Submission No. 746
(Inq into better support for carers)

A.O.C. 14/7/08

Building Community Spirit
Bringing Cultures Together
St George
Migrant
Resource
Centre Inc.

1 July 2008

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600

Dear Sir/Madam

Re: Inquiry into Better Support for Carers

St George Migrant Resource Centre provides support and services to CALD communities across St George and Sutherland local government areas.

In September 2002, St George MRC undertook a community consultation involving Carers form culturally and linguistically diverse (CALD) background living in St George and Sutherland areas.

Cultural groups participating in the consultations were: Chinese, Arabic, Muslim women, Egyptian, Macedonian, Greek, Italian, Spanish, Hungarian, Russian, Maltese, German.

The consultations have identified a range of issues for CALD Carers related to the following:

- Poor Access to existing services for the Carer and the person they are caring for
- Social isolation and the need for emotional and social support for Carers
- Inadequate Respite Options and a shortage of culturally and linguistically appropriate support
- Communication issues including lack of professional interpreters and bilingual community workers

- Shortage of culturally appropriate “in home” support
- Special needs of Carers of people with mental illnesses, as well as
- The aging Carer and their changing needs

The Report makes a number of Recommendations in relation to addressing identified issues, as well as identified service needs and gaps. Although the report was completed in 2002, the issues, needs and recommendations are still current, therefore we ask that the attached copy of Report is accepted as our submission to this parliamentary inquiry. If further information is required please do not hesitate to contact the writer on (02) 9597 5455.

Yours sincerely

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“Nobody cared about me before….”

REPORT

CONSULTATION FOR "CARERS" OF CULTURALLY AND LINGUISTICALLY DIVERSE BACKGROUNDS

26 September 2002

The Marana Hall
Hurstville

All enquiries or comments on this publication should be directed to:

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“It is the first time I have become aware that I am a Carer”

Arabic Speaking Carer

“I can’t get out”

Greek Carer

“You have no choice”, you have to care for a sick family member.

Chinese Carer

“I need someone to tell me how to deal with my child's (special) needs - am I doing the right thing?”

Egyptian Carer

“We have nothing like this back home….”

Spanish Speaking Carer

“Respite care? What is it?”

Macedonian Carer

Acknowledgements

St George Migrant Resource Centre would like to thank all people who were involved and participated in the consultation for their assistance and time. In particular, we thank bilingual facilitators for facilitating group discussions and scribes who transcribed the individual reports.

Thanks to NSW Department of Ageing, Disability and Home Care for funding this event, to Hurstville City Council for the use of the venue; and to Carers NSW for their support and interest in sharing their ideas.

Thank you to the following organisations for assistance in promotion and encouraging Carers to come along: Al Zahra Muslim Women's Association, Australian Chinese Community Association, Inner South West Community Development Organisation, Macedonian Australian Welfare Association, St George Joint Lebanese Committee, St Mark's Coptic Church and St Mary & St. Mina's Coptic Church.

Many thanks to Mario Bustamante for his time given to the organisation of this consultation, to Dean de Haas who spent hours in drawing up the first draft of this comprehensive report, to Jem Askew Social Work student from UWS for the first edit and to Maree Gill, a consultant who brought the report to printing stage.

Special thanks also to staff and management committee members of St George Migrant Resource Centre, especially staff of the Multicultural Aged and Disability Services team, for their support and contribution throughout the consultation.

The MRC hopes that this report will assist in creating an increased focus on the needs of Carers from culturally and linguistically diverse backgrounds!

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EXECUTIVE SUMMARY

The consultation for Carers of culturally and linguistically diverse backgrounds has sought to research the perception of the needs of culturally and linguistically diverse (CALD) Carers from their lived experiences.

Consultations were undertaken with resident Carers in the St George and Sutherland areas in September 2002, through qualitative methods - focus groups, individual interviews and semi-structured questionnaires. Cultural groups participating in the consultations were: Spanish, Chinese, Arabic, Muslim women, Egyptian, Italian, Greek, Macedonian and Hungarian.

In doing so, emphasis was placed on the particular needs of "the hidden Carer"- who does not identify as such and most likely does not currently appear in available statistical collections.

The report presents detailed summaries of focus group discussions with these groups - capturing the richness and diversity of views expressed by the various community groups which participated in the consultations.

The consultations have identified a range of issues for CALD Carers related to the following:

- access to both services and respite
- social isolation and the need for emotional support
- inadequate respite options
- shortages of "in home" support; high care needs of the frail aged,
- special needs of Carers of people with mental illnesses, as well as
- the aging Carer and their changing needs.

The report outlines service gaps identified through the consultation. Specifically:

- poor access to services
- questionable service delivery and unsuitable service delivery to CALD Carers and
- lack of culturally appropriate service was a major theme.

The Report makes a number of Recommendations in relation to addressing identified issues, as well as identified service needs and gaps.

TERMS USED IN THIS REPORT

- Carer - A Carer is a family member, parent, partner, significant other, friend or neighbour, who provided care on an unpaid basis. The person they support may have a chronic illness, disability, mental illness or may be frail. (Carers NSW and the Carers Coalition).
- Caree - a person who has a disability, or who is frail aged, and is being cared for by a Carer
- CALD - Culturally and Linguistically Diverse
- DADHC - NSW Department of Aging Disability and Home Care
- Dept of Health and Ageing - Commonwealth Department of Health and Ageing
- CSTDA - Commonwealth State Territories Disability Agreement
- EACH - Extended Aged Care at Home
- Respite care - services provided for times when the regular Carer is away or requires "time out"
- Hidden Carer - a person performing a caring role but who does not identify with the term "Carer", and consequently receives no support in their caring role
- Centrelink - Commonwealth Department which provides a range of government services and payments to help Australians reach their goals and full potential
- CACP - Community Aged Care Package
- YPWD - Young People with Disabilities
- Carer Payment - a Government payment to a Carer who provides constant care in their homes to an aged person or person with a disability
- Carers allowance - a government payment to a person who is looking after a child or adult with a severe disability or medical condition who needs a lot of additional care or attention. This allowance may be paid in addition to the Carer Payment
- LGA - Local Government Area.

Definition of a "Carer"

The following definition of a Carer was used for the purpose of this consultation:

> *"Carers are people, usually family members, who provide support to children or adults who have a disability, mental illness, chronic condition or who are frail aged. Carers can be parents, partners, brothers, sisters, friends, relatives or children of any age. Some Carers are eligible for government benefits, while others are employed or have a private income".* (Carers Australia Website)

Carers consulted during this research were not in receipt of private income for their caring roles ie. they were not "professional" Carers.

RECOMMENDATIONS

This Consultation has identified numerous service gaps and needs which need to be addressed in order to support CALD Carers and ensure equity.

The Consultation also recognised the need to change/impact on existing service structures.

Recommendation 1

The implementation of a bicultural/bilingual case management project, using bicultural staff to support CALD Carers.

This project could:

- provide culturally appropriate assessment which could be utilised by providers of other services
- provide case management
- support Carers to access mainstream services
- provide information and emotional support to Carers
- facilitate Carers support groups/social groups or networks in their own cultures
- provide and organise community education in their own culture, targeting the hidden Carers.

This project would be based in the St. George region but would have responsibility for accessing CALD Carers in the Sutherland region.

Recommendation 2

The development of stricter and more defined outcome measures for DADHC and CSTDA funded services (with specific focus on respite), to support CALD people.

Similarly more defined Departmental expectations on community advertising/promotion targeting CALD people. This should be a contractual agreement in areas of high CALD population.

Recommendation 3

Funding for the recruitment, development and training of a pool of bilingual/bicultural workers who can be brokered by other services so as to meet "new Government accountability guidelines in regards to CALD clients participation."

Recommendation 4

A pool of funds to provide or purchase culturally specific support to CALD Carers in areas such as personal care, domestic support, transport, respite etc. to provide flexible service provision, on a culturally/linguistically specific basis.

Recommendation 5

Increased respite funding for the St. George/Sutherland region, with a specific dedication to respite for CALD Carers.

Recommendation 6

The need to increase one-on-one “in-home” respite care.

Recommendation 7

A Government funded community development/ education program / campaign targeting CALD Carers - specifically "hidden Carers" on identifying:

- Carers in Australian Society
- support available to Carers in Australian Society
- benefits available to Carers.

This could be a state-wide promotion or specific to the St. George/Sutherland regions.

Recommendation 8

The EACH Program (Extended Aged Care at Home), to be piloted / implemented for the CALD population in the St. George area, in order to alleviate pressures on Carers of the high support frail aged, and to balance the shortage of culturally/linguistically appropriate nursing homes.

Recommendation 9

To investigate the possibilities of “break-away” options where Carer and Carees can have a break together, similar to sports and recreational camps for families model.

Recommendation 10

The development of community directories that outline where culturally and linguistically appropriate support can be accessed.

BACKGROUND TO THE CONSULTATIONS

The St George Migrant Resource Centre provides support and services to CALD communities across the local Government Areas (LGA's) of Rockdale, Hurstville, Kogarah and Sutherland. The majority of CALD residents are found in the St George area. 9.5% of participants were from Sutherland Shire. This represents 18,000 CALD people in a total population of over 200,000 who reside in the Shire. In the St. George region there are over 64,000 who were born in non-English speaking countries (2001 Census).

In December 2001, the St George MRC received an additional $10,000 recurrent funding from DADHC to provide support to CALD Carers in St George and Sutherland areas. Prior to the receipt of additional funding, support to Carers was provided by telephone contacts and bi-monthly outings/meetings for identified Carers. Additional funding has meant that St George MRC was now in a position to investigate issues of relevance to Carers in their caring roles and so to identify the most appropriate way to provide services to CALD Carers in both St George and Sutherland areas.

The concept of, and term “Carer” is an alien one to many CALD communities. There is often no culturally appropriate comparison - either with the term “Carer” or with the implied role of the Carer in many cultural groups. According to Carers NSW Website, one (1) in eight (8) people in NSW is a Carer. It follows that a significant proportion of Carers in NSW will be people of culturally and linguistically diverse backgrounds.

The job of caring for people who are frail, or suffer chronic illness or who have disabilities, continues to fall on family members in many CALD communities. Of particular interest to this consultation are the “hidden” Carers who support and care for people within the community, often without recognition and financial and other support. Anecdotal evidence indicates that people from CALD communities feature prominently in this population.

Concepts of “respite” - a key component in supporting Carers - are neither well understood or acknowledged by many CALD communities.

These conceptual problems are further exacerbated by barriers of language and cultural sensitivity to currently available service types.

Currently, for many CALD communities the “burden of care” continues to be borne by the family (most often the women), and close social networks. Little is known about this population and their caring roles - from their own perspective.

It is these issues which the Consultation has attempted to explore.

Statistical Profile of People with Disabilities in the St George Area

The following Table[1] provides data concerning ethnicity and disability in St George area.

The exact number of Carers in the area is unknown. It is important to note that the ABS data provides an incomplete picture of both older people and people with profound and severe restrictions (See Table 1: 7)

Approximately 6% of people identified as having disabilities will have profound and severe restrictions (ABS term), and are therefore most likely in need of specialist services (MDAA). This population in particular would be likely to contain a large proportion of Carers. The statistics presented below provide an indicative but incomplete picture, from which to draw further assumptions about numbers of Carers in the area.

Table 1

	Hurstville LGA	**Kogarah LGA**	**Rockdale LGA**
1. Total population	70,010	49,884	87,658
2. Language other than English spoken at home	43.1%	43.3%	55.7%
3. Age over 65	15.5%	15.4%	15.8%
4. Born in a non-English speaking countries (NESC)	29%	28.3%	34.6%
5. People with disabilities who were born in a NESC[2]	3,654	2,541	5,459
6. Number of people from a NESC with disability [3]	7,300	5,080	10,910
7. Number of people from a NESC with profound and severe restrictions (estimate only)	438	304	654

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[1] ABS 2001 Census data.

[2] Estimation of number of people with disabilities who were born in a NESC – by using the formula from Multicultural Disability Advocacy Association (MDAA), ie. Numbers of people born in NESC divided by 100 and multiplied by 18 – this does not include second generation people from a NESB.

[3] Estimation of number of people with disabilities by using formula from MDAA, ie. double the above number (see Table 1:5) – this gives a reasonable indicator of real numbers.

AIMS

The consultation was held for Carers of Culturally and Linguistically Diverse backgrounds (CALD), residing in the St. George and Sutherland geographic regions[4].

The target population was people who support or care for a person with a disability, mental illness, chronic illness or who is frail aged in order to gain perspectives on issues of relevance to the Carer role.

The Consultation targeted CALD Carers with the following objectives:

To identify:
- support needs of Carers
- barriers to access existing services,
- knowledge of existing services
- service gaps and unmet needs
- culturally appropriate modes of support for Carers
- issues relating to respite care/respite services.

Target population
- People of Culturally and Linguistically diverse backgrounds
- Residing (or caring for a person) in the Rockdale, Kogarah, Hurstville, Sutherland LGAs, and
- Who support /care for a person or people with:
    - a disability
    - mental illness
    - chronic illness
    - frail aged.

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[4] LGA's of Rockdale, Kogarah, Hurstville, Sutherland.

METHODOLOGY

St. George Migrant Resource Centre invited CALD Carers to participate in this consultation through the following channels; ethnic and local media, ethno-specific organisations, regional service providers, religious leaders and peak organisations, ie People With Disabilities (PWD), and Carers NSW.

Special care was given to access the "hidden Carer" - people who don't identify themselves as Carers.

Language and culturally specific focus groups were held on 26 September 2002 with the following communities: Spanish speaking, Chinese speaking, Arabic speaking, Muslim women, Egyptian, Italian speaking, Greek speaking, Hungarian and Macedonian communities.[5]

In the main, focus groups were facilitated by independent bi-lingual community members. Use of focus group discussion was aimed to allow participants free and open discussion based on the reality of each person's situation. Prior knowledge of community care and health structures, was unnecessary for participation in the focus group discussions or for completion of the questionnaires.

Questionnaires in community languages were distributed to those who indicated interest, but who could not attend the forum. Personal/individual consultations in community languages were also conducted through the NESB Access project hotline. For consistency, questionnaires were based on the same questions asked of focus group participants. [6]

Information was collected from each cultural group and listed in point form. This information was forwarded to ethno specific welfare organisations for comment and consideration. Discussions were held with group facilitators to ensure that information had remained true to the discussions.

This report is focused on the responses of the 123 Carers who participated in the forum and comments extracted from returned questionnaires.

A focus group of service providers (n=11) was held at the same forum, and while the views of service providers were not central to this research, opinions supported the views of Carers which emerged from the various community language focus groups (See Appendix 5).

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[5] See Appendix 4 for Summary of Focus Group discussions
[6] See Appendices 2 and 3 for Focus Group Questions and Facilitator Notes

Participants

This consultation involved a total of (n=123 Carers), of whom (n= 85) attended the focus groups held on 26 September 2003, and (n=38) forwarded information through other means such as questionnaires, including (n=24) via telephone interviews through the access Hotline. The majority of participants or respondents to the questionnaires were female (89%).

Table 2: Cultural Breakdown of Participants in Focus Groups and Respondents to Questionnaires by Gender

Culture	Participants	Female	Male
Chinese *	23	20	3
Egyptian	24	20	4
Greek	10	9	1
Italian	10	9	1
Lebanese	8	7	1
Macedonian	23	19	4
Muslim Women **	17	17	0
Spanish	6	6	0
Other	2	1	1
	123	**108** **89%**	**15** **11%**

* Mandarin and Cantonese speaking

** specific cultural group necessary due to religious and cultural requirements

Place of residence of Participant or Respondent

Based on contact details provided, 9.5% were from the Sutherland Shire, 88.5% from the St. George region, and 2% from other locations.

Table 3: Place of residence

Place of Residence	% of Participants/Respondents
Sutherland LGA	9.5%
St George LGA	88.5%
Other	2%

Carers and whom they support

45% of the participants did not disclose specific information about the person for whom they cared, eg. a person with a disability, a frail aged person.

Of the (55%) of participants/respondents who disclosed information about the person for whom they provided care:

- 30% of respondents/participants indicated they provided care for a person with a disability
- 70% care for a person who is frail aged.

OVERVIEW OF ISSUES IDENTIFIED THROUGH CONSULTATION

Summary of issues

A wide variety of issues was identified during the consultation about the needs and perceptions of Culturally and Linguistically Diverse Carers.

The following table summarises the issues that emerged during this consultation. (Detailed comments follow in *Discussion of Issues* Section).

Table 4 Overview of Issues

Identified Concern	**Summary of issues raised**
1. Poor Access to existing services for the Carer & the person for whom they care	• The non identification of people from the CALD Community as Carers and the subsequent failure to identify both the need for, and availability of support to this community • Cultural expectations, roles and stigmas which create barriers to service access • Lack of awareness of existing services and health/community care structures • Linguistic barriers as a major impediment to service access • Culturally inappropriate assessment procedures, leading to unsuitable or unacceptable services • Lack of culturally and linguistically appropriate support structures • Cost of services prohibitive • Lack of awareness about Centrelink entitlements and difficulty in accessing the Carers entitlement.
2. Social isolation and the need for emotional and social support for Carers	• Loss of personal identity, social networks and social isolation – the need to redevelop those structures which socially and emotionally support the Carer • Shortage of bicultural/bilingual health and welfare professionals limiting professional support • Lack of transport and transport options affecting lifestyle choices.

Identified Concern	Summary of issues raised
3. Inadequate Respite Options and a shortage of culturally and linguistically appropriate support in St. George & Sutherland	• Culturally and linguistically inappropriate respite options reducing access and equity of service • Shortage of centre based respite for the aged • Shortage of emergency and flexible respite • Shortage of all respite options for Carers of younger people with disabilities respite care hours - in particular “blocks” of time for sessional respite • The need to facilitate 24 hour respite options and supported holiday environments where the Carer and Caree can enjoy a break together, attend family reunions & holidays.
4. Communication issues	• Limited availability and flexibility of professional interpreters- particularly in the community setting • The benefit of bilingual advocacy/support versus interpreting in relation to home and community care services • Difficulties Carers face with service providers.
5. Shortage of culturally appropriate “in- home” support, in St. George and Sutherland	• Shortages of the following: - Personal care - Domestic assistance - Culturally appropriate meals - Home maintenance & modification.
6. Meeting the needs of the frail aged with high care needs, in a culturally appropriate manner	• Residential care- shortage of culturally appropriate beds • Extended care support in the home as a more suitable option for people with high support needs, not only EACH but also CACP, and CACP for YPWD.
7. The ageing Carer and the future for those they support	• Shortage of appropriate residential placements for younger people with disabilities.
8. Lack of culturally appropriate support for Carers of people with a mental illness	• Lack of respite for Carers of people with a mental illness • Lack of professional and bilingual support for Carers and people with a mental illness • Social stigma of mental illness among the wider community.

DISCUSSION OF ISSUES IDENTIFIED THROUGH CONSULTATION

Identified Issue

1. POOR ACCESS TO EXISTING SERVICES FOR THE CARER AND THE PERSON FOR WHOM THEY CARE

The non identification of people from the CALD Community as Carers and the subsequent failure to identify both the need for, and availability of support to this community

The term "Carer" and the role of “Carer” are not recognised by many cultures.
The majority of CALD Carers consulted through this consultation, do not identify as a “Carer” and hence, as a person requiring or entitled to external support.
The premise that identification of an issue precedes the solution is applicable in this situation.

With no understanding of the term or role, often without clear and simple translation, and sometimes without culturally appropriate comparison, there is very limited awareness that external support is available to Carers.

Cultural roles, expectations and stigmas creating barriers to service access

There are a number of significant factors, grounded in cultural mores, that affect access to service by Carers of NESB. Participants indicated that these barriers need to be overcome through a process of community education to improve service access.

Issues raised were:

- The Carer role is seen as principally the responsibility of the family, (in most cases the female family members). Raising children, caring for the aged, frail, the unwell (whether chronic or short term), disabled people or a person with a mental illness, is seen as the family's responsibility.

- Seeking help outside of the boundaries of the family is a sign of inability to fulfil that familial role and can bring recrimination and lead to feelings of guilt, inadequacy, embarrassment and shame. Due to such cultural/family/gender expectations and values, it is not uncommon that even when a family crisis occurs related to the caring role, services may still go unused.

- Particular cultural views relating to care for aged people is significant in influencing the Carer’s motivation to seek support from outside services.

In many CALD communities, families wish to remain together, family members desire to be supported by the family during illness and incapacity, and wish to die in the home. For many- moving to a nursing home, or other residential care, is seen as being one step from death.

For example: the Egyptian Coptic community sees residential care as "a place to wait for death", a theme not attributed to this culture alone.

Due to social stigma, and feelings of shame or guilt, some cultures do not wish to identify with having a member of a family with a disability, mental illness or other debilitating disease. Without identification or acknowledgment of these issues, there can be no acceptance of the need for support.

For many CALD communities “problems“ are handled within the family. Discussing problems with others, especially strangers, is not acceptable. As this is central to seeking support in Australian society access opportunities are restricted.

For Carers, a lack of understanding of issues such as dementia, Alzheimer’s disease, mental illness and autism makes it more difficult to cope with the needs of the Caree. The consultation noted lack of linguistically/culturally appropriate information and education in these areas.

The cultural shame or lack of recognition often attributed to these conditions lead to increasing emotional stress.

Lack of awareness of existing services and health/community care structures

Carers of NESB exhibit a general lack of knowledge regarding service delivery modes and services in the St. George and Sutherland regions. This is highlighted by a very narrow list of recognised service providers and the lack of awareness of major Carer organisations.

Highlighting this lack of awareness and lack of understanding of government funded support structures are comments such as “*we have nothing like this back home*”. (Focus group participant)

This is also applicable to Centrelink benefits. CALD Carers often have no base knowledge to draw upon when support becomes a necessity. There is little understanding of availability of support or the strategies to identify or seek support.

Linguistic barriers and the need to utilise bilingual workers

The language barrier was seen as one of the key impediments to accessing support. Areas identified, where the issue of language and lack of bilingual workers have impacted, are:

- Availability of simple, accessible translated information, without jargon, in written format. Such information also needs to be available at culturally appropriate sites such as churches, bilingual doctors etc. (Organisations may have translated information. However, if potential clients do not know it is available, or cannot communicate to ask for this information, the presence of the document becomes redundant).

- Promotion of services both verbally, and through the ethnic media, to inform Carers of availability of services and entitlements.

- Communication barriers also impact on the Carer’s access to services. The initial point of contact and the referral process are often perceived as being difficult and intimidating. A positive experience at the initial point of contact is essential to disseminate appropriate information, and facilitate the commencement of the assessment process. Clients faced with language barriers are currently disadvantaged by the process.

- Carers often find requests for ongoing support and contact with services to be difficult and confronting. This sometimes results in the Carer rejecting the service and feeling that their needs are unmet. Equity of access is often not apparent to the Carer.

- Frequently, services are not provided in the appropriate language of the Carer, and consequently client needs are either unmet or perceived to be inadequately met. Where communication is restricted in this way, the development of empathic relationships is seen to be inhibited.

Culturally inappropriate assessment procedures leading to unsuitable or unacceptable services

The process of assessment impacts negatively on access to services for CALD Carers in the following ways:

- Due to a perceived lack of empathy and understanding, the process is inhibiting the client’s willingness to accept support.

- The process of assessment does not adequately assess or sustain the Carer's need for support due to an inability to gather the appropriate information.

Carers need support and understanding, beyond simply interpretation of language, to clearly get their message across to service providers. Assessment needs to be completed from a point of understanding, appropriate to the Carer.

More honest and therefore accurate assessment of Carer needs will be facilitated when cultural sensitivity is demonstrated in relation to the individual and Carer needs, including understanding of the religious base of the household coupled with effective communication.

Additionally, some Carers may “withhold” important information, which they consider embarrassing or culturally unable to discuss with people outside the immediate family. Often this information, which could be about a physical issue, lack of family support and cognitive dysfunction, is essential for service eligibility assessment.

A culturally sensitive assessment should provide an action plan that is tailored to meet the needs of the Carer, specific to the individual and not be service driven.

Lack of culturally and linguistically appropriate support

It is the experience of many of the participants who were aware of available services for Carers, that cultural or linguistic requirements are often ignored in structuring a plan to support them. Each culture has beliefs, attitudes and practices that are intrinsic to their way of life. The lack of culturally and linguistically appropriate support in these areas was seen as a major impediment to service access and hence support for Carers.

All service delivery modes were highlighted as not fulfilling this essential requirement. Strongly emphasised were the importance of culturally and linguistically appropriate services in the areas of: social support, respite support, nursing homes, meal services, transport, domestic support, personal care and professional clinical support.

The burden of the caring role restricts opportunities for social interaction and also makes it difficult for Carers to have opportunities to fulfil personal and social needs. This problem is exacerbated by poor access to support services to provide respite - relief from the Carer role.

Cost of service inhibiting participation

The Carer role can be a financially costly role, with its own financial demands on the individual Carer. For example the costs associated with equipment, medication and medical treatment can be prohibitive. For many Carers, the “caring role” can also deprive people of Career opportunities and hence income. Often, Carers manage on very tight budgets. Issues of service eligibility where “fee for service” applies can be barriers to access. This is especially the case when multiple avenues of support are necessary. Respite, aged care packages and transport were highlighted as being services that were difficult to afford. Often the family budget is limited, with the Carer’s government benefits most often contributing to family income.

Lack of awareness of Centrelink entitlements and difficulty accessing the Carers entitlement

This consultation brought to the fore an extremely concerning result - a large number of Carers are not aware of Centrelink entitlements and services. This group are illustrative of the “hidden Carers” in CALD communities. For a client group that is financially disadvantaged, this is a major issue.

Participants commented that it was often difficult to receive the Carers allowance and that the application process was time consuming and frustrating.

Participants also describe problems in their dealings with Centrelink, especially in relation to the organisation of interpreters or the Telephone Interpreter Service.

Suggestions were made at this consultation that Centrelink should play a more proactive role in educating Carers, in providing knowledge of available services, benefits and resources. Again the need for linguistically and culturally appropriate promotional activities is essential.

Identified Issue

2. SOCIAL ISOLATION AND THE NEED FOR EMOTIONAL SUPPORT

Loss of personal identity, social networks, social isolation and the need to redevelop those support structures which socially and emotionally support the Carer.

Clearly defined is shortage of opportunities and support structures, across all cultures, in regards to the facilitation of social interaction and emotional support for Carers. Carers identified social isolation as one of the major issues they confront, affecting most aspects of their lives. Social groups or social networks need to be developed and supported in order to break down isolation.

The caring role, is often described as 24 hours a day, 7 days a week (24x7). Such total demands are barriers to developing meaningful social interaction, experiencing a sense of fulfilment and emotional relief and support for Carers. The physical workload, demands, expectations and needs of the Caree, the emotional and physical commitment of the Carer to the role, all decrease personal and social opportunities. This is exacerbated for the CALD Carer, due to cultural expectations that the women of the family, who are usually the Carers, be dedicated to the home/family environment.

Feelings of depression, loneliness, lack of motivation/goals, loss of personal identity, anxiety, loss of self and stress, as described by participants, are associated with this lack of social interaction. The link with emotional and psychological well-being is clear; resultant physical ailments such as tiredness and lack of energy are also attributed to this situation.

Other issues affecting their personal and emotional wellbeing identified during the consultations are:

- The uncertainty of the future of the Caree should anything happen to the primary Carer, especially significant for aging Carers of people with disabilities.

- The constant and ongoing need for vigilance due to fear of accidents.

- The duality of the role of the primary Carer, generally the female, in fulfilling the Carer role and maintaining and fulfilling all other familial and cultural obligations.

Shortage of bicultural/bilingual health / welfare professionals limiting professional support

Whilst the emotional support provided by structures such as family, friends and peers are acknowledged as central support for the Carer, these structures often cannot provide the information or professional guidance that is required to manage problems. The shortage of social workers, mental health professionals, psychologists and other health professionals who are bilingual/bicultural poses ongoing problems for the CALD community.

Ideally, the kind of support provided by these professionals should reflect cultural and linguistic understanding of the individual Carer - best facilitated through direct communication, rather than through the intervention of an interpreter.

Further, Carers noted a lack of understanding of issues such as dementia, Alzheimer’s disease, autism, schizophrenia and strategies to manage or deal with these issues. This lack of awareness needs to be managed through community education and through access to professionals who are trusted and can impart this knowledge.

Lack of Transport Options

Lack of appropriate transport for both Carer and Caree was identified as a major impediment for both groups. Availability of personal transport options for ageing Carers in particular, was extremely limited.

Participants cited the following examples where lack of appropriate transport options resulted in difficulties: attending appointments, doing shopping, social engagements, attending religious rituals.

The transport issue is magnified in situations where extra support is required for the Caree. For those supporting people with more severe physical disabilities or who are frail aged, requiring the Carer to assist with physical transfers or provide physical support, eg wheelchair access or hoists, availability and flexibility of transport is seen as inadequate.

Critically, Carers required culturally and linguistically appropriate personal support to be available in conjunction with the vehicle.

Other Transport issues highlighted during the consultations:

- For some of the cultural groups there were considerations about who was providing the transport. For example it would be inappropriate for a Muslim woman to get into a vehicle driven by a male. This precludes some cultural groups from utilising community transport.

- Carers indicated concerns regarding lack of transport in emergency or urgent situations. Services do not appear to have flexibility or resources to manage these situations at short notice and to provide appropriate transport.

- Costs associated with transport resulted in restricted usage of available options. Many participants expressed concerns, saying that their budgets restricted transport usage. This has an impact upon the lifestyle of the Carer and Caree.

Identified Issue

3. INADEQUATE RESPITE OPTIONS AND A SHORTAGE OF CULTURALLY AND LINGUISTICALLY APPROPRIATE SUPPORT IN ST GEORGE AND SUTHERLAND

Culturally and linguistically inappropriate respite options reducing participation

The concept of respite, acknowledged as one of the key components in supporting Carers, is not commonly recognised. People clearly identified the need for time to be "by oneself" and to have "time to oneself" as requirements, the need being noted but the services that support this need, and the availability of such services, remaining unknown to Carers.

This consultation establishes that Carers of NESB believe that respite options are not meeting their needs in relation to the provision of culturally and linguistically appropriate support. Some of the key areas in this regard are:

- The support staff needs to speak the language of the home environment

- The same support staff member needs to be used regularly to build trust

- The support provided needs to address the cultural and religious expectations and practices of the home environment

- CALD Carers may need time to themselves, or to spend with other members of the family, but often do not want to be separated from the person for whom they care. Respite care services do not currently acknowledge this cultural need

- Supported activities for both Carer and Caree could be developed as a culturally appropriate method of respite

- The need for the Caree to also have an enjoyable time whilst respite is being provided. In this way some of the culturally imposed "guilt" may be alleviated

- The inappropriateness of nursing homes and hostels as a form of respite because of the expectation that the family stays together and the perception of these facilities as a place where people wait for death. The need for the provision of more appropriate 24 hour respite options, such as in home respite and group home was identified

- Lack of flexible “outside hours” support, appropriate to the household (ie. weekends, after work hours).

Shortage of centre based respite for the aged

The consultation highlighted long waiting lists or absence of language-appropriate centre-based respite, or day care. The need for increased dementia specific groups was highlighted.

Culturally this option was seen in a positive light, with the Carer having the opportunity to have personal time and the Caree participating in an activity which is both enjoyable and perceived as secure. All language and cultural groups participating on the day strongly supported the facilitation of these groups. Further, they noted that more places needed to be found for:

- people with higher support needs
- people with disabilities
- people with a mental illness.

Shortage of emergency and flexible respite

Participants also desired respite options that:

- were available at short notice and in times of emergency or crisis
- allowed for the Carer to participate in activities in conjunction with the Caree
- provided enjoyable activities and outings for the Caree
- were available in the evening and on weekends.

The shortage of emergency respite was strongly highlighted; short notice and appropriate support being unavailable.

Shortage of all respite options for Carers of younger people with Disabilities

The consultation raised the point of a shortage of support for Carers when “projects” and schools closed for vacation breaks. Carers outlined:

- increased stress

- not being able to fulfil other roles that they normally took on ie. work, other Carers roles
- not providing opportunities for other children in the family
- inability to take holidays.

The need to increase the availability of support at these times was seen as vital. Lack of availability of respite support for weekends and evenings was seen as a continual problem, participants believing that support availability was decreasing in the region.

Lack of options for respite care hours - in particular “bocks” of time for sessional respite

The need for extended respite support was seen as important to Carers, the provision of one or two hours a week inadequate and not seen as providing opportunity for personal time. Carers noted they used respite for shopping, paying bills and personal medical appointments. However the commitment to the Caree and lack of extended respite options precluded other opportunities.

The need to provide blocks of time for respite, in a planned manner, at times when other personal needs/interests could be pursued was seen as essential to Carers.

Families are hesitant to utilise residential respite options due to cultural reasons. Participants identified the need for increased extended respite in the home, as a method of reducing family pressure and stress.

Whilst residential respite is seen as posing problems due to the cultural stigma of nursing homes, there is an acknowledged need for the provision of extended respite in a supported environment. The perception of participants is that this needed to be facilitated in a different environment or atmosphere to a nursing home and be community or church linked.

The need to facilitate family reunions and holidays though improved 24 hour respite options and provision of supported holiday environments.

The issue of the inability of the family to have holidays due to the caring responsibility was raised in this consultation. Whilst culturally there is a hesitancy to use outside support for care, the unavailability of culturally and linguistically appropriate respite options for Carers of the frail aged and people with a disability (especially for longer durations) diminishes opportunities in this regard. This issue becomes more poignant in relation to peoples inability to visit relatives in their home country, due to overseas travel for extended periods being impossible because of the Carers role. The necessity for affordable, longer term, 24 hour respite options, provided in a culturally and linguistically sensitive manner is central to overseas family reunion.

Suggestions were forwarded that it would be advantageous to have holiday destinations for families where support was available, ie. with transport, personal care and respite, to allow the Carer to spend not only quality time with the person for whom they are the primary Carer but also with the remainder of the family. Carers strongly indicated that family holiday opportunities would help to relieve the pressures faced by the entire family.

Identified Issue

4. COMMUNICATION ISSUES

Limited availability and lack of flexibility of Professional Health Care Interpreters

Participants expressed the need for interpreters for health related issues, such as in the hospital system or in consultation with specialists. Carers noted that they, and the Caree, often did not understand what was happening whilst in a hospital situation and that interpreters were not available at short notice to support them. This occurred frequently with specialist visits or when instructions were being imparted by nurses.

Issues around the lack of availability and inflexibility of appointment times were emphasised, resulting in family members often being utilised as interpreters in an inappropriate manner.

The benefit of bilingual advocacy/support in relation to community care services

People at this consultation expressed the belief that their message was often not clearly being delivered to the service provider. It was because interpreters either did not understand the complexities and structures of community care/welfare system, or due to the nature of their role were not willing or able to adequately support them to deliver their message clearly to the service provider. For example, clients cannot ask for respite if they don't have knowledge of the concept. Interpreters could help with drawing inferences.

Whilst this consultation reinforces the need for better resources for interpreter services, especially in the health care system, participants often did not see this as the only solution to their problems in areas of gaining support from community care services or other service providers.

Difficulties Carers face with service providers

In addition to difficulties previously outlined in relation to assessments- the following were also identified:

- Carers are faced with a situation where language is a barrier and therefore interpreters may assist
- a "stranger" from an unknown service expects an open discussion of the person's issues (often in the Carers home)
- the assessment is often long and involved
- they are expected to read and sign agreements in English
- a third person in the form of an interpreter may be present at the assessment so that it is difficult to build rapport with the assessor.

CALD Carers need support to clearly outline their needs when required. In some cases this support needs to take the form of advocacy, so that they receive appropriate support from service providers. For a Carer to agree to services it is necessary to facilitate a situation of trust and empathy.

This consultation, both directly through statements such as in the Chinese focus group "*we need a dedicated Chinese Case worker*", and indirectly through implications of the inability of mainstream services to provide bicultural/bilingual workers, identified the need for bilingual case management.

Identified Issue

5. SHORTAGE OF IN HOME SUPPORT

Personal Care

Personal care is an issue across all cultures, particularly in relation to gender issues where it is often difficult for a man to provide personal care to a woman, due to accepted roles in the household and cultural mores which often preclude these actions. In some cultures, it can sometimes be seen as demeaning, for both Carer and Caree, where a family member provides personal care support. Participants referred to feelings of "shame" and "embarrassment."

Physically, the provision of personal care can be extremely taxing. For the Carer (who will usually be female), the physical manipulation of a frail aged or older person with a disability can be a difficult task. The ongoing fulfilment of this role, over many years, can lead to physical problems for the Carer- back and neck injuries were commonly described during this consultation.

For those who were aware of the availability of this type of support the common thread was one of a shortage of services, inability to access services or find culturally appropriate services.

Domestic Assistance

A common thread, already discussed, is the workload placed upon the primary Carer (predominantly the female) due to her duality of roles. The expectation of managing the household, raising and fostering the family's growth as well as the caring role, places a heavy burden on the Carer. Feelings of inadequacy were often described. Carers often expressed concern that other members of the family were being neglected due to the high demand expectations of the Caree - especially the aged Caree.

In relation to domestic assistance the Carer could be providing support in one of two situations:

- the Caree being in the Carer's family home (predominant)
- the Caree being in their own residence.

Regardless of location - the burden remains the same in relation to expectations about cleaning, cooking, shopping, washing and ironing.

Carers believe that relief in this area would allow them to have a better quality of life, spend quality time with individual family members, including the Caree, and be seen as an individual in their own right.

Support with cleaning, washing, shopping, ironing supplied in a culturally and linguistically appropriate manner would not only alleviate the burden of workload but provide opportunities for communication with someone outside of the family - in itself breaking down isolation.

Culturally appropriate meals

Meal support was clearly defined as a separate issue in relation to the following;

- lack of awareness of the availability of meal services
- existing meal services were unable to meet the cultural requirements of the community.

Carers described the fact that they had to prepare and deliver meals to family members as they had no other options, culturally appropriate meals being particularly important to the aged. The fact that available alternate meals were not culturally appropriate was highlighted by the Italian, Egyptian Coptic and Chinese consultations.

Without any other sources of acceptable meals, Carees remain totally dependent upon the Carer. This has the obvious effect of restricting Carer's opportunities for social activities and personal independence.

Home maintenance and modification

The consultation highlighted issues concerning the home environment affecting both Carer and Caree. The need for equipment to support the Carer, modification of home structures to improve access, support to do the gardening and lawns were all mentioned as tasks that could make the caring role easier. Again issues of cost and lack of awareness of services were highlighted.

Identified Issue

6. MEETING THE HIGH CARE NEEDS OF THE FRAIL AGED

Residential Care – shortage of culturally appropriate beds

Residential care is seen by most cultures as the last option for supporting the aged. Movement to a nursing home is perceived in a negative light, with implications for the Carer, and pressure to maintain quality of life in the home.

For those who are willing to move to a nursing home, or have no other option, there is a shortage of culturally and linguistically appropriate beds. Issues highlighted are:

- need for culturally appropriate meals
- need for accommodation which meets religious needs
- staff and other residents speak the language
- long waiting times to access accommodation.

Extended Care in the Home as a more suitable option for people with high support needs

Participants indicated the need for 24 hour support for people with dementia or other high support requirements, with the majority maintained in the home due to cultural expectations.

Appropriate support needs to be available for those of high support needs- whether they be the aged or people with disabilities. Whilst there are Community Aged Care Packages (funded by the Department of Health and Ageing) to support the aged in the home, this support corresponds with hostel care support

– or people who need low level support. This level of care is often not enough to support the Carer, by the time the Carer accesses services.

There is a need for extended support packages that allow for support in the morning and evening and at times of greatest need on a seven day a week basis. For the Carer, three to five hours of support a day will allow them to spend time with other family members and have a quality of life for themselves. It also will maintain the family unit for as long as possible, which is culturally very important.

Identified Issue

7. LACK OF SUPPORT FOR CARERS OF PEOPLE WITH A MENTAL ILLNESS

Absence of Respite for Carers of people with a mental illness

The consultation identified the absence of culturally and linguistically appropriate respite support for Carers supporting people with a mental illness. Those participating at the consultation were not aware of available support.

Lack of culturally appropriate professional support for Carers and people with a mental illness

Concern was raised regarding the lack of culturally and linguistically appropriate case management and professional support for people with a mental illness. The need for professionals who understood the cultural implications of mental illness for the individual and significant others, and the ability to communicate directly through the appropriate language, was seen as an issue that needed to be addressed.

Also noted was the general lack of available information and education regarding mental illness. All avenues of support for Carers of people with a mental illness were seen as limited.

Identified Issue

8. THE AGEING CARER AND THE FUTURE OF THOSE WHOM THEY SUPPORT

Shortage of appropriate residential placements for people with disabilities

For the ageing Carer of a person with a disability, physical, sensory, intellectual or psychological impairments, the major concern raised is - what will happen when they are no longer able to support the Caree? Highlighted is a lack of options, especially linguistically and culturally appropriate, for those who are not eligible for nursing homes or hostels. Consideration needs to be given to:

- intensive support packages to assist the person to remain in their home
- accommodation options, with support, in small group settings.

SERVICE GAPS AND NEEDS

The following Table summarises identified service needs and gaps for CALD Carers, based on focus group discussions and other consultations conducted.

Table 5: Identified Service Needs and Gaps

1. General lack of culturally and linguistically appropriate support in St. George & Sutherland Shire areas
2. Culturally specific Carer support groups or facilitated support networks needed, available for Carer and Caree to attend
3. Culturally specific social groups or facilitated social networks for Carees
4. Culturally and linguistically appropriate assessment strategies
5. Bilingual/bicultural case management for Carers
6. Increased availability of culturally and linguistically appropriate and flexible respite for all Carers
7. Bilingual/bicultural domestic support for Carers in the home
8. Bilingual/bicultural personal care support for Carers in the home
9. Increased affordable transport options
10. Transport with the support of bilingual /bicultural staff
11. Authentic meal service provision
12. Extended packages of care in the home for people with high support needs
13. The need for more bicultural/bilingual health professionals
14. Community education for Carers
15. Increased resources for health care interpreters which extends to community settings

DISCUSSION OF SERVICE NEEDS AND GAPS

(See Table 5 above.)

Carers from Culturally and Linguistically Diverse Backgrounds painted a clear picture of poor access, questionable equity and unsuitable service delivery in regards to these support structures. The requirement of services to be client focused, meeting the needs of the individual does not appear to have been extended to the issues of linguistic and cultural needs.

In the focus groups, a wide variety of issues were raised in relation to service gaps and needs, with the main theme being lack of culturally appropriate support in the St. George and Sutherland area for CALD Carers. Increasing the availability of culturally and linguistically appropriate respite for Carers is seen as important. Availability in the home of appropriate bilingual/bicultural workers for Carers skilled in culturally and linguistically appropriate assessment strategies and case management, was also identified as very important.

Another important gap and need is having culturally specific Carer support groups or facilitated support networks where the Carer and Caree can attend together. Having support and social groups is vital to the well being and survival of the Carer. Lastly, support in the home for Carers with domestic support, personal care, meals, and transport were seen as important in supporting the Carer in their caring role.

General lack of culturally and linguistically appropriate support in the St. George and Sutherland Shire areas

All cultural groups participating in the focus groups indicated the following:

1. a shortage of service support in general to Carers in these regions
2. a significant shortage of services that provide culturally and linguistically appropriate support for CALD Carers.
3. concurrent culturally appropriate flexible or "in home" respite
4. appropriate support for the Caree at the same facility.

Culturally specific Carer support groups, or facilitated support networks

All cultural groups participating in the focus groups indicated the following:

1. a need for Carer support groups or facilitated networks supported by bicultural/bilingual workers
2. St. George region has a high need as identified through this consultation.

3. The Spanish speaking consultation supported the need for support in the Sutherland region.

Culturally and linguistically appropriate assessment

The consultation found that services must implement strategies to ensure that assessments are completed using culturally appropriate methods, across both the St. George and Sutherland Shire areas.

Bilingual/bicultural case management support for Carers

All cultural groups participating in the focus groups indicated the following:

- The need for advocacy support, referral and if necessary linguistic assistance.
- Whilst the need is strongly identified in St. George, population statistics would suggest a need also exists in the Sutherland Shire.

An increased availability of culturally and linguistically appropriate respite for all Carers

The consultation found that there is a shortage of all respite types that is culturally and linguistically appropriate in both St. George and Sutherland regions, and essentially a need for affordable respite services to be available on weekends and after work hours, in relation to the following service types:

- in home respite
- emergency respite
- residential respite, both short and long term
- centre based respite placements.

Such respite should provide opportunities for Carers of people with disabilities, the frail aged, mental illness and high support needs in circumstances such as respite support for school holiday periods for Carers of school children with a disability.

Bilingual/bicultural domestic support for Carers in the home

There is an acknowledged shortage of support in both St George and Sutherland regions for domestic support.

Bilingual/bicultural personal care support for Carers in the home

There is an acknowledged shortage of support in both St George and Sutherland regions.

Increased affordable transport options with support of bilingual/bicultural staff

There is a shortage of transport, and flexible availability of transport, in both St George and Sutherland areas.

Authentic meal service provision

The results of this consultation and the large and diverse ageing CALD community in St George indicate that the need is high for authentic meal service provision in this region, but it requires trust and cultural sensitivity to the family that is supporting the house-bound person.

Extended Packages of care in the home, for people with high support needs

Such Packages need to be provided by bicultural/bilingual staff, to support the cultural expectation of people remaining in the family home.

The need for more bilingual/bicultural health professionals

This need was identified in both the St George and Sutherland regions.

Community education of Carers

Carers (in particular the "hidden Carers") need information regarding entitlements, support, service providers and so on.

This consultation and demographics indicate that this need relates to both the St. George and Sutherland region.

Increased resources for health care interpreters

This shortage would appear to apply to both St George and Sutherland areas.

APPENDICES

Appendix 1: NESB Carers Consultation Agenda

St George Migrant Resource Centre
Multicultural Aged and Disability Services

DAY CARE AND & CARERS SUPPORT PROGRAM

NESB Carers Consultation

Marana Hall
Hurstville

26 September, 2002

10.30 am	Welcome and introductions
10.45am	Guest Speaker
11.10am	Morning Tea
11.30am	Workshop
01.00pm	Feedback from group discussion
01.15pm	Thank you and close
01.20pm	Light lunch

Appendix 2: Focus Group Questions

FOCUS GROUP QUESTIONS

- Do you identify yourself as a Carer?

- What is your perception of a Carer?

- What are the problems you face as a Carer?

- What if anything would help you deal with your situation?

- Are you aware of any services available to support you?

- Are you aware of respite services and what they provide?

- What type of support service may be appropriate for you to use?

Appendix 3: Notes for Facilitators

Notes for Facilitators
Carers Forum
26 September 2002

1 Do you identify as a Carer – what is your perception of a Carer?

(highlight the role of women as main Carers in most cultures, also *what are Carers means in their culture*, are they expected to provide the care as part of their roles as wives, daughters or daughters-in- law, mothers or friends and young Carers such as daughters, sons etc)

2 What are the problems you face as a NESB Carer?
(Identify issues affecting Carers of NESB)

- *Social isolation* due to barriers such as language, culture, demands of being a Carer, lack of family and support networks in Australia.
- *demands of other family members* such as spouse and other siblings
- *psychological and emotional tension* due to high level of stress
- *cultural stigmatisation* ie in many cultures it is a "shame " to have a family member with a disability, this leads to isolation and hiding the person with a disability from the community
- *financial hardship:* the need to quit paid work.

3 What if anything would help you most of all to deal with your situation?

4 Are you aware of any services available for NESB Carers?
(Identify community knowledge of existing services)

- are they aware of any services in their LGA (St. George / Sutherland), where they have heard about them, have they use them, if any used – how do they feel about them.
- barriers/difficulties accessing resources due to language difficulties, inappropriate service offered ie not culturally or linguistically appropriate , not understanding the Australian welfare system and fear of government services, shame to accept outside help, not having trust in outside help
- what would be the best way to find out about existing service ie. ethnic radio, ethnic newspapers, religious leader, community workers, doctors, newsletters etc.

5 Are you aware of respite services and what they provide?

- is respite considered as not being responsible and caring enough towards their Caree.
- is respite simply not available in their LGA or if so, services not appropriate, not enough hours given or too expensive.
- cultural/language barriers
- is there a need for weekend respite centres to enable Carers to contribute towards caring for the rest of their family needs (other children)
- what type of respite is needed: out of home centre based, weekend, overnight, longer term up to ---weeks?

6 The MRC has tried to provide services for NESB Carers such as telephone support, outings, home visits etc.
Which of the following support services may be appropriate for you?

- Respite (home visit) – culturally and linguistically appropriate
- Weekend or day care respite centres in your area
- Culturally and linguistically appropriate family support services
- Other home assistance
- Transport need
- Carers support groups/outings
- Telephone support (appropriate)
- Other

7 Identify other issues relevant in the role of the NESB Carer that need to be addressed.

Appendix 4: Ethnic Specific Consultations[7]

1. Spanish Speaking Community

6 participants, all female

Do you identify yourself as a Carer - What is your perception of a Carer?

- It is perceived and expected for women to take on this role when required. However there has been some shift in this area.
- **"L",** has been a Carer for 15 years however never identified her self as a Carer. (Was not aware of this concept of Carer).

What are the problems you face as a NESB Carer / Barriers in accessing services?

Issues (Difficulties)

- Language as a barrier for Carer and Caree
- Frustration
- Devalued
- Isolation
- The Carers ability to cater for Caree's needs, difficult to manage, time consuming, lack of understanding of dementia. Individuals with dementia demand a great deal of time as well as special care.
- Lack of Spanish speaking workers in the Area (Services)
- Financial hardship
- Frustration of not being able to contribute to the family financially.
- Need support to be able to attend to other chores.
- Lack of privacy
- Wish to live independently
- Having to give up social life

What, if anything, would help you most of all to deal with your situation?

Help / Need

- Day Care for Spanish speakers
- Respite
- Specific Day Care for clients with Dementia
- Services in Spanish
- More personalised information, culturally appropriate

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[7] Ethnic specific results have been written with great detail, so that individual services can benefit from knowing what certain groups need and where gaps need to be addressed. Ethnic Specific Results came from the Spanish community, Muslim women, Chinese, Arabic, Egyptian, Italian, Greek Hungarian and Macedonian community.

- Information about the type of services available to the Spanish speaking community
- Need to empower clients
- Nursing home in the area for Spanish speaking community
- An urgent need to develop and implement a plan for services for now and the future (for Spanish speakers)
- Stimulate / promote volunteerism within the community
- Create more social / peer support groups
- The need to have qualified staff to work with dementia sufferers and their Carers
- Mental health in general
- Transport
- Directory (listing services and workers of Spanish speaking background)
- Knowledge (Training) For Carers i.e. How best to care for your Caree, in particular those who have special needs
- Activities for Carers
    Relaxation / Recreation
    Socialisation
- Translated information in general in particular about services and entitlements for Carers and Carees (eg. Centrelink payments).

Are you aware of any services available for NESB Carers?

- Not aware of any services for Spanish speakers in the Sutherland area
- Aware of:
  Benevolent Society
  Miranda Neighbour Aid
  (No Spanish speakers)

Best way to promote services and activities:

- Through the Church
- Spanish Newspaper (El Espanol / Spanish Herald)
- Direct promotion / via phone
- Pamphlets / Mail outs / attached to Spanish newspaper
- Better use of Spanish media
- Pamphlets to be in simple and clear language (No jargon)
- Paid advertisement

Are you aware of respite services and what they provide?

- There are no respite services in the Sutherland Area for Spanish speakers. This is an urgent need
- Urgent respite is needed for nights and weekends

Recommendations

- A Spanish day care group

- Increased respite options, respite provided by staff that speak Spanish, available on nights and weekends. The Sutherland area was highlighted in this regard
- Improved promotion of services and information to the Spanish speaking community – utilising Spanish media, cultural networks and Spanish translations
- Increased support for Carers of people with dementia
- The development of opportunities for socialising and informal support for Carers
- A Spanish speaking nursing home, or Spanish speaking units in nursing homes
- Increase availability or access to trained staff who speak Spanish

Discussion

The Spanish speaking community outline a case of little or no culturally and linguistically specific support in the region. This shortage is applicable to most areas of support and service delivery, however respite, community information, support groups for Carers and centre based respite (day care) are seen as priorities. Further the participants described a generic shortage of support across most forms of support for both the Carer and Caree, also raising concerns regarding the affordability of service, especially respite.

The area of financial hardship was clearly identified by this group, this related to the cost of being a Carer, the cost of external support and the lack of Career opportunities due to the Carer responsibility. Further, some members of this group were not aware that there were Centrelink entitlements available to Carers.

2. Chinese Speaking Community

Mixed Cantonese and Mandarin speakers

16 attendees
7 questionnaires
20 female participants / respondents
3 male participants / respondents

1. Do you identify yourself as a Carer – What is your perception of a Carer?
Parents are expected to take up the Carer role for their disabled children or frail aged parents or parents-in-law. However, women would be the primary Carer due to cultural expectations that "caring" is the women's role and responsibility in Chinese family and community. Other reasons included:

- It is not appropriate for a father or son to provide personal care for their female family members.
- Men need to work and support their families financially

Carer means:
Responsible to provide support to family members who are sick or have a disability

- Commitment
- Obligation
- You have no choice

What are the problems you face as a NESB Carer / Barriers in accessing services?

- English Language barrier
- Carers' health problem- physically and mentally (depression, stress, anxiety)
- Ageing problem – Carers getting old themselves, find it hard to look after their Carees
- Feeling anxious and worrying about their Caree's everyday life and their future
- Feeling tired as "Carer," it is a 24 hours job
- Feeling guilty if the person is being cared for by other people, and /or being cared for outside the house, also worried about them being abused by others.
- Isolation due to workload
- Lack of support network in Australia
- Lack of knowledge of available services (very limited resources in Chinese)
- Do not access relevant information on services and assistance
- Do not understand the Australian welfare and community service system and service types
- Accepting their role as the primary Carer

- Do not understand the different types of respite care.
- Lack of Chinese bilingual workers generally
- No Chinese specific organisation / services for people with mental illness
- Lack of respite care during school holiday
- Inflexible respite care (Homecare respite does not take Caree out of the home)
- Lack of community transport for emergency
- Lack of Chinese authentic MOW
- Very limited respite care and centre-based activity for people with mental illness, and no Chinese specific service
- No Chinese specific day care for young people with disabilities, Carer cannot communicate with services
- Do not know how to help their family members who suffer from autism, no Chinese specialist on this area
- Lack of health care interpreters / specialists do not use interpreters
- Often there are long waiting lists for allied health eg speech therapy, over one year waiting.
- Expensive and costly eg. $70 per day for Handicapped Children Centre.

What, if anything, would help you most of all to deal with your situation?

- Chinese specific services for people with mental illness
- Dedicated Chinese case worker / key worker / contact person
- More Chinese interpreters (mainly for health)
- To have culturally appropriate services where Chinese speaking workers who have more understanding of cultural needs and issues
- Community transport (individual) services for emergency and weekend
- Transport in general
- Ageing / Disability services directory / Guide in Chinese
- More Chinese group homes for people with intellectual disability
- More day centres for young people with disabilities
- More weekend respite care
- More respite care for school holidays
- Respite care for extended period up to 4 weeks so Carers can go overseas visiting their family
- Community education about different types of respite care
- More promotion on relevant services through Chinese media eg Chinese newspapers, radio, Chinese aged group, Chinese organisations and special schools.
- More social activities and outings for Carers (and Carees) to lessen the stress
- More social activities held at weekends
- Social activities for the whole family
- Home based Respite care to be more flexible, (i.e. in-home / out-of-home)

Are you aware of any services available for NESB Carers?
The majority are not aware of any services that exist for Carers in the LGA's; some are aware of the following services:

- Community transport
- Respite care
- NESB Access Project
- St George shopping /outing services
- Group Home in Marrickville

They heard about these services from bilingual workers, friends, family, Chinese organisations and Chinese newspaper.

The best way to find out about existing service is:

- Major Chinese newspapers
- Chinese radios/ TVs
- Local doctors
- Chinese Churches
- Chinese organisations / social groups

Are you aware of respite services and what they provide?
The majority were not aware of this service and what it means. For those who have heard about it, did not know the different types of respite. Only one had used respite care before and did not like it as it was not flexible.

Barriers:

- Stigmatised for using respite care and not fulfilling expected role
- Guilt for not taking full care and responsibility
- Not flexible in terms of types eg. in-home services can't provide out-of home respite
- Expensive
- Not available when you need it (and also for extended period)
- Culturally inappropriate
- Not enough and very limited

Recommendations:

- Support group for Chinese Carers
- Information sessions on services
- Outing and social activities is a high demand to break social isolation
- Social activities for the whole family
- Respite care provided for some group meetings / outings
- Chinese specific services for people with a mental illness.

- Culturally and linguistically specific services for aged support
- Culturally and linguistically appropriate flexible respite, for the aged and for people with a disability, including weekend and after work hours and out of home respite.
- Culturally appropriate meal services
- Increased respite for school holiday periods.
- Information and education provided in a culturally and linguistically suitable manner, regarding services and issues relating to Carers ie. autism
- Bilingual/ bicultural caseworkers to support people with assessments, referrals, emotional support, information etc.
- Improved interpreter service

Discussion

This consultation group, containing both Mandarin and Cantonese speaking people, raised a variety of issues relating to caring for people with disabilities, mental illness and the aged. Culturally the caring role is seen as one for the family, especially women, and as an obligation to be fulfilled. This may in part support the fact that this group had limited understanding of services available to them as Carers. Whilst this may be one component, it would appear that information is not reaching this community in a manner that is understandable and/or culturally sensitive so as to be educative and informative.

The group when asked to consider “what if anything can help you most of all in your situation”, raised a variety of thoughts and ideas based around provision of culturally and linguistically appropriate support, social networks and outings and service delivery options. Whilst the Chinese community is accepting of the Carer role, it is clear from the discussions that increased support for this community is necessary before people reach “crisis” point. This support needs to take into account the culture, sense of family, and involve family inherently in service provision.

3. Arabic Speaking Community (Muslim Women)

17 in focus group – all women
2 specified caring for a child with a disability
2 specified caring for aged person
13 unspecified

Do you identify yourself as a Carer – What is your perception of a Carer?
It is an expected role for women to be a Carer (and the only Carer) for every one in the family in the Arabic Culture. It is an expected role from family and community.

Carer means:

- Helper
- Facilitator
- Responsible to provide support to family members and relatives
- Commitment
- Obligation
- Devotion
- Sacrifice
- Isolation from the whole community
- Acceptance of someone's fate
- Perspective - religious role
- You have no say or option
- No idea what Carer is
- It is a great feeling when you care for someone

What are the problems you face as a NESB Carer?
Things that limit Carer capacity to fulfil their roles:

- Language barrier (very limited resources in Arabic)
- Discrimination of Muslim women by neighbours
- Transport (lack of support)
- Health problem- physically and mentally (depression, stress, anxiety)
- Isolation due to workload
- Financial difficulties to afford services
- Lack of family support due to new immigration law (family migration)
- Denial of support from family members
- Embarrassment and uncomfortable having disabled person in the family
- Feeling guilty if the person being cared for placed outside the house
- Not aware how to get help when needed
- Lack of understanding how Carers services would be beneficial

- No problem, great support from family members

What, if anything, would help you most of all to deal with your situation?

- More awareness programs for us, as one of the participants expressed “it is the first time I am aware that I am a Carer” another said “ it is the first time someone thinks about me”.
- Availability of equipment for disabled (ie. wheelchair) would help Carer not to lift and would reduce the hard work
- External support (ie welfare agencies) to reach us
- To have services where it is culturally appropriate (ie. have Muslim worker where they have more understanding of our issues, purifying)
- To have respite care but have the understanding of our culture
- More social activities and outings to lessen the stress
- More information about our rights as Carers
- Community education about our role
- Have female workers to address our needs (in transport, home care)
- No need to do anything, as we are lucky in this country with the amount of services we have
- Encourage family members to provide support

Are you aware of any services available for NESB Carers?

The majority were not aware of any services for Carers, (gap in the service) some are aware of the following services:

- Multicultural Aged Care and Disability Service in Bexley - MRC
- Calvary Hospital
- St George Hospital

They heard about these services from bilingual workers, neighbours, friends, school counsellor, and their children.

Barriers in accessing resources are:

- Expensive and costly
- Language barriers (do not speak or understand English)
- Transport (not available)
- Have to ask to get help, we are not used to asking
- Religiously inappropriate to use some services
- Do not wish to be identified as a Carer
- Accepting their role as the primary Carer
- Community expectation from you as a Carer limits opportunities to access services
- Not used to using these services in home country
- Stigma associated with relying on outside help
- Not aware of existence of services

- Did not understand how these services could help

The best way to find out about existing service is:
- Local doctors as they visit them regularly, trust them, know family history, no need to explain, feel supported, speak the same language and in safe hands.
- Religious leaders as they are respectable and listen to their weekly speeches and seminars, well informed, and feel comfortable
- Community radio station (Arabic)

Are you aware of respite services and what they provide?
The majority are not aware of this service and what it means. For most of them this is the first time they hear about service gaps.

For those who are aware of respite services, they heard from health workers in St. George hospital, from the Arabic radio station (the program was about respite care).

Barriers:
- Stigma from using respite care
- Guilt for not taking full care and responsibility
- Not flexible in terms of time arrangement (long waiting list)
- Expensive
- Not available when you need it
- Culturally inappropriate
- Not enough and very limited

Recommendations:
- The Moslem Arabic Women's Group seems to be in greater need to identify their needs and develop strategies to address these needs properly
- Carer services must provide service with appropriate understanding regarding language, cultural, and religious issues
- Female workers – culturally and linguistically appropriate to support women
- Need to involve community members especially doctors to reach Carers
- Organise support group for Carers in Arabic to bring "normality" and "familiarity" within the group and to feel it is ok to be a Carer and use services
- Telephone support and the need to talk to someone seemed to be the highest option to support Carers as it is difficult to share issues with family, and relatives due to sensitivity, lack of understanding and afraid to be recognised
- Outings and social activities are in high demand to break social isolation, encourages and supports Carers in their tasks
- To consider face-to-face interviews in the future rather than the group setting, as it was emotional for some and was hard to handle in front of the group.

Discussion

Muslim women are the “Carers” in their culture, however the term “Carer” as related to the Australian welfare system has no meaning in the community. The role played by women is seen as a devotion or sacrifice and as an acceptance of one’s fate, however this group acknowledges that the role influences their life and the life of all the people for whom they care.

The general lack of awareness of options is one of the key issues raised by this consultation. This group is an extremely isolated group, acknowledging discrimination from neighbours as well as language barriers. This community does not appear to receive incidental information flow, it is a community that supports itself and is somewhat insular due to world activities. Thus information dissemination to Muslim women is poor, this is depicted through limited to no knowledge of services and support. As stated in the consultation “we’re not used to these services in the home country”, a statement that showcases that there is no foundation of knowledge for this community in regards to Community Care.

Whilst there is a perceived stigma and a cultural negativity to receiving “service” support, at this time this community does not appear to have the information to make a decision on whether they could use a culturally appropriate support service.

In analysing some of the “problems” faced in being a “Carer” in this community the main point appears to be the isolation and emotional strain placed on the Carer. In supporting this group culturally and linguistically appropriate methods of overcoming this problem through respite, social networks/groups, transport, bicultural/bilingual case managers need to be considered. In facilitating these actions the utilisation of any trusted community infrastructures will be an important prerequisite. A program of education is needed as a precursor to any direct service delivery.

Type of respite needed is:

Short-term respite care needed daytime only, few hours, longer hours but no weekends or no longer term. The services that are most appropriate:

- Telephone support
- Outing and social activities
- Home assistance (ie gardening, home maintenance).

4. Egyptian Community

20 in focus group – 16 female, 4 male
4 questionnaires – 4 women

5 specified caring for a child with a disability
16 specified caring for aged person
3 caring for an adult with a disability
3 unspecified
Note: one participant identified as a Carer for both an aged parent and a child with a disability.

Do you identify yourself as a Carer – What is your perception of a Carer?
It is an expected family role especially for women, it is also an expected role for the community.

The roles spoken about in this group, included:

- wife caring for husband
- son and daughter for parents
- parents for a child with a disability
- neighbour
- caring for children with a special need.

What are the problems you face as a NESB Carer?

- Not being able to take holidays – especially oversees due to the caring role
- School holidays, extra workload and little support
- Social isolation
- The person being cared for "Caree" not wanting to move, losing the will to live
- The "Caree" doesn't want an outsider to help them
- Lack of privacy and space in the home, wheelchairs, equipment etc also take up
- Physical problems for the Carer such as back & neck problems, stress, anxiety
- Loss of "self" and personal goals
- Duplication of roles – caring for own children as well as parents, not having enough time for all
- Loss of income and Career opportunities
- Financial difficulties, always having to budget and prioritise
- The "shame" of a child's disability, ie having to change nappies (older child with disability), dealing with behavioural issues
- Asking for help feels like not fulfilling their responsibility to their family member that they are caring for

- Parents being cared for feel like they are being a burden to their son/daughter when they should be the one giving support
- Nursing homes are not seen as an option as the culture sees a nursing home as a "place to wait for death"

What if anything would help you most of all to deal with your situation?

- More awareness and education for the Carer and Carees about the help that they can get from others
- People who operate services to speak the language and be of the same culture
- More school holiday respite options for children with a disability and with special needs
- Personal care support
- Home maintenance
- More after work hours support – so we can spend more quality time with the "Caree" and family
- More space at home
- People who speak the language, understand the culture, to advise me on how to deal with my child's special needs - "am I doing the right thing?" The same applies to dealing with dementia, ageing issues – not knowing how to handle things. Similarly support on services available without having to contact all the services – then be unsuccessful.
- Help with the heavy duties, lifting the Caree, gardening etc
- One worker, preferably from the church, to assist with care
- Services not changing the worker regularly as familiarity helps the situation
- The social needs for the "Caree" being met – makes the Carer feel good
- Home maintenance

Are you aware of any services available for NESB Carers?

A lot of people were not aware of the support available, some people were aware of:

- Live at Home
- Benevolent Society
- Meals on wheels

The response from those using services was:

- Not enough respite available
- Not enough emergency respite available (service has been cut)
- There has been a reduction in hours
- Fees are costly
- Have to pay for service even if away and not using

Meals on Wheels was mentioned. It was noted that this service is not culturally appropriate for use by this cultural group – especially when fasting on Wednesdays and Fridays.

Barriers in accessing services are:

- Expensive and costly
- Do not know about services
- Not language or culturally specific
- People feel they should not need outside help

Services that supply social outings for Carers should consult with them about where they would like to go, places should be interesting, different, where we haven't been before. Going out for lunch is not the only thing to do.

Services should be regular ie. Don't operate for a month and then stop the next month because Carers rely on a steady service.

Services should be sensitive, sincere and supportive, people should be treated with respect and not as if it is just a job for the worker.

Services should consider reducing their fee charges.

Are you aware of respite services and what they provide?

Some people were aware of respite however there was a general lack of knowledge. Issues that were raised regarding respite were:

- More respite is needed
- People did not know respite was available
- That the worker does not know the person and their needs – it would be better if the person knew them eg through the church. Further to this for people who do use respite there was a concern that the worker continually changed and did not allow either person to get to know the other.
- Respite was limited to 1 or 2 hours, people needed the entire day or an extended period of respite or service.
- It was suggested that a "mini nursing home" be set up where people could go for a day, where workers spoke the language and were part of the culture. It would be good if the government could provide a place for the church to provide this service. A suggestion was that it could be called "A club for the wise" as nursing homes were for most Egyptians "a place to wait for death".
- Frustration that workers came to people's homes to do assessments, offer help, do lots of paper work and ask lots of questions and then get back to you and tell you that they are sorry but the service is limited, not available. Unrealistic expectations are raised for people by service providers.

- Service should be continual, planned and reliable – should occur all the time so we can be organised.

Which support services may be appropriate?

- Outings with the Carer and Caree going out together
- Holiday home where Carer and Caree go together with support
- Practical support for people who can't speak English and need to solve a problem ie. With telecom, broken wheel chair, finding transport, etc
- Home assistance (ie. gardening, home maintenance)
- More Aged Care Packages for Egyptians – people do not want to go to nursing homes
- Out of home respite activities for the Caree so that Carer can attend to own social needs
- Transport support on Sundays for Carers to be able to take the Carees to church.

Recommendations

- Increased flexible respite, both for the aged and for people with disabilities, provided by people of the same culture, Egyptian.
- Respite should be in larger blocks of time, not single hours, and not always home based. Further the flexibility of respite needs to extend to out of work hours and weekends to allow for other family needs to be met.
- Increased respite on school holidays for young people with disabilities.
- Culturally appropriate, Egyptian, emergency respite.
- More culturally appropriate in home care, with hours of support extended beyond CACP hours for the aged, to assist them to remain in the family home rather than move to residential care.
- Culturally appropriate domestic support ie. Cleaning, cooking etc. to allow the Carer to spend more time with the Caree and family.
- Improved information and education, in a linguistically and culturally appropriate manner (Egyptian) on available service, support and about issues relating to Carers such as dementia, autism, Down's Syndrome etc.
- More home maintenance, gardening support.
- Meal services to provide culturally appropriate meals, especially when fasting, ie on Wednesdays & Fridays.
- Social outlets for both the Carer and Caree, isolation can be extreme.
- Improved transport – especially for church on Sundays, with a person to support the "Caree" in this transport.

DISCUSSION

The Egyptian Coptic community, through this consultation, expressed a great need for culturally and linguistically appropriate support. This need was farreaching, addressing needs for those with a disability and the frail aged, through areas such as respite, personal care, domestic care, social support, education on Carers issues, meals and transport.

Culturally the family takes responsibility for supporting those in need, this places other stresses on the family unit. The discussion often referred to the fact that another “member of the church” would be a good person to offer support. This reinforces the necessity to meet the needs of the culture if service support is to be accepted and successful.

This group, if indicative of the larger community, had limited knowledge of available services. This would suggest that the outreach of existing services needs to be improved through utilisation of community structures such as the church, media and doctors.

People also described the need for someone of their culture, speaking their language, to talk to them and advise regarding their issues as Carers. This could be provision of information, emotional support or support with a referral. In a similar vain people utilising services voiced frustration regarding assessment procedures, use of interpreters and lack of cultural understanding of people doing assessments, then at the culmination of the process, the lack of service or the provision of inappropriate service.

5. Italian Speaking Community

4 attendees
6 Questionnaires
3 people caring for adults with a disability
7 caring for frail aged

Do you identify yourself as a Carer – What is your perception of a Carer?
It is an expected role from family and community.

A Carer means:
Someone who does everything they can for the "Caree"

- Makes sacrifices to care for their relative
- Responsible to provide support to family members and relatives
- A feeling of guilt if they cannot fulfil the Carer role
- Obligation

What are the problems you face as a NESB Carer?

- Language barriers increase isolation - even using an interpreter can be difficult as messages are not always relayed accurately
- Racism
- Cultural beliefs and issues being ignored
- Always rushed and have no time for oneself
- Having someone in the home to provide respite feels like an invasion of privacy
- Not aware that services exist
- No information on services
- No access to support services
- Lack of privacy in the home
- Need to be available all the time - can't go out, loss of freedom
- Too little respite support for people with high support needs
- Cost of support too high, especially when on the pension, this leads to the Carer persevering without support

What, if anything, would help you most of all to deal with your situation?

- Affordable transport - community transport can be very expensive if used regularly
- Emergency respite - it was noted that there is not always service available even when the need was desperate
- More culturally appropriate services ie. Meals.
- Concern for aging Carers, what support is available for the "Caree" when the Carer can no longer cope or passes away
- In home respite - culturally appropriate
- Personal care assistance - difficult showering father/male relative

- Increasing support as the needs of the Caree increase with age
- Affordable support
- A greater knowledge of support services, cost, waiting lists etc.

Are you aware of any services available for NESB Carers?

There is a degree of knowledge that services are available but little understanding of the variety of services, how to access them and who they are available for. Knowledge seems to be based around personal care services.

One Carer felt that there were support services for older clients, and younger clients, but nothing for people who fell in between ie, 50 year olds. There were concerns regarding support services for aged people - belief that there needs to be more.

Concerns about future support when the Carer can no longer support younger person with a disability - where will they live, who will care for them?

People often had problems understanding allowances from Centrelink ie. Rental assistance, Carers allowance. People have lost allowances and do not know why, the Telephone Interpreter Service is often frustrating and does not clearly get the message across.

Are you aware of respite services and what they provide?

There was some awareness of respite services however the concept of respite had to be explained to a number of people.

Concern was raised regarding respite for people with high support needs and the lack of availability for some. Respite often was not available when it was required, needs to be greater flexibility of support.

When respite is provided the person is often not appropriate to provide the support, there is a lack of cultural awareness and staff often do not speak the language. Concern was expressed that having someone in the home to provide respite sometimes felt like an invasion of privacy.

Respite services do not listen to the Carer they do not understand the problems and issues faced by somebody supplying 24 hour care. Staff need to be more understanding of the issues facing Carers. It would be good if the same person could provide respite all the time so people got used to each other.

Which support services may be appropriate?

- Respite, both ongoing and emergency
- Outing and social activities for Carers with the appropriate respite link to support the "Caree". It is no good providing an outing if there is no one to provide support for the "Caree" whilst this occurs.

- Increased transport support - especially for the "Caree" at an affordable cost.
- Advocacy support - people noted they had problems with Centrelink and public housing, due to language barriers or poor interpreting. It was noted that using TIS is often very frustrating. Somebody who could listen to their problems and then advocate on their behalf was seen as a positive service.

Recommendations:

- Respite support (ongoing & emergency) which takes into account the linguistic and cultural needs of both the Carer and "Caree", being facilitated by a staff member accepted by the family.
- Italian meal services.
- Advocacy support, provided by Italian bilingual/bicultural staff, for dealing with services and government bodies in regards to issues related to being a Carer.
- Improved information flow from service providers regarding waiting lists, costs, type of service available. This should occur through language appropriate information and utilisation of Italian bilingual staff.
- It is important to increase knowledge of services, waiting lists and costs.
- Increased support for Carers supporting people with high support needs - whether they be aged or a person with a disability.
- Outings and social activities for Carers - these outings to be supported by Italian bilingual staff and linguistically/culturally appropriate respite support.

Discussion

Carers from the Italian community raised issues of isolation due to their Carer roles, methods of assuaging this problem being important. Emanating from this is a need for culturally appropriate respite, provided by bilingual/bicultural staff, this respite needs to be flexible and supplied regularly to allow Carers to develop or be supported to develop their own social life. Specific respite needs, that is a shortage of service in regards to people with high support needs and emergency respite, for both the aged and people with disabilities, was raised quite strongly by the group. The general consensus was that of a lack of culturally appropriate respite support, at an affordable level.

The ability of this community to access services was also raised, a lack of information in culturally and linguistically appropriate manner was noted as a problem in gaining an understanding of availability of support. This concern was aimed at all service providers including Government bodies such as Centrelink. The use of interpreters was noted as sometimes being difficult, using a bilingual worker either provided by the service or someone with an understanding of services was suggested as a more successful model.

Concerns for people with a disability who have Carers that are ageing were raised as a major concern. At this time this community did not know what the future would hold for their sons and daughters.

6. Greek Speaking Community

5 Greek Carers (all female)
5 Questionnaires
2 Caring for younger person with a disability
7 Caring for frail aged
1 Unspecified

Do you identify yourself as a Carer – What is your perception of a Carer?
From the responses the Greek group appeared to identify themselves as Carers.

What are the problems you face as a NESB Carer?

- Language barriers
- Isolation
- The Carer needs to be available all the time - can't go out, loss of freedom
- Lack of information for Carers – entitlements, what is available
- Cost of support too high, especially when on the pension
- Emotional stress
- Inability to live a normal life
- Financial difficulties
- Carers payments are inadequate
- Parents wanting to stay in the family situation and not go to a nursing home

What, if anything, would help you most of all to deal with your situation?

- Increased home nursing service
- Increased support in general, personal care etc. to help people remain at home.
- Services to be maintained and increased.
- Greek support workers
- More Day Care
- Emotional support
- Social and vocational support for people with a mental illness.
- Flexible respite – especially in the evening
- Support to be available on weekends
- More accommodation services for people with disabilities.
- More services in Sutherland
- Increased home care service
- Carer support groups and more Carer support hours
- Affordable support
- More Greek nursing homes

Are you aware of any services available for NESB Carers?
There is a reasonable awareness of service in general terms of:
- Home Nursing
- CACP
- Home Care
- Multicultural Day Care

It was suggested that there are needs for:
- Centrelink to provide information about activities for Carers
- Doctors to provide information about services
- More promotion of services

Are you aware of respite services and what they provide?
Amongst the respondents there appears to be a reasonable knowledge of the concept of respite and respite services. The following points were raised:

- More flexible respite is needed
- More respite positions
- Increase of service in Sutherland
- Respite can be very expensive, it needs to be more affordable
- More consultation is required with Carers about their needs
- Respite needs to be available to allow people to do tasks ie. Shopping
- Support needs to be available on weekends
- More Day Care places/groups
- Greek support staff / better training of staff

Which support services may be appropriate?
- Increased respite, ongoing and flexible, at an affordable cost – both for the frail aged and people with disabilities
- Carer support groups to be extended – more hours for Carers
- More day care positions
- Social support for people with a mental illness
- Vocational support for people with a mental illness

Recommendations:
- Affordable respite options for all Carers need to be increased across all types of respite with particular emphasis on flexible respite and respite provision on weekends and after work hours.
- More day care places need to be established for Greek people.

- Carer support groups need to be increased for the Greek community.
- Social functions or groups should be developed for the Greek Carers.
- Support for people with mental illness, including vocational and social support, needs to be provided.
- There needs to be an increase in culturally appropriate (Greek) in home support, ie personal care, domestic support, nursing, to support people to remain in the home.
- All services need to be affordable.
- Carers need to be educated on entitlements and service availability.
- Greek nursing homes or Greek dedicated nursing home beds (with appropriate support) need to be increased.

7. Hungarian Community

Individual Consultation

A member of the Hungarian community, living in Hurstville, came forward to advocate on behalf of the Hungarian community, a community with a number of people who migrated to Australia after the revolution in 1956.

- There is little or no information flow to the Hungarian Community regarding services available, there is a lack of understanding of the system.
- Throughout the Hungarian community there is a perception that in taking service they are "bludging" on the system. The community needs to be educated on the availability of services and support and the acceptability of taking advantage of this support.
- The existing Hungarian media - radio and newspaper - would be an ideal place to do community education.
- From her experience the ageing people of the Hungarian Community are gaining little or no service, meaning friends and relatives are taking responsibility for the "caring" role. It was noted that although this generation did have reasonable English skills that the ageing process has led to people reverting to their own language thus necessitating language specific support.
- Centrelink information is often inaccessible to the Hungarian Community. Often she has to translate, interpret or advocate for people.
- Information in general is often not available in Hungarian.
- In discussion it was also noted that there was a shortage of interpreters, especially in the hospital system. People often did not understand the information they were being given.

8. Macedonian Community

23 attendees
19 female participants
4 male participants

Do you identify yourself as a Carer - What is your perception of a Carer?

- A healthy member of the family taking care of an ill, sick or old person
- (Most people identified as Carers by raising their hands when asked)
- Women are usually Carers in the family, and they are better at caring duties than men
- Women are better at home duties
- In the older age group women make better Carers
- Men are usually no good as Carers and need to be educated about the caring role

What are the problems you face as a NESB Carer / Barriers in accessing services?

Issues (Difficulties)

- There is no support from the younger generation or younger members of the extended family
- Formal respite services are not affordable for Carers
- Carers are stressed and overburdened with their duties
- They need to get out of the house and release pressure and socialise
- There is a shame factor in the community in certain instances when caring for a disabled, sick or frail person
- The Carer and the Caree remain socially isolated and alone at home
- Problems associated with caring remain in the home and are not shared outside
- The Carer is psychologically stressed
- Communications with others is limited by isolation; there is no one to listen.
- English language is a problem, there is no one to understand the problems
- Interpreting services are not appropriate and hard to get
- Services for younger disabled people are not known, not accessible
- Linguistically appropriate material is lacking
- The needs of the Carer and the Caree should be properly assessed and checked
- Services are unknown, not familiar to people, lack of co-ordination between services when cross-referring, creates confusion with clients.

What, if anything, would help you most of all to deal with your situation?

Help / Need

- Macedonian workers are needed

- Personal support for Carers is not available or lacking
- There are no Carer support groups for Macedonian people to share experiences, or at least, I don't know of any.
- There are problems in extended families, others members' needs are satisfied first and the Carer's needs are neglected, and conditions for the Carers are bad
- Carers need more rest
- Better coordination of services, interagency agreement on service provision and coordination
- Better evaluation and preparation for service delivery
- There are no services available to Macedonian Carers – they need respite on a daily and ongoing basis they need "time-out"
- Services need to provide ongoing regular monthly respite to Carers
- Governments sponsored schemes for annual holidays for Carers and old people in specialised holiday centres / resorts, pensioners holiday / rest centres, at subsidised discounted rates
- Services do not provide weekend support, urgent /crisis support when Carers are most under stress
- Carers have compound problems with dementia people: cannot leave them for a minute and are afraid of accidents in the home if cared person left alone - this creates great stress for Carers
- Respite services, which are available, are unaffordable for the average Carer, very expensive therefore can not be used
- "Respite" – unknown term, unknown service type, not used, expensive, language problems, no weekend services, need for regular respite, relief, monthly respite options, annual respite options government sponsored.

Are you aware of any services available for NESB Carers?

- Carers NSW are not known to anybody
- Telephone services are useless for Macedonians, they have difficulty using such services, cannot get service or appropriate information.
- They are generally not familiar with services for Carers in St. George or wider area
- There are no Macedonian services – or they are little and limited
- Services are inappropriate
- Media should be used regularly to inform people about all issues – ethnic radio – SBS daily and weekends is being listened to, regular radio segment.

Which other services would be most appropriate for you?

- Telephone service in Macedonian
- Respite at home using Macedonian workers
- Organise more outings for Carers
- Carers support groups

Other issues

- Assistance with major spring-cleaning.

Recommendations

Regular respite services for people caring for the frail aged provided by a person from the same culture speaking the same language ie. Macedonian.

Regular respite services for people caring for people with a disability, both younger and older.

Proposal – the set up of community / church based schemes whereby volunteer Carers are placed on database to be recruited, be offered free accommodation in a Carer's home for assistance offered such home duties and respite care "free accommodation for service" or other mutual benefits that may be arranged, may be also government sponsored.

Discussion

The need for resite services dominated discussion for this group. There were obviously Carers present with high needs. The group had some understanding of services available, but felt that there were not enough services, particularly respite services.

Women were singled out for the Carer's role and this group emphasised the burden which caring for another person can be. They particularly commented on the isolation of the Carer that is left at home to care for others. A sense of shame is attached to having a disabled person in the family, which leads to further isolation of the Carer.

The group was very vocal in terms of having joint holidays with the Caree. It appeared that this form of "having a break" was available and government sponsored in Macedonia.

Appendix 5: Provider Consultation

PROVIDER CONSULTATION - same questions used

Points discussed by service providers at the forum

Identifying as Carers:

- People from some cultures do not see themselves as Carers – accepted as their role
- Carers need to be made aware of support services and given training/education
- A clearer definition of the term Carer needs to be develop
- Some community languages have no direct translation of the word /concept of Carer
- Carers are often women.

Problems facing NESB Carers (identified by service providers)-

- Carers are often distrustful of government programs aimed at assisting them ie. this is a legacy of past policy. Personal contacts with a service provider who speaks the language and understand the culture is then important from a trust building point of view
- Carers are not used to the offer of the service – assessment need to be completed in a culturally appropriate fashion
- Carers are not aware of Centrelink payments and services
- Carers need support and recognition of their extended responsibilities.
- Some workers do not have the cultural competencies to work with CALD families
- When NESB Carers contact services it's quite often as a last resort, this is due to lack of awareness of services and cultural expectations.
- Carers health is often affected by the role they take on – their needs often are the lowest priorities
- People do not know they are Carers so do not receive service. CALD communities need to be targeted in a manner appropriate to individual culture
- Older Carers are less informed than the younger Carers
- Lack of information in a culturally and linguistically appropriate form about specific disability – Carer don't get educated on how to manage issues and service available. Information is available in English only
- Carers and families often experience financial hardship as a result of the cost of caring, equipment etc. Further, Carees are often hindered due to the caring role.
- Lack of appropriate accommodation.

What can help to deal with the situation?

- More case managers are needed to manage, coordinate, lobby and resource clients of NESB Access Project
- Ethno specific and religious based organisation need to play a greater role in providing information.
- Service providers need to use interpreters more
- The community at large needs to become more active advocates and lobbyists for Carers and their families.
- Referral and assessment systems need to be easier to render them more effective
- Raising awareness of services
- Mainstream services not able to relate to people with a disability, this means they often refer the person straight away without trying to cater for the client. It is suggested that there be a support person available to assist the person through their interaction with mainstream services.

Respite

- Not enough hours available for respite, esp weekends
- Not enough bicultural and bilingual workers
- High demand for weekend centre based respite
- Demand for overnight respite.
- Need for respite for medical purpose
- Shortage of respite to support people with mental illness.
- Often concept of respite is not understood
- Appropriate linguistic, cultural and religious support not available
- Shortage if respite generally
- Services do not have knowledge or resources to deal with high support respite
- No respite for both Carer and Caree (together).

Needs/suggestions

- Transports with personal Carer
- Respite/home visits
- More weekend support
- Increased home support services eg. shopping help
- Carer support groups and outings, forums and discussion groups
- Group counselling
- Counselling services
- Telephone support
- Outreach services – DV support.