anglo-Australian carers as if they constituted two definitive and distinctive groups, we emphasise commonalities as well as differences. This means questioning monolithic and static notions of culture in order to analyse processes of cultural change as well as the interplay between and across cultures. The study seeks to include Anglo-Australian carers within the broader spectrum of difference that characterizes the Australian population rather than to offset CALD experiences and concerns against some mainstream set of cultural practices.

A cultural approach offers a conceptual shift by understanding cultural identity as a fluid and shifting term. It refers to the:

subjective way we think about ourselves as well as the ways we define our shared understanding of belonging to particular groups, for example cultural background. It is an open-ended process or always in the process of 'becoming'. That is identities are neither natural nor fixed, neither unified nor

singular across time or place. Indeed identities can be read as taking on strategic qualities. For example, it may be beneficial or empowering to identify with one group of people in one context while unnecessary or disabling at other times. In other words, identities are constituted by multiple factors that take on different meanings in particular contexts. Therefore one of the major shifts is thinking beyond essentialist or reductionist models of 'culture' as fixed and static entities shared by all people from the same cultural background. (Chalmers 2004)

This research also approaches the issue of organisational and professional culture(s) in terms of the specific contexts in which services and policies are designed and implemented. The cultural specificities brought by both providers and users of community care services, including notions of entitlement, individual rights and family responsibility intersect at multiple points resulting in varying capacities to negotiate differences. The absence of a more complex understanding of the cultural intersections where differences are negotiated at an individual level translates into a one size fits all model of service delivery which knowingly or unknowingly seeks to tailor needs to fit models rather than the other way around.

## **8.2 Definition of a Carer**

The Diverse Strategies for Diverse Carers Project used the Carers NSW broader definition of a carer as 'someone who looks after relatives or friends who have disability, chronic illness or are frail aged'. The carers were recruited by promoting the project through ethno-specific organizations, carers' networks, religious and cultural organizations and health services.

## **8.3 Strategies to reach carers**

The project was promoted through different organizations targeting children and elderly people such as play groups and senior citizen clubs. While attempting to include representation from a variety of culturally and linguistically diverse backgrounds, no emphasis was made to target any specific community. The aim was to examine whether ethnicity mattered and how it manifested in combination with other significant socio-economic and cultural factors within individual contexts, rather than focusing on an ethno-specific 'check-list' approach. Awareness of different issues pertinent to the migration experience, length of residence in Australia and level of English language skills were also given consideration in the promotion of the research in order to attract a diversity of views.

## **8.4 Cultural research on caring issues**

The challenges presented by the caring experience are shaped by both cultural and structural factors. Cultural factors determine the definition of the problem, possible solutions, and whether the problem is located in the private or public domain. Structural factors include those associated with support networks, the availability and accessibility of these networks, as well as socio-economic and political elements (Guberman & Maheu 2003). The socio-economic context includes the migration and refugee experience, the transformation of the family in the new country, the sexual division of labour, generational differences and social class and educational attainment levels.

Cultural research provides an innovative approach to the field of research on carers by exploring the impact cultural factors have on issues including perceptions of the carer role, notions of personal rights and entitlement, and family dynamics in carers from Anglo-Australian and culturally and linguistically diverse backgrounds. This analysis takes account of wider contextual factors to avoid a reductive understanding of carers as existing outside social relations of power, class and gender inequality. Micro and macro analysis informs us about the locations in which people find themselves, whether they be social structures, geographic locations, or historical times. All of these influence the availability of options from which carers fashion their identities (Stoller 2002).

### **8.5 Carer participants**

The interviews were conducted over the period April to May 2005 mostly at the carers' place of residence. The interviews lasted from 45 minutes to two hours and were recorded with the consent of the carers. Information sheets about the purpose of the study were distributed and subsequently consent forms were signed by the carers prior to the interviews. All participants received a copy of their consent forms and will also receive an executive summary of this report. Ethics approval was obtained from the University of Western Sydney. The interviewer was well informed about community care programs and able to provide carers with appropriate referrals to counselling and other services if required.

### **8.6 Profile of the carer participants**

#### **8.6.1 Anglo-Australian carers:**

The ages of the 8 Anglo-Australian carers ranged between 45 and 65. Five of them were looking after their spouses, two were looking after their daughters and one male carer aged 55 was looking after his mother.

#### **8.6.2 CALD carers:**

The ages of the 34 CALD carers ranged between 40 and 85. A total of 11 (6 female and 5 male) carers were looking after their spouses, 9 (2 male, 7 female) carers were looking after their parents, 12 (female) carers were looking after their children and one couple was looking after their grandson. Length of residence in Australia did not translate into knowledge of services, with some carers having lived in the country for more than 30 years but still unaware of the services available. Furthermore, the level of English language proficiency did not relate to length of residence with some carers requiring interpreters despite living in Australia for more than 20 years.

The majority of carers interviewed were from Western Sydney. Western Sydney has a population of over 1.7 million people with almost one third of residents born overseas. When combined with second-generation immigrants, the total CALD constituency increases to one in every two residents and there are over 100 nations represented within the region. For this reason, the choice of Western Sydney, along with the University of Western Sydney's position and networks within the region, seemed an appropriate choice to locate the

study. A small number of carers (3) were from North Sydney and 2 from the Eastern suburbs.

The following tables summarize the profile of the carers interviewed:

### Country of birth

Country of birth	Male	Female	Total
Australia	1	7	8
Afghanistan		1	1
Argentina	1	1	2
Armenia	1	2	3
East Timor		1	1
Egypt		2	2
Fiji		1	1
Greece	1	3	4
Iraq		1	1
Lebanon	1	2	3
Former R. of Czechoslovakia		1	1
Former R. of Yugoslavia		2	2
Jordan	1		1
Macedonia	1	2	3
Philippines		1	1
Papua New Guinea		1	1
Poland		2	2
Peru		1	1
Syria		1	1
Uruguay	1	1	2
Vietnam		1	1
<b>Total</b>	<b>8</b>	<b>34</b>	<b>42</b>



### Length of residence in Australia of CALD carers

Residence by years	0-5	5-10	10-20	20-40	Total
Afghanistan	1				1
Argentina			2		2
Armenia			1	2	3
East Timor	1				1
Egypt			2		2
Fiji		1			1
Greece			1	3	4
Iraq	1				1
Lebanon		1	2		3
Former Republic of Czechoslovakia	1				1
Former R. of Yugoslavia		2			2
Jordan			1		1
Macedonia			2	1	3
Philippines			1		1
Papua New Guinea				1	1
Poland				2	2
Peru				1	1
Syria		1			1
Uruguay		1	1		2
Vietnam	1				1
<b>Total</b>	<b>5</b>	<b>6</b>	<b>13</b>	<b>10</b>	<b>34</b>

### Person being cared for

Spouse	son/daughter	grandchild	mother/father	Total
16	14	1	11	42

### Number of frail elderly and people with disability or both being cared for

Frail elderly	Children with disabilities	Young adults with disabilities	Adults with disabilities	Frail with disability
13	4	6	9	10

### Number of carers working or receiving Centrelink entitlements

Carer	Employed	Carers payment	Pension	Carer Allowance	No benefit
CALD	5	4	8	7	10
Anglo	2	1	1	3	1
Total	7	5	9	10	11

#### **8.7 Issues affecting the interview process**

This project employed qualitative research methods. As such, the interviews with the carers were conducted individually to facilitate in-depth exploration of the specific issues pertinent to that particular caring role. Most of the interviews took place at the carer's home and in the majority of the cases without the presence of the care recipient. Some interviews (6) were however conducted in the presence of, and in some instances, with the input of the care recipient at the request of the carer who saw no reason why the person they cared for should not be present. This highlighted for us the problematic nature of labelling individuals according to a specific role 'carer' when there are a complexity of dynamic and evolving roles taking place simultaneously between the carer and the care recipient.

A small number of interviews (4) were conducted with the care recipient being present due to unavailability of alternative care arrangements rather than as a preferred choice by the carers. In these instances some apprehension to discuss issues such as the difficulties involved in the caring role, became obvious due to the sensitivity of the caring relationship. In three cases, two involving CALD carers, the carers requested not to be contacted at home and one interview had to be re-scheduled three times because of the care recipient knowing that 'something was going on' and not wanting the carer to discuss any issues pertinent to the caring situation. The complexity and, in some instances, the dependent character of the relationship between the carer and the care recipient (as well as the efforts to contain the perceived threat that outside intervention brings to this relationship) became evident.

Relevant to this interdependency between carer and care recipient was the issue of carers not accessing services due to the wishes of the care recipient. Also some families were not using services because they catered to either the carer or the care-recipient but did not offer the opportunity for both to use the service together. This is illustrated by the following comments about respite care:

I don't understand why I can't take the respite with my daughter. If we both get the respite I can relax because she is with me. (Karina, from Macedonia looks after adult daughter with disability)

#### **8.8 Use of interpreters**

Interpreters were used on request of the interviewees, with some carers preferring not to have an interpreter despite acknowledging low level of English fluency. On a couple of occasions carers indicated their preference for a friend or community worker known to them to act as an interpreter rather than using a professional service. Issues relating to relations of trust with

community workers and apprehensions that personal information could be disclosed to communities suggested the vulnerable position experienced by some carers in relation to their social and cultural identity and positioning within their own communities.

Some of the interpreters accessed through professional interpreter services lacked the expertise to translate due to discrepancies between community languages in Australia and the spoken dialect of recent migrants. Telephone interpreting was used in one of the interviews but this proved ineffective as it limited the opportunity for the carer to elaborate and be self-reflexive.

### **8.9 Volunteering information**

This was in some instances a reflection of personality and culture but in others cases it also reflected notions of individual rights and issues of control and power. Carers, particularly those older and from CALD backgrounds with limited English language skills were in most cases less inclined to acknowledge difficulties in providing care, fearing that this could lead to institutionalization against their choice. This perception, sometimes based on previous experiences, of limited individual rights to resist diagnosis, labelling and removal was also identified in research with Dutch elders (Kruijer 1990). Perceptions such as these were an additional factor inhibiting service usage and disclosure of need.

Present or past interactions with state institutions and government agencies can create anxiety and fear particularly around issues of state control. This was evident in some of the interviewees with regard to signing consent forms. Some participants, despite constant reassurance, feared their signatures could imply consent for unwanted forms of state intervention. This issue has broad implications for why some choose not to access services.

### **8.10 Conclusion: Methodology**

#### **8.10.1 Cultural research:**

- Culture and ethnicity are multidimensional and fluid concepts rather than a monolithic set of static norms and values.
- Cultural diversity is approached in terms of cross-cultural interactions at an interface in which all parties bring certain cultural frameworks.
- Emphasis is placed on the cultural context in which interactions between providers and carers occur.
- The caring experience is shaped by both cultural and structural factors.

#### **8.10.2 Definition of a Carer:**

- The research employs Carers NSW definition of a carer as 'someone who looks after relatives or friends who have disability, chronic illness or are frail aged'.
- Participants were recruited from various community groups and organisations including ethno-specific organisations, carers' networks, religious and cultural organizations and health services.

- Participants had diverse histories in terms of migration and length of residence as well as English language skills.

#### **8.10.3 Carer participants:**

- 42 carers took part in the study, 34 from CALD backgrounds and 8 from Anglo-Australian background.

#### **8.10.4 The interview process:**

- The majority of interviews took place at the carer's home and without the presence of the carer recipient.
- In situations where the care recipient was present there was sometimes apprehension to discuss personal caring issues.
- At other times it was assumed that the relationship between carer and care recipient was more than a closed unit, allowing for an inclusive three-way conversation to occur.

#### **8.10.5 Interpreters:**

- Interpreters were either offered or made available on request.

## 9 Research Findings

### 9.1 *More than a carer: Labels and relationships*

Identification with the role of 'carer' acted as a strategic means to access services, including Centrelink payments. Yet this identification was rarely used to describe the relationship between the carer and the care recipient. A degree of cultural competence was required to understand the utilitarian value of self-defining oneself as a carer in order to become a recipient of services and payments. This degree of cultural competence varied between individuals and had a direct impact in their ability to access services and payments. Beyond being a useful label for transactions with service providers, the term carer was of little consequence to most interviewees, as indicated in the following comment from a participant (self-identified as a carer with Centrelink):

Oh, there's so many names. I mean, I don't have time to be involved in that garbage, worried about what names, what they want to call stuff. I don't have time to be involved in that. (Jennifer, Anglo-Australian, looks after young adult daughter with disability)

The difficulty some carers, particularly from CALD backgrounds, had in identifying themselves as 'carers' reinforces previous research that demonstrates that caring roles within family contexts are continuous relationships:

(I am) a carer, and more than a carer! (laughs) You can call me a nurse, a carer ... I do everything for him. Not only a carer. You name it. Everything. (Emilia, from Lebanon, looks after frail elderly husband with disability)

The fact that a carer's payment is income tested means that little recognition is given to the amount of work involved in caring. The result is a growing number of mainly women who are low income full-time carers (Millward 1998). This policy assumes that carers provide care as part of their family responsibility. Such an assumption sits uncomfortably with many of the interviewees who saw their contribution at best as unpaid work or at worst as simply taken for granted:

As a carer I think I qualify for some allowance, considering that for over ten years I have been caring for Michael, not picking up any allowance or pension or pharmaceutical benefits, which has saved the government an awful lot of money. (Marcia, Anglo-Australian, looks after husband with disability)

What can I do? He's my son. I don't look after him for the ninety dollars, you know what I mean? Because he's my son, even if they didn't pay me that money, I'd look after my son. But if he was somebody else's son, I wouldn't look after him for ninety dollars! A fortnight, I'm talking about! (Zarohi, from Armenia, looks after adult son with disability)

It shouldn't be based on your income. If you are doing a job, you are doing a job, right That's all there is to it. (Karina, from Macedonia, looks after adult daughter with disability)

My husband and I could say that we're separated, go down to Centrelink, fill out the forms, put his clothes in another bedroom, I can get \$430.00 a fortnight for carer's payment and stay at home for \$430.00! But you don't do that. It's a moral issue. I get \$92.00 or \$94.00 per fortnight for carer's allowance, which is not means tested. (Jennifer, Anglo-Australian, looks after young adult daughter with disability)

Carers who were receiving the carer's payment (only a minority of the interviewees) had less difficulty identifying themselves as carers. This points to the connection between financial remuneration and identification with the role of 'carer'. Identification with the role of carer was also in some instances correlated to the more specific provision of personal care such as toileting and showering. When personal care of this more intimate nature was not required the caring was often understood as part of family work.

This raises significant questions regarding the boundaries people may consciously or unconsciously draw around issues of physical care and where it sits in relation to medical and health care. Physical care is associated with the daily activities of ordinary living (getting up, going to the toilet, washing, dressing, preparing and eating food, going shopping, washing clothes, maintaining a home). As Aronson (2002:3) writes:

Against medicine's claims to scientifically-based treatment, cure and rehabilitation, the purposes and outcomes of physical care are vague. Its association with the mundane and domestic means that it is easily overlooked, trivialised and pushed into the private domain of families or commercial care markets.

The relationship between carers and care recipients is often affected by other interactions and configurations between the carer and other family or non-primary carers. The way in which such multiple interactions provide different dynamics in the caring relationship needs to be acknowledged and explored given the impact it has on carers' ability to make choices, access informal support and engage in different non-care related activities.

I would like a bit more support with my son. I want a sibling's peer support. The Respite Centre had organised one evening with a psychologist, but I think it was a bit too late for my son. He's older than Maria (care recipient) and he feels there's nothing they could do that would change the conditions that we're living under. He thinks this is going to be for the rest of our lives. And he's right, in one sense. He's right. It is going to be for the rest of our lives. (Olympia, from Greece, looks after adult daughter with disability)

I haven't got time to rest ... I'm busy all the time. If not with him, then with the baby (grandson). I have the baby Monday, Tuesday and Friday. Three days. (Lana, from Egypt, looks after frail elderly husband)

My son lives far away. If we need to go to the doctor, he has to take a day off from work, this is sometimes not possible. (Interpreter for Theresa, from Poland, looks after frail elderly husband)

Also important to highlight are the instances where carers had positive interactions with service providers and the efforts and commitment of individuals within the NSW Department of Ageing, Disability and Home Care and community organisations to improve service quality.

They (Community Transport) go around picking people up and we have a talk and go to the shops and rush around and do our shopping and then sit down and have a talk. That was so good. That was such a help. (Lina, from Papua New Guinea, looks after frail elderly husband)

You don't know because you were born here. When you go somewhere like Europe, you can see how good Australia is. I'm on the pension. It's enough for me, the pension. It's enough. I don't complain. I have a doctor for nothing. Medicine is cheap. What do I want? I don't care about some big money. But my daughter has very good schooling, very good services here in Australia. (Irene, from Poland, looks after daughter)

One aspect of the caring experience that was consistently reinforced by all carers interviewed was their profound concern for the well being of their loved ones. This concern took many shapes and impacted in different ways on all carers. Indeed, it was this very concern of the carers for those close to them that led them to form opinions about what wasn't working in the formal care system. These diverse personal accounts of non-encounters and encounters with the HACC system generated real and heart-felt stories.

Money is always not a problem for people – money is a problem, but it's not always when there is a need for love and care, for support. It's very important. Someone smiles at you, or takes you by the hand to go and sit in the sun outside, to have a walk, to chat with the plants and animals, that makes your mind more fresh, more clear, and you have less pain, your pain is relieved, and you feel you are wanted in this society. When this society puts you indoors, when there is no support, how will a person feel? He will feel more of his pain, more of his trouble, and he will feel isolated. It's happening – if you go and look in different houses, you will find much of this happening. (Ronda, from Fiji, looks after frail elderly mother)

But I see it's alright, it's alright now with services, but I am still scared: what will be after? What will be after? (Elena, from Poland, looks after daughter with disability)

As the above quote demonstrates, satisfaction with present services can coexist with concerns about the future. Our research found that the attitude of carers to HACC services was most often complex and ambivalent rather than categorically positive or negative. Also, it became evident that carers were often located neither fully within nor completely outside of the HACC system. For instance, some carers were utilising community transport but no other services. Among these, many were unaware that this very service was provided through government programs. There is a need for both researchers and policy makers to be aware of the complexity of carers' relations to the official systems of home and community care.

## **9.2 Carers and culture – Cultural notions of caring**

Some carers understood the caring experience to exist within a limited time framework, particularly those looking after their elderly parent. The expectation of an imminent end to their caring relationship meant that they had short term commitments to caring with the view of returning to a 'normal life':

If she dies within the next five years, then I will return to my normal life, and I hope to pick up the pieces again, but I don't see myself working full-time again. You don't know what's ahead. I'll have to pick up from where I left off. Just be independent again. (John, Anglo-Australian, looks after frail elderly mother)

The perception that life is being put on hold while taking a caring responsibility was a cause of anxiety and contradictory emotions for carers who not only wanted to provide care but also to participate in other meaningful social and economic activities. This need was more strongly articulated by carers who had previously been in paid work in Australia and who had developed social interactions through paid or voluntary work.

That would be lovely, if I knew that somebody would come and look after him for a full day, because I want to work. I used to work and be independent. (Emilia, from Lebanon, looks after elderly frail husband with disability)

Ethno-cultural beliefs concerning the role of the family in providing care were more often articulated by CALD carers to explain the caring relationship. References to cultural practices in their country of origin were often an attempt to fill in information gaps and position themselves and their caring experience within a historic and geographical cultural framework. These references may have a nostalgic component as carers come to terms with changes in the way the family views its responsibility of caring:

Our culture was different. We support the families from birth to the end, to be in a supportive environment. But it's changed now. It's almost close to thirty years, fifty years, it has changed a lot. People have started to move around, to be into themselves. Families supporting themselves to be themselves, and the amount of hours that was spent with the family as a unit, it's broken up. So, everywhere it's happening. The unit has broken. (Ronda, from Fiji, looks after elderly mother with disability)

Trying to negotiate the role of carer according to at times ambiguous and undefined interpretations of what a 'carer' should be, often demands creative negotiations of one's sense of self and personal identity within different contexts. The need of many carers to maintain a sense of personal identity besides that of a carer through interactions with others and by having time away from caring responsibilities (but not necessarily away from the care recipient) was strongly articulated by many participants:

I also do a volunteer job for Centrecare, because I love to do it. That is the time that gives me freedom to search my feelings. I want to have my experience, and one thing is good for me, and that is to go out and talk to others. And it really made me, myself, confident and I feel not lonely. (Tina, from East Timor, looks after son with disability)



I love the time I spend with the nuns. We can sit and chat for hours. My daughter can run around and someone would look after her. (Karina, from Macedonia, looks after adult daughter with disability)

If everything is OK, if I haven't got a stress, it's OK, but if I have something like this stress, it's too much for me. I can't handle it. And I think if people are going to care for someone in the future, they should think about it. Not just probably half way ... Like for carers, it's very important to get out for a longer break. Like, maybe two months ago I had a holiday for five days. It's not much, but it was fantastic. I visited my friends. And it was so nice to get up in the morning and not to think about anything. To have a coffee with them, to have a laugh, no responsibilities. (Helena, from Former Republic of Yugoslavia looks after frail elderly mother)

I go out and I can leave the house a little bit, talk to people. It's really good for me. When I go out, I might joke a little bit. I won't completely forget about my problems, but I change. Not many people know I have problems. (Komala, from Greece, looks after 2 young adult daughters with disability)

Helena's comments exemplify the notion that once the carer's role is formally assumed (in her case by leaving employment and accessing the carer's payment) there is little room for going back. Yet the very absence of a formal contract for carers means that they must individually (or in association with family) either already know or decide what they should be asking for or expecting from services and from themselves. The participants also drew attention to the fact that different government agencies can have different expectations as to what a carer should be doing and that this can lead to conflict and added stress:

I do feel that every now and then I need a break. And last year, because I put him (in respite) for two weeks extra, they penalised me at Centrelink ... But Centrelink gives me less than two hundred dollars a week and then treat me like that! (crying) I don't need that, because I'm not sitting down here bludging. (Emilia, from Lebanon, looks after elderly husband with disability)

Respite in that sense doesn't work. They provide support for families, but I thought – well, what? So then they're going to come in and then they see, 'OK, there's one parent who's really depressed and there's one parent who can't cope,' and then I end up having DOCS on my doorstep, so there was no way I was going to ask for help. (Deborah, Anglo-Australian, looks after husband with disability)

Carers also expressed concerns about state surveillance and control over their lives and how it creates fears and inhibits their decisions to approach services and disclose needs. For instance, one carer referred to auditing procedures undertaken by the Guardianship Tribunal due to the fact that her disabled husband did not have Power of Attorney in place. Punitive measures in particular may consolidate feelings of fear and mistrust. While most carers are aware of the responsibilities their role brings, a more flexible and personalized approach may assist in allaying these perceptions about government invasiveness.

### **9.3 Diverse carers need diverse strategies**

Previous research on carers has highlighted differences between CALD and Anglo-Australian carers in terms of cultural perceptions of family responsibility, disability and illness, networks of support available and usage of community care services (Ethnic Disability Advocacy Centre 2003, Plunkett & Quine 1996, Thomas 2003). However culture and ethnicity as frameworks of reference, although important, can offer only a partial explanation for diversity in experiences and service usage. These concepts run the risk of becoming the only framework of reference to explain disadvantage and exclusion from participation in service usage.

Often ethnicity and culture are understood in terms of 'problems' or 'barriers' CALD communities face. This assumes that cultural identity is fixed and unified. It also encourages policy interventions that seek to educate, redirect and inform CALD carers so that they can fully participate in the mainstream culture of service provision and delivery.

The crucial positioning of culture and ethnicity in terms of power needs further analysis. As Couldry (2002:2) observes, power relations 'affect who is represented and how, who speaks and who is silent, what counts as 'culture' and what does not'. Focusing on cultural difference while ignoring power relations driven by other forms of social discrimination such as gender, economic and political participation can only reinforce current inequalities and entrench the positioning of CALD carers as problematic.

#### **9.3.1 Cultural attitudes on caring**

Research on CALD carers has identified that cultural attitudes impact upon on the level of service usage (Plunkett & Quine 1996). These attitudes include a stronger sense of family responsibility compared to Anglo-Australian carers (Thomas 1996) and a consequent reluctance to use nursing homes. Ethnicity and culture have also been linked to issues of prejudice among some CALD communities in relation to intellectual disabilities. Such prejudice leads to feelings of shame, guilt and isolation, particularly for mothers of young children with disabilities (Ethnic Disability Advocacy Centre 2003). Unpacking these issues is important to understand the extent to which cultural values in conjunction with gender, socio-economic status and notions of entitlement determine the outcome of interactions between carers and service providers.

#### **9.3.2 Anglo-Australian and CALD carers: similarities and differences**

There was a significant convergence of attitudes and values among the carers interviewed regarding the role family plays in caring for the frail and disabled. Most of the carers interviewed believed, regardless of cultural background, ethnicity or gender that they had a duty to care for their family members. This points to the existence of common cultural spaces (Couldry 2000). Nonetheless, CALD families referred more often to ethno-cultural values to explain their caring commitment while Anglo-Australian carers tended to describe this responsibility as one associated primarily with family roles understood outside a broader cultural frame.

This tendency of Anglo-Australian carers to understand their role as culture-free confirms other recent studies that suggest that Anglo-Australians - even if they are not actively prejudicial or discriminatory – often fail to recognize that they inhabit a racial category that carries with it a number of unspoken and largely unchallenged social benefits (see Riggs 2004). For carers from a CALD background, the perception that their role is embedded outside of the mainstream Anglo-Australian culture can lead to a reluctance to request service provision that would accommodate or draw attention to their specific cultural needs.

### 9.3.3 Personal care

In attempting to explain their caring role, several CALD carers made recourse to traditional perceptions of gender, age, and social positioning to describe the process by which the work of caring is assigned or assumed within the family. Diverse views were expressed regarding the capacity of carers to fulfil caring roles. On one hand some of the male carers cited gender issues in personal care as a barrier while on the other hand traditional roles were challenged. When personal care, including showering, dressing and toileting was involved different attitudes emerged regarding the extent of the responsibility and capacity to provide this care:

Only in extreme cases people go to nursing homes (in Uruguay). Only in extreme cases they go to a nursing home, when they can't look after themselves like bathing or doing personal care. My father can take care of himself, that's why he doesn't go to a nursing home. He agrees with me that once he can't look after himself he will go to a nursing home. (Aurora, from Uruguay, looks after frail elderly father)

My daughter, she can not help us at all ... she has no courage and no patience ... We can't count on her. It is preferable to have a neighbour than her to assist us. (Javier, from Argentina, looks after wife with disability)

Because she needs to change the nappy ... It's not right for the son to help the mother. (Abdulah, from Syria, looks after frail elderly mother with disability)

Looking after him day and night is not easy. And I'm not young ... Well, he can't open his bowels, so I have to always watch his bowel. Like every third day, if he doesn't open his bowels, then sometimes manually I have to bring it out ... This is a new thing for me, looking after him. He's completely incontinent. Paralysed. Can't feed himself ... So it took me a while to adjust to a new type of work as a carer. (Emilia, from Lebanon, looks after frail elderly husband with disability)

These comments suggest diverse interpretations of the caring role in relation to personal care. The extent to which carers see it as their responsibility to provide personal care varies according to cultural, gender values and the relationship between the carer and the care recipient. The assumption that family members are best positioned to provide care, especially personal care, must take into account cultural perceptions around bodily contact and gender practices.

#### **9.4 Workforce development issues**

The status attached to the work performed by paid carers also needs re-evaluation given the poor financial remuneration, training and work conditions faced by women in these jobs. The impact of poor training and work conditions on the quality of care was an important issue identified by some of the carers interviewed:

She (respite care worker) didn't even know how to talk to my daughter or what to do with her. (Karina, from Macedonia, looks after adult daughter with disability)

Costs and financial difficulties may stop many carers from accessing services, creating a vicious circle of poverty, dependency and under-utilization of services.

Well I just don't – I really don't understand how you can stop somebody who wants to go to work. I mean, they'd be receiving money back into the community with me going to work, which is the taxes, to turn around and pay for all the people who are on the dole and benefits! They're stopping me from doing that ... because I can't afford care! So you shut down. You just shut down. (Jennifer, Anglo-Australian, looks after young adult daughter with disability)

They (services) are doing a lot of things for him, and I can see there is a lot of improvement. He's not able to sit, he's not able to, but they provide a good service and I'm quite happy with them. But the point is, I'm going to have to withdraw him because of my finance problems ... We should have the right to have that money (payment), not based on our household income. Why? Because they only see how much we earn. They don't realise how much we spend. (Tina, from East Timor, looks after son with disability)

They need someone to help with personal care for Julia at least once a week. One of the other ladies said her mother receives personal care for free, and that's what they basically wanted to have. (Mr. and Mrs. Zodakh, from Former Republic of Yugoslavia, look after granddaughter with disability)

Socio-economic issues played a critical role in determining the resources that carers could provide for family members. Caring for a family member not only restricts ability to participate in paid employment but also brings extra expenses (ABS 1998, NATSEM 2004). Given the gendered nature of caring, it is women who are the most economically disadvantaged by their role as primary carers (Carers Association of Australia 2000).

#### **9.5 Under-utilization of services**

Under-utilization of services was not only the result of financial constraints but also related to negative experiences and/or perceptions of these services. The need for culturally appropriate services to meet the specific cultural needs of CALD carers and their families has been extensively documented in other research (Ethnic Disability Advocacy Centre 2003, Plunkett & Quine 1996, Thomas 2003, St George Migrant Resource Centre 2004). Calls for more flexibility in service delivery to accommodate specific needs, for the review of assessment procedures, and for staff training and promotion are only a few of

the many recommendations made by a recent report on carers (St George Migrant Resource Centre 2004).

The provision of emotional support for carers must take into account cultural perceptions around the disclosure of need and models of counselling, given the reservations some carers may have about accessing support services.

I think this is more like a personal matter, so it's not a good thing to say things outside if you can do things yourself, but people have to understand with their own mind how we can help each other. It's no use saying things outside when you're not getting any help. You will only be talked about. (Ronda, from Fiji, looks after frail elderly mother)

No, we don't use a lot of counselling. Because I'm not a person who likes to talk about it. I always want to swallow it. (Tina, from east Timor, looks after son with disability)

The cultural framework informing service provision requires further attention given the concerns of many carers with the attitudes, values and quality of services being provided:

I didn't like the service because he was locked up. He had his bedroom and he couldn't walk around. He could only walk around the part he was put into, you get what I mean? And if I went in to see him I had to press a bell to get in, and then I had to press the computer to get out ... they were frightened of Dennis taking off. My daughter told them about taking off ... we didn't realise when she said that, that he was going to be locked up. (Matilda, Anglo-Australian, looks after husband, talking about in-service respite care)

When carers come to look after them (elderly frail people) they should spend time with them. Some of them will talk on mobile phones. Some of them will read the newspaper, do the crossword ... and specially with elderly people, they need a bit to talk to them, be nice to them. (Helena, from Former Republic of Yugoslavia, looks after frail elderly mother with disability)

Another time, someone else came to help me with cleaning the bathroom ... she used to come but never cleaned it properly ... one day I showed her the Ajax, to give her a hint that she should be using it ... she didn't clean it. Just water. But she didn't ... I'm very upset because they come to help you out, but they don't help you. Whoever comes, they don't go and do their job properly. They don't go in the corners to clean, to dust ... 'We're not cleaners,' they say. (Maria, from Greece, looks after adult son and daughter with disability)

Looking after the frail elderly at home was for some carers not a matter of choice but the only alternative given the negative perceptions of nursing homes. Further research needs to look at the culture of nursing homes and how it approaches later life, given the apprehensions and at times fear associated with institutionalized care:

Because I work there (nursing home) too. I see sometimes different things, and I don't like to say. Maybe nurses, maybe staff. It's very hard. But I can't do anything. I work just for food. (Carer's sister from Syria, looks after frail elderly mother with disability)

Nursing homes are big business. They want people to go there so they can take 85 per cent of his money. That will kill my father. He likes to spend and manage his money. That would be the worse that could happen to him. (Aurora, from Uruguay, looks after frail elderly father)

(What I would like of a nursing home is) first when you go in, there is no smell! And a single room. Nice colours, so when the family wants to spend time with the patient, they can spend it like they're sitting at home ... They can watch TV, videos, movies and the patient feels like they are at home. (Sonia, from Lebanon, looks after frail elderly mother with disability)

Not all carers viewed nursing homes in negative terms. Some carers felt a sense of relief and security after having placed their relatives in a nursing home:

It's a nursing home at Greenacres, but it's clean, there's good care, and also, the food's quite good. I can't complain. (Sara, from Armenia, looks after frail elderly husband)

These comments reaffirm the need for cultural understanding and cultural dialogue between carers and services so continuity and consistency of care can be maintained. From this perspective calls for flexibility in service provision entail something more than accommodating difference. Rather, difference in all its manifestations must become the unifying common ground informing social policy.

Concerns with issues of under-staffing were echoed by many carers. These are also a concern for health and community workers (Health Services Union of Australia 2004). In recent times, there have been changes in the organisation of the public sector with an emphasis on performance management, outputs, concerns for resource rationalization and competitive tendering (Hoggett 1996). The impact of markets and competitions in the delivery of community care in Australia needs to be further researched, along with the challenges in the training and retaining of staff to maintain quality of care. In the case of CALD carers, these impressions regarding staffing levels may be influenced by issues of language, access to services, formal and informal networks, and expected quality of care. Regardless of the methods used to set staffing levels in the public sector, these perceptions themselves are relevant as they appear to contribute to client satisfaction as well as the use or non-use of services by CALD carers.

Furthermore, the majority of interviewees in this study did not distinguish between services provided by different government departments, making judgements that reflected their attitudes to general trends in service provision and social policy. These impressions are a challenge that any 'whole of government' approach must confront.

## **9.6 Language barriers**

Carers with limited English language skills, knowledge of the community care sector and/or cultural competence to locate services were often unaware or only partly aware of the help available to them. Lack of culturally relevant information in their first language makes this task even more difficult:

Yes, I'd like to have someone to help. But who is it? Nobody comes. And a lot of the information is in English, so I don't understand it. (Maria, from Greece, looks after adult son and daughter with disability)

All the material is in English and they said to her, 'Your daughter can translate to you ... but the daughter is never around. (Interpreter for Ahmara, from Egypt, looks after husband with disability)

Services were also refused to some carers on the assumption that language barriers could compromise duty of care:

She said that they refused (to provide the service) because of the lack of English. The fear was that once they come and there is no one to communicate with the worker and the girl, because the grandparents can't speak English, they can't say whether the water is hot or cold ... I tried to argue, saying that even if a person is English speaking, if the person has a disability, they can't let them know whether it is hot or cold, you know? But their reasoning was that because of occupational health and safety issues they couldn't provide a service for them, so basically they were rejected because of the lack of English. (Interpreter for Mr. and Mrs. Zodakh, from Former Republic of Yugoslavia, look after granddaughter with disability)

Instances where services are refused because of the language spoken by the carer should be treated as racial and cultural discrimination on the basis of ethnicity and culture and dealt with according to legislation. It should also be noted that according to the NSW Community Relations Commission and Principles of Multiculturalism Act 2000 it is necessary for public agencies to 'make provision for the culture, language and religion of others within an Australian legal and institutional framework where English is the common language' (NSW Government 2000, Section 3.1b). Similarly, the Premier's Memorandum No 98-22 states:

Since July 1989, it has been NSW Government policy that NSW Government agencies fund the provision of language services (that is, interpreters and translated materials) when dealing with clients, in order to provide all clients with access to Government services (NSW Premiers Department 1998).

Access to language services is the baseline for culturally competent service provision on the part of public agencies. The evidence of poor practice supplied by interviewees for this study suggests the need for investigation of this matter as a policy implementation issue.

Access to services was also found to be framed in terms of a hierarchy of needs. The distinction between needing and 'really' needing a service – for example, emergency respite – favours carers who are able to articulate their needs in terms of crisis but discriminates against those who are unable to clearly and/or forcefully express themselves. Needing a service may not always seem obvious, particularly for carers providing emotional support rather than physical and personal care.

She gave me a respite number and I rang. Two days later she calls me: you can have the service only if I need. I try to explain to them, I also study ... the respite told me that when I really (added emphasis) need like when I go

shopping, then I can call them. Because of my anger I'm not able to express anymore ... 'When I need? I need now, that's why I'm ringing! If I don't need why should I ring?' (Tina, from East Timor, looks after son with disability).

CALD carers with limited English language skills and minimal knowledge of and assistance in accessing the community care system often relied on friends and relatives to inform them about services. This often results in inaccurate or incomplete information that may deter carers from seeking formal support. This highlights the need of bilingual case workers who could act as cultural brokers and facilitate the transition from informal care to formal support and service usage.

### **9.7 Dealing with disability issues**

The stigma and prejudice in regard to disability, which is so often referred to as a prominent cultural value among CALD communities, has framed the discourse about CALD families (Ethnic Disability Advocacy Centre 2003, St George Migrant Resource Centre 2004). Carers in this study from CALD backgrounds had as many diverse views and values regarding disability as did the Anglo-Australian carers. Prejudice and stigma in relation to disabilities were expressed by some CALD carers when describing the cultural environment in which care takes place. However these attitudes were not articulated by all CALD carers.

CALD carers who referred to issues of stigma and prejudice regarding physical and intellectual disabilities felt less supported by their own communities and extended families. This added to their sense of isolation but also in some instances to their determination to provide the best care possible for their children:

No one in my family understands what it is like ... people judge you ... I don't promise, but in my mind and my heart I am going to do the job as much as I can until my last day. Even if I'm really sick or if I break my arm and I'm not able to carry him, or I break my leg or I have mental problems and I'm not able to. But while I'm good, I will take care of him until my last day. (Tina, from East Timor, looks after son with disability)

The effects of community stigma on the carer's own self-esteem and mental health need to be more fully recognized with the introduction of culturally appropriate support models by health and community services.

Carers looking after young children with disabilities expressed the highest need for immediate support. This was evidenced by their higher levels of emotional distress and concerns on the impact that the disability was having on the quality of life and future options for their children. The specific needs of these carers included immediate access to services for their children such as physiotherapy, speech therapy, and equipment as well as community services such as home support, carer's support, and community transport.

In relation to young adults with disabilities, reviews of the Adult Training, Learning and Support program (ATLAS), which led to the creation of two new programs, the Transition to Work program and the Community Participation program were perceived by some carers as falling short of meeting the



educational and training needs of their young adult children with disabilities. Despite the new focus on individualized training programs, some (3) carers saw in the new programs a significant reduction in the hours of training available for their children and the quality of the programs.

We want quality, and if they can make them budget a bit better, yes, fine, but don't reduce the quality of the service. What's the point in that? What are we getting? Maria does repetitive, boring work. It won't improve her skills, won't improve her social skills at all, or her behaviour, and she won't be able to improve her skills with other people, with her peers. She's become negative and she's become difficult. (Olympia, from Greece, looks after young adult daughter with disability)

Policies emphasizing ability, independent living and 'integration' into the community represent a social model that embodies the aspirations of people with disabilities and their organizations (Stuart 1996). But translating this model into practice remains a challenge. Recent changes to the post-school transition program have been identified by some of the carers interviewed as a step backwards. Indeed, some interviewees who care for young adults with disabilities have lost trust in the system, as the following comment illustrates:

My daughter has been left at home doing nothing, and this is a system that is supposed to support her. (Joanne, Anglo-Australian, looks after young adult daughter with disability)

The promotion of 'integration' and 'ability' does not necessarily lead to the creation of sustainable socio-economic and cultural conditions to support such laudable initiatives. This can result in unmet expectations and the erosion of confidence in the ability of the state to represent the rights and interests of people with disabilities. Such an inconsistency between social policy discourse and practice points to the complexity of the relations between people with disabilities and those who design and deliver services to them (Stuart 1996).

If everyone recognised people with disabilities, it would be ... I don't know. I know not everyone's as compassionate as each other, but boy, I wish they were sometimes because there's some nasty pieces out there. I mean, going to school – they're making all the schools now wheelchair-accessible, but there's no encouragement there at all. I mean, they still feel like a fish out of water, and that's not good. (Mary, Anglo-Australian, looks after young adult daughter with disability)

I remind myself, 'Come on. Come to reality, you deal with ignorant people. You're dealing with a society that thinks the world only belongs to them, or to good people, not to people with a disability'. (Tina, from East Timor, looks after son with disability)

An approach to disability that accounts for social and cultural context, if applied to social policy, would represent an important step in redefining need and shifting the focus from individuals to the systems and structures which limit people with disabilities. Such a shift in cultural thinking about disability would also need to approach difference, including ethnic and cultural difference, not as a problem but as a tool to galvanize critical reflection on

notions of inclusion, cultural diversity and civil rights in Australian society.

### **9.8 Carers and mental health issues**

The vast majority of the carers interviewed reported they had never had the opportunity to talk in depth about their lives, their relationship to the family member they were caring for and the impact it has had on their daily existences. This research provided many with the opportunity to be heard for the first time, which was an overwhelming experience for many carers who were still grieving for their child, sick partners or parents. It became evident through the interviews that many carers were also grieving for what they saw as their own loss of basic yet essential human needs such as personal space, meaningful interactions with other people and freedom to plan their daily activities.

Supporting the carer through this grieving process highlighted the importance of counselling and support services for carers as well as the need to consider, when conducting interviews, that more than one visit may be required to properly cover all the issues. This means respecting the carer's right to be heard and allowing them to focus on what is crucial to them. The disclosure of intimate and private information to a researcher can only be achieved by building up relations of trust over an extended period of time.

Mental health issues such as depression, dementia and Alzheimer's disease presented unique challenges for carers. Often the combination of physical and mental health problems proved overwhelming. The loss of communication, intimacy and joint decision making between couples due to mental health problems leaves carers in an ambiguous position in relation to their identity with their partners:

And certainly our relationship as a couple has certainly weathered under the strain of me vaguely feeling like I was carer rather than a wife. (Debora, Anglo-Australian, looks after husband with disability)

The reluctance of male partners to support their wives in looking after children with disabilities leaves carers in a vulnerable position and reinforces perceptions of women's responsibilities as the main carer:

And my only complaint is that my husband is not supportive in this way, and I will have to take this to my grave. And if he was to be more supportive, my life would have been different. (Kathy, from Greece, looks after 2 young adult daughters with disability)

Caring for someone with complex needs can also impact on the mental and physical health of carers and add to a sense of hopelessness:

My life is going to bed, sitting in the house, and going to the Plaza. That's my life, to be honest ... I don't have much hope for the future, I'll be honest about that, because I keep thinking to myself that by the time I can do what I want I'm going to be too old and sick. I might be in his (husband's) place, if you get what I mean. (Matilda, Anglo-Australian, looks after frail elderly husband with disability)

And I'm feeling guilty about what I'm wanting to do for myself. My sister's actually calling her a 'thorn' (laughs). We sort of laugh about it, but it's true. It's like a thorn in my side, and I haven't been able to pull it out all these years, and I do need that time for me now. I just feel so drained and tired. (Mary, Anglo-Australian, looks after young adult daughter with disability)

My only break is when she goes to sleep, and then I go to sleep too. It is my only chance to get a break. Sometimes she wakes me up in the night having an attack and I don't get a rest anymore. (Javier, from Uruguay, looks after wife with disability)

The different positions in which carers find themselves, the nature and severity of the disability, and the relationship between carer and care recipient highlights the fact that carers are not a homogeneous group dealing with the same challenges. The caring experience includes multiple experiences, moments of joy as well as demanding and challenging tasks. Often caring takes place in a constant, fluid and interconnected exchange of varied, complex and often contradictory emotions. This mitigates against trying to conceptualize issues of care around single issues or themes.

### **9.9 Notions of entitlements and citizenship rights**

In common understandings the notions of culture and citizenship are rarely seen as significantly related. Culture is understood to pertain to life ways, identity and community while citizenship is conceived of as a formal system of nation-state belonging, rights and obligations. Yet a recent study (Stevenson 2003) highlights the need to examine questions of rights and responsibilities far beyond the institutional agendas of mainstream politics. This means forming an understanding of the ways in which 'ordinary' notions of duty and responsibilities are constructed both within and outside of the formal structures of administration. In other words, there is a need to ask how questions of entitlement and duty relate to the diversity of culture evident in everyday life. In terms of this study, there is a need to rigorously examine the ways in which the cultural positioning of CALD carers, alongside other factors such as gender and socioeconomic status, conditions their sense of entitlement as regards access to support services.

Active engagement with formal care including initiating contact and negotiating services demands not only a level of cultural competence but also a strong sense of citizenship rights, responsibilities and entitlements. Notions of entitlement varied among the carers interviewed, depending on factors such as age, ethnicity, socio-cultural background, and settlement history. Feeling entitled to ask and to be provided with appropriate services had a direct impact on access and service usage. Some carers also expressed the need to be resourceful to ensure such access to services was met:

To get him into the day care I had to lie. I told them I lived there so he could get into the program. Close to here there are no services for the aged. So I got services by lying. For everything you have to lie to get what you want ... It should be enough to say 'he needs the service'. They make it so difficult for them and for us too. (Aurora, from Uruguay, looks after father).

In some cases, carers clearly understood the processes involved in gaining access to services but, experiencing difficulties and barriers in the system, asked those they perceived to have greater social status to intervene on their behalf:

He had to have his blood pressure taken everyday and his temperature taken everyday, and I couldn't manage him in the shower, and we couldn't get any help. We couldn't get the nurse, we couldn't do anything, so I went to the GP and he rang and he got it ... He has a lot of power! (laughs). (Fiona, Anglo-Australian, looks after husband)

I then had to go out, under this particular program, I then had to go and find a service that accommodated the needs that I thought were in Bridget's best interest. Now, I am capable. What about the other parents who are not capable, who can not advocate for their own child? ... Anytime I've needed to do anything with Bridget, I've gone and got a job with them (the service) to find out what they're like and how they operate, and then I've come back and, well, it's the only way to do it. (Anne, Anglo-Australian looks after daughter with disability)

Wanting to be a good citizen, not asking for too much or not wanting to burden the system were some of the beliefs articulated particularly by carers from CALD backgrounds. Migration history also resulted in complex and often conflicting perceptions of citizenship rights and feelings of gratitude along with fears of drawing attention to themselves, particularly for elderly carers.

We are grateful to be here in Australia, to get the pension ... the rest we can manage. (Julio, from Uruguay, looks after frail elderly wife)

He needs help with everything, he is blind and he suffers from cholesterol as well and he needs to exercise everyday but it is hard for us to walk ... My eyes are not good either ... We don't really need anything at the moment. I am still strong ... if we could have a wheelchair it would help me a lot ... but thank God we are still capable. (Laura, from Peru, looks after frail elderly husband)

We took the Oath of Allegiance to the Australian government when we came here and got our citizenship ... we like to work and be dependent on ourselves to support ourselves. Not to be a burden to the government. (Ronda, from Fiji, looks after frail elderly mother)

Notions of citizenship rights and entitlements reflect gender, age, socio-economic inequalities and/or an awareness of the individual's access to shared cultural resources. This highlights the need for strategies and processes, including assessment, to encompass a complex understanding of the cultural context and migration history of individuals and families who may require services.

### **9.10 Carers in a global and cross-cultural context**

Despite the diversity of local contexts and socio-cultural forces shaping the varieties of women's 'carework' experiences around the world, research has identified many commonalities in terms of the experiences of women in carework (Litt & Zimmerman 2003). These include women's predominant role as caregivers, the undervalued nature of carework and the integral role of caring in maintaining the existing fabric of society (Litt & Zimmerman 2003).

International research on carework has highlighted the extensive scope of women's unpaid and paid caring labour (Litt & Zimmerman 2003, Aronson 2002), the exploitation of women's carework being exacerbated through transfers of work across various boundaries and borders and from one social group of workers to another. The global context of care giving responds to inequalities which can pressure women into migration as careworkers, often leaving behind their own caring responsibilities and placing them in vulnerable positions given the 'hidden' context in which carework takes place.

Restrictive domestic immigration laws and social welfare policies in the First World increasingly structure women's carework through migration, pushing many toward vulnerable and exploitative work in nursing homes, middle-class domestic households and giving them only partial citizenship rights or none at all (Anderson 2000, Salazar Parrenas 2001). The movement of women from developing economies as service and careworkers to developed nations plays a significant and essential role in some countries where social and economic structures and family dynamics have resulted in a diminished number of carers available to look after the elderly and frail. Countries such as Israel, Japan, and Denmark rely on migrant women from countries such as Bangladesh, Philippines, Vietnam, Thailand and Brazil to fill in the gaps in the provision of care (Goss & Lindquist 1995). This study found that, rather than local services, some CALD families were using international connections, often through extended family relations, to meet the needs of care. While immigration policy is beyond the scope of this report, the issue of migrating relatives and availability of culturally appropriate carers are ones that will need to be addressed within a global context.

Concerns with the availability of suitable carers to provide quality of care were echoed through the interviews with some CALD families attempting to sponsor female relatives to migrate to Australia to take on the caring responsibilities they were unable or unwilling to fulfil. As in the carework examples discussed above, it was primarily migrant women who were assuming the burden of care.

She used to live with me all these years until two years ago. She is living now with my sister. She came from Lebanon to look after her. (Sonia, from Lebanon, looks after frail elderly mother)

My mother she says God bless you, and bless the government of Australia! ... My mother she needs her daughter to stay here (in Australia) ... 'no one under heaven can help me like she can help', she says, 'My son is busy with the children and talking to the school, the universities, things like that. Busy. There is no-one to help. And my daughter in law, she is also working and no-one can help, only my daughter, she can help'. (Abdulah, from Syria, looks after frail elderly mother with disability)

He put an ad in the Czech newspaper for a carer and Zhadia, who was visiting Australia got the job ... they got married to speed up the process with migration. (Interpreter for Zhadia, from Former Republic of Czechoslovakia, looks after frail elderly husband with disability)

They came here from Bosnia to take care of their granddaughter. (Interpreter for Mr. and Mrs. Zodakh, from Former Republic of Yugoslavia)

Some carers also resort to options such as sending the care-recipient overseas to other family members so they can be looked after in a culturally appropriate manner and the carer can have a break.

And if I'm going away for a couple of weeks or a couple of months, for example, by chance I am having a holiday coming up so my sister said, 'Send her over to Fiji, we will look after her.' So we share her within the family, so we don't feel that we are burdened with her. (Ronda, from Fiji, looks after frail elderly mother)

Those carers who recently migrated to Australia to take on caring responsibilities had very limited social interactions and opportunities to engage in activities such as learning English or joining local ethnic community organisations. In addition, changes to limit the range of social services and benefits available to new migrants have also impacted on the capacity of these carers to provide adequate care and afford essential services.

They have to wait another few months, until November, to be eligible for the pension. In the meantime they are on a special allowance ... she receives the allowance, which is not much ... sometimes they need help with paying the bills and everything. (Interpreter for Mr. and Mrs. Zodakh, from Former Republic of Yugoslavia, look after granddaughter with disability)

Zhadia doesn't know (about services) because she is not a permanent resident yet, and she doesn't have many rights, so she doesn't know much about services either. (Interpreter for Zhadia, from Former Republic of Czechoslovakia, looks after frail elderly husband with disability)

These comments raise the issue of specific disadvantages CALD carers face by virtue of their migration status and their ability to link in with access that is afforded Australian citizens. As discussed above, changes to limit the range of social services and benefits available to new migrants have a significant impact upon the capacity of carers from CALD backgrounds to provide assistance to other family members (Batrouney & Stone 1998).

Further research is also needed in Australia to ascertain the composition of the formal and informal care workforces, the socio-economic and ethnic backgrounds of its participants, their migration histories and employment statuses. If CALD households in NSW continue to use international migration to fill their care needs, this will have implications for policy development across a range of government levels.

### **9.11 Research Findings: Conclusion**

The following major issues were identified as shaping the experience of carers from diverse backgrounds:

#### **More than a carer: Labels and relationships:**

1. Most carers felt ambivalent about the term 'carer'. Rather they saw themselves involved in an on-going relationship within a family.

2. The term 'carer' was primarily invoked to gain, when possible, financial assistance from the government, for e.g. Centrelink payments. This was particularly the case when 'carers' were involved in the provision of intimate physical care.

3. Carers are not just carers. They also have other family, community and financial responsibilities. The ability for carers to access and navigate formal services directly impacts on their capacity to make choices and engage in other meaningful activities.

**Diverse cultures of caring:**

1. Ethno-cultural beliefs regarding the role of the family in providing care were more often articulated by CALD carers. By contrast, Anglo-Australian carers, while also perceiving care as a family responsibility, tended not to perceive their role as one shaped by their cultural background.

2. The above cultural references may integrate both past and present circumstances as carers come to terms with changes in the way the family views its responsibility to caring.

3. Approaching services and disclosing need can be influenced by a perception that formal services are keeping carers under surveillance. A more flexible and personalized approach may assist in allaying these concerns.

4. Many carers miss their financial independence and extra-familial social activities which impact on their own sense of physical and mental well-being.

5. While ethnicity can play a role in how carers negotiate the caring process, it needs to be placed in a broader cultural context in which other social, economic and political factors play an equally significant role. Isolating 'ethnicity' outside of these structures, creates a situation in which CALD carers become the 'problem' and people are expected to tailor themselves to the system rather than the system being tailored to meet the needs of the people.

6. In contrast to Anglo-Australian carers who perceive their needs as culture-free, CALD carers perceive their needs as culturally specific and this can lead to some reluctance in requesting service provision that might draw attention to their specific cultural requirements.

7. Responsibility for care, particularly intimate physical care, was generally taken up by women. This was the case for both Anglo-Australian as well as CALD carers. There was some evidence to suggest that among the CALD carers in this study, women were particularly disadvantaged in terms of difficulty in accessing financial aid and the provision of formal carer services.

**Workplace development issues:**

1. Lack of appropriate language skills by formal carers to adequately communicate with either the family carer and/or the care recipient.

2. Poor financial remuneration, training and work conditions impact on formal carers ability to care effectively for care recipients.

3. The level of training of paid carers impacts on carers' perceptions of the quality of care services can provide. This has particular consequences for CALD carers in that cultural competency skills are seen as something to be added on rather than understood as 'core' training.

4. The cost associated with accessing formal care, becomes a barrier preventing carers from re-entering the workplace, creating a vicious circle of poverty, dependency and under-utilization of services.

5. A clear distinction was made between the needs of caring for young adults with a disability and elderly care in relation to what is needed from service providers.

**Under-utilization of services:**

1. Several participants referred to the lack of culturally appropriate services.

2. Issues such as disclosure of need were embedded in cultural meanings which affected CALD carers ability/confidence to seek support. This impacts on the transition from informal to formal service usage.

3. The difficulties of cultural understanding and cultural dialogue between carers and services can lead to fears that formal care may not be able to meet the consistency and quality of care provided by the primary carer.

**Language barriers:**

1. Language issues were one of the major obstacles to locating and navigating services for CALD carers.

2. Availability of bi-lingual workers and interpreters was seen as an integral service for CALD carers in order to communicate with carers and care recipients as well as accessing appropriate services.

3. All service providers are bound by NSW legislation and policy to make interpreters available to clients when necessary.

4. CALD carers who were not proficient in English and who were unfamiliar with services available had more difficulty in articulating their needs both culturally and linguistically.

**Dealing with disability issues:**

1. Carers from CALD backgrounds had as many diverse views regarding disability as did Anglo-Australian carers.

2. Prejudice and stigma in relation to disability still exists within all communities. For CALD carers, this discrimination impacted on the level of support available to them from their own communities and extended families.



**Carers and mental health issues:**

1. Many carers while accepting their 'caring' role were also grieving for their former (non-caring) lives. This highlights the importance of counselling and support services for carers to be able to express and deal with their grief in a culturally appropriate manner.

2. Depression, dementia and Alzheimer's disease presented unique challenges for CALD carers. The combination of identifying these afflictions and knowing how to respond to them in terms of relating, caring and service provision were found to be particularly difficult.

3. Several CALD carers also identified their own battles with depression as former 'healthy' relationships with family members deteriorated.

**Notions of entitlements and citizenship rights:**

1. Wanting to be a good citizen for CALD carers sometimes meant not asking for too much or not wanting to burden the system.

2. Migration stories, particularly those that recounted journeys from countries where state surveillance and repression occurred, evoked complex and often conflicting perceptions of citizenship rights. The former was often accompanied by a fear of drawing attention to themselves. This tied in with feelings of gratitude towards Australia that often hindered disclosure of needs and requests for service assistance.

**Carers in a global and cross-cultural context:**

1. Concerns with the availability of suitable carers to provide quality of care were echoed through some of the interviews with CALD families. Indeed, in some cases female relatives were being encouraged to migrate to Australia to take on caring responsibilities.

2. Alternatively, some carers referred to sending the care-recipient to other family members overseas. This was generally in the context of having a break and knowing the care recipient would be looked after in a culturally appropriate way.

3. Carers who have recently migrated to Australia are particularly disadvantaged. For those who have limited English language skills, minimal informal networks and who are unfamiliar with the formal care system, caring is extremely difficult and isolating.

4. Changes to social services and benefits available to new migrants have also impacted on the capacity of CALD carers to afford essential services in order to provide adequate care.

## 10 Discussion

### 10.1 Tailoring needs to fit models

Important to the findings of this research are the social policies and institutional structures that inform community care. Globally there have been changes in the public sectors of developed countries with a new emphasis on resource rationalization, competitive tendering and output measures. This entails a concomitant shift that values program delivery over program performance (Hoggett 1996). Social values guiding social policy in Australia, as in most modern societies, reaffirm individualism and self-reliance. Dependence is stigmatized and the 'interdependencies inherent in human experience obscured' (Aronson 2002:2).

Responsibility for wellbeing and security are left in the hands of individuals expected to navigate mixed economies of care as self-interested and atomised consumers rather than as citizens with shared interests, rights and obligations. This individualising ethos is compounded for older people by a dominant imagery of successful or positive ageing that enjoins them to age actively and self-sufficiently. (Katz quoted in Aronson 2002:2)

The care of people at home and in the community is arguably the result of a discursive shift and attitudinal changes towards the ageing population and groups with disabilities – one that emphasizes choice, social participation and quality of life. These changes have been informed by policy research that has demonstrated the preference for home and community care over institutional care (Shaver & Fine 1995). The shift has also been driven by the belief in small government and the belief that families ought to look after their own members (de Vaus 1996).

The current policy of separating acute residential care and community care funding arrangements with acute residential care still capturing more of the long term budget (McCallum et al. 2001) means the emphasis continues to be placed on institutional care. This results in limited choices for high need consumers wishing to access services from home. If the consumer requires or chooses high-care residential facilities they will have all their accommodation and care needs met. Alternatively, if the consumer prefers or chooses to live at home with family support, even with high levels of dependency, they do not receive support for accommodation and may not have all their care needs met in a pressured HACC system (McCallum et al. 2001).

The money is not enough to cover all the money we are going to spend. Linen service, nappies, food, medicine, creams, patches for blood pressure, the beds, chairs, lifter ... all these things we need to pay for them. Like I know the government pays in a nursing home, so they can provide all the help and they have all the equipment there. They don't hire. I have to hire. (Sonia, from Lebanon, looks after mother)

Economic imperatives, de Vaus (1996) explains, are fundamental to the policy directions in aged care, with nursing home care costing about 12.4 times more than HACC services. The inability of HACC services to meet the level of demand, due to under-funding and other factors, de Vaus suggests, is

changing HACC from a preventative care system to a crisis care system. One result of this, he argues, is that there will be an increasing reliance on friends and family to provide the care and support for older people and people with disabilities that HACC and other aged care services cannot meet (1996:2). More recent reports (McCallum et al. 2001) point out the limitations of the HACC programs to meet the needs of high need consumers wishing to access services from home, leading to a reliance on family to provide care.

Eligibility criteria in the community care market give priority to people with acute needs and those without families. Carers, particularly those looking after the elderly, are often presumed to be willing and able to provide care (see also 9.3.2). The provision of services including help at home, maintenance and community transport is first given to people that have no family or carers to provide these services for them (Bittman et al. 2004). This need to prioritize services to target the most needy and vulnerable limits the access of carers – mainly women – to essential services (see also 9.6) that ease their caring responsibilities and improve their own quality of life and well being.

They take the attitude – which is OK, I suppose – that if you've got family, if they all pull together, then that's fine. You don't need outside help ... But it is not always available ... Or they could have a broken family, a dysfunctional family who are not close and haven't spoken to each other, that sort of thing ... They don't say 'Would you prefer a stranger or your family?' They just think that they can (have) someone else because you've got family. They might believe that family is better than a stranger, I don't know. (John, Anglo-Australian, looks after frail elderly mother)

This indicates a need for further clarification of the role of carer, which has become an important issue for social policy. Further research must address the problem of how to prioritize resources without penalizing caregivers. Internationally, it is interesting to note, the Israeli home care scheme virtually disregards the availability of informal care, on the assumption that to take it into account would be likely to penalise those with caregivers and provide an incentive to families to desert those in need of support (Bevan 1998).

A number of carers within this study expressed the opinion that social policy based on economic rationalism and on principles of self-reliance, independence and individualism undermines diversity and leads to standardization of needs. Carers judged that the capacity to tailor services to needs is limited by these constraints, meaning that needs are tailored to fit models of service delivery (see also 9.5). Calls for flexibility of services to accommodate difference must always face the reality of financial limitation. Nonetheless, an appreciation of difference is essential to meet the combined challenges of cultural, social and economic diversity within the Australian polity.

You've got to fit the service. The service doesn't fit you. And they were telling me when we were going down to Sydney last time that the people using the service had dropped off, and I think it's because it doesn't fit their needs. (Fiona, Anglo-Australian, looks after husband with disability)

Yes, I had to find a private service that was able to come at 8 o'clock ... Mum can't shower him and change him anyway, on her own, so I needed some help that early in the morning, but the community services didn't come that early. They came about 11 o'clock, which is too late. That was my main problem with them. It was a lot cheaper for my parents, but it couldn't be done. It just couldn't be done with them. (Liza, from Armenia, looks after frail elderly father)

Yeah, I never used respite ... why should Bridget go from a normal household to somewhere where behavioural problems were operating? I mean that's ridiculous. It would be just like saying, you know, the Prime Minister's sitting down there in Kirribilli House, but if he is going to go on holidays he should go on holidays to, oh, I don't know, where he'd normally probably go on holidays overseas somewhere, but instead we'd send him down to the blowhole at Kiama or something, you know! You can sit down there in a caravan! (Laughs) It's just a different lifestyle. (Jennifer, Anglo-Australian, looks after young adult daughter with disability)

This diversity of lifestyles and cultural values individuals bring to their transactions with services necessitates systems capable of approaching difference and cultural diversity integral to the very fabric of Australian society.

### **10.2 Cultural competence: Negotiating a complex system**

The capacity of carers to find information, make contact and negotiate services was influenced by what we describe as 'cultural competence' (see also 9.6). This encapsulates knowledge of how the system of community and social care works, including the culture of service delivery, language of care provision, and the power structures within and across both government and non-government organizations. The fact that many carers, particularly CALD carers, knocked at the wrong doors, did not know or use the 'right' language, and/or disclosed needs to the wrong person resulted in frustration and led to many participants taking on an excessive burden of care.

You'd hear their 'buts' sort of thing, and that put me right off. Of course, the community service down the road saying, 'Oh, we only do this ...' You can ring around so many places and they say, 'No, we only do this and we only do that.' (Lina, from Papua New Guinea, looks after frail elderly husband)

I used the ambulance service to take Dad to the dentist; I thought it would be much more comfortable. They said 'Why are you using our service? Why couldn't you just get a taxi?' I felt as if I was doing the wrong thing. So the next time I got a taxi. I didn't even ring them. (Liza, from Armenia, looks after frail elderly father)

Cultural competence not only requires the training of service providers but also relates to the ability of individuals in a society to make sense of others and be made sense of by others. CALD carers, particularly newly arrived migrants and carers, have diminished cultural competence to negotiate complex models of health and community care and articulate need in a language accessible to health practitioners and staff (see chapter 9, Research Findings: 9.6 and 9.9). The cultural framework informing service delivery displays little tolerance for difference, with its emphasis on uniformity and on individual need. This becomes evident in the CALD carers' comments on the inability of services to accommodate their specific needs, diverse cultural

frameworks and understandings of the caring experience. In the following examples, carers mention needs related to religion and dual access to respite:

Mum is all Friday by herself, and she likes to take a shower on Fridays because we are Muslim. She has to pray, to be more clean on this day. And always Mum has a shower without anybody there ... the service can come but not early in the morning. (Hadila, from Egypt, looks after frail elderly mother)

Respite would be good ... we both need respite. (Veronica, from Philippines, looks after frail elderly husband)

Attempts to help people negotiate the complexity of the community care system have been pursued through various strategies including the creation of Commonwealth Carelink centres to provide centralized referral and information on services. However not many carers, including some of those who knew what Carelink was, were aware of what it could do for them. This raises concerns about how information is constructed and disseminated and the importance of a personalized approach to assist carers in making sense of what services such as Carelink can actually do for them and their families.

Consistency in what is being promoted and what carers actually receive also needs further consideration given the number of comments about services not meeting initial expectations (see also 9.5). Disappointment often leads to withdrawal and under-utilization of service despite the obvious acute needs. This further promotes the cultural perception of carework and physical care as mundane and with blurred boundaries between the professional and the informal carer.

Sometimes, after he's finished with the toilet and the worker cleans him, sometimes after she's finished cleaning him, he wants to do again. So Ahmara cleans her husband (again), the worker says she's finished the first time, and Ahmara has to do a second time. (Interpreter for Ahmara, from Egypt, looks after husband with disability)

The role of Centrelink was crucial for most of the carers interviewed in terms of access to carers' payments and as a source of information about services. The reliance on Centrelink as a source of information is a logical connection made by individuals between payments and referral. Centrelink has the potential to play a significant role in referring clients to Carelink centres. Awareness of additional communication tools required to make this information accessible to CALD carers needs to be incorporated as well as strategies to address the apprehension and mistrust some carers have of government agencies.

### **10.3 Discussion: Conclusion**

Tailoring services to meet diversity of lifestyles, needs and cultural values necessitates approaching difference and cultural diversity as integral to the very fabric of Australian society.

Attempts to help people negotiate the complexity of the community care system have been pursued through various strategies, for e.g. the Commonwealth Carelink Centres that provide centralized referral and

information on services. However, there appears to be a gap between these strategies and dissemination of information about these strategies.

## **11 Conclusions and Recommendations**

### ***1. Translation and interpretation***

#### **Conclusion**

1.1 Language barriers still remain a major obstacle in disseminating information to CALD carers and informing them about their entitlements and the strategic value of identifying as a carer.

#### **Recommendations**

1.1 Re-evaluate translated materials. Identify the major language groups and ensure that translations appropriately describe and explain the pathway to and through services.

1.2 Train interpreters to recognise the broader cultural needs of carers. Although interpreters should not be expected to mediate between carers and government, they could, with such training, perform a role in referring carers to a cultural broker (see 2 below).

### ***2. Cultural brokers***

#### **Conclusion**

2.1 Cultural competence not only requires the training of service providers but also relates to the ability of individuals in a society to make sense of others and to be made sense of by others. There is a need for cultural brokers, i.e., expert mediators with interpreter skills, familiarity with the administrative aspects of relevant government programs, and the ability to work across both government and non-government organisations. The role of these workers should in no way be understood as a way to alleviate the legislative obligation of government services to provide adequate language services when dealing with clients. Culture cannot be reduced to language alone. Therefore there is a need for cultural brokers to i) explain the strategic value of identifying as a 'carer' and, ii) provide culturally appropriate information and personalised guidance as how to access benefits and services.

#### **Recommendation**

2.1 Pilot a program in which cultural brokers work between government and community.

### ***3. Re-conceiving points of entry***

#### **Conclusions**

3.1 The results of this qualitative research suggest it is incorrect to assume that CALD carers exist either wholly within or fully outside of the existing service provision arrangements. Many CALD carers including the so-called 'hidden carers' may use one or two services without necessarily being aware that they are provided by Government.

3.2 Community organisations can assist governments in disseminating information to carers who may experience barriers in accessing information directly from government departments. Clients who resist dealing with

government agencies due to concerns about privacy or a minimal sense of entitlements may be more likely to access services introduced to them in this way. Cultural brokers would have an important role to play in facilitating this process. There are a range of other factors that shape the situation of carers and may be strategic in identifying 'carers' and disseminating information. For instance, informal networks based around clubs or religious affiliations or key locations where carers perform daily activities (for e.g. shopping malls, general practitioner offices or public transport) could be used to present information in a respectful and discreet manner.

3.3 Centrelink is an important institution in the dissemination of information to carers. However, CALD carers perceive that the available services do not always match the complexity of their needs.

### **Recommendations**

3.1 Develop collaborative partnerships with community and non-government organisations to identify alternative and multiple points of entry for CALD carers. These points may well exist within the grey areas, neither inside nor outside the system, for e.g. community transport, clubs, religious organisations etc.

3.2 Encourage Centrelink, through innovative partnerships, to play a more significant role in referring clients to on-going services such as Commonwealth Carelink Centres.

## ***4. Building flexibility into care plans***

### **Conclusion**

4.1 Care plans must be culturally appropriate as well as spanning the variety of situations within the care spectrum. For instance CALD carers may experience particular cultural sensitivities around the care of children with a disability or elderly parents. There is a need to design short and long-term care plans with flexibility that takes into account the dyadic nature of the care relationship and the diversity of family structures. Cultural brokers can assist in the task of designing care plans that account for the specific circumstances of newly arrived migrants including extended family members who are brought to Australia to assist with support. They can also assist CALD carers at the points of entry and exit from the care relationship providing information as well as referral to and mediation with the appropriate services.

### **Recommendations**

4.1 Develop flexible care plans that meet the specific needs of CALD carers.

4.2 Assess feasibility of using cultural brokers as the main agents in the development of flexible care plans.



## **5. Service provision training**

### **Conclusion**

5.1 Cultural competency should not be approached as an add-on to existing training but be incorporated as part of training in all areas of service delivery. Cultural brokers could play a role in training the trainers within service provider organisations.

### **Recommendations**

5.1 Provide education and training to service providers to work effectively with interpreters and/or cultural brokers.

5.2 Provide education and training to interpreters to work effectively with service providers and identify the need for cultural brokers.

## 12 Future Research

Commissioned as a pilot study, *Diverse Strategies for Diverse Carers* generated an unexpected amount of material. This was largely due to the activities of the researcher. Her connections to the realities and her personal and professional knowledge sustained this project. This resulted in a huge amount of rich cultural material which could not be done proper justice due to the length and budget constraints of the project. Further research should address the following tasks:

1. To conduct a research project on the links between carer's well being, quality of life, appropriate social services and infra-structure including the physical environment and the social models of care informing government policy.
2. To extend this pilot project to examine the interface of the organizational and professional cultures of service provision with the diverse cultures of both formal and informal carers. This would require an innovative approach that may extend across government departments to explore possibilities for the creation of flexible service networks.
3. To develop a project that allows for several follow-up in-depth interviews with the same families, including where possible interviews with both the carers and care recipients. Given the sensitive nature of this research, building up trust is integral to unpacking the more nuanced and subtle implications of caring for an elderly and/or disabled person.
4. In-depth research that examines the complexity of carers' daily experiences that determine the type and amount of usage and where to direct information dissemination at multiple entry points needs to be undertaken.

## 13 Appendix

### *Diverse Strategies for Diverse Carers: The Cultural Context of Family Carers in NSW*

#### QUESTION SHEET

##### **1. Demographic information**

Carer Information

Age:

Sex:

Family size:

Other carer responsibilities:

Relationship to relative:

How long having you been caring for your relative?

Country of birth:

Relative's information

Age:

Sex:

Country of birth and if born outside Australia, length of time in Australia:

Language(s) spoken:

##### **2. Cultural background**

What is your cultural or religious background?

What language do you speak at home?

##### **3. Migration history**

How long have you lived in Australia?

How long has your relative lived in Australia?

How did you come to Australia?

Do you have any other family members here?

Do you still have family members in your country of origin?

How would you describe your English language skills?

How would you describe your relative's English language skills?

##### **4. Patterns of care in country of origin**

How are people in your relative's situation cared for in your country of origin?

Who would usually be responsible for their care?

What would that care involve?

Where would they be cared for?

## **5. Needs of person being cared for**

Who do you care for?

What is their relationship to you?

Are you their primary carer?

How did it come about that you took on the primary role of carer?

Did something happen to them?

Tell me about what sort of care they need. What are the specific challenges the person you care for have? How do you deal with these challenges?

## **6. Care givers role in providing care**

Can you tell me about your care giving role?

What do you do for your relative?

-physical care: bathing, dressing, feeding

-financial assistance: banking, paying bills

-social assistance: driving them around, visiting, attending functions

-health care: going to see doctors, get medicines or other health service

What is a typical day like for you? Can you describe what you did yesterday (ask for details)

Do you go out with your relative? How do you get around? Are there any difficulties?

What sort of problems do you experience in your care giving role? egs. physical and/or emotional demands, financial, transport, mobility etc.

Has your role as carer changed over time?

Interactions with other service providers

Are you aware about government and community support services available to you?

Is anybody else involved in the care of your relative?

-GP, community nurse, meals-on-wheels, family, friends, local centre

If so, what does this person/organization do for your relative?

Have you used any existing aged/disability services for your relative? If so, which ones? What was that like?

Do you feel confident and in control when communicating with service providers? Are some easier to talk to than others?

Do you have any breaks from your caring responsibilities? Who takes care of your relative while you're doing other things?

How would the person you care for feel about a professional carer assisting in their care?

What issues do you see as obstacles in bringing in outside carers?

What issues do you think the person you care for would see as problems with being cared for by outside carers?

### **Supports for Carer**

Do you get a break or a rest from your caring role? Tell me about that

What do you do to support or help yourself when you are exhausted?

Do you think the government has a role in assisting you with taking care of your relative?

### **Cultural support networks**

Do you know any people in a similar situation to you? Can you tell me about that?

How do religious and cultural practices influence the way you care for your relative?

What religious or cultural activities are you involved in?

### **Plans for the future**

How do you see the future for your relative's care?

Are you concerned or worried about anything for yourself or your relative in the future?

What sort of help would you like to have? What support would help you in caring for your relative?

## 14 References

- Aldrich, R. & Mooney, G. (2001). 'Agenda-Setting in Health Reform: The Role of Community', *Australian Health Review*, 24 (1).
- Anderson, B. (2000). *Doing the Dirty Work?: The Global Politics of Domestic Labour*, London: Zed Books.
- Aronson, J. (2002). 'Elderly People's Accounts of Home Care Rationing: Missing Voices in Long Term Care Policy Debates', *Ageing and Society*, 22(4): 399-418.
- Australian Bureau of Statistics. (1998). *Caring in the Community*, Canberra.
- Australian Institute of Health and Welfare. (2004). 'Carers in Australia: Assisting Frail Older People and People with a Disability', *Age Care Series* no. 8(October), Canberra.
- Batrouney, T. & Stone, W. (1998). 'Cultural Diversity and Family Exchanges', *Family Matters*, 51(Spring/Summer):13-20.
- Bevan, C. (1998). *Successful Ageing: Perspectives on Health and Social Construction*, Artamon, NSW: Mosby Publishers.
- Bittman, M., Fisher, K., Hill, P., Thomson, C. & Thomson, D. (2004). 'Identifying Isolated Carers: Contacting Carers with Unmet Needs for Information and Support', Final report for the Australian Research Council Linkage Grant Project, Kensington: Social Policy Research Centre, University of NSW.
- Carers Association of Australia. 2000. 'Warning – caring is a health hazard' 1999 National Survey of Carers Health and Well-being, Canberra.
- Chalmers, S. (2004). 'We All Come from Somewhere: Mainstreaming 'Ethnicity' in Children's Health Care', *International Journal of Diversity in Organisations, Communities and Nations*, Vol: 3B, Melbourne: Common Ground Publishing.
- Chalmers, S. and Allon, F. (2002). 'We All Come from Somewhere: Cultural Diversity at Sydney Children's Hospital', Multicultural Health Unit, South East Sydney Area Health Service.
- Chandraratna, D. & Cummins, M. (1988). 'Ethnicity and Ageing: The Anglo-Asian Experience', Kensington: Social Welfare Research Centre, University of NSW.
- Couldry, N. (2000). *Inside Culture: Re-imagining the Method of Cultural Studies*, London & Thousand Oaks, Calif: Sage.

de Vaus, D. (1996). 'Children's Responsibilities to Elderly Parents', 5th Australian Family Research Conference, Brisbane.

Delgado, L., Sorensen, S. & Coster, D. 2004. 'An Exploratory Study of Preparation for Future Care among Older Latinos in Utah', *Journal of Family and Economic Issues*, 25(1):51-78.

Dilworth-Anderson, P., Williams, I. C. & Gibson, B. (2002). 'Issues of Race, Ethnicity, and Culture in Caregiving Research: A 20 Year Review (1980-2000)', *The Gerontologist*, 42(2):237-273.

Ethnic Disability Advocacy Centre. (2003). Carers Research Project Report, W.A. (<http://www.edac.org.au>).

Fine, M., Graham, S. & Webb, A. (1991). 'Benchmarks and Other Approaches to Planning Community Support Services: A Review of International Experience', Kensington: Social Policy Research Centre, University of NSW.

Fox, K., Hinton, W. L. & Levkoff, S. (1999). 'Take up the Caregiver's Burden: Stories of Care for Urban African American Elders with Dementia', *Culture, Medicine and Psychiatry*, 23: 501-529.

Gibson, D. (1998). 'Aged care: Old Policies, New Problems', Cambridge: Cambridge University Press.

Gillies, B. (2000). 'Acting Up: Role Ambiguity and the Legal Recognition of Carers', *Ageing and Society*, 20: 429-444.

Goss, J. & Lindquist, B. (1995). 'Conceptualizing International Labor Migration: A Structuration Perspective', *The International Migration Review*, 29(2):317-330.

Guberman, N. & Maheu, P. (2003). 'Beyond Cultural Sensitivity: Universal Issues in Caregiving', *Generations*, 27(4): 39-44.

Health Services Union of Australia (2004). Care Complaints Top Concerns About the State of Aged Care – December 10.

Hinton, W. L., Fox, K. & Levkoff, S. (1999). 'Introduction: Exploring the Relationship among Aging, Ethnicity and Dementia Caregiving', *Culture, Medicine and Psychiatry*, 23: 403-413.

Hoggett, P. 1996. 'New Modes of Control in the Public Service', *Public Administration: An International Quarterly*, 74(Spring):9-32.

Kolar, V. & Soriano, G. (2000). 'Parenting in Australian Families: A Comparative Study of Anglo, Torres Strait Islander, and Vietnamese Communities', Research Report No.5, Melbourne: Australian Institute of Family Studies.

Kruijjer, A. (1990). 'An Ethnic Community Perspective', Paper presented at the Conference on Social Support and Monitoring, 28th February, Melbourne: Wesley Central Mission.

Legge, V. & Westbrook, M. (1993). 'Attitudes towards Disabilities in a Multicultural Society', *Social Science and Medicine*, 36(5):615-629.

Litt, J. & Zimmerman, M. (2003). 'Global Perspectives on Gender and Carework: An Introduction', *Gender and Society*, 17(2):156-165.

Litwin, H. (2004). 'Social Networks, Ethnicity and Public Home-Care Utilisation', *Ageing and Society*, 24:921-939.

McCallum, J., Calder, R., Walsh, J., Moy, S., Adamczuk, S., Bye, R. & Nakamura, T. (2001). 'Australian Aged Care & the New International Paradigm', *Australasian Journal on Ageing*, 20(3 Supplement 2):5-14.

MacIntyre, M. (1994) 'Migrant Women from El Salvador and Vietnam in Australian Hospitals', in Waddell, C. & Peterson, A. R. *Just Health: Inequality in Illness, Care and Prevention*, Melbourne: Churchill Livingstone.

Millward, C. (1998). 'Family Relationships and Intergenerational Exchange in Later Life', Melbourne: Australian Institute of Family Studies.

Misic, A. (1996). *The Hidden Society: A Study of Non-English Speaking Background Carer Issues in the Western Sydney Region*, Sydney: Carers NSW.

Morrissey, M. (1997). 'The Uses of Culture', *Journal of Intercultural Studies*, 19(2):93-107.

NATSEM (National Centre for Social & Economic Modelling), (2004). 'Who is going to care? Informal care and an ageing population', Report prepared for Carers Australia.

NSW Government (2000). *NSW Community Relations and Principles of Multiculturalism Act 2000* No. 77. <http://www.legislation.nsw.gov.au/maintop/scanact/inforce/NONE/0>. Sydney: NSW Government.

NSW Premiers Department (1998). *Premier's Memorandum No 98-22 - Interpreter Budget Requirements in Contracting out Services and Funding Services Delivered by non-Government Organisations, Government Trading Enterprises and State Owned Corporations*. [http://www.premiers.nsw.gov.au/pubs\\_dload\\_part4/prem\\_circs\\_memos/prem\\_memos/1998/m98-22.html](http://www.premiers.nsw.gov.au/pubs_dload_part4/prem_circs_memos/prem_memos/1998/m98-22.html). Sydney: NSW Government.

Neysmith, S. M. (2000). 'Carers as a Labour Force', Paper presented at 2nd Annual International Conference on Caring, Share the Care: A Critical Time for Decision Makers around the Globe, 29-31 March, Brisbane.



Parker, G. (2000). 'Disability and Caring: The Cutting Edge', (Keynote Address), 2nd Annual International Conference on Caring, Share the Care: A Critical Time for Decision Makers around the Globe, 29-31 March, Brisbane.

Payne, T. & Ehrlich, F. (1998). *Coping at Home: Carers' Use and Non-use of Community Services*, Sydney: Carers NSW.

Plunkett, A. & Quine, S. (1996). 'Difficulties Experienced by Carers from Non-English Speaking Backgrounds in Using Health and other Support Services', *Australian and New Zealand Journal of Public Health*, 20(1):27-32.

Riggs, D. (ed.) (2004). 'Why Whiteness Studies?' Special Issue of *Borderlands ejournal* 3(2): <http://www.borderlandsejournal.adelaide.edu.au>

Salazar-Parrenas, R. (2001). *Servants of Globalization: Women, Migration and Domestic Work*, Stanford, CA: Stanford University Press.

Saunders, P. (1996). 'Dawning of a New Age? The Extent, Causes and Consequences of Ageing in Australia', Kensington: Social Policy Research Centre, University of NSW.

Schofield, H. (1998). *Family Caregivers: Disability, Illness and Ageing*, Melbourne: Allen & Unwin (in association with the Victorian Health Promotion Foundation, Vic Health).

Shaver, S. & Fine, M. (1995). 'Social Policy and Personal Life: Changes in State, Family and Community in the Support of Informal Care', Kensington: Social Policy Research Centre, University of NSW.

St George Migrant Resource Centre. (2004). 'Culturally and Linguistically Diverse Disability Research Project', St George, NSW.

Stevenson, N. (2003) *Cultural Citizenship*. Milton Keynes: Open University Press.

Stuart, O. (1996). "'Yes, We Mean Black Disabled People Too": Thoughts on Community Care and Disabled People from Black and Minority Ethnic Communities', in Ahmad, W. I. U. & Atkin, K. (eds) *'Race' and Community Care*, Buckingham: Open University Press.

Stoller, E. P. (2002). 'The Full Explanatory Power of Ethnicity: Linking Two Strands of Theorizing about Old Age', *The Gerontologist*, 22(5): 709-713.

Thomas, T. (2003). 'Older Migrants and their Families in Australia', *Family Matters*, 66(Spring-Summer):40-46.

Tsang, E. Y., Liamputtong, P. & Pierson, J. (2004). 'The Views of Older Chinese People in Melbourne about their Quality of Life', *Ageing and Society*, 24:51-74.

Wilson, G. (1998). 'Later Life, Gender and Ethnicity: Changing Theory for Social Policy Research', Kensington: Social Policy Research Centre, University of NSW.

Wolfson, C., Handfield-Jones, R., Glass, K., McClaran, J. & Keyserlingk, E. (1993). 'Adult Children's Perceptions of Their Responsibility to Provide Care for Dependent Elderly Parents', *The Gerontologist*, 33(3):315-321.