



In Their Own Right

Assessing the needs of
Carers in Diverse
Communities



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Multicultural Carer Profile (Mental Health)
Project Report 2004

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EXECUTIVE SUMMARY

The Multicultural Carer Profile (Mental Health) project was funded through the Australian Transcultural Mental Health Network (now Multicultural Mental Health Australia) by the Australian Government Department of Health and Ageing. The project aimed to examine the effectiveness of the Carer Profile assessment strategy, which examined the value of carer assessment in supporting carer/family relationships for carers from culturally and linguistically diverse (CALD) backgrounds caring for a relative or a friend with a mental illness.

CARER PROFILE

Research has identified the importance of supporting carers in their caring role because of the emotional and physical toll it can place on a carer's health and wellbeing. In 1997 the Carers Coalition discussed the need for carer assessment in the community care sector. In May 1998 a discussion paper on carer assessment was published in partnership with Carers NSW Inc. A series of focus groups and consultations with carers and service providers was subsequently held. This led to the development of an assessment strategy, known as the Carer Profile, and a report titled 'Carer Profile: the value of carer assessment in supporting carer/family relationships' (Hughes, 1999).

The Carer Profile sets out principles and guidelines for service providers to conduct a carer assessment. It encourages and helps service providers to understand a carer's unique experience. The strategy is about identifying a carer's strengths and limitations as well as exploring the carer's health, emotional, financial, social and information needs. Whilst the Carer Profile lists the topic areas to be covered, it is not presented as a standard form or a set of questions that need to be followed.

MULTICULTURAL CARER PROFILE (MENTAL HEALTH) PROJECT

The Multicultural Carer Profile (Mental Health) project was funded to examine the effectiveness of the Carer Profile for carers from culturally and linguistically diverse backgrounds who care for a relative or a friend with a mental disorder. The Carer Profile was piloted among Chinese and Greek carers in NSW. The project involved bilingual workers in the recruitment of carers and in facilitating focus groups and interviews with carers. Participating carers were from metropolitan Sydney who had been in contact with at least one service provider.

The project was carried out in three stages during 2001 and 2002.

STAGE 1 – WORKING TOGETHER

In Stage 1, questionnaires were sent out to carers and service providers asking how carers were currently involved in services, and to what extent they should be involved. Responses from both groups indicated that there was little carer involvement. It was also suggested that a carer's contribution would be more substantial if he/she was involved in planning, monitoring and evaluating services. Service providers, however, expressed concern about a carer obtaining confidential information without consent from the person with a mental disorder.

Whilst it was generally agreed that carer assessment was much needed in the mental health sector, there was minimal involvement of carers in services at the time of the survey.

STAGE 2 – WORKING IN PARTNERSHIP

In Stage 2, carers and service providers participated in focus groups to discuss the anticipated issues in relation to the implementation of carer assessment and its purpose in mental health service planning and provision. The focus groups also discussed and reviewed the principles of the Carer Profile. (See summary of the principles on page 5.)

The results from the focus group discussions were again similar, and built on the findings of Stage 1. The focus groups felt that in order to have a holistic assessment of the person with a mental disorder, a strong carer/service provider partnership should be developed. For this to be effective, service providers need to be aware of, and be empathetic towards, carers and their issues.

Allowing carers to use their community language was also considered important as most carers express their emotional experience and deep feelings more comfortably in their own language. Other factors enhancing the effectiveness of the strategy included availability of information in community languages, availability of community care services and personal support services.

STAGE 3 – STRENGTHENING RELATIONSHIPS

In Stage 3, the Carer Profile was trialled over two months with carers from Chinese and Greek backgrounds. The service providers selected for the trial were keen to be involved. They were also bilingual. They attended a full day's training on the Carer Profile to ensure a broad understanding of carer issues. As part of the training, service providers were required to demonstrate their awareness and sensitivity of carer issues and knowledge of available information and services. In an effort to make the assessment more culturally appropriate, service providers were encouraged to adapt the content and process of the Carer Profile. A Training Manual was produced specifically for the training session.

Carers and service providers responded very positively to the experience. Many referred to the experience as one 'type of support' to carers.

Overall, carers were comfortable with the content of the strategy, and indicated the importance of examining the impact of caring in all aspects of a carer's life.

It was concluded that the Carer Profile was effective in assessing carers' needs and supporting them in their caring role, and should be adapted as a core part of mental health services. In order to do this effectively, the following strategies should be considered:

- a) Training provided to all mental health service providers on carer and caring issues, the Carer Profile strategy, and carer support.
- b) Carer Profile Training to be introduced and integrated with generic mental health training courses.
- c) Policy relating to carer involvement in service provision in the mental health sector to be reviewed, revised and carer inclusive.
- d) Appropriate and cost-effective language support provided to carers from culturally and linguistically diverse backgrounds to enhance their involvement.
- e) Community care services (including respite) to be more inclusive of people with a mental illness and their carers.

CONCLUSION

The Carer Profile strategy helps carers to identify their various needs in partnership with service providers through a formal process. Such information will allow early intervention and crisis prevention. This will not only enhance the effectiveness of mental health services, it will also reduce the social and economic costs of crisis support and management.

Throughout the duration of this project, both carers and service providers have highlighted the value of carer involvement. The Carer Profile has also been accepted as an effective assessment tool. It is, therefore, vital for relevant government bodies to recognise and reflect the need for carer involvement in mental health through policy changes and funding allocation.



INTRODUCTION

The Multicultural Carer Profile (Mental Health) project was funded by the Australian Government Department of Health and Ageing through Multicultural Mental Health Australia (previously, Australian Transcultural Mental Health Network). The project aimed to examine the effectiveness of the Carer Profile assessment strategy for carers from culturally and linguistically diverse (CALD)¹ backgrounds who cared for a relative or a friend with a mental disorder.

BACKGROUND

Worldwide, families of people with a mental illness have been in constant crisis since deinstitutionalisation, a process in which governments reintegrated people with mental disorder into the general community from a mental health/psychiatric institution. This has placed tremendous pressures on families as primary care providers. Despite their confirmed major and positive role in the rehabilitation of their relative, there has not been adequate support for carers and families of people with a mental illness (Briffs, 1999; Finley, 1998; Guarnaccia & Parra, 2001; Henwood, 1998; Mental Health Council of Australia and Carers Association of Australia, 2000; Parra & Guarnaccia, 1998; Schulz & Beach, 1999).

The Carers Australia survey of almost 1,500 carers reports that carers provided on average 104 hours of care to their relative with a mental illness in 2000. It also indicated significant health and wellbeing issues for all Australian carers, including:

- up to 30% of carers had health problems which they had not addressed or had delayed seeking help for because of their caring role;
- nearly a third of all carers had been injured at least once in the course of caring;
- two-thirds of carers said that their mental and emotional wellbeing had been affected by caring, with 85% feeling worse as a result of their caring role; and

- the two main health problems for carers, physical injury and emotional stress, were preventable.

Moreover, many carers said they were sad, depressed, anxious or worried. Some mentioned being mentally exhausted, stressed, bored, frustrated and easily upset. Most attributed these problems to the stress of caring, social isolation, loneliness, changing relationships, loss and grief. Worsening health and inability to continue paid work were also significant factors for some carers. Carers may need to change their lifestyle, family and work arrangements in order to care for their relative or friend, resulting in financial hardship because of reduced income and the costs of caring. This can be further compounded by social isolation, lack of access to information and support services, inadequate caring skills, and a lack of awareness and recognition by the general community (Mental Health Council of Australia and Carers Association of Australia, 2000; Schofield H, 1998).

In the 2000 survey, carers also reported satisfaction was extremely low in areas such as: accessing information; education and training provision; emotional and social support; personal information; consultation with professionals; policy decision making; provision of respite services; backup help; and rights and responsibilities. Carers of people with mental health problems were excluded from many mainstream or generic community care services such as respite assistance and practical home help services. Moreover, the complexity and extent of the needs of people with a mental disorder and their carers was not understood by many community care service providers (Mental Health Council of Australia and Carers Association of Australia, 2000).

Mental health has become one of the major health issues in Australia, and family carers are increasingly providing care for people with mental health problems. Therefore, it is crucial to ensure that the emotional impact of caring is explored, understood, appreciated and supported by the wider family, the community and by government (Wood, 1999).

It is also vital for governments and service providers to consider a practical strategy in supporting carers. Assessing these carers' needs and providing emotional support to them is another step forward to a better mental health system. It has been evidenced that allowing carers to talk to service providers about their caring relationship and their needs is in itself a form of emotional support for carers (Carers Association of Australia, 2000; Payne, 2000; Rose & Wood, 1997).

CARERS FROM CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) COMMUNITIES

The term 'carer' is one of the most misunderstood concepts in many culturally diverse communities where caring is often seen as a natural part of family life. There is currently very limited information about people from CALD backgrounds who care for a relative or friend with a mental illness.

People from CALD backgrounds are generally underrepresented in mental health services, therefore their carers are even less likely to have the support they need. Factors contributing to low use of mental health services by people from CALD backgrounds include:

- insufficient coordination between existing services
- language barriers to access
- inadequate income
- lack of cultural awareness and sensitivity by service providers
- stigma and shame associated with mental disorders
- delay in the accurate diagnosis and detection of psychiatric symptoms
- more common use of indigenous/traditional healers

- general practitioners' lack of resources and skills in providing mental health care and timely referral to appropriate mental health services
- lack of information about mental illness, mental health issues and available services
- exposure to trauma in the past (NSW Health Department, 1998).

In her study in 1998, Schofield compared carers from CALD backgrounds with other carer populations. These carers, especially female carers, generally rated their health more poorly. However, there were no significant differences in the rating of emotional wellbeing between the two groups.

Schofield did not find significant differences in the demand for caring, informal support received and the needs for support and services between the two groups. However, carers from CALD backgrounds had a lower usage of community services. The needs of carers for formal services, including respite, and the pattern of preferred care required by both groups was similar, but a higher level of unmet need was identified among carers from CALD backgrounds. Access to information about services was also significantly lower for carers from CALD backgrounds (Schofield, 1998).

Carers from CALD backgrounds face similar issues to English-speaking carers in addition to a range of factors further impacting on their wellbeing. These include:

- lack of information about the medical condition of the person for whom they are caring in a form that they can understand
- role change, financial burden and an overwhelming sense of responsibility
- emotional responses, including grief, loss, guilt, anger, anxiety, helplessness, depression and fatigue
- relationship problems, family conflict and loss of contact with social networks.

These problems can be compounded by language difficulties, cultural norms regarding disability, the acceptability of assistance from outside the family, and expectations of who should adopt a carer role (Curtin & Helen, 2001; Lilley, 1999; Schofield, 1998).

THE CARER PROFILE

In response to the needs of carers, carer assessment was first conceptualised by the Carers Coalition in the community care sector in 1997. The discussion paper, 'Carer Profile', was published in May 1998, which led to widespread consultations with carers and service providers in the community care sector. An assessment strategy, the Carer Profile, was developed and piloted, and followed by the report 'Carer Profile: the value of carer assessment in supporting carer/family relationships' (Hughes, 1999). The report outlined the steps and rationale for the development of the strategy and recommended it as an essential part of the comprehensive assessment process for people with complex needs.

The Carer Profile strategy sets out principles and guidelines for service providers to conduct carer assessment (see summary of principles at right). It encourages and helps service providers to understand a carer's unique experience. The strategy identifies a carer's strengths and limitations as well as exploring the carer's health, emotional, financial, social and information needs. It is, however, not a form or a set of questions a service provider needs to follow.

SIGNIFICANCE OF THE PROJECT

This project primarily aimed to evaluate the effectiveness of the Carer Profile strategy in assessing the needs of, and providing support to, carers from culturally and linguistically diverse backgrounds who care for a relative or friend with a mental illness.

The project aims to provide a better understanding of CALD carers to the mental health sector by providing information about the factors to consider when assessing carers from CALD backgrounds and the effectiveness of carer assessment.

¹ 'Culturally and Linguistically Diverse' refers to the wide range of cultural groups that make up the Australian population and Australian communities. It includes groups and individuals who differ according to religion, race, language or ethnicity. For ease of expression the abbreviation CALD is used interchangeably with 'culturally and linguistically diverse'.

Summary: Principles of Carer Profile Strategy

It is a process in which:

- a carer and a service provider get to know each other, through allowing the carer to talk about his/ her story in a respectful and safe environment;
- the carer and the service provider work in partnership to identify issues and needs of the carer;
- the service provider addresses the concerns and issues of the carer, and makes referrals as appropriate;
- the carer and the service provider develop plans and strategies that will have a positive impact on the carer's life.

The 'Carer Profile' should form part of a holistic assessment for the person with a mental illness. Carer input should be taken up and valued, and should have an impact on the service plan for his/her relative with a mental illness.



OVERVIEW: THE MULTICULTURAL CARER PROFILE (MENTAL HEALTH)

The Multicultural Carer Profile (Mental Health) project aimed to examine the effectiveness of the Carer Profile strategy for carers from culturally and linguistically diverse (CALD) backgrounds who cared for a relative or friend with a mental illness by trialling the strategy with carers from two ethnic communities.

THE PROJECT

The Advisory Committee members decided to divide the project into three stages. Each of the stages involved carers and service providers and provided insight into carer involvement and assessment in mental health service provision. Each stage provided information for the development of the subsequent stages.

Stage 1 - Working Together

Carers and service providers were asked to complete questionnaires about carers' current involvement in services. The findings from the surveys showed that both carers and service providers felt that carers should be involved in the planning, monitoring and evaluation of services. The consistency of these findings led to the trialling of the Carer Profile strategy with regard to carer assessment.

Stage 2 - Working in Partnership

One service provider and three carer focus groups were established to look at: what role carer assessment should play in mental health; how carer assessment should be conducted; and what support materials and resources are needed for effective carer assessment. The content of the Carer Profile strategy was discussed in terms of its effectiveness in assessing the needs and supporting carers from CALD backgrounds. A number of factors contributing to the effectiveness of the strategy were also identified. These factors include the need for: information and resources in community

languages; community services; culturally appropriate personal support services – e.g. counselling, carer support groups and bilingual workers.

Stage 3 - Strengthening Relationships

The Carer Profile strategy was trialled during Stage 3 of the project. It consisted of two components – a full-day workshop for bilingual service providers and the trial of the strategy with carers. As a result of the factors identified in Stage 2, the service providers selected for the trial were keen to be involved. They were also bilingual. The primary aim of this stage was to allow carers and service providers to trial the strategy and evaluate its effectiveness. Service providers attended a full day's training on the Carer Profile to ensure a broad understanding of carer issues. As part of the training, service providers were required to demonstrate their awareness and sensitivity of carer issues, and knowledge of available information and services. In an effort to make the assessment more culturally appropriate, service providers were encouraged to adapt the content and process of the Carer Profile Strategy.

WORKING WITH THE CHINESE AND GREEK COMMUNITIES

The Multicultural Carer Profile (Mental Health) project relied heavily on carer participation and contribution; therefore, access to carers was the main criterion used when selecting the two communities for the trial.

The Chinese and Greek communities were selected because both communities are relatively well established in Australia, and bilingual workers in different areas of health and community services are relatively accessible. Specialist mental health professionals, services and support groups are also available in the two communities.

Furthermore, the Chinese and Greek communities are diverse within themselves. Differences include:

- length of residence in Australia
- immigration experiences
- level of English proficiency
- educational and vocational background
- socio-economical background
- access to information.

Additionally, some culturally appropriate information in these communities' languages is available.

THE CARERS

Participating carers were recruited and referred to the project by bilingual service providers who had contact with or supported them. Carers participated on a voluntary basis and came from different areas of metropolitan Sydney.

Carers of people with dementia also took part in Stage 1 of the project. Their involvement allowed comparisons between groups and isolated specific mental health-related restrictions in carer participation.

THE SERVICE PROVIDERS

Service providers also participated in Stages 1 and 2 of the project on a voluntary basis. Service providers who participated in the survey also identified themselves for the focus group.

The service providers who took part in Stage 3 of the project were invited to participate based on their level of involvement with carers and the mental health sector, as well as their language and communication skills in the selected communities.

LIMITATIONS OF THE PROJECT

All carers participating in this project lived in metropolitan Sydney. A small proportion of service providers participating in Stage 1 of the project were from outside Sydney. Therefore, the project did not address any potential issues that might have been raised by rural and remote carers.

Due to resource constraints, the project did not seek out hidden carers. All carers participating in the project were in contact with at least one service provider.

Due to the small sample, the project only aimed to gain an in-depth qualitative understanding of carer assessment in the mental health sector with carers from CALD backgrounds rather than to provide quantitative information.



STAGE 1: WORKING TOGETHER

A Carer Survey Questionnaire and a Service Provider Self-Completed Questionnaire were designed and distributed in Stage 1. The aim of this stage was to examine the level of carer involvement in mental health services at the time of the study.

CARER SURVEY

The questionnaire was designed to find out how, and to what extent, carers were involved with services. The questionnaire also asked carers with whom, when and where they preferred to talk about their issues.

The Carers

The carers who participated in the survey were in contact with or accessing at least one mental health or community service at the time of the survey. Carers were interviewed either over the phone or face-to-face by bilingual service providers who spoke the same community language.

Fifteen Chinese carers and thirty-three Greek carers participated in the survey. Two Chinese and nine Greek carers involved were carers of people with dementia. Carers of people with dementia were included in this survey because dementia is perceived as a mental condition; moreover, their input permits comparisons to be made between groups of carers. Analysis of the results primarily focused on carers of people with a mental illness, and responses from carers of people with dementia were only considered when a comparison was required.

Table 3.1: Carers participating in Stage 1

	Chinese	Greek
Carers of people with a mental illness	13	24
Carers of people with dementia	2	9
Total	15	33

Findings of the Carer Survey

A number of issues were immediately identified. Firstly, there was no equivalent translation for the term Carer Profile and there was no effective substitute in either Chinese or Greek.

To overcome these issues, the purpose and content of the project were translated into Chinese and Greek. The survey, however, remained in English. It was decided that service providers would be sufficiently familiar with the survey to be able to ask the questions indirectly and in their community language. This allowed for more appropriate communication and assisted in the development of relationships. Other issues relating to personal information were particularly relevant to the carers within the Greek community. The service providers were requested to gather personal information in a culturally sensitive manner.

The majority of carers were aged between 19 and 65 years. All the carers lived in metropolitan Sydney. The carers of people with a mental illness were either a spouse or a parent. The Chinese participants mainly cared for a relative with a mood disorder, such as various types of depression, whereas the Greek participants mainly cared for a relative with schizophrenia.

All the carers agreed that talking to them about their needs was important. The most important issues for the carers were information about their relatives' conditions and medication, health information and adequate support.

Most of the carers did not perceive 'talking to a service provider' as a way of identifying and addressing their own needs. 'Talking to a service provider' generally referred to the giving and receiving of information about their relative with a mental disorder. The most important reason to talk to service providers was to exchange information.

Regardless of cultural backgrounds and the nature of their relatives' illness, all the carers indicated a

strong desire to be part of the 'care team'. All the carers wanted to know 'what was happening', to have their input valued, and to take part in decision making for their relative with a mental disorder.

The carers identified a variety of service providers as the appropriate ones to talk to about their needs. These included the case managers and treating professionals of their relatives, the bilingual community health support workers or counsellors, and their general practitioners.

Most carers were comfortable talking to their identified service providers. However, some indicated discomfort caused by language difficulties and their exclusion in current practice.

Half of the carers wanted to be interviewed before or after their relative's assessment, and the other half wanted it to be done whenever appropriate or required. Some carers preferred to be interviewed in their own home while some were comfortable at the service provider's premises. Most carers wanted regular interviews, preferably every 3-6 months in line with their relative's review. Some carers also stated that when changes occurred in their caring role, a reassessment or interview should take place as soon as possible.

Most participants understood the concept of the project, although the term Carer Profile only made sense to approximately half of the group.

In comparison, carers of people with dementia were more aware of the necessity to talk about their needs and issues. They focused more on the emotional impact of the caring relationship as well as their need to learn new skills and techniques. They were more involved and better aware of the planning, delivery and monitoring of services for their relatives. At the time of the survey, participants had access to the most appropriate service providers to assess their needs.

SERVICE PROVIDER SURVEY

This self-completed survey was designed to find out, from a service provider's point of view, how and to what extent carers should be involved. The survey also asked about service providers' experience with carers from CALD backgrounds, in particular with carers from Chinese and Greek backgrounds, and their knowledge of and experience with translated materials.

The Service Providers

Two hundred and thirty-two self-completed surveys were sent to service providers across NSW, including mental health, health and community care agencies. Fifty surveys were returned. Of these, 20 were excluded due to the service providers' lack of experience with carers of people with a mental disorder and/or carers from culturally and linguistically diverse backgrounds, or the lack of a relevant response by the service providers. Services for people with dementia and their carers were included in the analysis to allow comparisons.

Among the 30 respondents, 13 services were located in metropolitan Sydney, eight in rural NSW, two had a statewide focus, and seven did not specify their locations. Six services targeted people from CALD backgrounds, four were Chinese-specific services and one was Greek-specific.

The service respondents consisted of: nine mental health services (six community mental health teams and three other mental health services); six community health centres; three residential services; ten non-residential community care services; and two other types of services.

Findings of the Service Provider Survey Carer Involvement

To the first question about current carer involvement, half of the service providers responded that they were providing a service to their relative. These services included providing information and referral, education, unspecified services for a relative with a mental disorder, linking to or involving carers in a support group and assistance in service coordination for the relative with a mental illness. Eight service providers involved carers in service planning and

implementation at the time of service. Another four referred to carer involvement as a combination of provision of a service to their relatives with a mental illness and included the carers in service planning. One service provider indicated no carer involvement and two others did not specify how carers were involved.

In response to the question about how carers should be involved, two service providers indicated that carers should not be involved in any part of service provision. Nearly half of the service providers believed carers should be consulted and included in the planning and decision-making process because they held the most information about their relatives' conditions and situations. Four service providers believed that carers should be informed about their relatives' disorder and conditions, but the relative's consent must be obtained before releasing any personal health information. Five service providers wanted carers to be involved in programs, though they did not specify which programs. Twelve service providers wanted carers to assist in service provision that included volunteering in services and filling in the gaps where services were not available.

Different types of services appeared to have different levels of carer involvement and different expectations of carers. In general, non-mental health services indicated higher levels of carer involvement in consultation for service planning for their relatives. They also highly valued carers' contributions and input to the process.

At the time of the survey, participating mental health services tended to have less carer involvement than the other participating services, stating that they 'provided a service' as their main type of carer involvement. However, these service providers generally expressed a willingness to involve carers throughout their services. One mental health service stated that carer representatives should be included on the management board.

Impressions of Chinese and Greek Carers

Twenty-four service providers commented on the questions asking about their impression of Chinese and Greek carers. Twenty-two commented on Chinese carers and sixteen commented on Greek carers. Six service providers indicated no experience with either group of carers.

One service provider responded that Chinese and Greek carers were no different from other carers. One community service expressed the diversity within the cultural groups. One Chinese-specific service also mentioned the diversity within the Chinese population and also commented on gender differences in caring. Most service providers perceived Chinese and Greek carers as caring, helpful and supportive. Generally, service providers also perceived Chinese and Greek carers as being very conscious of family bonds and responsible for their relatives. A couple of service providers described Chinese and Greek carers as overprotective. Some service providers perceived Chinese and Greek carers as actively and willingly involved, whereas some described them as passive and unwilling to be involved.

Major problems identified by service providers related to the carers' lack of knowledge, language barriers and problems in accessing and communicating with services. Mental health service providers also reported a poor tolerance of mental disorders among Chinese and Greek carers. Some service providers stated that carers prefer to go to cultural and language-specific services and workers.

Although the service providers' profiles of Chinese and Greek carers appeared to be very similar, some service providers identified social isolation as a characteristic for the Chinese carers but not the Greek carers. A few service providers believed that cultural values and beliefs restricted some carers' ability to care for their relatives.

Although it was generally agreed that carers and their inputs were highly valuable, non-mental health service providers described Chinese and Greek carers more positively than their mental health counterparts. They also reported fewer communication problems with carers from CALD backgrounds. However, there were more multicultural and language-specific non-mental health services; therefore, language barriers might have less impact on these services.

Translated Materials

Service providers were asked to rate translated materials in nine different areas on a scale of zero (very bad) to ten (very good). The nine areas included illness and disorder, treatments and medication, rights and responsibility, law and

advocacy, community services, accommodation, financial support, prevention of crisis, and family help.

In general, Chinese materials were rated slightly higher than Greek translated materials. Most of the Chinese translated materials fell into the range between 4.25 and 5.69, except in prevention of crisis, which had an average of 3.92. Greek materials generally rated between 4.00 and 5.33, and prevention of crisis an average of 3.65. Some service providers did not rate the materials but commented that materials were generally inadequate or poorly translated. One service provider did not rate the materials due to lack of awareness of their existence.

Non-mental health services appeared to be more aware of existing materials and resources for carers from CALD backgrounds, and they tended to rate translated materials slightly higher.

SUMMARY OF STAGE 1

Both carers and service providers pointed out that current involvement of carers in mental health includes:

- providing information about the ill relative
- being part of education programs when available
- caring for the ill relative
- informing service providers when a relative's condition changes
- filling in the gaps when a service is not available

However, carers have expressed their desire to be better informed about their ill relative's condition, treatment options and what support and services are available

The Role of the Carer Profile

It has become very clear that there is a need to have a formal way to involve carers in mental health. The Carer Profile strategy addresses a number of issues identified in Stage 1.

The strategy encourages communication between carers and service providers, and allows carer contribution and input to be formally recognised. It provides an opportunity for carers to identify and discuss their concerns and issues with service providers. It is also a way for service providers to inform and make appropriate referrals within and outside the mental health sector, so that carers are better supported in their roles.



STAGE 2: WORKING IN PARTNERSHIP

Following the completion of Stage 1, which consolidated the need for carer assessment in the mental health sector, a series of focus groups was conducted with carers and one focus group was conducted with service providers. The aim of the focus groups was to discuss issues around carer assessment and to discuss the content of the Carer Profile strategy (see summary of the Carer Profile principles on page 21).

CARER FOCUS GROUPS

Carers were recruited and referred to the project officer by bilingual workers who had been providing support to the carers.

The Carers

Three carer focus groups were conducted: one Greek men's group; one Greek women's group; and one Chinese mixed group. None of the carers in the focus groups took part in the survey, hence, carers in the groups had no knowledge of the project prior to the meetings.

Findings

When carers talk to service providers, they are generally provided information about a relative with a mental illness. Focus group discussions indicated that carers felt that their wellbeing, needs and issues were not a priority for themselves, their families or service providers. Many carers believed their contribution in caring for their relatives should be recognised and acknowledged.

Some carers stated that they did not have experience talking to someone about their own issues prior to the focus group discussions. Before the focus group discussion began, one carer asked if she would be charged to be listened to. After the discussion, a carer said with tears, "I always thought if I wanted to talk to someone, I needed to pay."

Two male carers felt that talking to someone was not beneficial as no one would understand their caring experience.

Generally, the carers expressed a concern that the information they provided should be used to inform relevant government departments for improvement in mental health and community services for people with a mental illness and their carers. Carers had identified a range of professionals to talk to them about their issues. The majority of carers preferred to talk to their relative's case manager. A few carers preferred to work with their bilingual community health workers, while a couple wanted to talk to their relatives' psychiatrists.

Communication Issues

Carers who participated in the focus groups identified the following communication barriers:

- Carers might not have any opportunity to communicate with the health and mental health professionals who treated their relatives due to privacy issues.
- A number of the carers felt that language was often a barrier as many terms and expressions did not translate into their first languages.
- Some of the carers were not comfortable asking questions and raising issues with health and mental health professionals.
- Carers felt that they were not skilled enough to competently participate in discussion with service providers.

Information Sources

General practitioners and local (bilingual) health workers were identified as the main information source and support for carers.

Many carers did not identify themselves as carers and as such did not have access to carer support services. The main source of information and support for multicultural carers was provided by doctors, especially bilingual doctors, who provided not only medical support but emotional support.

Other sources of information and emotional support for carers were not always available. Bilingual workers from different sectors (health workers, settlement workers, family support workers and social workers) provided most language support for carers from CALD backgrounds.

The Carer Profile Strategy

All of the carers appreciated the proposed content of the Carer Profile strategy, although each carer had different priorities and experiences. (See summary of the Carer Profile Principles on page 21.) The focus groups discussed the content in a way that was meaningful to them. The responses from the carer focus group discussions are highlighted below.

Carers' Roles and Tasks/What a carer does not or cannot do

- Each carer's situation was unique.
- Carers were not aware of the need to set up boundaries until they talked to someone about their role, strengths and limitations.
- Many carers experienced feelings of guilt when refusing their relatives.

Carers' Health and Wellbeing

- Many of the carers' lifestyles were affected by their relatives' condition. Disrupted sleep and other problems were common.
- Carers also had their own life issues and difficulties, and many of the carers lacked the ability to cope with these. Caring for a relative with a mental illness often made their limitations more obvious.

A mother said, "When my children had a problem, my husband just walked out. My husband's family blamed me for not disciplining my children, and my family also criticised my parenting skills a lot. I felt very unsupported."

- Carers also experienced different types and levels of abuse from both their relative with a mental illness and other family members.

Emotional Impact of Caring

- Carers expressed their need to have someone to talk to and to support them emotionally.

Many carers discussed the need to look after their own mental health.

- Carers often had no one to talk to and felt that they had to hide their relative's disorder.
- Some carers did not want to talk to anyone about their issues because they might get too emotional and worried that others might not understand or know how to handle the situation.

One carer said, "I did not want to discuss with my friends about my issues. I am afraid that tears would just come out. Every time I talked about it, I just got too emotional and lost control. So now I avoid talking to anyone about my situation."

Family and Social Relationships

- Mental disorders did not only affect the person with the disorder and the carer, but also other family members.

A mother told us her worry: "My daughter often tells me her fears about getting her brother's illness. She is very cautious about her mental health status. I sometimes worry that the pressures she puts on herself may make her ill."

- Many carers stated they had no time for other family members.

A husband told us that because of his wife's illness, he had little time for their two young children. He often had little energy to spend time with their children, and he felt very guilty because their children missed out a lot.

- Carers needed to put up with the reactions and issues of the other family members.

A father told us: "My son's illness frightened my wife. When my son had an episode and screamed, my wife hid herself in our wardrobe. She would not come out because she was too scared. I did not only need to care for my son's illness but also needed to look after my wife."

- Social isolation was a common experience. Many carers talked about difficulty in sharing their experience and concerns with other

people because very little was known about mental illness in their communities.

Many carers related to the comment made by one carer that, “Other people would not understand. They may look at us differently if they knew a member of our family is mentally ill. I would not tell anyone about it.”

Financial Impact of Caring

- Many carers withdraw from paid employment while some changed their status from full-time to part-time employment to care for a relative. Some carers also experienced reduced income because of emergency situations when they had to leave work to fulfil a caring role.
- Most of the carers were not eligible for the Carer Payment or the Carer Allowance as they did not meet the criteria set out by Centrelink – people with a mental illness are not viewed as requiring a high level of care, therefore their carers would not need to provide fulltime care.
- Some carers also became financially and/or legally responsible for the decisions of the relative being cared for.
- Carers had their own financial requirements to look after themselves, such as housing, transport, food and medical needs.
- Caring often led to increased additional expenses, for example financial support to their relative, extra travel and food costs. Many carers also had the experience of being forced to cover the unreasonable spending of their relative with a mental illness.

Information and Training Needs of Carers

- Carers seek information about the illness of their relative including: the nature and causes of the disorder; interpreting the signs and understanding the symptoms; available medications/treatments and their side-effects; and other support for their relatives.
- Carers had difficulty finding information and other resources in community languages.
- Some carers had low levels of literacy in their own community language, therefore printed materials were not helpful.. Audio and audio-visual materials would be more useful to these carers. Carers also said that translated materials were difficult to understand because some terms or concepts did not exist in their language.

- The carers who took part desired training on how to handle the physical, mental and general support needs for their relative. The carers also wanted to communicate and manage the behaviour of their relative.
- The carers indicated that they were not aware of available training or education programs.

Emergency Care Plan

- Generally, an emergency referred to a relapse of the relative’s disorder. Overwhelmingly, the carers felt that crisis and emergency support was ineffective. There were often lengthy delays in response time by crisis and emergency services.
- Most of the carers did not have an emergency care plan, and did not think about alternative arrangements in an emergency situation, e.g a carer’s health problem.
- Generally speaking, the carers focused on their relative and not themselves when developing an emergency care plan, for example the carers did not consider what would happen if they became sick and could no longer care for their relative.

Respite Needs

- Respite was not a commonly used term for carers, but the need for respite was expressed through other terms.
- Many carers expressed a need for regular short breaks from their caring responsibility.

Having a break or a holiday was seen as impossible by many of the carers, because their relatives might get into trouble. A few carers expressed that they would never be able to have a holiday because their relative with a mental illness would get into trouble and they would have to fix it immediately.

- The carers experienced difficulties in accessing generic respite services.

Carers Plan for the Future

- Most of the carers worried about future arrangements for their relatives, especially ageing parents.
- Many of the carers were seeking alternative care arrangement for their relatives.

Other Issues

- Transcultural issues adversely affected the caring relationship.

A mother told us, “My son wanted to attend to a support group and get to know others with the same illness. But we could not find him a group. He would not come to a support group with me because he cannot speak my community language. He would not go to a mainstream one because he does not feel comfortable with some of the things, such as food they eat. He blames me for this.”

- Many of the carers felt that their understanding and interpretation of the mental disorder and the caring relationship were different from their relative’s interpretation. Talking to someone helped them to understand the situation better.

SERVICE PROVIDER FOCUS GROUP

The aim of the focus group was to identify factors that contribute to the effectiveness of the Carer Profile strategy, and to discuss issues around carer assessment and involvement in mental health service provision.

The service providers who participated were asked to discuss issues concerning carer assessment and involvement in mental health service provision and to make recommendations to enhance the effectiveness of the Carer Profile strategy.

The Service Providers

Service providers who participated in the focus group formed part of the group surveyed in Stage 1. The group consisted of statewide, multicultural and ethno-specific services. Two service providers from rural areas contributed their input via the telephone.

FINDINGS

Carer Inclusion

The service providers argued that carer involvement needed to be recognised in policy and that carers should be included in mental health service provision as an integral part of a service’s practice.

Carer-specific support positions are needed to: provide and coordinate education and training programs; emergency and personal support for

carers; to facilitate social and peer support activities; and to advocate on behalf of carers when required. Training should be provided to health and mental health service providers to enhance both their awareness and sensitivity towards carers, and their understanding of carer issues. The service provider focus group discussed the importance of being aware of carers including those who do not live with their relative with a mental illness.

Training should be made available to bilingual service providers who currently support carers of people with a mental disorder or who are willing to provide support to these carers. The training should cover counselling skills, family support, mental health issues, and case management skills.

Communication Issues

The focus group identified communication as the major problem in supporting carers from CALD backgrounds. Easy and affordable access to interpreter services is needed in order to improve communication between carers and service providers, including all health, mental health and community services. They felt that it was preferable to have bilingual service providers to overcome this issue.

A useful strategy discussed by the focus group was to record carer interviews or meetings as this allowed carers to listen to the content as many times as they needed. At the very least, recording was seen as an important strategy as it enabled carers to improve their knowledge and prepare for upcoming meetings. The service providers who participated in the focus group agreed that it was important to encourage carers to be more involved in planning and service development.

Information Sources

Information on mental illness, health care, medication and its side-effects, treatment, emergency procedures, rights and responsibilities, and other relevant areas need to be available in community languages. Moreover, information should be available in both visual and auditory formats to accommodate for carers’ different needs. When developing resources, service providers should work in partnership with cultural groups, community organisations, service providers and carers.

Additional funding needs to be allocated to appropriate community languages. Individual services need to be responsible for reflecting this need in their budget proposals. It was suggested by the participating service providers that the cost of translating resources might decrease if their usage increased. However, coordination of material and resources is required to avoid duplication and ineffective use of resources.

Conducting the Carer Profile

Service providers generally agreed that the Carer Profile is an effective strategy that allows communication between carers and service providers. Information about what the strategy is about and how it is implemented needs to be made available in community languages to help carers understand it.

It was suggested that service providers who are experienced in working with carer issues, and who speak the same community language as a carer, conduct the Carer Profile strategy. Training on carer support and assessment should be provided to different service providers in different communities according to the preference of carers.

The focus group identified and discussed the limitations surrounding referrals. It was argued that programs were either not culturally appropriate or were non-existent. Carers of people with a mental illness perform a wide range of tasks and required assistance in their caring role. Generic community care services therefore need to be more inclusive of people with a mental illness and their carers. Moreover, family and group therapies, which have been proven useful for many families, are not available in many communities. These therapies may help some families to achieve better understanding between the generations and overcome some difficulties many families currently experience.

Another issue raised concerning referrals was the availability of education and training programs. There is a need for different carer training programs that cater to carers in different stages of their caring experience. These programs should cover information and skills on the practicality of caring as well as support for carers.

*See next page for Summary of Stage 2.

SUMMARY OF STAGE 2

The Carer Profile strategy was accepted by both carers and service providers as an effective strategy which connects a carer with a service provider in a meaningful way.

Principles of Carer Profile Strategy

It is a process in which:

- a carer and a service provider get to know each other, through allowing the carer to talk about his/her story in a respectful and safe environment;
- the carer and the service provider work in partnership to identify issues and needs of the carer;
- the service provider addresses the concerns and issues of the carer, and makes referrals as appropriate;
- the carer and the service provider develop plans and strategies that will have a positive impact on the carer's life.

The Carer Profile should form part of a holistic assessment for the person with a mental disorder. Input of a carer should be used and valued, and should have an impact on the service plan for his/her relative with a mental illness.

Skills of Service Providers

Although carers and service providers were not asked to specifically identify skills a service provider needs to conduct the profile, these skills have been identified naturally as:

- advanced communication skills, speaking the same language as the carer is most preferable
- broad understanding of carer issues and the whole of life impact of mental disorder
- understanding of relationship issues and needs in a caring relationship
- knowledge about services and referral criteria
- sensitivity and understanding of cultural issues.

These skills are identical to those identified in the 1999 Carer Profile project.

Contents of Carer Profile Strategy

Both carers and service providers alike appreciate the proposed content. However, it was strongly recommended that the process complement a carer's readiness and preference for an assessment of his/her situation. It needs to be flexible and reflect the carer's situation and needs at the time.



STAGE 3: STRENGTHENING RELATIONSHIPS

Stage 3 included three components: a training workshop for service providers who indicated interest in trialling the Carer Profile with carers; the actual trial; and the evaluation of the trial.

TRAINING WORKSHOP

Four bilingual service providers were invited to take part in the trial. These service providers came from both mental health and non-mental health sectors and had made no previous contribution to this project. A training manual was produced specifically for the training workshop.

A full day's workshop was developed, which covered:

- communication skills
- carer issues and the impact of caring
- impact of mental disorder
- relationship issues
- cultural issues
- the Carer Profile strategy
- information about services and referral criteria.

A manual including information about mental illness, caring for a relative at home, the impact of caring, services, and some other relevant information in both English and the two community languages was included.

Issues were identified and discussed throughout the workshop. The following issues had a direct impact on the effectiveness of the Carer Profile strategy:

- Mental health services already worked with limited resources, which made allocating time for carer interviews and follow-up impossible.
- Mental health service providers were not fully aware of the range of community care and personal support services available, which made referral difficult.
- Mental health services currently had no structure to incorporate carer information; hence, storage of information after the trial became problematic.

In addressing these issues, the following arrangements were made:

- An introduction letter to carers was developed to explain the scope of the trial and to encourage the carers to contact the Carer Resource Centre after the trial if they needed additional support.
- The letter was translated into the two community languages.
- A number of community care and personal support services were identified and their referral procedures discussed at the workshop, so that service providers were more prepared to make referrals.
- A carer information record form was developed to record the content of the trial. The service providers consulted with the carers to decide where the information should be kept.

THE TRIAL

Twelve Chinese and ten Greek carers took part in the trial.

The time allowed for the interview (one hour) was generally accepted as appropriate, although some aspects were not covered. All carers referred to the process as a comfortable experience that looked at their needs and wants as a carer and allowed them to say what they wanted.

Most of the carers who participated in the trial had previous contact with the participating service providers prior to the trial. This ensured that the service providers had some knowledge of the carers and, hopefully, their caring experience prior to the trial. Other carers were referred to the bilingual service providers by another service.

The carers were given an introductory letter in their community language. The letter explained to carers that the project aimed to examine the effectiveness of the Carer Profile strategy, which was described as:

- a process which allowed the carer to identify his/her own needs and work with the service provider to develop plans and strategies to address their needs;
- a process which allowed a service provider to learn more about a carer by listening to his/her story.

The carers who participated were given the option of having the letter in either their community language or in English. Service providers read out the letter for carers who required assistance in reading. Each assessment took approximately one hour and was conducted in the carer's preferred/ community language. All assessments took place at a venue or at a time that was most convenient to the carers. Each carer was asked to complete a feedback form after the interview to evaluate his/her experience during the process. Service providers were asked to complete a separate feedback form after each interview. The feedback form was divided into three parts:

- an evaluation of the experience;
- ideal conditions for using the Carer Profile strategy;
- the relevance of the Carer Profile strategy to carers.

THE EVALUATION

Both carer and service provider feedback was collected to evaluate the effectiveness of the Carer Profile.

Carer Feedback

Almost all carers responded very strongly that they felt listened to, respected and felt like a full partner in the process.

All interviews covered the following areas:

- the value of the carer's contribution to caring
- effect of caring on the carer's emotional health
- effect of caring on the carer's relationship with others
- the carer's physical needs
- the carer's emotional needs
- the carer's information needs.

Most interviews covered:

- the role of the carer
- what the carer could not do
- the carer's needs for support services

Some interviews covered what the carer cannot or does not do as well as the effects of caring on the carer's:

- physical health
- finances
- social life
- life experiences
- other responsibilities.

Some carers stated that they did not understand the meaning or concept of 'what you cannot or do not do in your caring role'.

Ideal Conditions for Carer Assessment

All aspects identified by the Carer Profile strategy were rated as important or very important.

All the carers referred to the following as very important. That:

- the Carer Profile be conducted by a trusted service provider;
- the service provider understand the carer's role;
- the service provider be sensitive to the carer's culture;
- the carer's need to take care of the person be respected.

Carers identified the following as important or very important:

- time and place should be suitable for the carer;
- enough time is allowed for the process;
- the service provider tries to see things from the carer's point of view;
- the service provider speaks the carer's language;
- the carer is included in deciding what will happen next.

Relevance of the Carer Profile Strategy for Carers

Carers rated all areas of the content of the Carer Profile as either important or very important.

Some carers commented on the process as a very beneficial and therapeutic experience. Some carers took the opportunity to express their view about the lack of respite.

Service Provider Feedback

Service providers generally experienced difficulty in arranging and conducting the assessments due to workload and lack of carer support resources in their services. Carer's situations also made arrangement for the trial difficult. Some service providers had to reschedule the interview a few times because of a crisis in another family or because the carer was not able to make it..

Most interviews took place at the carer's home or the service provider's premises. A few took place after a focus group. Some were conducted at the workplace of the carers. A carer's workplace was rated as unsuitable by carers for the assessment

while the other places were rated as suitable.

Service providers generally rated the time allowed for the process as adequate and believed that the carer felt safe and secure throughout the process. In general, the service providers' responses were identical to the carers' responses, and they referred to the trial as a positive experience.

It is important to note that very few action plans or referrals were made as a result of the trial because of the lack of access to community care and personal support available for carers of people with a mental illness.

SUMMARY OF STAGE 3

Carers and service providers who took part in the trials had a very positive experience with the Carer Profile strategy and regarded the strategy as effective in assessing and supporting the needs of carers.

All aspects identified by the 'Carer Profile' strategy were very important for carers to discuss with service providers, although carers may have different priorities in terms of their importance.

When assessing carers, it is most important that:

- the 'Carer Profile' is conducted by a trusted service provider
- the service provider understands the carer's role
- the service provider is sensitive to the carer's culture
- the carer wanting to take care of the person is respected.

It is also preferred that:

- time and place should be suitable for the carer
- enough time is allowed for the process
- the service provider tries to see things from the carer's viewpoint
- the service provider speaks the carer's language
- the carer is included in deciding what will happen next.

However, a number of issues arose as a result of the trial. These included:

1. Carer assessment was not a common practice in mental health services as service providers were required to limit the amount of time they spent with each carer.
2. Due to the lack of existing policy and procedure in regard to carer information, service providers had difficulty finding an appropriate place to store the information gathered in the process.
3. When a community care or respite need was identified, there was general difficulty in referring carers to appropriate services due to eligibility criteria of community care services.

These issues need to be addressed in order to effectively implement carer assessment in the mental health sector.



DISCUSSION AND WAY FORWARD

Several recent major studies in Australia (Briggs, 1999), the UK (Henwood, 1998) and the USA (Schulz & Beach, 1999) agree that while caring for someone can be a positive experience, many carers have few, if any, ways to avoid the potential adverse physical, mental, emotional and social impacts of their caring responsibilities.

Specifically, the results of Carers Australia's survey of almost 1,500 carers indicate significant health and wellbeing issues for all Australian carers. These include:

- up to 30% of carers had health problems which they had not addressed or had delayed seeking help for because of their caring role;
- nearly a third of all carers had been injured at least once in the course of caring;
- two-thirds of carers said that their mental and emotional wellbeing had been affected by caring, with 85% feeling worse as a result of their caring role;
- the two main health problems for carers, physical injury and mental stress, were preventable.

Most carers reporting mental or emotional problems said they were sad or depressed, and anxious or worried. Smaller numbers mentioned being mentally exhausted, stressed, bored, frustrated and easily upset. Most attributed these problems to the stress of caring, social isolation, loneliness, changing relationships, loss and grief. Worsening physical health and being unable to continue paid work were also significant factors for some carers.

The Carers Australia study identified a range of factors which contribute to carer wellbeing, including information and practical support, availability of adequate respite care, accessible primary care (particularly from general practitioners), and strategies to independently address needs of carers and assist them to develop their own strategies for coping.

ISSUES FOR CALD CARERS

While carers' needs are not uniform, and although carers from CALD backgrounds were under-represented in this Australian study, these studies consistently indicate that carers' needs are so poorly met that their health and wellbeing are jeopardised. The Carers Australia study states that "there is anecdotal evidence to suggest that their [CALD Carers] health and wellbeing are as bad as, if not worse than, that of other carer groups". (Briggs, 1999; 14.)

Carers from CALD backgrounds will not only face similar issues to English-speaking carers but will also encounter a range of factors further impacting on their wellbeing. These include:

- lack of practical information and knowledge of the medical condition of the person for whom they are caring in a form that they can understand;
- role change, financial burden and an overwhelming sense of responsibility;
- emotional responses, including grief, loss, guilt, anger, anxiety, helplessness, depression and fatigue;
- relationship problems, family conflict and loss of social networks (Lilley, 1999).

These problems can be compounded by language difficulties and cultural norms regarding disability, the acceptability of assistance from outside the family, and expectations of who should adopt a carer role.

CALD Carers as Partners in Care

Carers and the mental health consumers for whom they provide care are identified as key stakeholders in the delivery of mental health services in both the Second National Mental Health Plan and the National Standards for Mental Health Services. The rights of carers to be involved in decision making on all aspects of mental health care is well recognised.

The Carer Profile project found that although CALD carers are identified as an essential part of the care team and should have more involvement, a range of issues impacted on, and potentially restricted their involvement.

Communication

Issues related to lack of communication or failure to recognise the needs of carers in their own right repeatedly came up during the different stages of the project. The most significant of these was the lack of communication between carers and service providers, which left carers feeling that they were not valued, listened to, protected or supported. This neglect of carers' issues and needs adversely impacts on carers' experience of the care process and the mental health system.

Lack of Access to Multilingual Information

Both carers and service providers perceived the lack of availability of information about mental illness and services in community languages as a major barrier for carers from CALD backgrounds. Lack of translated information limited carers from culturally diverse backgrounds from learning more about their relative's condition. Carers also felt disempowered by lack of knowledge and understanding of mental illness and not being able to communicate in a language with which they were comfortable.

Lack of access to multilingual information and difficulty in accessing interpreters further restricts service providers' ability to support carers from diverse backgrounds, especially when a language-specific service or bilingual worker is not available. This can be especially common in rural and remote areas.

Carer Education and Training

Both CALD carers and the community service providers working with them reported a lack of knowledge about mental illness, treatment, medication, services and the mental health 'system', and highlighted the importance of education and training for carers. Carers pointed out that information in community languages and culturally sensitive training for carers is rare, whereas some service providers believed that CALD carers were responsible for acquiring skills and information themselves. There was also an assumption that CALD carers would automatically be able to access information given to their relative with a mental illness.

Lack of Resources for Carer Support and Services

Service providers indicated a lack of resources to provide service and support to carers, and to expand their services for people from CALD backgrounds. This was especially reported in this study, in areas of high population and where communities included many language groups. It is not, however, unreasonable to assume that the same situation would apply in small and remote communities, with small but potentially diverse CALD populations.

Services also cited the scarcity and costs of cultural awareness training, the time and money required for translation of information, and the cost of interpreters, which could often not be provided within service funding. Lack of respite and other community and carer support services also came up as constantly impacting on services' capacity to meet carer needs.

The Role of Carer Assessment

Many carers reported having experienced difficulty in accessing information about their relative's condition, particularly in their own language, and in developing skills and strategies for caring. Carer assessment enables service providers to identify these needs and refer carers to appropriate support services early, thus potentially reducing the negative impact of caring.

TOWARDS A CALD CARER AND SERVICE PROVIDER PARTNERSHIP: THE WAY FORWARD

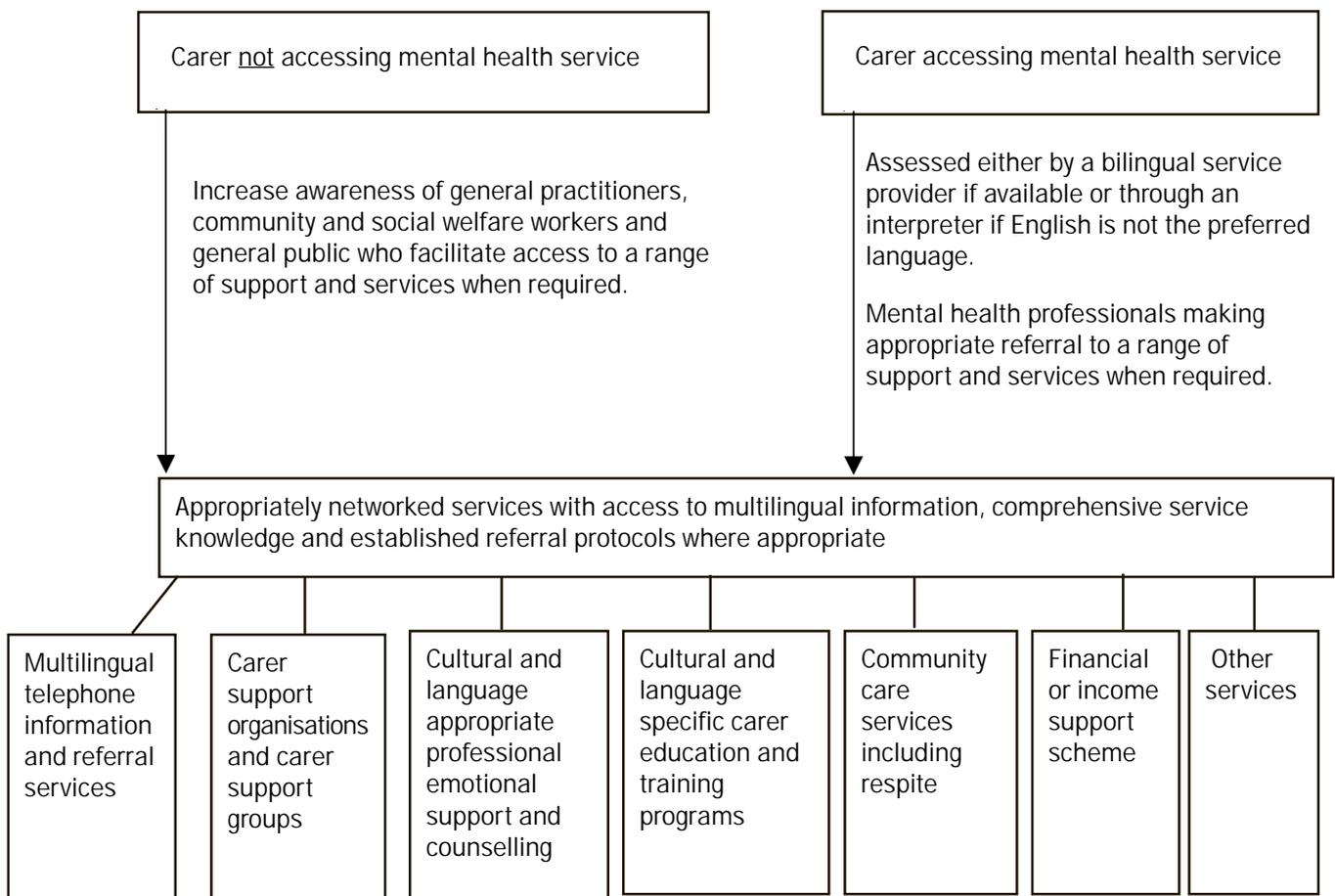
Individual Service Provision

As carers access different services according to their relative's condition and the availability of services in their local area, it is important that all mental health service providers acknowledge the importance of recognising the discreet needs of carers and the specific difficulties faced by carers from CALD backgrounds. They should also be aware of resources and support services for CALD carers of people with a mental illness. This is equally important for generalist health professionals, including general practitioners and community workers, because not all people with a mental illness and their carers have access to or choose to utilise specialist mental health services.

Diagram 1, below, shows an ideal model of carer support services, able to be accessed by carers via a range of pathways, if all services are aware of the needs of CALD carers and have access to appropriate information and referral protocols. While the range of services required by, and provided to, CALD carers of people with a mental

illness may not be available in all areas, appropriate and timely information and referral will minimise the adverse effects of caring for individual carers.

Diagram 1 – Pathways to good individual carer support



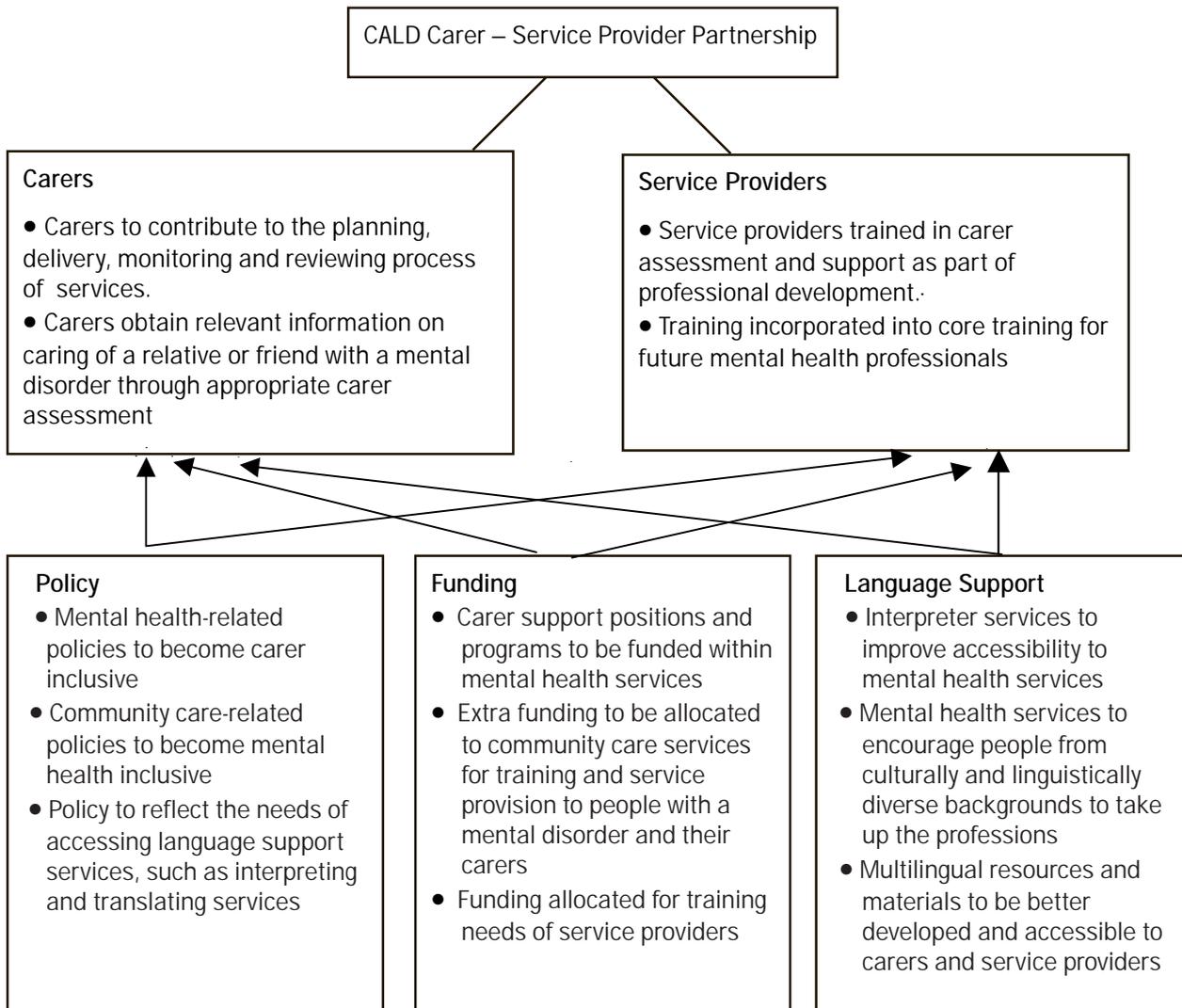
System Reform

Throughout the three stages of the project, there was a general agreement about the importance of carer involvement in the planning, provision and monitoring of mental health services at the systemic as well as the individual level. Both carers and service providers indicated the positive impact of CALD carer involvement in supporting people

with a mental disorder, and in contributing to the provision of carer-friendly and culturally sensitive mental health and carer support services.

Diagram 2, below, shows the complex interrelationships involved in a comprehensive CALD carer-service provider partnership. In order to effectively meet the needs of CALD carers at the systemic and policy level, the following key action areas need to be addressed.

Diagram 2. CALD Carer Service Provider Partnership



Policy

Policy relating to carer involvement in service provision in the mental health sector needs to be reviewed and revised to make it culturally appropriate and carer inclusive. Particular attention needs to be paid to the provision of culturally and linguistically appropriate services which recognise the discreet needs of carers.

Carer Assessment as Good Practice

The adoption of a carer assessment process like the Carer Profile strategy, which encourages communication between carers and service providers and allows carers' contribution and input to be formally recognised, provides an opportunity for CALD carers to identify and discuss their concerns and issues with service providers. It is also a way for service providers to inform carers of resources and make appropriate referrals within and outside the health system, so that carers are better supported in their roles.

Further Targeted Research on Models of Carer Support in CALD communities

Demonstration projects to trial various methods of carer assessment with different populations, which involve training for mental health professionals on carer issues, cultural awareness, and strategies for supporting carers, would allow comparisons of support and training strategies to inform future workforce development strategies for the mental health sector. Any demonstration project should include development of referral protocols that can be tailored to local conditions, including community and personal support, services to: encourage cross-sector referrals; address non-medical and non-mental health needs of carers; and to inform future service development in both community care and mental health sectors.

Service Provider Training

A nationally recognised training program is needed to facilitate the provision of: training on CALD carer and caring issues; the philosophy and utilisation of carer assessment, such as the Carer Profile strategy; and the importance of carer support for all mental health service providers. This training should be delivered in a range of settings to maximise its uptake by the mental health workforce. This includes incorporation into undergraduate and postgraduate training, existing workforce development programs and mental

health awareness courses for the general health sector.

Provision of Culturally and Linguistically Appropriate Information and Language Services

Both carers and service providers participating in this study referred to language barriers as the most important factor restricting a carer's capacity to be involved with services. For carers from CALD backgrounds, access to appropriate multilingual information about mental health, mental illness, the caring process, and cost-effective language support, is required to enhance their involvement as partners in care.

Partnerships between and across jurisdictions, and with the non-government sector, to use innovative technologies addressing the information and emotional support needs of CALD carers across Australia, will help to defeat stigma and fears associated with mental illness, and encourage early help seeking. The development of communication strategies at the national level minimises the substantial cost of translation and provision of information in multiple languages. The development of partnerships between existing organisations with skills and experience in the development and provision of information and referral services for the general community, CALD communities and carers, will maximise the reach and benefit of this initiative across Australia.

One possibility is provision of a multilingual carer telephone information service in the substantial existing infrastructure of the Carer Resource Centres. This would contribute to overcoming issues around stigma, availability of bilingual workers in rural and regional areas, and issues around diversity of cultures in different areas.

It should be accompanied by education of mainstream crisis services and information providers around issues for CALD carers and the development of a referral database, to assist service providers to refer carers to appropriate services.

Access to quality printed and audio resources in community languages is also essential to improvement of carer involvement.

Inclusive Community Services

Community services (including respite care), particularly those targeting people from CALD backgrounds, need to be more inclusive to people who have a mental illness and their carers. Community education and consultation are highly valued as tools to reveal hidden carers of people with a mental disorder; encourage early intervention and diagnosis; and to improve access to mental health and community care services. Community service providers - many of whom have limited knowledge of mental illness and the mental health system - require accessible resources about mental health and caregiving in CALD communities.

Conclusion

Throughout the duration of this project, both carers and service providers have highlighted the value of carer involvement. The process of carer assessment, in this case using the Carer Profile, has also been accepted as an effective method of promoting the health and wellbeing of carers in their own right.

Therefore, it is extremely important for government bodies to recognise and reflect the need for carer involvement in the provision of effective mental health care and the promotion of good mental health through all levels of the health system. This includes increased focus on the needs of CALD carers, including holistic independent assessment of carers' needs, support strategies for reducing injuries and stress, awareness raising among health care professionals about carers' needs, improved support to carers following discharge from care, and more effective use of local community health services to reduce the need to travel to distant services.

Strong partnerships between service providers and CALD carers are required to ensure that effective, culturally sensitive and ethical intervention strategies are devised and implemented. When carers are actively involved in consultations around the development and implementation of interventions, the potential negative outcomes of stigma, stress and increased prevalence of mental health problems, are more likely to be averted. By making services more responsive to the needs of carers, carer participation becomes more effective, improving the quality of mental health services and delivering improved mental health outcomes for Australia's culturally diverse communities.

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The Carer Profile Strategy is a process in which:

- a carer and a service provider get to know each other, through allowing the carer to talk about his/her story in a respectful and safe environment
- the carer and the service provider work in partnership to identify issues and needs of the carer
- the service provider to address some of the concerns and issues of the carer, and to make referral when appropriate
- the carer and the service provider develop plans and strategies that will bring positive impact on the carer's life.

The '*Carer Profile*' should form part of a holistic assessment for the person with a mental disorder. Input of a carer should be taken up and valued, and should have an impact on the service plan for his/her relative with a mental disorder.

Contents of the Carer Profile Strategy

The following areas need to be considered in developing a Carer Profile

- the carer's goals for themselves and their hopes for the person requiring care
- current strengths in the caring relationship, what the carer currently does and the time this takes
- current pattern of responsibility and time commitment
- support that is currently received (formal and informal)
- respite needs (home, community, residential)
- other unmet needs
- caring capacity (carer's perception of the caring situation, attitude towards continuing and ability to continue providing care)
- health impacts (current and future)
- emotional impacts (acute or chronic problems of emotional adjustment)
- emotional support (what are the needs and what supports are currently available and utilised)
- carer's own work, domestic, family and relationship responsibilities and how the caring responsibilities impinge on these (e.g. attitudes of family members, employers and significant others)
- impact on sleep.

It is very important that the process complement a carer's readiness and preference for an assessment of his/her situation. It needs to be flexible and reflective to the carer's situation and needs at the time.

Skills of Service Providers

The following skills are essential for service providers when conducting a Carer Profile:

- advanced communication skills, speaking the same language as the carer is most preferable
- broad understanding of carer issues and the whole-of-life impact of mental disorder
- understanding of relationship issues and needs in a caring relationship
- knowledge about services and referral criteria
- sensitivity and understanding of cultural issues.

Key Skills and Techniques in Assessment

The key elements of an effective assessment interview can be defined as:

<i>Environment</i>	Safe, comfortable, free of interruptions and private.
<i>Opening</i>	There are three things to be accomplished in the opening stages: <ul style="list-style-type: none">- building rapport- explaining the purpose of the interview- motivating the interviewee to actively participate.
<i>Physical Behaviour</i>	Eye contact, facial expression, posture, gesture and body language. Be free to move naturally and adopt a body position that encourages the other party to be open.
<i>Vocal Behaviour</i>	Calm, audible and paced.
<i>Language</i>	Avoid jargon. Choose words that are understandable to the other person. Check regularly that words and their meanings are understood.
<i>Feedback Behaviour</i>	Remember that this is more than just verbal. Laughing, smiling, nodding, checking assumptions and understandings, congratulating.
<i>Role</i>	Role differences can exert significant influence on the interview. Clarity of roles is essential and power differences should be minimised.
<i>Active Listening</i>	Use the whole body as a listening tool. Use the eyes, ears, and your body reactions to assess congruence. Listen first before responding.
<i>Questioning</i>	Where specific and short answers are required – use closed questions. Use open questions when you want the person to have the freedom to answer in an unstructured way.
<i>Closure</i>	Remember to do four things: <ul style="list-style-type: none">- Check that the information you have gathered is accurate- Ensure all parties understand and agree to the next step- Gain permission to make referral- Thank the parties for their contribution.

Note: Adopted from “*Carer Profile: the value of carer assessment in supporting carer/family relationships*”. p. 62.

A Checklist

Principles	Contents
<ul style="list-style-type: none"> • Allow enough time • Conduct in a safe and secure environment • Conduct in an atmosphere of trust • Purpose of Carer Profile explained • Introduce Carer Profile in a non-threatening way • Focus on the needs and wants of the carer • Let the carer tell his/her story • Focus on the carer's perspective on the situation • Value carer's need to provide care • Develop goals together • Give information on complaints 	<ul style="list-style-type: none"> • Carer roles and tasks • What carer doesn't/can't do • Carer's contribution to care • Impact on carer's physical health • Impact on carer's emotional health • Impact on carer's finances • Impact on relationships with others • Impact on carer's social life • Impact on carer's sleeping, eating • Impact on other responsibilities (work, home) • Physical needs of the carer (e.g. sleep, health) • Emotional needs of the carer (e.g. feelings) • Information and training needs of the carer • Service provision needs of the carer

Note: Adopted from “*Carer Profile: the value of carer assessment in supporting carer/family relationships*”, p. 63.

Carer Survey Questionnaire

APPENDIX B

This survey is part of a wider project, *Carer Profile*, which aims to identify different needs of family members of people with a mental illness in order to help service providers better support these families. Carers NSW recognises the diversity and the complexity of issues affecting families from different cultural and linguistic backgrounds, and believes that these issues should be better addressed.

Following the completion of the *Carer Survey*, a number of focus groups for carers will be convened. Information gathered from both the questionnaires and focus groups will form the basis of the *Carer Profile* which will then be trialled with families and service providers.

All information contained in this questionnaire is entirely **confidential** and **anonymous**.

We greatly appreciate your contribution to this project. Please do not hesitate to contact Grace Chan on 02 9280 4744 for any query.

(This project is based on the generic *Carer Profile* developed by Carers NSW in 1998.)

Demographics

Gender Male
Female

Age Under 19
19 – 45
46 – 65
65+

Area carer lives Metropolitan
Rural

Person cared for is Parent Spouse Child Sibling Other

Diagnosis of person cared for _____

Additional information about caring

Question 1

Do you think talking to carers/families about their needs is important?

Yes
No

Question 2

What things are most important to you when providing care and support to the person you care for?

Question 3

What things do you think are important to talk to the service provider about?

Question 4

Who is/are the appropriate service provider(s) to talk to about your needs?

Question 5

Would you feel comfortable in talking to the service provider(s)?

Yes
No
Not sure

If yes, what makes you feel comfortable talking to the service provider(s)?

If no/not sure, what would help you feel more comfortable talking to the service provider(s)?

Question 6

When would you like the assessment to be done?

Where would you like the assessment to be done?

How often should the assessment be reviewed?

Question 7

Does the term “Carer Profile” make sense to you?

Yes

No

Question 8

Are there any comments?

Are you interested in taking part in the carer focus group?

Yes

Contact detail:

No

Would you like to be informed of the results of the *Carer Profile* project?

Yes

No

Thank you very much for your time and participation.

Service Provider Survey Questionnaire

APPENDIX C

This survey is part of a wider project, *NESB Carer Profile*, which aims to identify different needs of family members of people with a mental illness in order to help service providers better support these families.

Following the completion of the *Service Provider Survey*, a series of focus groups will be convened. Information gathered from both the *Carer/Service Provider Surveys* and the focus groups will form the basis of the *Carer Profile* which will then be trialled with families and service providers.

All information contained in this questionnaire is entirely **confidential** and **anonymous**.

We greatly appreciate your contribution to this project. Please do not hesitate to contact Grace Chan on 02 9280 4744 for any query. (This project is based on the generic *Carer Profile* developed by Carers NSW in 1998.)

Service represented: _____

Service(s) provided:

Accommodation Service

Advocacy/Legal

Case Management

Counselling

Crisis Support

Education

Family Support

Home Help

Information and Referral

Medical/Health Service

Rehabilitation

Respite

Social/Recreational

Support Group

Therapy

Others

Please specify _____

Over the past 12 months, how many clients to your services have been from:

a non-English speaking background _____

a Chinese background _____

a Greek background _____

Does your service target:

People with physical disability

Families/Carers of people with physical disability

People with intellectual disability

Families/Carers of people with intellectual disability

People with mental illness

Families/Carers of people with mental illness

Other

Please specify _____

What involvement does your service have with family members/carers?

Should family members/carers be involved in any part of service provision? If yes, how?

What is your impression of family members/carers of Chinese origin?

What is your impression of family members/carers of Greek origin?

What is your view about linguistically/culturally appropriate reading materials about:

(Scale of 0 to 10 where 0 indicates very bad and 10 indicates very good)

Chinese

Illnesses and disorders	_____
Treatments and medications	_____
Rights and responsibility	_____
Law and advocacy	_____
Community services	_____
Accommodation options	_____
Financial assistance	_____
Prevention of crisis	_____
Family help	_____

Greek

Illnesses and disorders	_____
Treatments and medications	_____
Rights and responsibility	_____
Law and advocacy	_____
Community services	_____
Accommodation options	_____
Financial assistance	_____
Prevention of crisis	_____
Family help	_____

What is your view about services in terms of cultural appropriateness?

Any other comments?

Would you be interested in attending to a service providers' focus group re NESB carers of people with a mental illness?

Yes Contact detail: Name _____

No Tel _____

Thank you very much for your participation in this survey.

Carer Focus Group Discussion Topics

APPENDIX D

Many carers have expressed that they would like to talk to the mental health professionals who also assess their relatives or friends with a mental illness. There is a clear indication that carers want to be listened to and to be told and educated about the illness and other relevant information.

Inclusion of carers in the “caring team” is very important. However, the aim of a “Carer Profile” is to identify the carer’s strengths, difficulties and needs, which is much broader than being an information source or being part of programs for their relatives and friends. A “Carer Profile” looks at different aspects of caring as well as other aspects in a carer’s life.

That includes:

- Caring pattern
 - current pattern of responsibility and time commitments
 - home environment
 - current strengths and areas of difficulties
 - information and training needs
 - caring capacity
 - emergency arrangement
- Support and services
 - formal support currently received
 - informal support currently received
 - unmet needs
- Caring relationship
 - current strengths and obstacles in caring relationship
 - needs
- Impact of caring on carer’s life
 - workplace arrangement and relationship
 - domestic/family arrangement and relationship
 - other relationship
 - health (including sleep) impact
 - financial impact
 - social impact
 - emotional impact
- Current situation and future expectation
 - need for personal support
 - care plan
 - hope for the person being cared for
 - carer’s caring goal
 - carer’s personal goal
- Other information

By pulling pieces of information together, the assessor and the carer will develop a more objective picture of the carer’s situation. The information will help to identify needs and, hence, allow effective referrals and supports.

Discussion

1. What do you think about the concept of a “Carer Profile”?

If so, how could we achieve the aims? E.g.

- Who should assess carers?
- Where should the information go?

2. Discussion of the items

3. Expectation of outcomes

4. Others

Although providing services to people from culturally and linguistically diverse (CALD) backgrounds raises different issues in different areas (e.g. metropolitan and rural differences) there are common issues concerning service providers across NSW. These issues include:

- Communication problems (including language barriers)
- Lack of information and knowledge (illness and treatment, system and services, roles of different people involved in care, etc) for CALD communities
- Difficulty in providing and referring to culturally appropriate services.

Communication

- What issues around communication with service users from CALD backgrounds can you identify?
- What method(s) or strategy does your service currently employ to enhance communication with service users from CALD backgrounds?
- What other support would you require to improve communication with your service users?

Lack of information and knowledge

- What information and/or knowledge do CALD service users need but are not currently available for them?
- How can we improve information and/or knowledge?

Cultural appropriateness

- How does your service accommodate people from CALD backgrounds?
- How can it be achieved?

Please also look at the questions prepared for the carer assessment and comment on them.

Thank you very much for your time and contribution!

OUTLINE

8:45am	Registration
9:00am	Introduction Welcome and overview of the day Overview of Carers NSW Background to the Carer Profile
9:30am	Overview of participating agencies Service provided Current assessment practice and procedures
10:00am	Project Overview – What is the Carer Profile Project? Aim and objectives What do the survey and focus groups tell us? Brief description of resources to be used in conducting Carer Profile
10:30am	Morning Tea
10:45am	Understanding Carers Issues in carer assessment Dealing with emotion Skills required in undertaking assessment
12:15pm	Preparation for Afternoon Session
12:30pm	Lunch
1:15pm	Developing a Carer’s Profile Structure of assessment interviews Assessment principles Assessment content Brainstorming example of questions
1:45pm	Exercise and Discussion
2:45pm	How to record the information?
3:00pm	Afternoon Tea
3:15pm	Introducing the Carer Profile Project to Carers
3:30pm	Evaluation Assessor’s Feedback Form Carer’s Feedback Form
3:45pm	Questions and Final Comments
4:00pm	Close

**Multicultural Carer Profile (Mental Health)
Project Training Manual/Materials**

APPENDIX G

Contents

1. Training Materials
 - Training Session Outline
 - Project Background
 - About the Project
 - Overall Aim
 - Specific Objectives
 - Expectations on Participating services
 - About the sample
 - About Good Practice in Carer Profiling
 - About the Project Materials
 - About the Process
 - Key Skills and Techniques in Assessment
 - Developing Carer Profiles – A Checklist
 - Notes Pages (Note: This project adopted partial materials from the 1999 Carer Profile training, *Carer Profile: the value of carer assessment in supporting carer/family relationship*, J. Hughes, 1999)
2. Trial Materials
 - Introduction letter to Carers in English and appropriate language (Chinese or Greek)
 - Carer Profile Record Form
 - Carer Feedback Form
 - Service Provider Feedback Form (extra copies of materials also provided but not as part of the manual)
3. Information About Carers
 - Carers: the Myths and Realities
 - Facts about Young Carers in Australia (Fact sheets developed by Carers NSW)
4. Carer Services
 - Advocacy
 - Carer Respite Centres
 - Using Respite
 - Carer Support Groups
 - Guardianship Tribunal (Fact sheets developed by Carers NSW)
5. Financial Help for Carers
 - Benefits and Entitlements
 - Carer Allowance
 - Carer Payment
 - Health Concession Cards
 - Pharmaceutical, telephone and rent support (Fact sheets developed by Carers NSW)
6. Former Carers
 - Former Carers
 - After Caring: Grief and Bereavement
 - Coping with Residential Placement (Fact sheets developed by Carers NSW)
7. Other Useful Resources for Carers
 - The Seven Habits of Highly Effective Carers
 - Ten Tips for Feeling Good About Caring
 - Twelve Tips for a Good Relationship with Your Partner (Fact sheets developed by Carers NSW)
8. Information in Community Languages
 - Fact sheets from Carer Support Kits (Commonwealth Department of Health and Ageing)
 - Fact sheets from the Transcultural Mental Health Centre

APPENDIX H

Dear Carer,

Carers NSW, the organisation that represents the interest of NSW carers, is seeking 10 Greek carers of people with mental illness to help us in our “Multicultural Carer Profile” project. Your contribution to the project would be appreciated and valued.

The project aims to look at how services can take into account the needs of carers at the time of assessment. Most current assessment tools succeed in measuring the needs of the person you are caring for. However, it is also very important that part of the assessment looks at how much you give to the caring relation, how it affects your life and what support/services you need for your own wellbeing.

In order to include carers in the assessment process, we need to know whom carers prefer to talk to and what they want/need to talk about. We are also interested in what makes carers comfortable when talking about their experiences.

In this pilot project, a worker who speaks your language will spend 1 hour with you as an initial interview. The worker will talk to you about what it is like for you as a carer and will refer you to appropriate services/support if necessary. After the interview, the worker will fill in a short feedback form with you. The form will review your overall experience in the process, issues that are not covered, and whether you feel comfortable talking about the listed items.

Should you have any question, please contact Grace Chan (Project Coordinator) on (02) 9280 4744, or if you are calling from rural NSW, please use our free call number 1800 242 636.

Your details will be treated in the strictest confidence. Your name and contact details will not be passed on to Grace unless you choose to contact her, or are interested in her calling you to discuss what the assessment was like for you.

Thank you for your time and assistance.

Yours sincerely,

Joan Hughes
Executive Director

APPENDIX I

Date	ID Number
/ /	

CARER INFORMATION RECORD

Title	Full Name	Prefers to be called

Usual Address			
	Suburb	Postcode	

Current Address (if different)			
	Suburb	Postcode	

Contact Number							
day		after hours		mobile		fax	

Country of Birth	Ethnicity	Religion
Language	Interpreter	

Source of Referral				
Name		Tele		Org
Note				

Carer Financial Detail

- Full Pension
 Part Pension
 No Pension
 Work F/T
 Work P/T

Other information

Services currently being used to support the caring situation

- | | | | | |
|--|--|---|--|--|
| <input type="checkbox"/> Hospital | <input type="checkbox"/> General Practitioner | <input type="checkbox"/> Specialist | <input type="checkbox"/> Home Nursing | <input type="checkbox"/> Other Health |
| <input type="checkbox"/> Aged Care Service | <input type="checkbox"/> Disability Service | <input type="checkbox"/> Personal Care | <input type="checkbox"/> Community Access | <input type="checkbox"/> Home Help |
| <input type="checkbox"/> Residential Service | <input type="checkbox"/> Residential Respite Service | <input type="checkbox"/> In Home Respite | <input type="checkbox"/> Out of Home Respite | <input type="checkbox"/> Recreation |
| <input type="checkbox"/> Equipment | <input type="checkbox"/> Home Mod/Main | <input type="checkbox"/> Transport | <input type="checkbox"/> Food Service | <input type="checkbox"/> Neighbour Aid |
| <input type="checkbox"/> Carer Support | <input type="checkbox"/> Carer Info and Training | <input type="checkbox"/> Informal Support | <input type="checkbox"/> Private Service | <input type="checkbox"/> Other |

Name of Service(s)	Contact Person	Tele

Person(s) cared for

Name	Relationship to carer
DOB / /	Live with carer? Condition(s)
Name	Relationship to carer
DOB / /	Live with carer? Condition(s)

Carer also looks after
 Dependent Child/Children

Older Person/People

Description of caring responsibilities

Information on informal support by family, neighbours or friends

General Carer Issues and Carer Needs

Recommended/Agreed Action to address carer’s needs and priorities (what, who, when)

Follow-up Details and Responsibilities if required

Information about next assessment

Date		Time		Venue	
Notes					

Service Provider’s Detail

Person conducted Profile		Position	
Notes			

Carer’s Consent and Signature

I _____ consent to this information being available to services nominated under Recommended/Agreed Action.

.....
Signature of Carer

...../...../.....
Date

If written consent has not been given, has the carer given verbal consent?

No Yes

.....
Signature of Assessor

...../...../.....
Date

Carer Feedback Form

APPENDIX J

Thank you very much for your participation in the Carer Profile trial.

To fully understand your experience with and the effectiveness of the Carer Profile, please spend a little time completing this feedback form.

Please tick the box that best describes your experience.

Overall Experience

	Yes	No	N/A
You felt comfortable in the process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You felt comfortable with the length of time used	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your needs and wants as a carer were covered	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You were allowed to say what you wanted to say	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You felt listened to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You felt respected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

About the Interview

In your opinion, how important are the following when compiling a Carer Profile?

	Important	Not Important	N/A
Time and place should be suitable for you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enough time is allowed for the process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A professional/worker you trust conducts the profile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The professional/worker speaks your language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The professional/worker is sensitive to your culture	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The professional/worker tries to see things from your viewpoint	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The professional/worker understands your role as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your need/decision to take care of the person is respected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You are included in deciding what will happen next	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Offers you some practical solutions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Content of Profile

In your opinion, how important is it to talk about the following items and how comfortable do you feel when talking about them?

	Important	Not Important	Not Comfortable
About your caring role	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
About what you can't or don't do in your caring role	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
About the value of what you do in your caring role	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
About the effect of caring on your physical health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
About the effect of caring on your emotional health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
About the effect of caring on your finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
About the effect of caring on your other relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
About the effect of caring on your social life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
About the effect of caring on your life pattern	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
About the effect of caring on your other responsibilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
About your physical needs (e.g. sleep, health)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
About your emotional needs (e.g. support)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
About your need for information on caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
About your need for support services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
About what will happen next	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other Comments

**Thank you very much for your participation!
Your input to the project is valued and appreciated!**

Carer's Situation

Relationship of carer to the person being cared for: _____

Diagnosis of the person being cared for: _____

Does the carer:

- | | |
|--|--|
| <input type="checkbox"/> live with the person | <input type="checkbox"/> live somewhere else |
| <input type="checkbox"/> care full-time for the person | <input type="checkbox"/> care part-time for the person |
| <input type="checkbox"/> care for children as well | <input type="checkbox"/> care for adults as well |

Does the carer think that caring responsibilities are:

- heavy moderate light

From your observation, how does this affect the carer physically and emotionally?

Assessment Situation

Was the assessment held:

- | | |
|--|---|
| <input type="checkbox"/> in the client and carer's home | <input type="checkbox"/> in the client's home |
| <input type="checkbox"/> in the carer's home | <input type="checkbox"/> at the agency's office |
| <input type="checkbox"/> somewhere else (please specify) _____ | |

Who else was present when the carer's profile was completed?

- | | |
|---|--|
| <input type="checkbox"/> the person being cared for | <input type="checkbox"/> advocate |
| <input type="checkbox"/> other service representative | <input type="checkbox"/> other family member |

In your opinion, was the environment in which you did the carer profile:

- | | |
|--|--|
| <input type="checkbox"/> suitable for the carer | <input type="checkbox"/> unsuitable for the carer |
| <input type="checkbox"/> suitable for assessment | <input type="checkbox"/> unsuitable for assessment |

If unsuitable, please give reasons

Assessment Principles

To what extent were the following principles carried out during the development of the carer profile? Tick a rating between 1 and 5, where a rating of 1 means “not at all” and 5 means “fully”.

Time allowed for the process is adequate	1	2	3	4	5
The carer felt safe and secure	1	2	3	4	5
A trust atmosphere was established	1	2	3	4	5
The assessment’s purpose and expectations were explained	1	2	3	4	5
The profile was introduced in a non-threatening way	1	2	3	4	5
The process focused on the needs and wants of the carer	1	2	3	4	5
The carer was encouraged to tell his/her story	1	2	3	4	5
The process focused on the carer’s perspective on the situation	1	2	3	4	5
The carer’s need to take care of the person was respected	1	2	3	4	5
Goals and desired outcomes were jointly developed	1	2	3	4	5
Relevant information was given to the cared	1	2	3	4	5

Assessment Content

During your discussions with the carer, to what extent do you think the following carer issues were covered? Tick a rating between 1 and 5, where a rating of 1 means “not at all” and 5 means “fully”.

What the carer does in the caring role	1	2	3	4	5
What the carer doesn’t do in the caring role	1	2	3	4	5
Recognition of the carer’s contribution to care	1	2	3	4	5
Impact of caring on carer’s physical health	1	2	3	4	5
Impact of caring on carer’s emotional health	1	2	3	4	5
Impact of caring on the carer’s financial resources	1	2	3	4	5
Impact on relationship with others	1	2	3	4	5
Impact on carer’s social life and supports	1	2	3	4	5
Impact on carer’s life patterns (e.g. sleep, eating)	1	2	3	4	5
Impact on other responsibilities (work, home)	1	2	3	4	5
Physical needs of the carer (e.g. sleep, eating)	1	2	3	4	5
Emotional needs of the carer (e.g. feelings)	1	2	3	4	5
Information and training needs of the carer	1	2	3	4	5
Service provision needs of the carer	1	2	3	4	5

Notes

