

Deakin University
Faculty of Arts and Education
School of International and Political Studies

Marie Terese O'Toole
Bachelor of Arts (Honours) - (University of Plymouth, UK)

Student ID: 800704597

**Meeting the Respite Needs of Carers Living in Perth from a Culturally and
Linguistically Diverse Background**

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Table of Contents

CHAPTER 1: Introduction	1
Why is this project to be undertaken?.....	1
What will be included in my definition of “Respite”	1
Underrepresentation of CALD carers in the use of respite services.....	2
The Research Question	3
The Approach.....	3
Limitations of the study	3
CHAPTER 2: Literature Review	5
A Profile of CALD Carers in Australia.....	5
Additional Challenges Faced by CALD Carers	5
Women and young CALD carers are at even greater risk.....	7
Why is it important that CALD carer needs are met?	8
A community development approach to addressing need	8
Defining CALD carer ‘need’ for respite	10
Respite Access Barriers for CALD Carers.....	12
Addressing the barriers – the way forward	14
What further information is needed from Primary data?	19
CHAPTER 3: Research Methodology	21
Research Participants.....	23
Justification of research approach taken.....	25
Potential pitfalls and dilemmas	25
CHAPTER 4: Analysis of Results and Discussion	27
Is there a need for respite for CALD carers?.....	27
Barriers to service access.....	28
Services are not culturally appropriate.....	28
Fragmented and complex system	31
Lack of flexibility and choice in supports available	34
Using community assets to address needs.....	35
CHAPTER 5: Conclusion.....	37
Summary of outcomes.....	37
Further related research.....	38
REFERENCES.....	39
Appendix A: Research Questionnaire	47

Abstract

The aim of this research is to examine the nature and drivers of exclusion from respite services for culturally and linguistically diverse (CALD) carers living in Perth. The research seeks to find out if CALD carers need respite, if their needs are being met and if not, to identify the barriers and how they can be addressed.

My findings indicate that CALD carers, according to participants in this research, can find the respite system difficult to navigate, are unable to access services due to cultural and language barriers, and that support offered is often inflexible and unresponsive to their needs. The research also found that some CALD carers are prohibited by cultural and community pressures from seeking external support, and there is subsequently a need for CALD communities and carers to acknowledge the importance of carers looking after themselves.

Addressing this situation will require the government to undertake a systemic re-engineering of the current model of carer respite, which I believe needs to be driven by CALD carers themselves to ensure that their needs are identified on their own terms rather than being defined by external 'experts'. In the meantime, my findings suggest that service providers can improve access and inclusion for CALD carers within the current system by developing more person-centred service responses, improving their cultural competency and working more closely with each other.

CHAPTER 1: Introduction

Why is this project to be undertaken?

After over ten years' professional work and volunteering experience in the community sector I have developed a passion and commitment for tackling the ways in which some people and groups are systematically excluded from participation in mainstream society and from achieving an acceptable quality of life, whether that be due to factors relating to mental and/or physical health, disability, age, cultural background, gender etc. More recently, I have become involved in multicultural settings which have given me insights into the difficulties faced by non-Anglo/Celtic cultures when navigating and understanding the norms, systems and contexts of Australian society.

This research project was conceived after discussions with the Australian Red Cross and the Chung Wah Association. These organisations highlighted an issue regarding carers from a culturally and linguistically diverse (CALD) background being under represented in their use of carer respite services and expressed concern that many CALD carers would not be having their needs met, and with some not receiving any support at all. Yet, research shows that the adverse impacts of caring on health can be reduced if carers take time out from their role by using planned and regular respite (Victorian Department of Health, 2010).

What will be included in my definition of "Respite"

For the purposes of this research project, I have decided to take a broad view of carer respite and include both respite targeted at the person with care needs, as well as activities targeted specifically at carers, as both these forms of 'respite' allow a carer to take a break from their caring role.

There are currently a wide range of respite service providers in the Perth metropolitan area, who are funded by the Federal and State Governments to provide respite support to carers and care recipients. In broad terms, respite services available can be categorised as follows:

- Services providing Information, advice and referrals to other agencies;
- Carer and/or care recipient activities and interest groups;
- Home help support, for example, with personal care, shopping and cleaning;

- Daytime respite to allow carers to attend work or other commitments, which can be provided in the home or out of the home (day care facilities, organised trips/activities etc);
- Short-term respite (for example, overnight, weekends, holiday period residential stays and holidays/ breaks away from the home); and
- Long-term accommodation respite, usually for elderly care recipients or people with high/complex mental or physical needs that can no longer be cared for at home.

These services are provided in Perth by a mix of mainstream agencies (e.g. Australian Red Cross, Carers WA), ethno-centric services (e.g. Chung Wah Association, the Italian Association) and multicultural services (e.g. Fremantle Multicultural Centre, Ishar Women's Service).

Underrepresentation of CALD carers in the use of respite services

According to the Australian Bureau of Statistics (2003), approximately half (53%) of all primary carers in Australia reported that they have no major source of assistance. For those that did receive help, they most commonly used informal carers (55%), relatives, neighbours or friends (40%), and spouses or partners (32%). CALD carers on the other hand often do not have extended networks of family and friends to provide them with similar support, given they may have left their families behind when they moved to Australia or arrived with only immediate family members. Despite this, it seems that CALD carers are even less likely to report, or seek external assistance, for their needs than non-CALD carers (Black & Madden, 1995). The Multicultural Disability Advocacy Association (MDAA) (2007) claims that less than 15% of CALD carers use carer support services and the National Ethnic Disability Alliance (NEDA, 2010) contend that three quarters of CALD people eligible for disability service support prefer to "grin and bear it" rather than be seen as failing their families and community in their responsibilities as a carer by seeking help.

There is therefore evidence that CALD carers are underutilising, and are underrepresented as clients of, carer respite services in Australia. In the absence of statistics specifically pertaining to Perth on this issue, it is assumed that this situation is reflective of Perth for the purpose of this research.

The Research Question

This project therefore seeks to examine the nature and drivers of exclusion from respite services for culturally and linguistically diverse (CALD) carers living in Perth, in order for them to live more fulfilled lives. I specifically want to address the following research questions:

- What are the needs of CALD carers in relation to respite?
- Are these needs being met?
- What are the barriers preventing them from accessing assistance with their caring role?
- How might these barriers be overcome or reduced?
- How might a community development approach assist in better meeting the needs of CALD carers?

The Approach

This research comprised a literature review of existing (or secondary) data to provide information to address the above research questions. The focus of the secondary research was on exploring existing data gathered in the Australian context around the specific needs of CALD carers from respite, whether there is a need for respite for this category of carers, and how these needs might be met with particular reference to a community development approach.

The primary research then sought to expand on this information and provide further insights and clarity on the research questions posed. The primary research stage comprised five in-depth qualitative interviews of approximately 90 minutes duration with key staff members in organisations involved in the provision of respite care to CALD clients. The questionnaire used in the primary research comprised a checklist of general questions covering topics and themes relevant to the research questions and used a conversational open-ended interview style to allow greater spontaneity and flexibility of response from participants (Soriano, 1995).

Limitations of the study

I acknowledge that the research approach I have taken has its limitations. The ideal research approach would have encompassed both an initial qualitative stage followed by a wider quantitative survey of the CALD carer community to help validate the qualitative findings and establish priorities areas for action (Mason, 1994; 1996; Bryman 2001; Marlow 2001; Greene, 2002). However, given that this research is being undertaken as a minor thesis comprising part of a Masters Degree, which

must be completed in a short time frame and funded by myself as the researcher, the time and financial resources required to undertake such a significant research exercise were not available.

The research was also conducted with representatives from organisations serving CALD carers (i.e. external 'experts') rather than speaking directly with individual CALD carers to determine their needs and identify service gaps. I took this approach as I recognised that it would be both difficult and time consuming to speak to CALD carers directly, given that previous research studies have reported some difficulty in engaging CALD participants without the active involvement of key local multicultural organisations to provide access to the community and provide resources to projects (Bell, 1993; Carers NSW 2003-2006; National Health and Medical Research Centre, 2005; Multicultural Mental Health Australia, 2004). Direct interviews with CALD carers would have also presented language and communication difficulties, requiring the services of a reliable translator to interpret materials and interviews appropriately, which was not possible within my resource constraints.

CHAPTER 2: Literature Review

In this section, I look at the existing research literature on the respite needs of CALD carers in Australia. The main points clearly enunciated by existing literature are that CALD carers have additional and quite specific challenges and needs that differentiate them from non-CALD carers. This can make it difficult for CALD carers to access respite support, particularly as services and systems in the respite area are, in the main, culturally inept.

A Profile of CALD Carers in Australia

There are around 2.5 million carers of Anglo/Australian and CALD backgrounds living in Australia who are 15 years of age or older (or 16% of the population), with 102,400 living in the Perth metropolitan region (Australian Bureau of Statistics, 2006). A carer is defined as a person who provides regular and ongoing assistance without payment (MDAA, 2007) to a friend or family member who is frail aged, has a disability, mental illness, drug dependency, dementia or is living with some form of chronic, terminal or long term health condition (NSW Health, 2007; ABS, 2008).

While there has been considerable research into the broader needs of carers in Australia (ABS, 2008; Carers Australia, 2008; Dow et al, 2004; Hodgson, King, Leggatt, 2002; Moore & McArthur, 2007; Schulz & Sherwood, 2008), there is far less data on the more specific needs of CALD carers. Culturally and linguistically diverse (CALD) carers are defined as migrants, or migrant descendents, whose first language is not English and whose culture is not Anglo-Celtic (Ethnic Disabilities Advocacy Centre, 2003). According to the Australian Bureau of Statistics (2007), there were 75,900 primary carers in Australia in 2003 that were born in non-English speaking countries and 76% of CALD carers in Australia are over 45 years of age (ABS, 2008). The statistics show that people living in Australia from CALD backgrounds are more likely to have a disability or be frail aged than those born in Australia (ABS, 2010; Dutchcare, 2010; NEDA 2010).

Additional Challenges Faced by CALD Carers

A carer's financial situation, relationships and sacrifices of their own needs can take a heavy toll on them (EDAC, 2003), with CALD carers facing several additional challenges that can lead to them being left alone to care for someone with very limited financial, social, emotional and health support

(National Ethnic Disability Alliance (NEDA) & Federation of Ethnic Communities' Councils of Australia (FECCA), 2003).

CALD carers have difficulties with English language proficiency (NEDA & FECCA, 2003), with almost a fifth (17%) of carers born overseas not being able to speak English very well or at all, according to ABS (2008). This creates communication barriers which can impact on many areas of their lives, such as being able to gain employment and gain awareness and understanding of the system and services available to them, particularly if there is no help with translation (Neidzweiki & Pierce, 2003).

Language difficulties can also impact on CALD carers finding work. This is then further compounded by lower levels, or recognition, of overseas educational qualifications, work skills and experience. Yet the conditions of certain residency permits, such as waiting periods, imposed on new migrants can lead to them being unable to access income support and this in turn can also bar them from using day care respite services which would enable them to leave the care recipient in order to earn a living, creating a vicious circle of financial disadvantage (MDAA, 2007; NEDA & FECCA, 2003).

There is also significant evidence in the literature to demonstrate that carers have poorer physical and mental health than the rest of the population (Dow et al, 2004), lower satisfaction with life, and higher levels of stress, anxiety and depression than non-carers (Victorian Department of Health, 2010; ABS, 2003; Schulz & Sherwood, 2008). However, CALD carers also face additional challenges such as a particularly stressful migration experience in which they may have endured loss of control, social status, and identity, extreme physical suffering, torture and human rights violations, and/or the undermining of religious, racial, political or cultural integrity, which can often lead to mental health issues. These survivors need assistance to begin the healing process and tackle their deep sense of isolation and loneliness (Robertson, 2000; Lipson, 1993), but this form of support can be challenging to access if a new migrant has caring responsibilities that keeps them isolated at home, and might also impact on the quality of care they are able to provide. Further to this, the additional stressors faced by CALD carers can render them susceptible to chronic health issues such as diabetes, asthma, insomnia, hypertension and fatigue (Plunkett & Quine, 1997).

New migrants to Australia also need to adapt to new cultural norms, behaviours and values whilst simultaneously coping with significant life changes such as leaving behind family members, perhaps living together as a family for the first time, long separations and changes in societal and familial roles (FECCA, 2010). The loss of cultural and familial support networks often leaves carers without

any support in a culture which they are not familiar with, and where they do not understand or know how to navigate the system and where language can impede effective communication.

Other challenges faced by CALD carers which might prevent them seeking assistance, as highlighted in the research, are a fear of authority; a fear that their confidentiality will not be kept; the stigma that many cultures associate with disability and mental health issues and a fear that respite services may not be culturally appropriate and accessible to them (FECCA, 2010; Sedger and Boyde, 2008; ARAFMI, 2005; Carers NSW, 2003; MDAA, 2007; EDAC, 2003).

Women and young CALD carers are at even greater risk

At particular risk of marginalisation are female and young CALD carers. Over two-thirds (71%) of primary carers in Australia are female and they face social isolation given they often need to stay at home to take care of children and undertake unequal domestic household responsibilities, which can limit their access to settlement services, such as training, language courses and childcare allowances (Canadian Council for Refugees, 2001; Chung, 1998). In the case of refugee women, many have been subjected to sexual abuse during their journey to Australia which leaves them at risk of developing psychiatric disorders (Chung, 1998).

The other hidden form of carer with special needs is young carers i.e. carers aged 25 years or less, and it is estimated that there are many more young carers in CALD communities than in the general population (Schofield, 1998). Young CALD carers are said to have more complex needs than young non-CALD carers and a greater need for emotional and other support to help them in their caring roles (Centre for Multicultural Youth et al, 2010). For example, the challenges and stresses of transitioning to adulthood for teenagers will be compounded by the demands of a caring role, their ability to continue their education is threatened which will limit their future economic prospects and also possibly (for refugee young people) they are simultaneously transitioning to a new culture which may interfere with their identity formation (Garbarino and Kostelny, 1996). Yet, research shows that there is insufficient or sometimes no support provided to young carers from refugee or migrant backgrounds, as service organisations find it hard to identify them and even harder to provide culturally competent services to this group (CMY et al, 2010; Moore & McArthur, 2007).

Why is it important that CALD carer needs are met?

Clearly then, existing research indicates that CALD carers are often isolated and face additional challenges which can prevent their needs being met. They have little opportunity to develop networks and agitate for what they need (NEDA & FECCA, 2003), which can lead to a feeling of helplessness, passive acceptance and loss of social identity, ultimately leading to a process of marginalisation and social disintegration (Ivanov & Muras, 2006).

From a social policy perspective, the 'rights-based' approach recognises that social inclusion is a fundamental right that must be protected to ensure that everyone has the opportunity and ability to be included in society (Omidvar & Richmond, 2003). People who are marginalised have a right to have their voices heard so that their claims to rights can be voiced and acted upon and they can achieve their 'full humanity' (Tesoriero, 2010). Therefore, there needs to be a focus on CALD carers achieving human fulfilment, which requires dignity, a sense of self worth, value and belonging (Kenny, 2011). This is the responsibility of everyone in society.

There are various national and international commitments under which Australia is obligated to recognise the human rights of marginalised people (including those from diverse CALD backgrounds), and offer the widest possible protection and assistance to families and children (FECCA, 2010). These include the International Covenant on Economic, Social and Cultural Rights (Department of Foreign Affairs, 1976), and the Government's own Social Inclusion Agenda (Commonwealth of Australia, 2009). However, I believe we have a long way to go to achieve the Government's vision of "*building a nation in which all Australians have the opportunity and support they need to participate fully in the nation's economic and community life, develop their own potential and be treated with dignity and respect*" (Commonwealth of Australia, 2009).

A community development approach to addressing need

I have now established that CALD carers face significant additional challenges, but the next question is what approach we should take in order to effectively identify and address their needs?

In a pure welfare model, the Government and external agencies decide what interventions should be implemented, largely based on the assumption that experts can make judgements about a person's situation and can administer appropriate support (Martin, 2000; Kenny, 2011). However, this approach gives little consideration to the wider framework in which these people are living their

lives and focuses on 'experts' helping people to address their deficiencies rather than people building their own capacities, which according to Osborne and Gaebler (1992, pg 66-70), has the *"increasing effect of convincing families that they are incompetent to know, care, teach, cure, make or do. Only certified people can do that for you"*.

A more effective approach, for which there is strong support in the literature, is a community development practice framework within which the community itself must decide what it needs, what constitutes a better life and to be actively involved on its own terms in determining its future (Kenny, 2011; Carozza, 2003). This approach is also based on the premise that social problems are deeply entrenched in the inequities of the social (welfare) system itself (Kenny, 2011; Shaw & Martin, 2000). It proposes that certain groups, such as CALD carers, are systematically excluded from full membership and participation in society (Marshall, 1950), and discriminatory, exclusionary and oppressive actions essentially give dominance to favoured groups, for example white English-speaking people (Ward and Mullender, 1991). Accordingly, a community's needs cannot be addressed by those dominant groups, and change cannot occur until the structures, institutions, processes and beliefs that cause them are broken down (Kenny, 2011; Shaw & Martin, 2000).

A community development approach proposes that people need to take control of changing their own behaviour or circumstances in order to improve their wellbeing (Fowler, 1997; Industry Commission, 1995). It is not a systematic, predictable process unaffected by surrounding influences, but rather a people-centred, organic, complex and evolving approach that, according to its advocates, has the potential to bring about real and sustainable long term change (Kenny, 2006; Fowler, 1997).

In taking a community development approach to this issue, I subscribe to the belief that the current system of carer respite support in which CALD carers are 'located' is systemically flawed and needs to be adapted in order to address the root causes of disadvantage in this community. However, in acknowledgement that changes of this nature can be protracted and difficult to achieve, I will also include a focus in this research on how the existing system can be adapted in the shorter term to remove some of the impediments to CALD carers receiving appropriate support.

Defining CALD carer 'need' for respite

The next task is to clarify how I will define 'need' for the purpose of this research. There is much debate about the distinction between needs and wants, who is responsible for defining them, how they should be prioritised and whose responsibility it is to address them.

Some carers may be open to the idea of respite and understand that they need to keep themselves healthy and refreshed to be able to care for their loved one (Ali, 2006; Carers NSW, 2006; Sedger and Boyde, 2008). However, the literature also shows that there are CALD carers that do not feel a need for respite support (NSW Aged Care Alliance, 2004; Sedger & Boyde, 2008 etc). For these carers, the concept of respite is outside their field of experience as care is generally expected in their culture to be provided by extended family members in the home, and is not a social or government responsibility (Migrant Information Centre (MIC) & Yooralla, 2006; FECCA, 2011; EDAC & Muslim Women's Support Centre of WA Inc (MWSC), 2006). For example, Nyawaragak Dei Wal (2004) states that in the Sudanese culture, family and the wider community perceive themselves as having an obligation to support and care for people with disabilities.

In many cultures, there is also a concern that a carer might look selfish or self-absorbed to others in the community if they were to use respite care (MIC & Yooralla, 2006). This may be linked to cultural and religious beliefs, for example, in the Muslim faith it is believed that disability is a test from God and may be given as a punishment for the mother who has failed in her Islamic duties, according to Ali (2006). As a result, informal caring arrangements often happen automatically without the person necessarily recognising themselves as 'carer', and so they do not think of, or perceive a need to access, respite services (EDAC, 2003; MDAA 2007; Centre for Cultural Research, 2006). In fact, in many cultures the terms "carer" and "respite" are not easily translated and therefore are frequently not understood, even if the English term itself is familiar (Carers NSW, 2006 & 2007; MIC & Yooralla, 2006).

This raises the question of whether or not these CALD carers have a real need for carer respite. Bradshaw's (1972) states that real need only occurs when normative (defined by experts on the basis of their knowledge), felt (articulated directly by the community themselves), expressed (manifested by some form of action by the community) and comparative (based on a comparison of resources between communities) needs coincide (Percy-Smith, 1996). This view would therefore suggest that these CALD carers do not have a need, because they have neither expressed nor felt it. Sedger and Boyde (2008), however, state that some of these carers may have an unexpressed need for assistance but feel constrained from reaching out or verbalising this need, for example if the care

recipient refuses to accept help from external services. Further to this, EDAC and MWSC (2006) claim that need may not be expressed if respite options are not appropriate, for example if the carer and care recipient are unable to enjoy respite together, which is often the preference in CALD families. This points to possible systemic issues affecting the expressing of need.

Taking a community development approach, CALD carers must be able to identify problems as they see them and have control of the way in which these issues and needs are satisfied in order to uphold their rights and avoid disempowerment (Kenny, 2007; Doyal and Gough, 1991; Ife & Tesoriero, 2006), including the right not to express needs or seek help if that is what they choose. Balancing this however, is Ife and Tesoriero's (2006) view that need is a human right rather than something that must be felt and expressed and that people have a universal set of objective needs that they are entitled to have fulfilled, such as reducing the physical and emotional burden commonly created by the demands of the caring role. I have chosen to align my approach with this rights-based view of needs to ensure that the findings of this research apply to the widest possible group of CALD carers who might benefit from carer respite.

I will also take an asset-based approach which identifies the strengths and capabilities within a community that they can use to make their community a better place to live, rather than a deficit approach which focuses on the problems and issues of a community that need to be addressed (Kenny, 2011). However, as pointed out by Kenny (2011), I acknowledge that CALD carer assets may not be sufficient on their own to address their needs and that some external facilitation may be required.

I feel that is important at this stage to highlight that CALD carers are not one large homogenous group and that the needs between, and within, CALD communities and individual CALD carers can vary (Sedger & Boyde, 2008). Needs also vary between generations and genders (EDAC, 2003) and between individuals, who have a uniquely different collection of contradictory feelings, needs and values that evolve over time (Slater, 1970; Alexander & Seidman, 1990) based on their heritage and family/cultural traditions, their resilience, intelligence, persistence, sense of identity, self esteem, ability to form relationships and to learn languages, and on the "society they live in" (Ahearn, Loughry and Ager, 1999). Clearly then there is not one single way of knowing or understanding all CALD carers or a one-size-fits-all framework; they are simply a collection of individuals from different ethnic communities who have "*...widely disparate cultural beliefs, ways of accessing health information and services, and language capacities ...*" (FECCA, 2011).

Respite Access Barriers for CALD Carers

Having established that there is evidence of an unmet need for respite for some CALD carers, I will now turn to examine what the literature says about why they are not accessing support to the same degree as non-CALD carers.

CALD carers lack information on the different health, medical, community and service care options available (Cleary et al, 2005; St George Migrant Resource Centre, 2002, MDAA, 2007). They often lack information about where to go or how to start finding out about services and supports available for a range of reasons including the demands of their caring role, the physical, social, cultural and linguistic barriers and the sheer complexity of the services available. Consequently many only seek assistance in an emergency (EDAC, 2003; FECCA, 2011; EDAC & MWCS, 2006; Sedger & Boyde, 2008). If they do find services, they are often discouraged from accessing them as they are not culturally appropriate, do not offer the flexibility they want or exclude them in planning and decisions about the care to be provided to their loved one (EDAC, 2003; NEDA & FECCA, 2003; Dow et al, 2004). Some of these key barriers are discussed in more detail below.

Lack of cultural appropriateness

There is strong support in the literature for the proposition that the services system is 'culturally incompetent' and therefore unable to meet the needs of people from CALD backgrounds (Carers NSW, 2003-2004, 2003-2006, 2004, 2007; Cleary et al, 2005; Multicultural Carers Alliance, 2004, 2006, 2007; Multicultural Disability Advocacy Association, 2007). There are complex and major cultural implications for experts, professionals and helpers dealing with CALD families which, according to NEDA and FECCA (2003), need to be understood and respected such as cross-gender communication, home entry and faith issues. However, all too often the cultural needs of CALD clients can be unwittingly dismissed if services have insufficient understanding and knowledge about other cultures (EDAC, 2003; FECCA, 2010), which Peterson and Brooks (2004) claim makes some professional interactions with CALD people look rather like "*..bashing away blindly at a piñata.*"

FECCA (2011) proposes that in order for health systems to become culturally competent they need to work at the systemic, organisational, professional and individual levels, and needs to value diversity, regularly self-assess, institutionalise cultural knowledge, be aware of cultural interaction dynamics and adapt service delivery to reflect cultural diversity. In the aged care sector specifically, there is a concern expressed in the literature that cultural diversity is being seen as either requiring additional and discrete special needs services or can be catered for by 'tweaking' mainstream services, rather than embedding cultural competency and ethno-specific pathways into the aged

care system on a more permanent and systemic basis (FECCA, 2010, 2011; Australian Multicultural Foundation, 2002).

Cultural competency is clearly then far more encompassing than just interpreters and diagnostic tools. There are many examples in the carer literature of ways in which services may be culturally appropriate or inappropriate for CALD carers. For example, the client assessment tool used by carer respite services may require information that respondents from some cultures are unwilling to share with strangers (FECCA, 2010; Sedger & Boyde, 2008; MDAA, 2007) or service staff may have limited understanding of cultural practices, such as the Muslim rituals associated with washing, appropriate clothing, halal food and prayer times (EDAC & MWSC, 2006).

There is a particular concern expressed in the literature that the cultural needs of elderly CALD recipients and their carers are not being met appropriately by residential services, making the transition from home-based care to residential care distressing and isolating at a time when people are at their most vulnerable (FECCA, 2010; 2011), and residential services tend to therefore only be used as a last resort (NEDA & FECCA, 2003; FECCA, 2011). People from CALD backgrounds tend to be calmer and need less medication in ethno-specific nursing homes where their language is spoken (Victorian Association of Health and Extended Care, 2005), which also relieves the pressure on their carers and families.

Communication barriers

Communication issues were touched on above, but I feel that this area deserves separate mention given the major role it plays in preventing CALD carers from accessing services.

EDAC (2003) contends that low English proficiency is one of the key barriers CALD carers face in accessing respite support, and that strategies used to address this are lacking (Carers NSW 2004-5; Pagnini, 2005; Sutherland Shire Community Care Network Inc 2005; MDAA,2007). Other research suggests that greater and more routine use should be made of bilingual community workers and interpreters (FECCA, 2011), particularly when assessments are carried out or service agreements explained (Sedger and Boyde, 2008). However, despite the fact that under the Western Australian Government's *Language Services Policy* government agencies are expected to budget to provide appropriate language services to clients who are not fully proficient in English (EDAC, 2003), it is claimed by NEDA & FECCA (2003) that the move towards a user-pays basis for interpreter services has led to a significant reduction in their use.

Communication barriers extend beyond understanding of language to include a failure by professionals to adapt their communication methods to different learning needs and styles (Johnson

et al, 2007; Multicultural Mental Health Australia, 2004; Newtown Neighbourhood Centre, 2007; MDA, 2007). There is no one size fits all for this, as some less literate carers would respond better to the presentation of the information in pictorial or colour-coded form (Carers NSW, 2004-2005; FECCA, 2011) whereas Sedger & Boyde (2008) contend that other people from a CALD background, and in particular seniors, generally respond better to face to face engagement (FECCA, 2011). However Hall (1959, 1976) highlights that this must be done in a way that is sensitive to the differences between cultures in communication styles. The Australian communication style values individual goals, identity, needs, independence and achievement (Gudtkurst et al, 1996; Brislin, 1994; Ting-Toomey, 1999), in contrast to many other CALD community communications which focus on group goals, harmony, solidarity and interconnectedness, and an indirect, compromising style where the messages are often covert and non-verbal (Ting-Toomey, 1991 & 1999). The way to overcome this is to ensure that verbal communications are delivered by someone from the same cultural and linguistic background, although this might not always be possible.

Lack of service integration and flexibility

It is reported that limited resources and funding criteria demands constrain the system's ability to provide an integrated, holistic service which is coordinated around individual CALD carer needs (EDAC, 2003). Yet, Dow et al (2004) report that carers want services that are responsive and flexible to their needs and provide choice in terms of type of service, timing, location and preferred staff etc. Carers need to navigate a complex and disjointed system of service providers to choose from services already formulated to meet their various needs, often requiring separate needs assessments and contact points which can be especially daunting and difficult for people who do not speak English, either at all or well, and for whom respectful relationships of trust are particularly important.

Addressing the barriers – the way forward

The literature indicates that there are substantial barriers limiting CALD carer access to support. The current limited respite care options provided are insufficient to meet the needs of persons from a CALD background, and the multiplicity of services and their lack of coordination leads to considerable confusion and misinformation (EDAC, 2003). There is a need for a more integrated, coordinated and personalised service approach to ensure that CALD carers and their families are no longer marginalised, and for a case management approach to help CALD carers to access appropriate support and information and help them overcome their anxiety about seeking help. Sedger and

Boyde (2008) contend that the lack of support given to these carers will become a major health problem if services do not start to listen to their needs and respond appropriately.

So the next question that I must ask is what, if anything, can be done to address this situation? In the following section, I therefore look at some of the ways the literature suggests that barriers to access for CALD carers can be addressed, citing examples of how this has been achieved in practice.

Transcending cultural and language barriers

CALD carers in the main seem to prefer care to be provided in the home by someone they know and trust to be sensitive to their cultural needs, such as a family member (EDAC, 2003; AIHW, 2006; AIHW, 2007; FECCA, 2011; National Centre for Social and Economic Modelling, 2004). To facilitate this, FECCA (2011) proposes that family members, friends and other community members providing care be entitled to be nominated as "approved providers" and be reimbursed in cash, thereby empowering consumers to purchase support from someone who understands their culture, speaks their language and meets their specific needs.

However, CALD carers in many cases do not have access to extended family support in Australia, particularly those from new and emerging CALD communities (EDAC, 2008). There is support in the literature therefore for targeted migration and training pathways for CALD migrants who are unemployed to help address this need, given the shortage of service provider staff with appropriate language and cultural skills (FECCA, 2011; EDAC, 2008). There are also many examples in the literature of carer respite services employing bi-lingual case workers to support and advocate for CALD clients, as being implemented by the Victorian Support Access Pilot and in NSW by St George Migrant Resource Centre, for example (FECCA, 2010; MDAA, 2007). Another option suggested is for the Government to provide greater funds to ethno specific providers to assist, as they have the skills, knowledge and connections with CALD communities to be able to meet their needs more effectively (FECCA, 2010; MDAA, 2007) and more readily link families to appropriate services (EDAC, 2003) than mainstream services.

It has also been proposed that ethnic support groups are effective for CALD carers as they are based around language and culture, and carers gain significantly from sharing their issues and the realisation that they are not alone (EDAC, 2003; EDAC & MWSC, 2006). Such groups can help to improve carer knowledge of the supports available to them and can also become a collective voice to advocate for the views and rights of CALD carers to be acknowledged and considered by Government. However, the carers themselves need to identify a need and commitment to participating in a group to ensure its sustainability and it can be a slow and painstaking process to

keep the group momentum going, according to MDAA (2007), which cites difficulties such as retaining bilingual group leaders and the need for significant unpaid time to keep the group running, which is also a drain on service provider resources (Var, 2004). There are many examples in the literature of ethnic support groups such as the Victorian Government Department of Health pilot respite project which used a bi-lingual staff member to recruit Italian-speaking carers and care-recipients for a group program, in order to better meet the needs of this large ethnic group within the Bendigo catchment area (State of Victoria, Department of Health, 2010).

However, carer support groups are just one method of providing ethno-centric respite to meet the needs of CALD carers. Many service providers are developing culturally appropriate programs and activities for specific ethnic groups. Examples of successful programs range from carer events or workshops conducted in different languages and targeting carers from specific cultural groups to multicultural activities that celebrate a range of different cultures. For example, the South East Dementia Action Group in Victoria, which comprises five service providers, coordinates Tastes to Remember multicultural feasts, which are attended by mixed groups from local Vietnamese, Greek, Filipino, Hungarian, Cambodian, Spanish, Polish, Chinese, Russian, Tamil, Indian, Afghan, Arabic, Turkish, Bosnian, Italian and Dutch communities (State of Victoria, Department of Health, 2010). The success of this model has led to it being adopted by other regional Victorian groups.

An example of an ethno-centric respite approach is that used by Yanada House in Northcote which runs a 'Men's Out and About' group comprising eight men of Greek or Italian origin who socialise and exercise together with activities including swimming, going to the gym and sharing meals. The Chinese and Afghan Lifelong Movers Program is another good example of how CALD carer and care recipient respite needs can be effectively met, according to the Victoria Department of Health (2010). The program focuses on health and wellbeing of Afghan and Chinese care recipients with dementia by coordinating social activities for small ethno-specific groups. To meet cultural requirements the Afghan participants were split into separate male and female groups for the exercise session. Meanwhile, carers attend carer support groups to receive information and gain a better understanding of dementia.

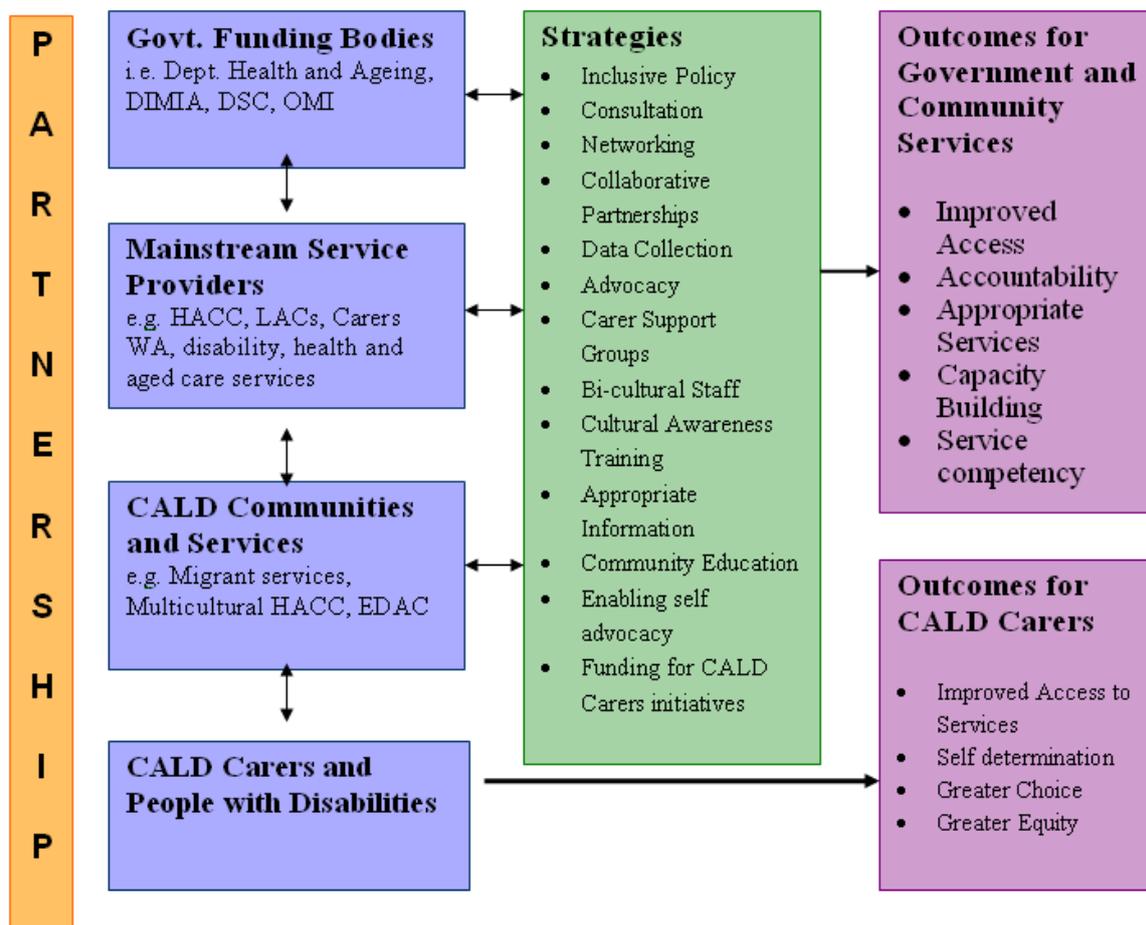
Delivering more flexible and personalised support

Another key barrier identified in the literature to CALD carers is the inflexibility and complexity of respite services provided. To effectively address this using a community development approach, the structures and systems that are disempowering CALD carers would need to be dismantled, and this is clearly not a simple task. The place we need to start from is how CALD carer needs can be identified and addressed with the carers themselves in the driving seat, rather than service

providers. To start with, CALD families should be included in the development of policies and strategies to ensure language, religious and cultural issues are appropriately addressed, and culturally appropriate projects need to be developed which are initiated and directed by CALD communities (EDAC, 2003).

EDAC (2003) also argue that there needs to be better coordination of respite services using referral and coordination access hubs, each of which would have at least one CALD professional. It also proposes improvements to information by providing one shared format to show options and avenues for support that suit each carer's individual needs, more bilingual workers, greater use of Translating and Interpreting Services, and developing new and easier-to-understand forms of information. In addition to this, EDAC believes that a holistic and coordinated approach should be developed where caseworker or similar models of support are used, resources are allocated to CALD services to build cultural awareness, greater flexibility and appropriateness of care is provided for via the use of paid family carers and the sharing of care between family members and care facilities (see illustration below).

Holistic Approach to Service Provision for CALD Carers (EDAC, 2003 pg 34)



However, MDAA (2007) argues that service providers need encouragement, opportunities and support to work together to achieve better outcomes for CALD carers. Without this occurring, it claims that any system changes will stall, as good intentions alone will not bring about the changes required in how the system operates.

Apart from the inflexibility and complexity within the system itself, I believe there also needs to be a move towards the provision of more individualised ongoing support to help CALD carers to navigate the complex support system and help coordinate their access to suitable services from different providers that meet their specific needs. I feel that the ultimate aim here should be to empower CALD carers by developing their skills to be able to manage and integrate their own care needs over time. An approach of this nature is used by case managers for higher needs clients, such as older people with dementia, psychiatric illness or long term homelessness, whereby a case manager identifies an individual's needs, finds suitable activities that match these needs, connects them to suitable providers and attends for the first session or two to ensure they are comfortable (Victorian Department of Health, 2010).

A key way in which I believe the system could better meet CALD carer needs would be to provide more respite opportunities for the carer and care recipient to participate in together to help reduce their social isolation, as many CALD families do not want to be separated as per the respite model currently used. There are services offering these joint experiences, some provided by community respite houses or day centres while others are using an informal cafe-style approach to provide opportunities for carers and care recipients to socialise with others, and get counselling, education and information about support services. An example is Alzheimer's Australia in Victoria which runs eight cafes in three different locations each year (Victorian Department of Health, 2010).

However, mostly the literature shows that services are adapting their service model to provide more flexibility by adapting their existing service offerings, bolting on "choice", rather than totally reengineering the supports offered to base them around a solid understanding and response to CALD carers' specific and individual needs. Much of the flexibility therefore being offered does not cater specifically for the needs of CALD carers but for carers in general. For example, offering choice in terms of days or hours of service operation, different respite forms and being available 24 hours a day to help carers with crisis situations (EDAC, 2003). An example here is of the Brotherhood of St Laurence Banksia Services for Seniors who adapted their respite services to be more accessible and offered one hour units of service rather than the usual six hours, by producing a book of coupons for 156 hours of respite care services which could be used to purchase services ranging from overnight or

weekend respite to day activities such as shopping, picnics, exhibitions and in-home support (Victorian Department of Health, 2010).

However, services are attempting to offer more choices to suit different needs such as flexibility in terms of number of respite nights away, day options, different formats and for carers to access services with or without their care recipient, according to the State of Victoria, Department of Health (2010). Some services also offer different respite formats to cater for individual needs. An example of this might be alternative activity-based therapy groups in art or music which are more suited to some carers than the standard support group format, such as the one run by the Commonwealth Respite and Care link Centre, Carelink North in Victoria which offers pet, massage, horticultural, laughter and aroma therapy groups etc (Victorian Department of Health, 2010). Another example provided by the literature is the community respite house model, such as Mayfair House in Victoria, which comprises non-traditional domestic style houses which provide accommodation for overnight or short stay breaks complete with activities and therapies for carers, such as hairdressing, podiatry, lunch, bus outings, movies and games (Victorian Department of Health, 2010). For people who are more comfortable in smaller and more intimate settings, host home respite might be suitable, where care recipients are looked after by a host home worker who has aged care qualifications and offers a safe and suitable home environment. For example, the House of Pamper in Rosebud (NSW) caters for five women at a time who attend for a full day to chat, share meals and have their nails polished, hair set in rollers and hands massaged - "*...when you visit this home you hear the women's laughter from the time you walk in until you leave*" (Victorian Department of Health, 2010).

Another emerging model of care is using aged care facilities to provide day respite to expand the respite options available to carers and an example of this is the Caring Cafe in Victoria which shares facilities with the Sir Eric Pearce Aged Care Facility and Yarra Health Services in Richmond (State of Victoria, Department of Health 2010). This program includes flexible pick up and drop off times, meals, experienced staff, support services for carers and a range of services such as hairdressing, dental care, exercise classes, guest speakers, and pastoral care etc. It also enables people in care to join other respite groups for outings and socialising.

What further information is needed from Primary data?

This literature review provides me with much valuable information and insights on which I will base the primary research of this thesis. While the above quoted secondary information establishes the

broad needs of CALD carers in Australia and ways in which their needs are not being met, the following primary research will focus on these issues in the context of Perth, Australia.

In conducting the primary research my intent will be to both identify systemic issues, and as indicated earlier, to also identify enhancements and improvements that could be made to current services and supports. This will ensure that this paper provides insights into how both the longer term system issues can be addressed, and what can be done in the short to medium term in order to enhance the quality of life of CALD carers in Perth.

CHAPTER 3: Research Methodology

In determining the best research method for this project, I have been mindful of the importance of matching the method used to the specific research purpose and questions developed, whilst working with a finite set of resources – financial, people and time – which constrains the implementation of an ideal research methodology (Hawtin & Percy-Smith, 2007; Sim & Wright, 2000).

The first stage of this research involved a literature review of existing (or secondary) data to provide a base of information on the CALD carer respite needs, the barriers preventing them from accessing respite and ways that these might be overcome, as summarised in the previous chapter. In my review of existing literature on the subject, I focused on studies that had been conducted in Australia and would therefore provide a relevant context for my Perth-based research. I specifically looked for literature that highlighted the needs and issues of carers from a CALD background rather than carers more generally, to ensure that my research is clearly focused on the issues and barriers specifically related to a carer being from a non Anglo-Celtic background. I also limited my literature review to research addressing the issues associated with carer respite rather than investigating broader carer needs, ensuring that in my definition of respite I included both respite primarily targeted at the carer as well respite aimed at the care recipient (which by its very nature often provides respite for the carer also). Lastly, I conducted a review of community development literature to determine how a community development approach might assist in better meeting the respite needs of CALD carers.

The secondary literature review revealed limited information regarding the respite needs of CALD carers in general, and in particular, CALD carers living in Perth, and therefore only partly addresses the aims of this research project (Hawtin & Percy-Smith, 2007). Hence, in the primary research I sought to expand on this information and provide further insights and clarity on the research questions posed. The primary research stage comprised a general interview guide approach (Patton, 1987) in which I conducted five in-depth, qualitative interviews of approximately 90 minutes duration with key staff members in organisations involved in the provision of respite care to CALD clients. I conducted each interview face-to-face with each participant at their place of work and recorded each interview, with the participant's permission, to allow a comprehensive analysis of findings. Following each interview, I conducted an analysis using my written notes and the tape recordings to identify issues of commonality, difference and insights which can be used in addressing

the research questions. The findings and discussion resulting from the primary research stage can be found in the next chapter.

The questionnaire used in the primary research comprised a checklist of general questions covering topics and themes relevant to the research questions and a conversational open-ended interview style to allow greater spontaneity and flexibility of response from participants (Soriano, 1995). The questionnaire commenced with introductory warm up questions to find out more about each participant's experience in dealing with CALD carers and the carer respite services provided by their respective organisations (as summarised later in this chapter). The questions then progressed to asking participants about the effectiveness of their organisation's CALD carer respite services and about the effectiveness of the sector as a whole in Perth, particularly focusing on what they thought CALD carers needed from respite, whether these needs are being adequately addressed and what they felt were the barriers to carers receiving respite support, in order to address the questions posed for this research. An area of particular focus in the interviews was whether or not CALD carers needed respite and how to define 'need' for this target group. The questioning also explored participant perspectives regarding system-wide approaches to carer respite and a one-size-fits-all versus an individualised approach to addressing the needs identified, highlighting the differences between CALD carers due to factors such as ethnic background, age and recency of arrival in Australia. This line of questioning was intended to address the research question about whether a community development approach can assist in meeting CALD carer respite needs. The full questionnaire used for the primary research can be found in Appendix A.

In both the secondary and primary research stages, I have pursued an asset-based community development (ABCD) approach (Kenny, 2011). An ABCD approach is based on the key principle that a focus on the positive strengths and assets of a community is more likely to inspire a desire for change and proactive community effort than a focus on its needs and problems (Mathie & Cunningham, 2003). It is an empowering process where associations of community members act as "*engines of community action*" (Green, 2000), building a sense of community and relocating power to CALD carers to drive the process of change while community organisations and government departments involved step back to allow the community to engage with external institutions on their own terms (Kretzmann & McKnight, 1993). The role of these external agencies, such as government and service agencies, will become one of facilitating the definition of the community's vision and the mapping and mobilisation of local resources (Mathie & Cunningham, 2003).

Research Participants

The key criteria applied in selecting organisations and participants for the primary research were:

- An understanding and dealings with either multicultural or ethno-specific clients to ensure broad representation of different CALD populations in the research;
- Provision of a range of respite support services to carers from CALD backgrounds across the spectrum of aged care, disability, mental health, and physical health issues; and
- The availability of a key staff member(s) to participate in the research who has considerable practical and hands-on experience and understanding of the respite needs of CALD carers.

A brief profile of the five organisations who agreed to participate in this research are as follows:

- **Fremantle Multicultural Centre (FMC).** Since 1981, the FMC has been providing services to migrants and refugees from a diverse range of cultural and linguistic backgrounds. The organisation's core services are crisis accommodation, mental health services, settlement support and employment and training programs and it caters for both older and newer, emerging migrant community needs. The organisation mainly connects with CALD carers through care recipients who are its primary focus, many of whom have mental health issues.
- **Australian Red Cross (ARC).** Red Cross operates myriad community services both nationally and in WA supporting families, youth, the aged, migrants and Aboriginal and Torres Strait Islanders. Red Cross connects with CALD carers in WA through its Carer Respite Service (which provides carer information, advice and referrals) and its CALD Carer Support Group.
- **Umbrella Multicultural Community Care Services.** Umbrella provides assistance to the frail aged and people with disabilities to help them remain living in their own homes. Its services are directed towards, but not limited to, people from culturally and linguistically diverse backgrounds. The organisation connects with CALD carers via its centre-based day care program and the approximately ten CALD carer support groups who meet in various venues around Perth. Each of these groups has a different CALD focus (including multicultural groups) depending on the cultural demand from the local area in which it meets.
- **Chung Wah.** Chung Wah has been running in Perth for over 100 years and was established in 1901. The organisation was set up to provide community support for non-English speaking people living in Perth from a Chinese background. It now provides community and aged care community services along with programs to promote the Chinese language and culture, and

has widened its remit to also now serve people from other countries in Asia as well as people from China. The organisation connects with carers through its community networks, events and through delivery of its respite programs in which carers are heavily involved, such as the day care centre program and in-home support services.

- **Carers WA.** Carers WA assists carers living in WA who provide unpaid care and support to a family member or friend who is frail and elderly, has dementia, a mental or chronic illness, a disability, or complex needs, or receives palliative care. The organisation provides counselling, information and advice, education and training, social support, carer representation and participation, policy and research, runs a young carers program, training for clinical hospital staff, and access to respite facilities and funds to enable carers to take a short break. Carers WA therefore connects with CALD carers in various ways through these programs, but also hosts a CALD-specific carer social group.

In total, I interviewed seven staff from these five organisations, as two of the interviews comprised two organisational representatives in order to bring different backgrounds and perspectives to bear on the research topic. In addition to the organisational experience as outlined above, the seven participants brought the following experience to the research:

- All of the participants have been working with CALD carers for many years, with two of the participants having over 20 years experience;
- Five of the participants are themselves from CALD backgrounds and speak one or more languages other than English. The participants have experience working with carers from a wide variety of CALD backgrounds including the former Yugoslavia, Poland, Italy, Macedonia, China, Vietnam and Burma;
- The participants have experience working with CALD people of various ages/life stages, caring for family members who have mental health issues, are frail aged, and/or have some form of disability, and also working in a variety of settings including day care, in-home support, residential care, carer support and interest groups, individual support, advocacy, referral services and policy; and
- Three of the participants have either been carers themselves or have experienced other extended family members being involved in caring roles.

Justification of research approach taken

I acknowledge that my findings are not necessarily representative of the CALD population. In order to be representative my research approach would have encompassed both an initial qualitative stage followed by a wider quantitative survey of the CALD carer community to help validate the qualitative findings and establish priorities areas for action (Mason, 1994; 1996; Bryman 2001; Marlow 2001; Greene, 2002). However, given that this research is being undertaken as a minor thesis comprising part of a Masters Degree, which must be completed in a short time frame and funded personally, the time and financial resources required for such a significant research exercise were not available.

From a community development perspective, a preferred approach would have involved the research being conducted directly with CALD carers rather than using an expert-outsider approach which gives power to “experts” to identify a community’s needs. This would seek to engage the community by facilitating their expression of needs and issues, thereby building new skills and confidence and hopefully a desire to be involved in further action to address the needs identified (Hawtin & Percy-Smith, 2007). However, I determined that it would be both difficult and time consuming to conduct research directly with CALD carers, given that previous research has found that its success in gaining participation would be reliant on key local multicultural organisations providing access to the community and helping to resource the project (Bell, 1993; Carers NSW 2003-2006; National Health and Medical Research Centre, 2005; Multicultural Mental Health Australia, 2004). In addition to this, the investment required by each organisation in the research may have compromised the independence of the research findings as they may have wanted to influence the areas of focus and questioning in a way that would be inconsistent with the research’s aims.

Direct interviews with CALD carers would have also presented language and communication difficulties, requiring the services of a reliable translator to interpret materials and interviews appropriately, which was not possible within the resource constraints of this project. I am also conscious that such an approach would have needed great care given that I would not share the same cultural background as participants, and would need to have ensured that cultural misunderstandings did not become a communication barrier (Kenny, 2011).

Potential pitfalls and dilemmas

In terms of potential pitfalls or dilemmas in my research approach, one of the key ethical research principles that must be applied concerns the way in which I, as the researcher, represent the

information generated. I am conscious that power and ethics are closely interrelated in the data generation process (D’Cruz & Jones, 2004). The knowledge generated by any research is never the “absolute truth” but rather a partial view of the situation based on the researcher’s and participants’ positions of power and subjectivities (D’Cruz & Jones, 2004). I therefore need to be careful not to process the information collected using my own subjective value frameworks (Hawtin & Percy-Smith, 2007) and thereby objectify the community being researched as “the other” (Tuhiwai Smith, 1999 in D’Cruz & Jones, 2004) and I aspire to validating difference and diversity by not categorising people or perpetuating stereotypes (Skeggs, 1994; Chandler, 1990; Humphries & Martin, 2000, D’Cruz, 2000; D’Cruz & Jones, 2004), but rather by trying “*..not to see through the eyes of someone else, but to see with (my) own eyes from a position that is not (my) own*” (Biesta, 2001).

I must also highlight here that if change is to be sustainable, CALD carers must be integral to any change agenda arising from this research– they need to decide what their priorities are and act on these on their own terms (McKnight & Kretzmann, 2005; O’Leary, 2007). According to Mathie & Cunningham (2003), the role of external agencies should ideally then become one of facilitating the community’s vision and the mobilisation of local resources. Wadsworth (1992) claims that this is a far better approach than experts trying to control and direct the process of change which would ensure that CALD carers remain dependent on external help.

CHAPTER 4: Analysis of Results and Discussion

Is there a need for respite for CALD carers?

All of the primary research participants (that is, agency professionals working in the CALD respite services sector) stated that one of the main reasons many CALD carers who they had worked with did not seek support is that the terms 'carer' and 'respite' are not understood in many ethnic cultures where it is traditional that the family provides any help needed by a family member. In these cultures the person doing the caring does not identify themselves as a 'carer' and it is felt to be inappropriate to speak to someone outside the family about their issues. The participant from Fremantle Multicultural Centre claimed that 99% of clients she sees, who come from around 60 country ethnicities every year, see their situation in this way.

"You can translate all the brochures you want, but if they (CALD carers) don't understand or see the need for respite, they simply won't make any sense..." (FMC Participant).

However, the participant from Umbrella felt that this does not necessarily mean that these carers do not have a need for respite, and stated that often carers *"..feel I should be able to do this, I married this person and this is my responsibility.."*. For some, according to this respondent, the community pressure and stigma in their culture to seeking external help can discourage them from acknowledging their needs. She felt that this pressure is more marked in smaller communities tied by experiences related to migration, which are more established in Australia and congregate frequently for church or social purposes, and to illustrate this gave the following example:

"There was a son of a Polish woman in Victoria who was a successful Polish businessman and was generous in his support to his community and therefore well thought of. However, when he allowed his mother to be put into a nursing home is name was mud.... there may not have been any other choice given the level of care his mother needed or his mother may have wanted to go into the nursing home, but this had no bearing on the community's reaction..."

She feels that some carers who do not feel or express a need for assistance might still require help to understand and recognise that they are playing an important role and that they will only be able to continue caring for their loved one if they look after themselves.

A few of the participants felt that many carers did not have time to think about or look for respite support as they are so busy and absorbed in their caring role which then renders them increasingly

socially isolated. It often takes a crisis event or emergency for them to reach out for help, that is, they only recognise a need for respite and ask for help when they cannot cope any more on their own. One of the Carers WA participants highlighted that this was why the organisation started their *Hospital Prepare to Care* service in late 2011, which trains clinical staff in all the metropolitan public hospitals in how to recognise and appropriately deal with carers of patients, given that a hospital setting in an emergency is sometimes the first time that carers are forced to come into contact with support services.

The primary research findings therefore indicated that it should not be assumed that CALD carers will acknowledge and express their needs. In addition to the demands of their caring role, they also face the pressures of culture, familial responsibility and community opinion which may inhibit their ability to validate their real need for support. Understanding the need of CALD carers does not therefore appear as straightforward as the secondary research has suggested. We need to be mindful that although some carers might seem happy to continue their duties with no assistance, they should not be assumed to have no need for information or access to support services. All of the respondents emphasised the need for greater and wider promotion of carer respite services in Australia with a focus on educating the public about what a carer is and on positive reinforcement of the important role carers play.

There are also many CALD carers who do perceive a need for help and try to engage with the system to assess what is available to them, but are faced with barriers that impede their ability to find appropriate support. I have summarised these barriers as expressed by the participants in the primary research phase next, comparing them to the earlier findings of the secondary literature review.

Barriers to service access

Services are not culturally appropriate

The secondary research indicated that one of the major barriers to CALD carers accessing respite support was cultural incompetency, which is ingrained at a systemic level. This finding was confirmed by primary research participants, all of whom believed that cultural fit and appropriateness was a major inhibitor to service use.

The inability to speak or read English is a major barrier to carers finding out about services and supports available. Many organisations, such as Carers WA, provide materials in a range of languages which are available on line and in printed form, but this requires a carer to be literate, and

as two of the participants pointed out, translations may not be accurate making the information unclear. Some CALD carers will not even pick up the phone to call a service if they do not speak English and are not aware of, or comfortable with, using an interpreting service. Not surprisingly then, CALD carers most often find out about supports available via word of mouth from friends, family, neighbours and contacts.

All participants claimed that the ideal situation is for service providers to provide carers and their families with a support worker from the same cultural background. This reduces the resistance from CALD families to allowing a stranger into their house to provide care or to using a respite facility for example, as they have confidence that the care recipient will be able to communicate and have their needs understood. This is particularly important, claimed two of the participants, in conducting needs assessments, given how critical these are to the carer receiving appropriate help. This is the model of care provided by Chung Wah, which has a complement of around fifty Chinese-speaking staff who therefore understand how to provide care that is culturally appropriate. Their day respite centre provides Chinese food, games and company for clients, resulting in many of them referring to it as “my second home”, according to the Chung Wah participant. It is understood that there are other ethno-centric respite care services which provide a similar service in Perth to the Italian and Polish communities, for example. An important focus for ethno-specific services however is to ensure that staff do not bring a cultural mindset to their work that would be detrimental to clients, such as being judgemental about a carer’s need for external help.

Another way to effectively provide culturally competent care, as shared by one of the Carers WA participants, is for carers to employ a family member, friend or person from their community to assist them. She regards this as a practical alternative solution to CALD carer needs that empowers them to make their own decisions in the interests of their wellbeing. It is being used not just in CALD communities but also in remote aboriginal communities where there is a dearth of formal service providers, and in the UK. However, this model is being stymied by the cut back in the number of family carer visas now being issued by Australia and the Productivity Commission’s recommendation against it which may prevent it being included as a care option in the new individualised funding model for community services being developed by the Government. One of the Red Cross participants also pointed out that employing family or personal contacts had become more difficult due to the current requirements on the carer to set up as a business with an ABN, get insurance and other legal responsibilities incumbent on them as an employer.

Mainstream services have great difficulty overcoming cultural incompetence due to a limited pool of support workers from different cultures and therefore staff in these services need to have a good

understanding of different cultural needs and be respectful of customs (e.g. whether or not to shake someone's hand or leave shoes at the door), according to the majority of the participants. For example, ensuring support workers are of an appropriate gender and age. The Red Cross participant gave an example of one client from the Middle East who was not allowed by her culture to be in the house with an unrelated male, even though they had to have a male support worker for her son who had a disability, and so she had to leave whenever he was in the house. She believes that services do not show great sensitivity to this type of issue.

All participants also highlighted the importance of using independent interpreters to aid communication with CALD clients if their language is not spoken by the service/worker. It was reported by several participants that services often do not offer, or use, interpreters. It was proposed that this could be due to not having the budget, finding it too hard/not understanding the importance of doing this or finding it easier to use family as interpreters, which is fraught with danger. According to the Umbrella participant, some staff are simply intolerant of having to make special efforts to communicate in another language and many have no understanding that crises, traumas, dementia and the ageing process often results in someone from a CALD background reverting to their mother tongue.

However, one of the key potential barriers to respite access for CALD carers raised by all the participants in their interviews, was the attitude and approach of the person dealing with the carer and care recipient, regardless of whether or not they can speak the same language as the family. Someone who shows understanding, empathy, friendliness, courtesy and above all respect for the carer/care recipient will reach a person in a way that is appropriate to them, upholds their dignity and is therefore more likely to be accepted, listened to and trusted. If respect is lacking, people from CALD backgrounds can sense it immediately, will not feel comfortable and will not accept the service – particularly if being delivered in their own homes where they expect their values to be respected. A few of the participants highlighted the importance of taking time with people to get to know them and their individual circumstances, as otherwise older people in particular will just not speak up as they find it too hard and are too proud to ask for what they need. The Umbrella participant noted that many ageing CALD people have memories of torture, imprisonment and other terrible traumas in their lives which can re-emerge as people age, and particularly if they get dementia, as they have often never talked about these experiences or had any form of support or treatment.

“We are dealing with humans not equipment or machines here – people come with feelings, baggage, histories – and some of these histories have been quite brutal.” Umbrella Participant

However, in order to build relationships of trust it is also important that the same person continues to deal with the carer and their family over time, and this also helps a service to learn more and be able to help with each carer's specific needs, according to a couple of the participants. The Chung Wah participant demonstrated this with an example of a male carer that she had known growing up who was now caring for his mother but needed help to sort out an issue between his wife and mother. As the staff at the organisation had a relationship with him for many years, including providing respite to his mother, he felt comfortable opening up and seeking their advice on what to do. Unfortunately, the new centralised system of needs assessments and follow up recently implemented in the aged care and carer sectors works against this in terms of care needs planning, as reviews are conducted by people unknown to the client who are not directly involved in service provision, according to one of the Red Cross participants.

The Umbrella participant described some mainstream residential services she had seen in Victoria which had made efforts to accommodate the cultural needs of different ethnicities within their system. For example, undertaking regular cultural briefings with their staff, employing staff who speak the same language, having non-English literature and magazines available, cooking meals from different cultures, and using basic communication aids such as a language translation cards for key phrases. One facility she was involved with sought to keep residents integrated into their cultural community by inviting Polish Club members to visit the facility and socialise with residents, many of whom had been members of the club when they were living in the community. However, many mainstream services are not as committed to the inclusion of CALD carers and fail to take even basic steps to ensure that their support is culturally appropriate.

Fragmented and complex system

Another key barrier to CALD carers having their needs met raised in secondary research and attested to by all of the participants in the primary research phase, is that the system is disjointed and difficult to navigate.

According to one of the Carers WA participants, the problem is caused by funding being delivered in silos across different areas of health need (e.g. mental health, disability, aged care). This creates a huge barrier for carers who have to cross these boundaries and navigate different sectors to find assistance, while also making service providers juggle inefficient pockets of funding. She feels that a far better approach would be to see disability as a condition that happens at different times over a lifetime which requires a continuum of care. Respite provided would then take a holistic approach to the wellbeing of a family placed in a community rather than focusing on separating the carer from the care recipient as it does now. The current funding regime is much too restrictive and does not

allow this to happen, whereas a social inclusion model would mean that we do not have to label someone as having a disability or mental health issues, which would also avoid the stigmatism that accompanies this approach.

The FMC and Chung Wah participants concurred with this view. They pointed out that poor resourcing of carer respite services, competitive tendering to deliver the same service in different areas of Perth and the fragmented and uncoordinated service system in Perth inhibits effective service delivery to CALD clients. In addition to this, the new centralised Home and Community Care (HACC) assessment and referral process compounds the complexity of the system as it is no longer possible to make direct referrals between services. Funding provided to deliver services is often more about efficiency than service quality and effectiveness in producing outcomes for clients and services can be reluctant or too stretched/busy to share information and work more closely together, despite many organisations often being involved in different aspects of a carer's life. CALD Carers have to navigate an overly complex system of agencies to help them with their different needs, meaning that there is no continuum of care. If the agency that they are familiar with does not offer the services they require, they must be referred on to other agencies and will often come back to the agency they have a relationship with if they feel that other services did not understand or were not responsive to their needs. This is often related to services lacking cultural competency.

“The problem is that they have to go thru so many different doors to find services. People are not products – they need someone to trust and should not have to repeat their stories over and over to different providers.” Chung Wah participant

The Chung Wah participant proposed a new model whereby ethno-centric and multicultural agencies provide cultural assistance to mainstream providers, working in partnership with them to deliver services to CALD clients in a more holistic continuum rather than referring clients between services. She feels that this would meet the needs of CALD carers better and is hoping the new aged care reforms underway will enable this approach. In this way, Chung Wah and organisations like it, could contribute much more to the mainstream system. However, she pointed out that it is important that mainstream services understand and appreciate the assistance that ethno centric or multicultural organisations are able to provide to improve service delivery.

“The essence of caring mustn't be lost – we need to have efficiency and streamline services, but we must not destroy the basic essence of why we are here”. Chung Wah participant

Not only is the system itself disjointed, but primary research participants also highlighted that a key flaw in the system is that funding horizons are far too short to effectively support carer respite

initiatives. Participation by CALD carers in respite initiatives can take a long time and a lot of patience to achieve as they need to be sure that they will be accepted, not feel judged and be with others who understand them, whilst also being given time to get comfortable with leaving their loved one in someone else's care. It takes time, and this is something that funders rarely allow for, wanting quick and measurable results to justify their support.

One of the Red Cross participants pointed out that nobody understands what a carer goes through unless they are or have been a carer themselves – the frustrations, the anger, the sense of loss – and often just knowing that they are with other carers makes them feel safe, and able to share their stories, fears and emotions in a supportive space with others who will understand where they are coming from and will not judge them. The FMC participant commented that the way in which others in the group accept and integrate new people joining them is key and that just being accepted for who you are is a universal language that transcends cultural and language barriers, as she has seen in their art groups where people find ways to communicate and accept each other even with no common language. However, the participants from Chung Wah and FMC said that in their experience, it often took twelve months to successfully establish new respite initiatives as it takes a long time to persuade CALD carers to attend and for the group of attendees to bond. The difficulty is that funding for such projects is usually very short term and does not acknowledge the lead time required to establish well patronised initiatives, particularly where carers from CALD backgrounds are involved.

The other consideration is that many CALD carers find it traumatic to leave loved ones as they are fearful that they will not be comfortable, and are often racked with guilt. The Umbrella participant pointed out that this process also takes time and explained strategies they use to gradually increase the carer's confidence, such as targeting services to the care recipient and inviting the carer to attend with them initially, and then weaning the carer out and encouraging them to have time to themselves. For example, the participant from Chung Wah described a new wellness program that the organisation is rolling out that will take this same approach and will enable carers and care recipients to develop skills and participate in recreational activities that appeal to their individual interests such as learning to use a computer, music therapy, gardening or playing majong. The strategy they are using to encourage participation in the program is to introduce the program to carers via the care recipients, in anticipation that once they see their loved ones enjoying the activities and being fine on their own, they will be more open to participating themselves.

Lack of flexibility and choice in supports available

All the research participants raised as a key issue the need to shift from a one-size-fits-all model of care to an individualised approach. This would require CALD carers being asked what they want and how, where and when they want services delivered as opposed to the current largely top-down approach where the people central to the service are not involved and consulted, services are provided as a suite of pre-determined options, and there is limited flexibility about where or when the service is provided. Not only does this finding align with the secondary research, but is also in line with the key tenets of a community development approach. As the FMC participant put it *"...otherwise, we will continue to waste millions of dollars on this model that is not working"*.

The key here, claimed the FMC participant, is to listen to people, be open minded, and understand that every individual has different circumstances, values and needs and that we cannot predetermine what might be important to them, stating *"there isn't a formula that works for everyone... none of us is an expert on what someone else needs"*. She provided examples of one carer who wanted someone to teach her how to drive so she could take her mother on trips, and another who wanted someone to take her husband out for a walk each day so she could have time on her own.

The Umbrella participant feels that it is possible to provide individualised care within a group setting if the service listens and responds to what each person in a group needs, such as the organisation's "home at home" program involving small groups of carers from the same ethnicity/language group who find group and facility-based respite too overwhelming. The program is conducted in one of the carers' homes and they are transported to and from the activity by staff. Group activities will depend on the interests of the carers involved but may include craft making, outings etc. Other organisations involved in this research also run groups for carers based on their interests such as walking, making craft or gardening, which would also seem to be good ways to target individual needs. The FMC participant believes that the art and craft classes the organisation runs are popular with carers as they provide an opportunity to develop practical skills, feel a sense of achievement in creating something and provide an interest outside of their caring role that acts as a lifeline to the outside world. The Carer WA Vietnamese and multicultural social support groups are also reportedly very successful and as they are self managed and directed, empower the carers attending them and improve their wellbeing and sense of self.

One of the Carers WA research participants envisages that self directed funding will force community services to change once introduced in Australia, as families will become the purchasers and shapers of services. She claims that the experience in the UK where this model of funding has

been operating for some time show that it leads to a growth in the number of peer or family based carer support groups i.e. groups who coalesce around a commonality related to a health condition, cultural background or geographic base. These groups can become very coherent and supportive, for example helping each other with referrals and joint service arrangements, and helping each other to learn how to use the individualised funding packages. They build on the existing support networks that the members already have in their communities and give people empowerment and the right to have a choice in what supports they want.

One of the Carer WA participants felt that current respite services and funding models are focused largely on separating the carer and care recipient, and that a family-centric approach is needed, particularly with CALD families who would often prefer to stay together.

“The assessment process needs to not just offer products off shelf a, b or c but should be an assessment process that asks what are the aspirations of this family and where does it want to be. This is far more likely to hit on the real issues and needs.” Carers WA Participant.

By taking this approach, services would look at non-traditional services that can meet a particular family’s needs: these may not be services in the carer respite or disability fields, but are offering services relevant to this family’s needs e.g. recreational activities. The focus would be on enhancing the family’s relationships or improving their health and wellbeing, rather than separating them. Examples of how this could be done is by participating in activities together in a supported way e.g. families going on holiday together but taking a formal support worker with them so that the carer gets a break or joint participation in cultural festivals or activities at a temple. Services of this nature are lacking at the moment and are particularly relevant to CALD carer needs.

Using community assets to address needs

I believe that in order to address the barriers outlined above effectively and to implement community development principles, an asset based approach (Kenny, 2011) to addressing need is required. Such an approach would mean that the strengths and capabilities of CALD carers are identified and used to address their needs, rather than an approach focused on addressing the community's deficits. For example, one of the key assets that CALD carers could use to address their needs is the strong base of support and relationships found in many ethnic communities and within families. This could be used, as illustrated in the primary research findings, to develop carer respite initiatives based around family and friends taking on paid carer roles rather than seeking help from external services, for example. There were other examples in the literature, and also captured in the

primary research, of CALD carers taking control of their lives and building social capital, for example by forming and running their own self-help/recreational respite groups. However, it is apparent to me that given the sizeable barriers facing CALD carers in accessing respite that their assets may not be sufficient on their own to address their needs (Kenny, 2011), and that external facilitation may be required to help CALD carers to be able to take responsibility and drive their own agendas forward, on their own terms.

CHAPTER 5: Conclusion

Summary of outcomes

The research showed me that defining the need of CALD carers for respite support is challenging. On balance, it seems too simplistic to assume that CALD carers will acknowledge and express their needs given the influence that cultural norms and community pressure can have on a carer's ability to seek external help. There is therefore a widespread need for greater education and information dissemination at all levels about what a carer is, positive reinforcement of the importance of the role and the vital place for self-care to enable the carer to continue to provide support to their loved one.

However, carers who do look for support find that many barriers face them that make it difficult to find services that suits their needs, and this often discourages CALD carers from seeking help again.

The key barriers highlighted by the research are:

- Services not being culturally appropriate;
- The system being fragmented and complex; and
- The lack of flexibility and choice in support available.

Addressing these barriers effectively requires systemic change to the way in which the system operates, and I feel that only by doing this will the needs of CALD carers be appropriately and comprehensively addressed. However, CALD carers need to drive these changes and be integrally involved in how the system is re-engineered to address their needs. If this does not happen the new model will be fundamentally flawed from a community development perspective as it will not empower and uphold the rights of CALD carers to equal access to services required.

Such changes will take a long time to achieve, as there are deep, systemic issues that will only gain momentum if driven by a strong sense of both community and political desire and commitment. In the meantime, there are ways that service providers can adapt the current system and improve access to CALD carers, by listening to CALD clients and finding ways to address their needs via innovative and personalised service responses, improving the cultural competency of services provided and working more closely with each other to help streamline the system for CALD carers and make it easier for them to find the support they need.

Further related research

Further research is required to validate these findings, testing them both with CALD carers themselves and quantifying them in a large-scale quantitative survey.

However, I also found that although there have been many research studies regarding carer needs in Australia, there was more limited research focused more specifically on the needs of CALD carers. It would be most valuable therefore for future research to build a more comprehensive profile of CALD carers and their needs, and to investigate factors that differentiate CALD communities such as location in Australia, specific cultural makeup and recency of arrival, for example.

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Appendix A: Research Questionnaire

Broad areas of questioning used to maximise information gained from each interview...

1. Tell me about the contact you currently have with carers from culturally and linguistically diverse backgrounds:
 - i. Type/form of contact
 - ii. Profile of carers dealt with (ethnic backgrounds/demographics/recent vs. long term residents)
 - iii. Specific focus on aged care/disability and/or mental health or all forms of carers?
2. What form of respite services do you offer?
 - a) Residential overnight and longer stay respite
 - b) Day respite options - out of home
 - c) In home respite support
 - d) Other (specify)
3. What do you feel are the strengths and weaknesses of the respite services your organisation offers with respect to CALD carers?
4. Give me an example of when you felt you could have provided better respite care to CALD carers, and an example of when you felt you excelled in the care service offered?
5. For the specific geographic area and/or type of carer that your organisation serves, how effective do you think you are in reaching CALD carers who need your respite services? Why do you think this (probe further - why/why not)?
6. Do you think that CALD carers in Perth have respite needs that are not being currently met? Why do you think this (probe further)? What respite needs do you think are/are not being met?
7. Do you think there are major differences in the needs of CALD Carers from:
 - a. ... different ethnic backgrounds,
 - b. ...different age groups
 - c. ...and/or based on recency of arrival in Australia?
8. What do you think is the impact on CALD carers of being able to access appropriate respite? What about if they are unable to access appropriate respite - what would be the likely impact of this and can you think of any examples of this happening that you may have seen or heard of?

9. How well do you think your service and other respite care organisations are in providing services that are based around people's unique needs vs. providing a more standard or generic one-size-fits-all model of care? How important do you think it is to provide person-centred or individualised care and why?
10. What do you think are the difficulties in reaching and providing respite services to CALD carers? Can you give me your thoughts about the 3-5 most key barriers or impediments?
11. What do you suggest could be done to improve the way in which CALD carer respite needs are addressed in Perth?
 - a) Have you seen or heard about any new best practice approaches that could be applied here in Perth (forms or models of service delivery)?
 - b) Do you think that it would require changes of a more systemic or holistic manner (attitudes, perceptions, structural, political etc)? What and why?
12. Do you have any other ideas or thoughts on how CALD carers living in Perth could be better catered for in terms of their respite needs?