

Carers News Survey 2004

1. Introduction

In 2002 Carers NSW distributed its first survey to members receiving our newsletter, the Carers News. That year there were 185 respondents. In 2004 the second survey was distributed in the same manner and 466 fully or partially completed surveys were returned to us. This high response rate makes the survey results more representative of carers opinions about the state of family caring in NSW.

1.1 Results: Respondent Profile

The first page of the survey containing questions 1-8 gathered profile information about the survey respondents such as their carer status, age, information about the person they provide care for and whether they were from Aboriginal and Torres Strait Island (ATSI) or culturally and linguistically diverse (CALD) backgrounds. The results are shown in Table 1 below.

Table 1. Profile of Respondents

Respondent	83% carers, 8% service providers, 4% former carers, 1% care recipient, 4% didn't answer
Gender	73% female, 24% male, 3% didn't answer
Care recipient	39% disability, 30% frail aged, 10% chronic condition, 6% mental illness, 42% didn't answer
Age of Respondent	1% under 18, 1% 18-24, 5% 25-34, 8% 35-44, 20% 45-54, 22% 55-64, 37% 65+, 6% didn't answer
Residence	61% metropolitan incl Sydney, Wollongong, Newcastle, 37% regional/rural, 2% didn't answer
ATSI	Less than 1%
CALD	9%

Source: Carers News Survey, 2004

It is notable that there was a very low response rate regarding the main condition of care recipient (42% didn't answer). This perhaps indicates that many carers are caring for people with complex conditions or that they didn't identify with the categories used in the survey.

Questions 8-13 of the survey asked for feedback about the newsletter, Carers News, which has been collated and is being used to improve that publication.

1.2 Results: Issues

Questions 14-19 of the survey were devised to gather information about issues for carers. The questions were in an open format so as not to limit responses. Multiple responses were allowed (other than for question 15 which only allowed one response). The implications were that a wide range of answers came back which then had to be collapsed into broader categories for further analysis. To address the risk that some of the diversity of data may be lost through this process this report provides some exemplary responses that were included in each category.

The key issues that were recurrent throughout the survey were the need for more respite services, more general community services, better financial assistance, more information and support for carers and greater awareness in the community, among health professionals and government of carers.

Broadly the survey results will be presented under three headings. These are the types of assistance required by carers, carer recognition and other comments.

The percentages used in this report represent the number of respondents that chose a particular answer out of the total number of respondents. Therefore in many cases the percentages add to more than 100% as respondents gave more than one answer.

2. Types of Assistance Required by Carers

Survey respondents gave respite absolute priority when asked about the types of assistance they would like and needed the most. Within this category there were a range of responses from simply more respite to specific respite models and services as well as comments about the quality and appropriateness of respite. Not surprisingly the need for carers to have a break came through as the most significant reason for requiring assistance.

The need for community services and general support was also substantial throughout the survey. This category broadly encompasses many types of support for both the carer and person they support primarily including assistance at home but also incorporating supported accommodation for people with disability and assistance in the community.

The need for financial assistance was apparent but, interestingly, did not take precedence over the need for services. It was the third most needed type of assistance and financial issues rated fourth as a reason carers needed assistance. Throughout the survey the need for better financial support was apparent but less significant than the need for services indicating that, although carers (as we know) face financial hardship, the need for more services and support and the frustration faced in trying to get these services outweighs financial concerns. However it must also be noted that for many restricted access to services may also be a result of inadequate financial support.

While there was some mention of the need for more information and services for people from CALD backgrounds the numbers were quite small. This is likely to be a result of the demographic mix of survey respondents. It is quite possible that many members of Carers NSW from CALD backgrounds may not have returned surveys as questions were provided in English only. This raises a further concern that the needs of CALD carers are not being heard and represented through mainstream data collection such as this. Similarly the representation of workforce issues for carers was small possibly due to the large number of respondents (37%) above working age.

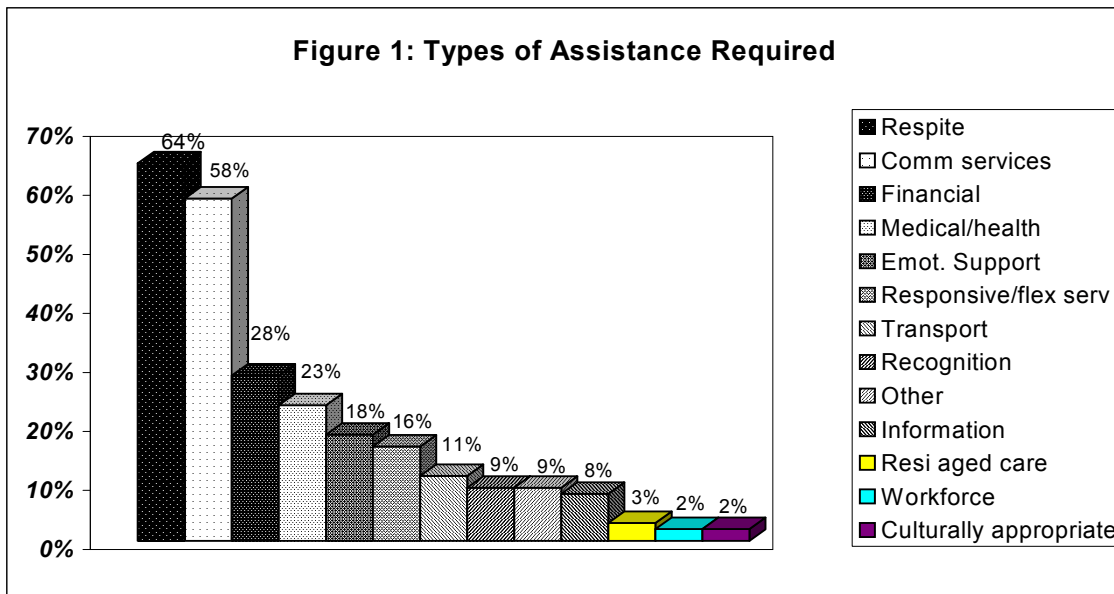
2.1 Types of Assistance that Carers Would Like

A high number (419 or 90%) of respondents answered question 14 which asked what type of assistance they would like in an ideal world and to list as many as they wanted. Figure 1 shows that the majority of respondents (64%, n=267) listed some form of respite here. Included in this category were a wide range of respite models such as appropriate day care and recreation for the care recipient, holiday respite, emergency respite and dementia specific respite¹.

Many respondents didn't use the word "respite" but wrote comments such as "**someone who can come in for two or three hours a day so that I could at least go for a walk and go to the gym**" (respondent #398).

¹ These programs, while not all specifically respite care, provide the respite effect for carers and therefore have been classified as "respite".

Almost as many respondents (58%, n=243) would like more community services and support such as domestic assistance, gardening, shopping assistance and home maintenance. As well as personal care, school, accommodation and work placement assistance for the person they support. Many different suggestions for both carers and the people they support were given such as **“organised social activities with other carers and cared for with staff to provide respite and supervision”** (respondent #458).



Source: Carers News Survey, 2004

Other frequent responses were around improved financial assistance (28%, n=119), more and better medical/health services (23%, n=97) and emotional support, counselling and education for carers (18%, n=77). The need for services to be responsive and flexible (16%, n=65), for better access to transport (11%, n=45) and for carer recognition (9%, n=36) were also frequently given responses. Less common were answers around better access to information (8%, n=33) for instance **“how to deal with Centrelink”** (respondent #83) and more residential aged care (3%, n=12). Assistance with workforce issues relating to carers and the need for culturally appropriate services were also listed but only by 2% (each) of respondents.

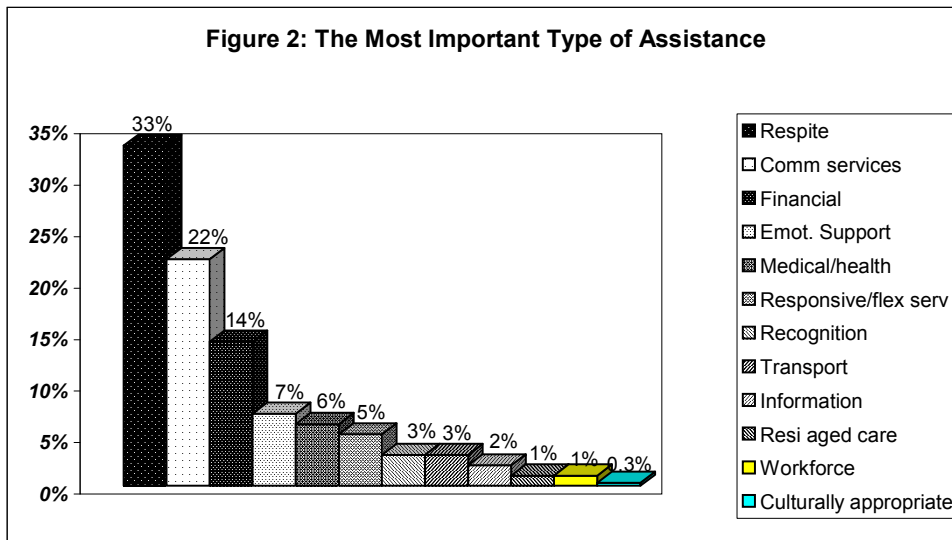
These results demonstrate that the majority of carers feel they are inadequately supported by formal services that can assist them to continue caring in the community. Awareness of programs and services was apparent however various complaints about existing services and comments about access to services were common.

Following from that question, respondents were asked which type of assistance from the list they identified was **most** important to them. Fewer people answered this question (399 or 86%) perhaps indicating that it was difficult for some carers to give priority to just one of the services they needed. One such typical response was **“Can not choose only one as they are all VITAL”** (respondent #487).

The results are presented in Figure 2 (see below). A third of those who did respond chose respite (33%, n=133). Assistance from community services and support was selected by 22% (n=86) of respondents and 14% (n=57) chose financial assistance as the type of assistance most important to them.

The other priority responses were emotional support (7%, n=29), medical/health services (6%, n=23) and more responsive or flexible services (5%, n=21). Carer recognition (3%, n=13), better

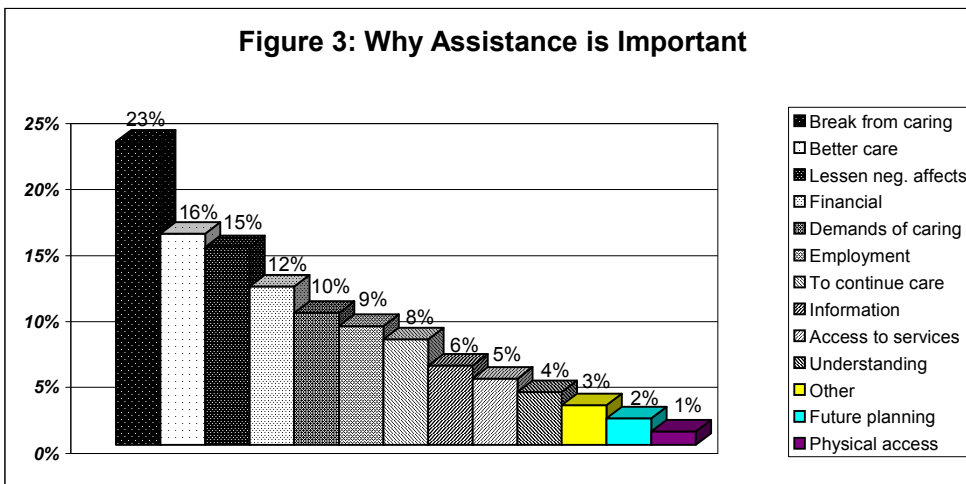
transport or disability access (3%, n=10), better information on services (2%, n=8), assistance with workforce issues (1%, n=2) and culturally appropriate services (0.3%, n=1) were also listed.



Source: Carers News Survey 2004

2.2 Why Assistance is Important

Question 16 asked why the chosen form of assistance was most important to respondents and 318 people (83%) chose to respond, many giving multiple responses. The purpose of this question was to determine in what ways carers most need support. The answers given highlight how critical carers perceive formal services such as respite care and community services, as well as financial assistance. Figure 3 shows the priority of responses.



Source: Carers News Survey 2004

Almost a quarter (23%, n=89) of respondents to this question wanted assistance to give them breaks from caring. This included those who needed time to themselves, time for other family members and social activities and for their own health and well being. One respondent answered **“My health is poor because of...the stress related to caring”** (respondent #179).

The second most frequently occurring reason carers needed assistance was so they could provide or access better care for the person they support. Sixteen percent (n=61) gave answers of this nature such as to provide better or more safe care, to ensure the care recipient is safe, happy,

interested or treated well during the day, to be able to spend more time with the care recipient or because there are no appropriate services for the care recipient.

One response from a male carer that exemplifies these concerns was **"I had my wife in [a] nursing home for two weeks last year, my first break for twelve years. It took me nearly two months to get her back to normal"** (respondent #389).

Fifteen percent of respondents (n=57) wanted the assistance to reduce negative social and family affects of caring such as family breakdown, isolation and depression. Twelve percent (n=47) gave a financial reason for needing the assistance, many of which cited the cost of disability, transport and equipment as significant. Ten percent (n=39) gave the demands of caring as a reason, 9% (n=34) employment, 6% (n=23) said it was for information and support. Other responses were to be able to continue caring (8%, n=32), for better access to services (5%, n=19), greater understanding from the government, community and service providers (4%, n=14), the need for future planing (2%, n=8) and to provide better access to the community (1%, n=4).

3. Carer Recognition

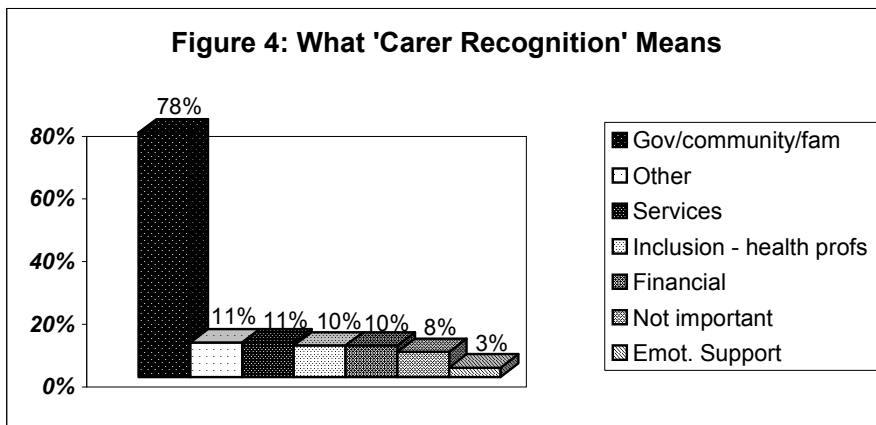
In the 2002 carer survey, respondents were asked to rank certain government issues as high, medium and low priority. 'Advocating for greater recognition of carers by government and politicians' was ranked by 84.3% of respondents as a high priority State Government issue. Given the significance of this finding two questions were included in the 2004 survey to further explore the importance of carer recognition and how it can be manifested in practical ways.

It is evident from the survey results that understanding from the government, families and the community in general embodies recognition for carers. It was most frequently suggested by carers that recognition could be realised through more and better quality services (of which respite was particularly noted) and through greater publicity, media attention and public awareness of carer issues.

Interestingly financial assistance did not feature as a component of the definition of carer recognition for many respondents. However when asked about practical ways that carers could be recognised, a third of respondents listed better financial assistance.

3.1. What Carer Recognition Means

In total 396 (85%) people answered question 17 about the meaning of carer recognition. The majority (78%, n=307) of respondents gave an answer about more understanding and recognition from the government, community and rest of the family of the impacts and needs of carers. For instance for one respondent (respondent #238) recognition is **"appreciation for the 24 hour, 7 day a week job we do"**. Other responses included recognition that caring is a full-time job, that



Source: Carers News Survey, 2004

carers save the government money, that carers possess specialist skills and knowledge and that carers are unselfish and have made great sacrifices in their own lives.

Other carers felt recognition was represented by available and responsive services (11%, n=43), inclusion by health professionals and services (10%, n=41), financial assistance or tax concessions (10%, n=38), and that carers are emotionally supported and looked after (3%, n=13).

“I don’t need a pat on the back and comments about how strong I must be. I need to be listened to, with respect by professionals when decisions regarding my child need to be made” (respondent #5).

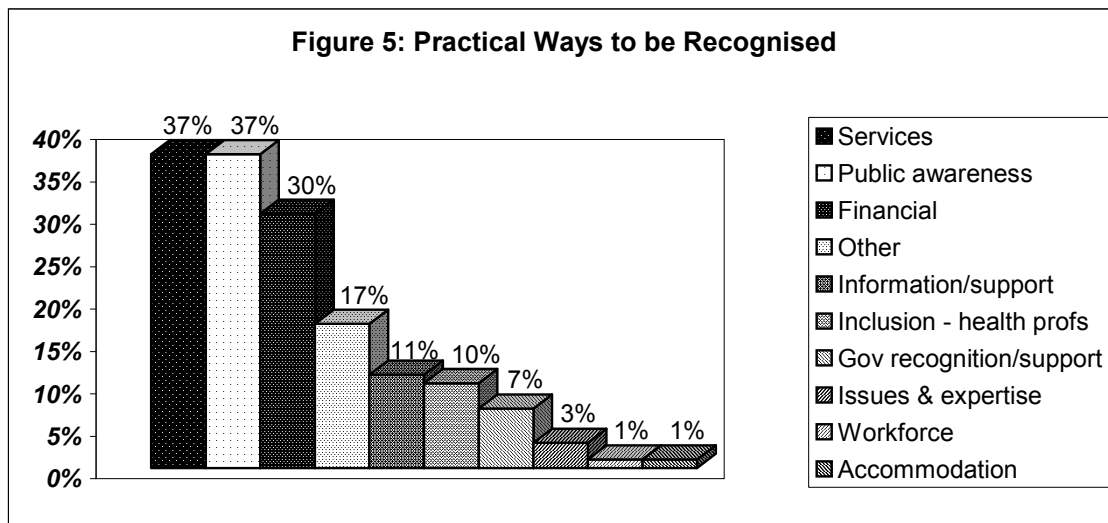
Only 8% (n=32) of respondents said that carer recognition isn’t important or doesn’t worry them although some of these answers indicated that the respondent felt recognition was idealistic but unobtainable.

One carer who identified themselves as being from a CALD background wrote **“I can’t talk much about “carer recognition” because sometimes I feel a bit uncomfortable to be [paid] for look[ing] after my husband and in my isolation who cares about what I am doing?”** (respondent #388).

3.2. Practical Ways to be Recognised

When asked in question 18 what are some *practical* ways carers can be recognised, the two top-rating responses (each with 37% or 133 occurrences) were for more and better quality services (including respite) and for more public awareness including carer stories in the media. Some suggestions to increase public awareness included carer badges, cards or broaches, publicity campaigns on television or radio and greater media exposure of carer events such as Carers Week.

More money, concessions, financial help or free services were chosen by 30% of respondents (n=106) and 11% (n=40) felt that information, support or education for carers could demonstrate carer recognition. One in ten of the people answering this question (n=36) suggested being included, informed and supported (particularly by health professionals) as a practical way to be recognised and 7% (n=24) felt this could be done through government recognition and support.



Source: Carers News Survey 2004

Other answers included recognition by general practitioners, service providers and families of the expertise/issues that carers have (3%, n=9), workforce issues (1%, n=5) and more long term care, supported accommodation and retirement villages (1%, n=3) as practical means of

recognising the work of family carers. Given the high proportion of older respondents to this survey, the low priority of the last issue indicates a need for greater investment into community care for the ageing population.

4. Other Comments

The final question of the survey asked for any additional comments about issues. This question had a response rate of 52% or 230 responses. The comments given highlighted the issues that are prevalent from the rest of the survey. These include the need for more access to services and the need for recognition, both financial and in the government and community. Some emotional issues were also raised here.

4.1 Services

Some of the comments relating to access to, and quality of services included:

- waiting lists are getting longer,
- there is little compassion from staff,
- in-home respite and other services are costly,
- carers need more information when they start caring,
- centre based respite and supported accommodation are still needed,
- more access to services in rural communities is needed, and
- services are only available when you're in crisis.
- "Keep fighting the government 'on our behalf' for more group homes and respite care"
(respondent #113)

4.2 Financial

Financial recognition included:

- just because your spouse works it doesn't mean you can easily afford caring,
- pay carers more to cover expenses/costs of disability,
- the cost of medication is too high,
- the Carer Allowance is too low, and
- it's hard to survive on income support.

4.3 Recognition

Government and community recognition included:

- politicians and Centrelink need greater understanding of carers issues,
- carers to march on parliament house,
- people don't know until they become a carer.

4.4 Emotional

At an emotional level, some of the comments included:

- carers' issues often include loneliness, tiredness and hopelessness,
- carers don't want to feel alone, and
- carers are not content; we have no time for ourselves.

Demonstrating the culmination of many of these issues for some carers and the frustration they continually face, one carer wrote (respondent #387):

“Recently I was told by Centrelink that I would have to do voluntary or paid work or a course to keep qualifying for my Parenting Pension once my daughter [with a disability] turned 12. I fought this issue as I felt insulted that they had assumed:

- 1. I was not engaged in work,**
- 2. I was not making a contribution,**
- 3. I was unskilled or unqualified,**
- 4. I had time to do this,**
- 5. My daughter was a normal 12 year old.”**

Carers also came up with innovative ideas in this section. These included developing “buddy” systems in local neighbourhoods to link volunteers with families, starting support groups in their local areas, providing funding packages for carers to choose the services they need the most and affording unpaid carers the same rights and protection that paid workers receive. Many respondents also took the opportunity to thank and congratulate Carers NSW staff on their achievements and work including the assistance provided, lobbying work and general comments.

Some respondents also called for the greater political action from carers. Such responses included **“we must all stand together as one voice”** (respondent #004).

5. Carer Population Groups

As discussed in the introduction, respondents were asked to identify their gender, age, cultural background and place of residence, as well as the main condition of the person they care for. The minority categories of carers were males, those aged under 45, Aboriginal and Torres Strait Islanders, people from culturally and linguistically diverse backgrounds, those living outside metropolitan Sydney and carers of people with mental illness. Although the numbers were small and in many cases cannot be used to create broader generalisations some of their survey responses will be discussed here. Figure 6 (below) shows responses to question 14, regarding services required, by carer type according to the categories identified below.

5.1 Male Carers

In total 24% of survey respondents identified themselves as male. This is closely aligned with the ABS (2003) estimate that 28% of primary carers in NSW are males (although respondents to the Carers News survey were not asked to identify whether they were primary carers). There were some noticeable differences between the issues raised by male carers compared with those raised by female carers.

Financial issues appeared to be more significant with 34% of male carers who responded to question 14 listing financial services as one type of assistance they need compared with 24% of female respondents. When asked which was the most important service 18% of male carers listed financial services compared with 14% of female carers. When asked why they most needed services 15% of male respondents gave financial reasons compared with 10% of female respondents. In terms of recognition 34% of male respondents highlighted financial recognition of carers compared with 27% of female respondents. There was also more need reported among male carers for information than among female carers.

There was less emphasis in responses from male carers on services and emotional support for carers. Male and female carers showed an equivalent need for respite services and to have a break from caring. For both genders this was the greatest issue raised in questions 14 and 15.

5.2 Younger Carers

Carers NSW identifies young carers as under 25 years of age. However there were too few respondents to the survey who fit this age group to provide any representative data on young carers. Some data, however, can be drawn from younger carers (those under 45 years). These

were also a minority of respondents (15%) to the Carers News survey, 37% of which were aged 65 and over and 44% aged 45-64.

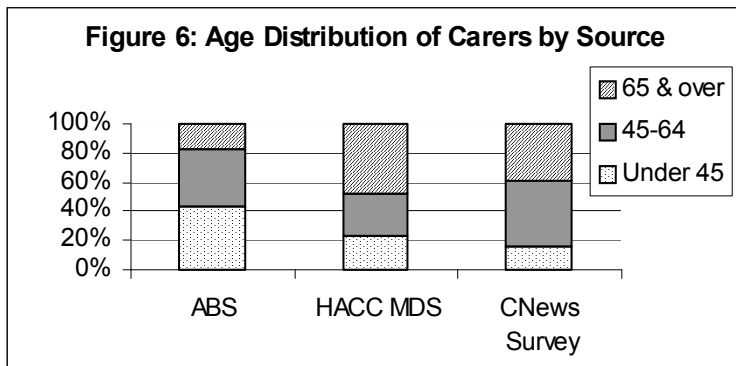


Figure 6 shows the age distribution of carers as reported by the ABS (2003) for NSW, the HACC Minimum Data Set (2002-03 unpublished data) and the Carers News survey. Comparison of the three sources demonstrates that younger carers are less likely to be Carers News respondents and to receive HACC services than older carers are.

Analysis of responses to the Carers News Survey from people aged under 45 and those aged 45 and over did not show any significant trends for the younger age group. There was a slightly greater emphasis on the quality of services. When asked how about practical ways for carers to be recognised, 39% of younger carers identified more and better quality services compared with 30% of older carers. In question 14 which asked respondents to list the services that were important to them 22% of younger carers identified responsive and flexible services compared with 12% of older carers. Younger carers were more likely than older carers to identify respite (56% compared with 51%) and breaks from caring (25% compared with 21%) as being important.

5.2 ATSI Carers

Less than 1% of survey respondents identified themselves as Aboriginal or Torres Strait Islander (ATSI). This small sample size will not provide representative data on the needs of ATSI carers. The responses given were generally reflective of all survey data. One in four identified respite as the most important service, two identified general community services.

5.4 CALD Carers

Only 9% of survey respondents identified themselves as from culturally and linguistically diverse backgrounds. This compares with estimates that around 20% of the total population are from CALD backgrounds, indicating either that CNSW has a lower representation of CALD people in its membership or that this group was less likely to return the survey.

The issues that carers from CALD backgrounds were more likely to raise than the total respondents were the need for emotional support, information and having understanding from the government and from service providers.

In question 17, regarding recognition, 21% of CALD carers gave an answer that was related to emotional support or looking after carer needs compared with just 3% of all respondents. CALD carers were more likely to list information, education or support as a means of practical recognition of carers in question 18 (14% compared with 11% of total respondents). Of the 40 CALD respondents answering question 14 about services they would like in an ideal world, 25% listed emotional support compared with 18% of all respondents.

The need for respite, general community services and recognition were less reported by CALD respondents and naturally the need for culturally appropriate services was a greater issue for this group.

5.5 Rural and Regional Carers

The proportion of rural and regional respondents to the survey broadly represented the distribution of all carers across regional and metropolitan NSW according to the ABS (2003).

Almost 40% of survey respondents were from rural or regional areas, compared with a total estimate of 31% of primary carers in NSW living outside major cities (due to the varying definitions the ABS estimate is expected to be lower than the Carers News survey).

There was a greater emphasis on types of services from carers in rural and regional areas. This includes general community services, medical and health services and more responsive and flexible services. In question 14, 23% of regional carers reported a need for medical and health services compared with 19% of metropolitan respondents and the need for responsive and flexible services was identified by 17% of regional carers compared with 11% of metropolitan carers.

Recognition was a slightly more important issue for carers in rural and regional areas but the margin was not significant. However interestingly rural and regional carers identified less need for public awareness and media attention of carer issues. This is perhaps due to the nature of non-metropolitan media and its ability to cover more local issues.

5.6 Carers of People with Mental Illness

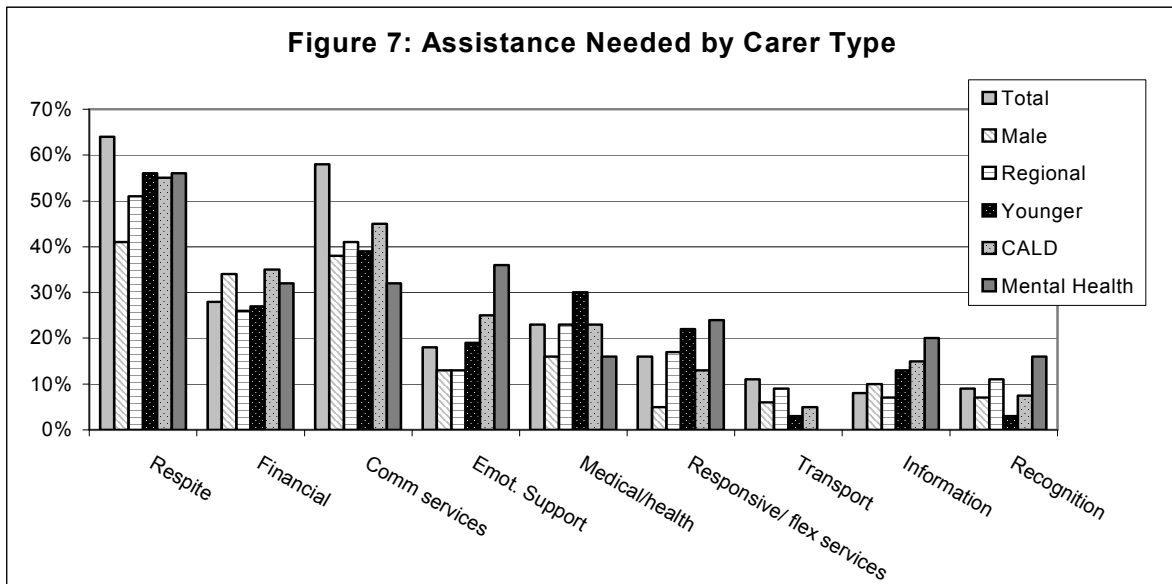
Only 6% of survey respondents identified that they were carers of someone with a mental illness. It is difficult to determine if this is representative of the proportion of carers caring for someone with a mental illness due to definitions and the prevalence of multiple conditions. There are many cases where people have multiple conditions and mental illness is considered to be secondary and therefore not recorded, hence it is likely that 6% is an under-representation.

Generally around 10% of carers calling the Commonwealth Carer Resource Centre care for someone with a mental illness and approximately 10% of all people with disability in NSW have a mental disorder as their primary health condition².

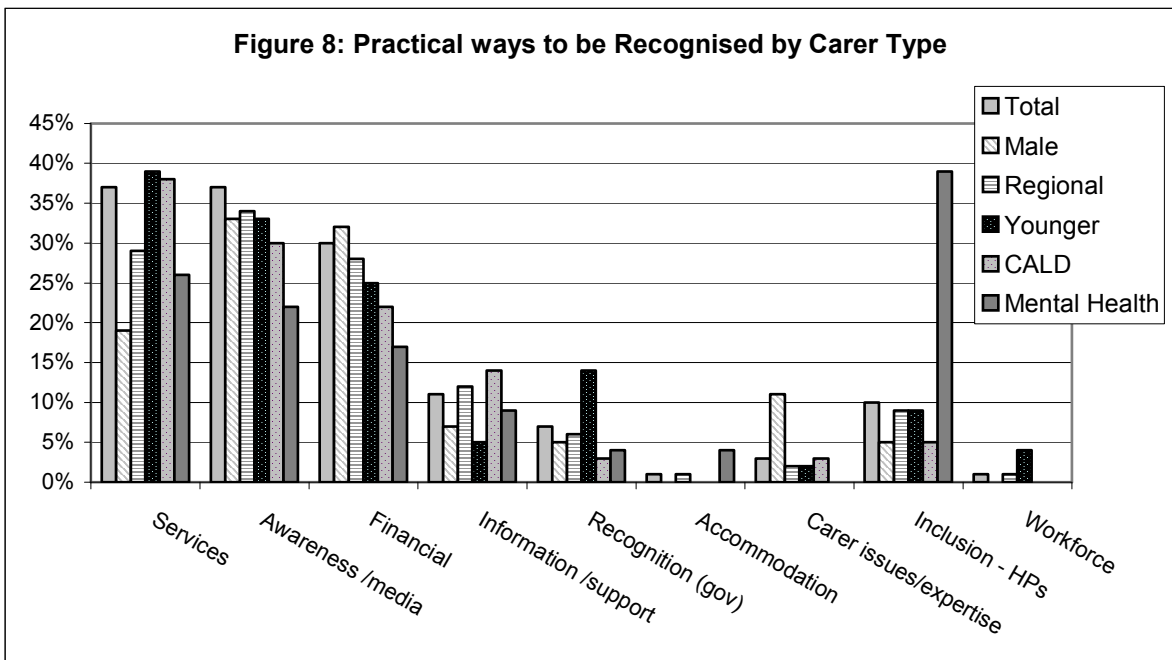
Carers of people with mental illness were more likely to identify emotional support and counselling as important services for them and inclusion by service providers and health professionals was more important than for carers of people in other disability/illness groups. In fact 38% said this was what recognition meant to them compared with just 3% of all respondents. This may reflect issues that carers of people with mental illness face regarding privacy legislation and the consequent limited access to information.

In question 14, 36% of carers for people with mental illness identified emotional support and counselling as being important compared with 13% of carers for people with disability, 26% with a chronic condition and 17% frail aged.

² Source: unpublished data from 2003 ABS SDAC.



Source: Carers News Survey, 2004



Source: Carers News Survey 2004

6. Conclusions

The most significant findings to come out of this survey can be summarised as follows:

- The main type of assistance that carers feel they need is respite from caring. This is not necessarily from formal respite care services but includes other services that give a respite effect for the carer (ie they can have a total break from caring for a period of time).
- After respite care they feel that general community services including domestic assistance would be the main type of assistance needed.

- The main reason that carers need the assistance they specified is because they need a break from caring and time to look after themselves.
- To the majority of carers, carer recognition means being understood and recognised by the government, the community and their families.
- The key practical way that carers would like this recognition to be translated into support is through more and better services, especially those providing respite.

These findings provide further evidence to support existing knowledge about issues faced by carers. Throughout the responses to the questionnaire the need for more formal services to complement the role of family carers is apparent. The implications of these findings for government are significant as unpaid carers are depended upon to provide the foundations for the success of de-institutionalisation policies and community care programs. Clearly carers feel undervalued and unrecognised by, not only the government and broad community, but often their own families.

The combination of inadequate levels of assistance, feeling like they do not get enough breaks and feeling unappreciated and undervalued in the role they fulfil essentially has a negative impact on carers. While there were some comments throughout the responses that carers were happy with the services and recognition they received, these were a very small minority.

7. Policy Implications

As a result of this survey report there are several key policy implications that should be considered by Carers NSW. These include:

- Greater investment needs to be made into services and assistance that provide a range of supports for carers in the community. The greatest need, as demonstrated in this survey, is for more respite services, general community services, financial assistance, information and emotional support.
- Greater awareness of carers and carer issues in the community, among health professionals and government continues to be a key issue for carers.
- Male carers have different support needs to female carers and therefore information and support should be tailored accordingly.
- Further research is needed on the support needs of Aboriginal carers to allow a greater understanding of what support is needed in Indigenous communities. There was not a sufficient sample size of Aboriginal people in this survey to present any meaningful data.
- Culturally appropriate information and emotional support are key issues for CALD carers. It is therefore vital that carer information be made available in relevant languages and be presented in a culturally appropriate format to all carers.
- Further investigation into the availability and quality of services in regional and rural areas, compared with metropolitan areas, should be considered.
- There appears to be a significant need for greater emotional support for carers of people with mental illness and for greater inclusion by health professionals and service providers.

8. Comments and Recommendations on Survey

Most of the recommendations made on the previous survey design were incorporated in this questionnaire.

These were the inclusion of profile questions such as sex and age, and collection of names and telephone numbers for referral and policy purposes. These recommendations should be carried through to future surveys as they have provided significant additional information and a good resource for further research.

The recommendation about ranking issues on a scale was not applicable as open-ended questions were asked in the 2004 survey.

The recommendation that SPSS be used to gain accurate cross tabulations has been agreed to in planning of future surveys.

Other comments and suggestions from the 2004 survey:

1. There was some confusion in the respondent profile part of the survey on whether the questions were about the carer or care recipient. This could be addressed by re-ordering the profile questions so that those relating to the care recipient are separate from questions about the carer.
2. In some surveys carers either ticked the wrong box or multiple boxes when answering the question about the condition of the person they support. Future surveys could address this by asking:
 - How many people the carer provides care for
 - The name of the person's condition as well as ticking the broad category
3. Number of years spent caring may help to produce information on services and supports required at various caring stages.
4. Some investigation should be made into the demographic of respondents as being mainly 65 and over as this is not representative of all carers. Suggested reasons for this finding are that:
 - Carers who are not workforce age are more likely to have time to complete and return a survey;
 - Historically, older carers are members of Carers NSW;
 - Confusion regarding the demographic part of the survey may mean that some people were referring to the age of the person they care for, rather than their own age.
5. Carers NSW should also consider the under-representation of Indigenous and CALD respondents to the survey. Some suggestions for this include:
 - That Indigenous and CALD carers are less likely to become members of Carers NSW;
 - People whose first language is not English are less likely to fill out a survey in English (open-ended questions may have presented an even greater barrier in this sense).
6. Adequate data on young carers (under 25 years) could be gathered by use of the young carer newsletter mailing list.