

Report on carers'
Focus Group

FEEDBACK ON
CARERS ACT SERVICES
AND
AREAS FOR IMPROVEMENT
IN 2008-09

2 MAY 2008



Carol Flynn & Associates Pty Ltd

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Executive Summary

Carers ACT asked Carol Flynn, Director of Carol Flynn & Associates and a Carers ACT volunteer, to conduct an independent focus group. The purpose of the Focus Group was to seek feedback from family Carers who have accessed a variety of Carers ACT services to inform the 2008-09 Business Plan process, specifically to identify areas where Carers ACT can improve its service delivery.

Seven key issues were identified by Carers ACT:

1. Contacting Carers ACT
2. Membership of Carers ACT
3. Role of Carers ACT
4. Effectiveness of Carers ACT
5. Access to Services
6. Knowledge and use of Carers ACT services
7. Improvements to Carers ACT services

Eleven women and three men participated in the Focus Group on 2 May 2008. They ranged in age from about 30 years to over 80. All were carers and one was a care recipient with her carer. The carers who attended indicated that they cared for a range of people: spouses, parents and children. Carers indicated that the care recipients required care ranging from full-time to intermittent care across a range of care types. They used a range of Carers ACT services with respite, counseling, support and education being the most commonly used.

Summary of Topic One: Contacting Carers ACT

- 67% heard about Carers ACT in a hospital or community organisation
- 83% agreed or strongly agreed that information about Carers ACT is easy to find or access, available in a variety of mediums and easy to understand. Only 41% agreed that information about Carers ACT was given out by other professionals or services and they make referrals.
- 92% agreed that their first contact with Carers ACT was welcoming, respectful, courteous and appropriate to the nature of their request.

Discussion showed that this response was very important and summarized by one participant:

- *It's not easy to ask for help and Carers ACT listened, provided information, were reassuring so I felt no longer alone.*
- 73% agreed that their on-going contacts with Carers ACT are welcoming, respectful, courteous and appropriate to the nature of their requests.
- 83% contact Carers ACT by telephone with 17% of those using another method as well. 17% use email and 8% visit the office. Over 91% rate Carers ACT response as good or better.
- 41% had a negative experience with Carers ACT which they detailed.

Summary of Topic Two: Membership of Carers ACT

- 85% of participants were members
- there was some lack of knowledge about the purpose of membership.

Summary of Topic Three: Role of Carers ACT

- Only about 25% of the participants saw the wider role of Carers ACT in supporting the carer to maintain the care recipient at home and have a life of their own. The majority saw Carers ACT as a service provider, particularly of respite care.
- The services most known to the group were:
 - Respite (77%)
 - Counselling (61%)
 - Support (38%)
 - Courses/education (31%)
- The ways Carers ACT could better support carers were mainly in service provision and more support, including individual advocacy.

Summary of Topic Four: Effectiveness of Carers ACT

- 92% of participants felt understood, connected and better supported as a result of their contact with Carers ACT.
- The comments illustrated how difficult and isolating carers find their role. They appreciate the understanding shown them by Carers ACT and the support they receive through service provision.

- They felt they needed more individual support to assist them to reach out for the services they need.

Summary of Topic Five: Access to services

- 83% agreed that they have better access to services and support since contacting Carers ACT

Summary of Topic Six: Knowledge and use of services

Participants knew of the services they needed to use and a small percentage knew of one or two other services offered by Carers ACT which they had not used. Most were surprised at the number and comprehensive nature of the list of services and found some services of interest to them. One participant knew all the services.

Topic Seven: What improvements can Carers ACT make?

1. Help in finding out the services available to me
2. Help to remain healthy
3. Increased individual advocacy
4. Respite for siblings

Recommendations

Based on the Focus Group information and discussion, Carol Flynn suggests that Carers ACT consider the following recommendations:

Recommendation One: Switchboard and all other staff who deal with carers on the telephone should be commended on their welcoming, supportive and understanding responses. Carers ACT needs to continue to invest in training and effective systems to maintain this high level of excellence. This recommendation links to Recommendation Four below.

Recommendation Two: That Carers ACT works more closely with health and other professionals to help them to recommend Carers ACT to carers of their patients and to carers who become patients because of their stress.

Recommendation Three: That Carers ACT offers a service for carers, particularly new carers or carers new to the ACT/NSW area, that gives them information and plots a pathway through the individual care recipient's entitlements to service provision and funding. This service may already be offered but many carers in the group were unaware of it.

In addition to such an information/pathway service, Carers ACT offers a 'care coordination/ management' service to older carers who may have difficulty negotiating a consumer approach to service access.

This recommendation links to Recommendation Nine below.

Recommendation Four: That Carers ACT ensures staff and, through liaison, other service providers understand the impact of one negative experience on carers and the reputation of Carers ACT. Training and systems need to be put in place to avoid negative experiences for carers where possible. Customer management systems may be of use here and in Recommendation Three.

Recommendation Five: That Carers ACT makes the benefits of membership clearer.

Recommendation Six: That Carers ACT aims to use a clear, short sentence to explain their role to the members. Because many of the group felt that being a carer absorbed all their time and energy, the need to express the purpose of support for carers may be important in assisting carers set goals on their journey towards a balanced life for themselves.

Recommendation Seven: That Carers ACT provides more information and encouragement for carers to attend events when respite care is provided. That information could include what Carers ACT is offering for carers at the time of respite care, e.g. workshops, social groups, yoga, etc.

Recommendation Eight: That Carers ACT provides information about sibling respite care for parents of a child with a disability and encourages providers to offer respite for both the child with a disability and their sibling(s).

Recommendation Nine: That each member has a case manager who will contact them with suggestions for involvement on a regular basis (e.g. every three months). This recommendation links with Recommendations 3 and 4.

Methodology

Carers ACT asked Carol Flynn, Director of Carol Flynn & Associates and a Carers ACT volunteer, to conduct an independent focus group on 2 May 2008.

The Brief

The purpose of the Focus Group was to seek feedback from family Carers who have accessed a variety of Carers ACT services. Dee McGrath, CEO Carers ACT, wanted the focus group outcomes to inform the 2008-09 Business Plan process, specifically to identify areas where Carers ACT can improve its service delivery.

Seven key issues were identified by Carers ACT for the focus group to consider. They were:

1. Contacting Carers ACT
 - a. How did Carers first hear about Carers ACT?
 - b. How was their first contact experience?
 - c. How is their on-going contact experience?
 - d. How would Carers rate the type of response they received when contacting Carers ACT for assistance? (Identify service entry point)
2. Membership of Carers ACT
 - a. Are carers members of Carers ACT?
 - b. What do they see as the benefits of membership?
 - c. What would they like to see as the benefits of membership?
3. Role of Carers ACT:
 - a. What do people believe is the role of Carers ACT?
 - b. What ways can Carers ACT support and better support Carers?
4. Effectiveness of Carers ACT
 - a. Do Carers feel understood, connected and better supported as a result of contact with Carers ACT? If this is not the case, what needs to happen for them to achieve this outcome?
5. Access to Services

- a. Do Carers believe they have better access to services and support in their role of Carer since contacting Carers ACT?
6. Knowledge and use of Carers ACT services
 - a. Which services do Carers use?
 - b. Which other services and supports of Carers ACT are they aware of? (in addition to the one(s) they initially contacted)
7. Improvements to Carers ACT services
 - a. The group to name five key things that Carers ACT can do better in supporting Carers during 2008-09?

Carol Flynn mapped these issues into areas on the Network of Carers Associations Program Logic and the Guide for Good Practice (National Network of Carers Associations, July 2007) See Attachment A.

The Methodology

The Methodology had three stages:

1. Preparation including recruitment of participants
2. Conduct of the focus group and
3. Report.

See Attachment B for details of each stage.

1. Preparation

Kirsten Byrne, a Carers ACT volunteer, undertook the recruitment of participants. Fifty carers' names (every fifth name) were selected from the Carers ACT Client Manager data base. The carers had used services in the past three months including counselling, respite, advice/information, and the Employed Carers Program. The Carers ACT CEO, Dee McGrath, wrote to the selected carers to inform them that Kirsten would be in touch and to advise them, that if they did not want to give consent to share their personal details, they could inform Carers ACT and be removed from the list. 45 people agreed to remain on the list by not responding. Kirsten telephoned 30 people to obtain agreement from 15. Fourteen people attended on the day and one person left early.

Eleven women and three men participated in the Focus Group on 2 May 2008. They ranged in age from about 30 years to over 80. All were carers and one was a care recipient with her carer. The carers who attended indicated that they cared for a range of people: spouses, parents and children. Carers reported that the care recipients required care ranging from full-time to intermittent care across a range of care types. Carers reported the caring included:

- palliative care
- caring for a person with a serious illness
- caring for a person with a mental illness
- caring for a child with a disability
- caring for an aged person with caring responsibilities for their spouse
- carers with disabilities of their own and
- a carer with a child with a disability recently moved to Canberra.

They used a range of Carers ACT services with respite, counseling, support and education being the most commonly used.

Carol Flynn developed a brief PowerPoint presentation to keep participants on track. She prepared a survey format document which aimed to capture individual responses on the seven topics in the brief before the group discussion, to balance any 'group think'. Annemarie Ashton, from Carers ACT, commented on the draft to ensure its relevance and accuracy. See Attachment C.

Val Hones from Carers ACT arranged the room and lunch at the Belconnen Premier Inn and transport for the participants and respite care for their care recipients. She also assisted with the stationery and audio visual equipment.

2. Conduct of Focus Group

The focus group began about 12.15pm when the majority of participants were seated with their lunch. Carol followed the Focus Group session details in Attachment B and Kirsten Byrne assisted with recording Carer responses.

Participants completed the survey as each topic was discussed and then participated in a group discussion on the topic. Notes were taken of the main points of each discussion, displayed and summarized so that participants could edit or add to them.

Thirteen surveys were returned at the end of the Focus Group. One person did not do the survey documentation, one survey was completed by the carer and care recipient who came together, one survey was incomplete as the participant left early, and Kirsten and Carol assisted one participant with writing his comments.

All participated in the discussions and Carol ensured that all who wished were able to contribute on each topic. Some topics attracted more discussion than others (e.g. Contact with Carers ACT was a lengthy discussion while membership was quite brief). The final topic, *What improvements could Carers ACT make during 2008-09*, was completed by using post it notes and four main improvements were listed.

The discussion concluded by 2pm as scheduled and all carers' transport arrived as arranged.

Some carers were pleased to have been asked to attend and commended Carers ACT on conducting the focus group.

3. Report

The report has been prepared by Carol Flynn and discussed with Kirsten Byrne for accuracy and with Dee McGrath to ensure accuracy of language used.

The raw data from the survey forms and the discussion are at Appendix Two.

Focus Group Results

This chapter reports on each topic in turn, having first dealt with an introductory question. The raw data is available in Appendix Two.

As part of the introduction to the group, participants were asked

- To introduce themselves and, if they wished, their care recipient
- The Carers ACT services they used and
- What they considered Carers ACT did well.

The most frequently mentioned service which **Carers ACT did well** was

- respite care (57%)
- followed by providing advice and counseling on the telephone (29%). Many in the group (36%) commented at this time on the support they drew from their contact with Carers ACT:

- *They care about me*
- *They give me a cup of tea*
- *They listen well to me*
- *They are there to offer support*
- *They set up services for me.¹*

- Other services mentioned included counseling, information, courses and help with going to the movies.

As people mentioned services, others in the group realized they did not know about the extent of Carers ACT services and asked questions of those who used services that interested them.

¹ Text in italics in this report are direct quotes from the participants' survey responses.

Topics and results

1. Topic One: Contacting Carers ACT

1.1. The first question within this topic was **How did you first hear about Carers ACT?**

- 43% of participants had received information in a hospital setting
- 29% from community organizations
- 20% from friends or family and
- 14% from information sent out by Carers ACT.²

During the discussion a number of participants mentioned how it had taken several prompts from a variety of sources before they actually contacted Carers ACT for the first time. Four participants mentioned, and were supported by others in the group, that they had assumed that they would be able to cope as carers without help and initially did not see Carers ACT as relevant to them.

1.2 The second issue within this topic further explored how initial information about Carers ACT was received. Participants were asked to rate **Information about Carers ACT as:**

- **easy to find or access**
- **available in a variety of mediums**
- **easy to understand available in a variety of languages and**
- **given out by other professionals or services and they make referrals.**

The majority of participants (83%) strongly agreed or agreed that information about Carers ACT is easy to find or access, available in a variety of mediums and easy to understand. One person disagreed. In this group the availability in a range of languages was seen as not applicable by 90%. 41% agreed that information about Carers ACT was given out by other professionals or services and they make referrals. For 17% that was not their experience and 33% didn't know or it was not applicable. (See Table

² One example given was a Carers ACT kit handed out during Carers Week

One.) For one person the website was crucial as it was accessible and impersonal.

	Strongly agree	Agree	Disagree	Strongly Disagree	Don't Know / Not Applicable
Easy to find or access	3	7	1		1
Available in a variety of mediums	1	7	1		2
Easy to understand	1	7			2
Available in a range of languages		1			9
Given out by other professionals or services and they make referrals		5	1	This wasn't my experience	4

Table One: Availability and quality of information about Carers ACT.

1.3 The third issue within this topic was **My first contact with Carers ACT was welcoming, respectful, courteous and appropriate to the nature of my request.** This wording is taken from the immediate outcomes of the Program Logic.

92% of participants agreed with the statement and one could not remember.

The comments gave more detail of the welcoming and appropriate nature of the Carers ACT response to the participants' first contact:

- *I got the impression that it was no trouble at all.*
- *The phone call was helpful in trying to find a time for counseling and in assuming that I had to fight to get services.*
- *My first contact with Carers ACT was very encouraging and knowing I will have the support when things get harder is good.*
- *I have only really had contact through email and I have always been responded to very quickly.*
- *Yes, very kind. Girls can't do enough for me.*

- *We attended face to face counseling. Welcoming cup of tea, very relaxed sensitive discussion.*
- *Certainly very helpful.*
- *I was welcomed warmly into a writing group...*
- *Yes, I enjoyed my first contact very much. It eased my burden.*

In the group discussion, two themes emerged. The first was that when people made their first contact with Carers ACT it was at a crisis point for them. Comments included:

- *My first contact was in a crisis. Then you are at the end of your own resources and need help.*
- *Desperation.*
- *It took two weeks to decide to fill in the form. I thought I could cope, it is not easy to ask for help.*
- *Website is accessible and impersonal. Without it, I would not have made contact.*
- *When I first made contact I was exhausted. The 'chasing your own tail' feeling.*

Participants noted in the discussion that their first contact was very tentative. The positive and supportive responses they received were the impetus to continue dealing with Carers ACT.

The second theme was lack of knowledge about the provision of services in the ACT and the eligibility criteria for service provision. Some participants noted that Carers ACT was a lifeline in finding a pathway through a maze of services/ service providers with unfamiliar eligibility rules. Comments included:

- *A friend urged that I would be eligible.*
- *Carers ACT came to my home with a wealth of information.*
- *Carers ACT was the first door to open! It's not easy to ask for help and Carers ACT listened, provided information, and were reassuring so I felt no longer alone. They were accepting, in contrast to the services; they were not being 'gatekeepers'.*

It was clear from the discussions that participants fell into two groups which seemed to have a generational basis. The older carers were operating on a model of expecting to be provided the services to which they were entitled while the younger carers were operating on a consumer model in which they researched and understood their entitlements and then exercised choice in the service providers they accessed. Each group had different expectations of the support Carers ACT would provide. The older carers group expected someone, perhaps Carers ACT, to ascertain and manage their service provision and the younger group expected Carers ACT to provide information and individual advocacy.

Carers ACT is only one of a number of service providers accessed by half of the group and participants were sometimes unclear about which services they received from Carers ACT and which from other providers.

1.4 The fourth issue within this topic was **My on-going contacts with Carers ACT are welcoming, respectful, courteous and appropriate to the nature of my requests.**

73% agreed with this statement, 9% did not have any on-going contact with Carers ACT, 9% had only one contact and 9% found the ongoing contacts challenging. A typical comment was:

- *Always good and welcoming.*

The discussion was centered on the reassurance participants felt in knowing that they could contact Carers ACT when they needed to and they would receive support.

- *Reassuring that they are there to help with support on the phone.*
- *I don't use them often but know they will help when needed.*

There was general agreement with the statement of one participant that Carers ACT was:

- *Not judgmental, previously I felt a failure.*

1.5 The fifth issue within this topic was **How people contact Carers ACT and participants were asked to give a rating for the response they receive.**

83% contacted Carers ACT by telephone with 17% of those using another method as well. 17% used email and 8% visited the office.

When asked how they would usually rate Carers ACT's response to their requests:

- 66% rated the response as excellent and over 91% as good or better.
- The 8% who rated the response as very poor did not offer any comment.

1.6 The sixth and final issue within this topic was a request to **Comment on an experience with Carers ACT that was not satisfactory.**

Five participants (41%) participants said they had such an experience and four detailed their experiences:

- *Just once, the carer was 15 minutes late to arrive and I missed my appointment which was the reason for the carer to be there.*
- *Only once (in the context of a fantastic counseling service and counsellor) out of many times, when the counsellor promised to follow something up but it got caught up with what other staff were doing on the issue. It was a fair enough thing to happen (i.e. for the counsellor not to follow it up) but at the time I was very distressed about what was happening in a hospital with my care recipient and it felt as though I had been let down.*
- *Would like to have had more information going into Respite Care. We did not know that my spouse had to take their oxygen machine as it was not available at the home*
- *It was not the fault of the person on the other end of the phone. I wanted to know how many days I had left of my entitlement and they couldn't give me the answer.*

These experiences suggest the impact of a seemingly minor oversight on a stressed carer and the need for the highest quality standards to be met at all times. Because carers feel unsupported generally, Carers ACT support is highly valued and when it is unsatisfactory, carers remember.

Summary of Topic One:

- 67% heard about Carers ACT in a hospital or community organisation
- 83% agreed or strongly agreed that information about Carers ACT is easy to find or access, available in a variety of mediums and easy to understand. Only 41% agreed that information about Carers ACT was given out by other professionals or services and they make referrals.
- 92% agreed that their first contact with Carers ACT was welcoming, respectful, courteous and appropriate to the nature of their request. Discussion showed that this response was very important and summarized by one participant:
 - *It's not easy to ask for help and Carers ACT listened, provided information, and were reassuring so I felt no longer alone.*
- 73% agreed that their on-going contacts with Carers ACT are welcoming, respectful, courteous and appropriate to the nature of their requests.
- 83% contact Carers ACT by telephone with 17% of those using another method as well. 17% use email and 8% visit the office. Over 91% rate Carers ACT response as good or better.
- 41% had a negative experience with Carers ACT which they detailed.

Recommendations relating to Topic One: Carers ACT information and contact experience.

Recommendation One: Switchboard and all other staff who deal with carers on the telephone should be commended on their welcoming, supportive and understanding responses. Carers ACT needs to continue to invest in training and effective systems to maintain this high level of excellence. This recommendation links to Recommendation Four below.

Recommendation Two: That Carers ACT works more closely with health and other professionals to help them to recommend Carers ACT to carers of their patients and to carers who become patients because of their stress.

Recommendation Three: That Carers ACT offers a service for carers, particularly new carers or carers new to the ACT/NSW area, that gives them information and plots a pathway through the individual care recipient's

entitlements to service provision and funding. This service may already be offered but many carers in the group were unaware of it.

In addition to such an information/pathway service, Carers ACT offers a 'care coordination/ management' service to older carers who may have difficulty negotiating a consumer approach to service access.

This recommendation links to Recommendation Nine below.

Recommendation Four: That Carers ACT ensures staff and, through liaison, other service providers understand the impact of one negative experience on carers and the reputation of Carers ACT. Training and systems need to be put in place to avoid negative experiences for carers where possible. Customer management systems may be of use here and in Recommendation Three.

2. Topic Two: Membership of Carers ACT

85% participants were members of Carers ACT and 15% were not.

2.1 The first question in this topic was **What do you find most useful about being a member?**

- 45% of participants mentioned support.
- 45% mentioned information and other services, notably respite 27%.
- 18% were confused about what membership or Carers ACT offered.³

2.2 The second question in this topic was **What membership benefits would you like to receive?**

- 45% of participants mentioned services in response to this question.
- 18% did not know what was available to members.

There was some lack of knowledge about the purpose of membership which was evident in the survey responses and in the discussion. The responses which listed services, those which did not know what was available to members, and the lack of any response from a significant number of participants suggest this lack of knowledge.

The discussion mainly resulted in a list of services, some of which Carers ACT already provides (*magazine/newsletter*) and others which may not be Carers ACT responsibility (*wheelchair accessible transport*). There was one suggestion about having an enhancement to the website which allowed members to view the current state of their usage of their agreed respite care:

- *Records of days/entitlement (how many used/left) perhaps through a link on the website.*

³ Multiple responses total more than 100%

Summary of Topic Two:

- 85% of participants were members
- there was some lack of knowledge about the purpose of membership.

Recommendations relating to Topic Two: Membership of Carers ACT

Recommendation Five: That Carers ACT make the benefits of membership clearer.

3. Topic Three: Role of Carers ACT

3.1 The first question in this topic was **What do you believe is the role of Carers ACT?**

Of the 13 participants in the group, the responses fell into three groups of which the following quotes are the best illustrations:

1. *To provide or find what carers need to let them keep caring and have a satisfying life of their own.*
2. *Support, information and respite.*
3. *To help people: my spouse who I am caring for.*

About 23% were of the first type; about 46% were of the second type; and 23% were of the third type or more general comments: *Very kind and helpful*. The generational expectations (p.15) may be seen again in these responses.

The discussion expanded the role of Carers ACT for most of the focus group participants. One participant suggested the role was *To help carers to have the dual roles of work and caring, other life activities and caring* and while some agreed, other participants felt that dual roles would be impossible for them in their role as carer. This theme ran through the discussions. Some carers were in situations where they were on call 24/7/365 and felt that they were not in a position to have any other role. Others were attempting to or managing to have more than the carer's role in their lives. This may also relate to the carer's transition from initial crisis to a more supported role.

3.2 The second question in this topic was **List the ways in which you understand Carers ACT currently provides support to Carers**. The individual survey documents list the following.

- Respite (77%)
- Counselling (61%)
- Support (38%)

- Courses/education (31%)
- Information (15%)
- Advocacy on behalf of individuals (15%)
- Referrals (8%) and
- Recreation/development groups (8%)⁴

The discussion noted that participants would like more advocacy by Carers ACT to other organizations on behalf of individuals, including information on other organizations and referrals to them. The need for help finding a path through the service and service provider maze was discussed again. No participant mentioned advocacy on behalf of carers to governments or society.

3.3 The third question in this topic asked participants to **List some ways you think Carers ACT could better support Carers**. Participants' individual responses to the survey question ranged from those who are satisfied with their current relationship with Carers ACT: *I am happy to know that you can call and ask* to some suggestions about services not known as available or relevant to other service providers:

- *Alternative grief counseling i.e. art therapy, music therapy. Child care for carers attending courses.*
- *Babysitting for the sibling of my care recipient.*
- *Personal nursing..*
- *Advocate for services for elderly such as shopping buses to be more appropriate (e.g. shopping for one hour at the shops does not work for frail aged).*

There were also some responses about how the services could be better delivered:

- *When I ask for occasional respite to be supportive as they have all the data on computer and I don't need to feel I have to justify EVERY time.*
- *More advocacy workers, they are often very busy.*

The discussion focused initially on the support needed by parents with a child with a disability and specifically the support needed for siblings: *Occasional care for siblings* and *a club for siblings* were specifically

⁴ Multiple responses total more than 100%

mentioned. The carer's ability to attend support groups and education was often dependent not only on respite for the care recipient but also on support for the siblings. As the discussion widened into carers' ability to attend for other support services this need was expressed as receiving information about *Things on at times when respite is given*. For about 25% of the group this could include *body care for exhausted carers*. Another service that was supported by about 30% of the group was a *calendar of service resources*, not only for Carers ACT but for all support in the ACT.

Summary of Topic Three:

- Only about 25% of the participants saw the wider role of Carers ACT in supporting the carer to maintain the care recipient at home and have a life of their own. The majority saw Carers ACT as a service provider, particularly of respite care.
- The services most known to the group were:
 - Respite (77%)
 - Counselling (61%)
 - Support (38%)
 - Courses/education (31%)
- The ways Carers ACT could better support carers were mainly in service provision and more support, including individual advocacy.

Recommendations relating to Topic Three: The role of Carers ACT

Recommendation Six: That Carers ACT aims to use a clear, short sentence to explain their role to the members. Because many of the group felt that being a carer absorbed all their time and energy, the need to express the purpose of support for carers may be important in assisting carers set goals on their journey towards a balanced life for themselves.

Recommendation Seven: That Carers ACT provides more information and encouragement for carers to attend events when respite care is provided. That information could include what Carers ACT is offering for carers at the time of respite care, e.g. workshops, social groups, yoga, etc.

Recommendation Eight: That Carers ACT provides information about sibling respite care for parents of a child with a disability and encourages providers to offer respite for both the child with a disability and their sibling(s).

4. Topic Four: Effectiveness of Carers ACT

4.1 The first question in this topic was **Do you feel understood, connected and better supported as a result of your contact with Carers ACT?** This wording is from the intermediate outcomes of the Program Logic.

92% of the participants answered yes to this question in the survey, 8% had not had contact with Carers ACT yet⁵

Their comments show participants' appreciation of the understanding shown them by Carers ACT and the support they receive through service provision. Comments include:

- *I believe Carers ACT is aware of how hard it is for Carers without support or help.*
- *At this time of my life with my problem of caring, I know they listen and help me but I need to reach out more.*
- *Certainly feel supported. If they don't have information readily available, they will find out and get back to you AND THEY DO.*
- *Carers ACT organised (against a lot of resistance) for ACAT to do an assessment and to get a support package in place. They organised respite when I wanted to go away. They contact me to see if things are OK and are clear that they can help again if needed.*
- *Counsellor understood situation well and comforting to know support is available.*
- *Carers ACT helps me as a carer. I have no one to give me a hand. When I phone they are helpful.*
- *Through the course I went on.*
- *Yes, I can make plans now that I did not think were possible before.*

These themes were reiterated in the discussion of this issue. Comments which were supported by the group as a whole included:

- *Still don't have a full picture of the pathways to help; when you are down, it is hard to reach out.*

⁵ This participant may illustrate confusion about the services she received, e.g. information, being a Carers ACT service.

- *Caring is a 'pressure cooker' experience.*

4.2 The second question in this topic was **If not, what needs to happen for you and Carers ACT to achieve this outcome?** Individual responses underlined the themes of the difficulty of navigating service provision while in the caring role and the isolation carers feel:

- *Reaching out from both sides to relieve the pressure. People from CALD background need to be aware of services like Carers ACT; breaking the cycle or barriers for people from the CALD background.*
- *More information, which is not always available when needed.*
- *Advocacy.*
- *I would like an in-house visit and an explanation of all services relevant to our situation.*

The discussion reiterated these themes:

- *Reaching out from both sides (carer and Carers ACT) to relieve pressure.*
- *Relief from the grind of care so you can reach out for care.*

Summary of Topic Four:

- 92% of participants felt understood, connected and better supported as a result of their contact with Carers ACT.
- The comments illustrated how difficult and isolating carers find their role. They appreciate the understanding shown them by Carers ACT and the support they receive through service provision.
- They felt they needed more individual support to assist them to reach out for the services they need.

Recommendation related to Topic Four: Effectiveness of Carers ACT

Recommendation Nine: That each member has a case manager who will contact them with suggestions for involvement on a regular basis (e.g. every three months). This recommendation links with Recommendations 3 and 4.

5. Topic Five: Access to Services

5.1 This topic asked the question: **Do you believe you have better access to services and support since contacting Carers ACT?**

- 83% of the twelve participants who completed the survey question said they had better access and
- 27% said they did not.

In their individual comments, participants cited services they use and some noted:

- *Definitely. We had a case manager who did not do anything, including returning calls and didn't really seem to know what he was doing. Carers ACT made it clear to me that a case manager should be able to do more, and worked with him and also organised a community care package. I also feel as though, if I need another service I could ask them what was available.*
- *Absolutely, no doubt.*
- *They found paths for me and take away stress at not understanding what I can receive, both in assistance and rebates.*

The difficulty of 'reaching out' was mentioned by one participant:

- *Sometimes too busy to phone to get help. I like to be independent, I think.*

Summary of Topic Five:

- 83% agreed that they have better access to service and support since contacting Carers ACT

Recommendation relating to Topic Five: Better access to services and support

See Recommendation One

6. Topic Six: Knowledge and use of Carers ACT Services

This topic was completed by participants in the survey. It was not discussed. The Table is available on pp 34-38.

The main findings are:

- **Commonwealth Carer Respite Centre** was the most known and used service among the participants.
- 33% knew of **Residential Respite Care** but had not used the service;
 - 25% currently used the service;
 - 8% had used the service in the past; and
 - for 16% it was the first service they contacted Carers ACT to use.
- 16% knew of **In-home Respite Care** but had not used the service;
 - 16% currently used the service;
 - 8% had used the service in the past; and
 - for 16% it was the first service they contacted Carers ACT to use.
- 16% knew of **Emergency/crisis Respite Care** but had not used the service;
 - 8% had used the service in the past.
- 8% currently used **Home from Home Respite Care at the Cottage**;
 - 8% knew of the service but had not used it.

The next most used programs were:

- 8% of participants currently use these programs:
 - **Mature Aged Care Program: Emergency/crisis respite care.** This was also known by another 8% who had not used it.
 - **Employed Carers Program: Case by case support** to continue or return to work.
 - This service had been used by another 8% of the group in the past and was known to another 16% who had not used it.
 - One participant was obviously interested in its existence.
 - **Events in April and May 2008: Introduction to Yoga.**
 - This program was also known to another 8% of participants who had not used it.
 - **Commonwealth Carelink Centre:**

- **Transport:** This had been used in the past by another 16% of participants and
 - was known to another 16% who had not used it.
- **Personal Nursing:** This had been used in the past by another 16% of participants and
 - was the first service 8% had contacted Carers ACT to use.
 - It was known to another 16% who had not used it.
- **Household help:** had been used by another 8% in the past.
- **Assessment processes:** had been used by another 8% in the past.
- **Counselling: individual counseling services:** was the first service 16% of participants contacted Carers ACT to use; 8% used the service in the past; and another 8% knew of the service.
- **Education and Training: Particular course:** 8% of participants first contacted Carers ACT to use this service.

The second most known service was the **Flexible Families Support Program**. 50% of participants knew of the Program but none had used it.

The other programs were known by between 25% and 8% of the group and none had used them.

Summary of Topic Six:

Participants knew of the services they needed to use and a small percentage knew of one or two other services offered by Carers ACT which they had not used. Most were surprised at the number and comprehensive nature of the list of services and found some services of interest to them. One participant knew all the services.

7. Topic Seven: What improvements can Carers ACT make?

There were four main suggestions for improvement:

- 1. Help in finding out the services available to me e.g.**
 - a. Perhaps a Discussion Group to share information.
 - b. Getting the message out about Respite services.
 - c. More information about Social Groups.
 - d. Group discussion and Wheelchair accessible transport.
 - e. How can Carers ACT help when the carer is a bit disabled too?
- 2. Help to remain healthy e.g.**
 - a. Exercise for carers.
 - b. Massage.
 - c. Yoga on the Northside.
- 3. Increased advocacy e.g.**
 - a. To give reassurance that it is OK for carers to reach out.
 - b. Get more support from others who don't understand. Maybe more advertising in the local papers.
 - c. More help available and more hands to assist carers.
- 4. Respite for siblings**

There were some individual requests:

- a. Workshops.
- b. A Carers ACT Tuggeranong office.

Recommendations

In addition to considering the four main suggestions for improvement, Carol Flynn suggests Carers ACT consider the following recommendations based on the focus group findings.

Recommendation One: Switchboard and all other staff who deal with carers on the telephone should be commended on their welcoming, supportive and understanding responses. Carers ACT needs to continue to invest in training and effective systems to maintain this high level of excellence. This recommendation links to Recommendation Four below.

Recommendation Two: That Carers ACT works more closely with health and other professionals to help them to recommend Carers ACT to carers of their patients and to carers who become patients because of their stress.

Recommendation Three: That Carers ACT offers a service for carers, particularly new carers or carers new to the ACT/NSW area, that gives them information and plots a pathway through the individual care recipient's entitlements to service provision and funding. This service may already be offered but many carers in the group were unaware of it.

In addition to such an information/pathway service, Carers ACT offers a 'care coordination/ management' service to older carers who may have difficulty negotiating a consumer approach to service access.

This recommendation links to Recommendation Nine below.

Recommendation Four: That Carers ACT ensures staff and, through liaison, other service providers understand the impact of one negative experience on carers and the reputation of Carers ACT. Training and systems need to be put in place to avoid negative experiences for carers where possible. Customer management systems may be of use here and in Recommendation Three.

Recommendation Five: That Carers ACT makes the benefits of membership clearer.

Recommendation Six: That Carers ACT aims to use a clear, short sentence to explain their role to the members. Because many of the group felt that being a carer absorbed all their time and energy, the need to express the purpose of support for carers may be important in assisting carers set goals on their journey towards a balanced life for themselves.

Recommendation Seven: That Carers ACT provides more information and encouragement for carers to attend events when respite care is provided. That information could include what Carers ACT is offering for carers at the time of respite care, e.g. workshops, social groups, yoga, etc.

Recommendation Eight: That Carers ACT provides information about sibling respite care for parents of a child with a disability and encourages providers to offer respite for both the child with a disability and their sibling(s).

Recommendation Nine: That each member has a case manager who will contact them with suggestions for involvement on a regular basis (e.g. every three months). This recommendation links with Recommendations 3 and 4.

Topic Six: Knowledge and Use of Carers ACT Services: Table Two

This is a list of Carers ACT services –participants were asked to please place ticks in all boxes which apply to you

Program Name	Services Available	I currently use this service	This is the first service I contacted Carers ACT to use	I have used this service in the past	I was aware of this service prior to attending today but have not used it
Commonwealth Carer Respite Centre	Residential Respite Care	3	2	1	4
	In-home Respite Care	1 Care on call	2	1	2
	Emergency/crisis Respite Care			1	2
	Home from Home Respite Care at the Cottage (day, overnight, family respite care)	Day care			1
Young Carers Program	Listening, meeting other young carers, having some time out				1
	Ernst and Young tutoring and educational programs				1
Mature Aged Care Programs	In Home respite care for son/daughter with a disability		1		1
	Residential respite care at the Fraser House retreat				2
	Emergency/crisis respite care	1			1
Employed Carers Program	Case by case support to continue or return to work	1		1	2 No idea it existed
	Employed Carer coordinator to assist in discussions with your employer				1

Program Name	Services Available	I currently use this service	This is the first service I contacted Carers ACT to use	I have used this service in the past	I was aware of this service prior to attending today but have not used it
Flexible Families Support Program	Working with you and your family to: Identify issues and concerns Develop a sustainable relationship Develop your family's strengths Explore creative possibilities Support you as a primary decision maker Build on existing natural and community supports				5
Indigenous Support Programs	Koori Yarning Trips				
	In home respite support				2
	Koori Carers Support Group				
Culturally and linguistically diverse (CALD) Program	Monthly support group meetings The 18 CALD Carer Support Groups are: <ul style="list-style-type: none"> ○ Arabic ○ Chinese ○ Croatian ○ Filipino x ○ Greek ○ Hungarian ○ Indian ○ Italian ○ Mon ○ Polish ○ Samoan ○ Spanish ○ Sudanese ○ Tamil ○ Tongan ○ Vietnamese ○ Thai ○ Cambodian 				1

Program Name	Services Available	I currently use this service	This is the first service I contacted Carers ACT to use	I have used this service in the past	I was aware of this service prior to attending today but have not used it
Social Groups	Walking Group				3
	Craft Group				3
	Art Appreciation Group				3
Education and Training	Stress Management for Carers				3
	Keeping Families Connected				2
	Family Focused Practice				2
	Staying Afloat				2
	Seasons for Growth				2
	Other Education Workshop Please specify		1		
Events for April and May 2008	Safe Talk (practical help to persons with thoughts of suicide)				
	Introduction to Yoga	1			1
	Money Matters				1
	Legal Matters				1
Carer Advisory Service	Specialist Carer information, referrals, support and resources in a range of areas, including:				
	<ul style="list-style-type: none"> • Carer support and services in your area 				2
	<ul style="list-style-type: none"> • Financial supports and benefits you may be entitled to 				2

Program Name	Services Available	I currently use this service	This is the first service I contacted Carers ACT to use	I have used this service in the past	I was aware of this service prior to attending today but have not used it
Carer Advisory Service	Specialist Carer information, referrals, support and resources in a range of areas, including:				
	<ul style="list-style-type: none"> Your health and wellbeing 				1
	<ul style="list-style-type: none"> Respite 				3
	<ul style="list-style-type: none"> Grief and loss issues 				1
	<ul style="list-style-type: none"> Education and training 				1
	<ul style="list-style-type: none"> Specific Carer Programs 				1
	<ul style="list-style-type: none"> Social events and groups 			1	1
Commonwealth Carelink Centre*	Information about:				
	<ul style="list-style-type: none"> Household help 			1	2
	<ul style="list-style-type: none"> Transport 	1		2	2
	<ul style="list-style-type: none"> Home modification 				2
	<ul style="list-style-type: none"> Special services for dementia 				2
	<ul style="list-style-type: none"> Personal nursing 	1	1	2	2
	<ul style="list-style-type: none"> Meal services 			2	2
	<ul style="list-style-type: none"> Aged care homes 				2
	<ul style="list-style-type: none"> Assessment processes 			1	2
	<ul style="list-style-type: none"> Support Groups 				2

- *Yes, although I am not really sure what it is or how it connects to Carers ACT*

Program Name	Services Available	I currently use this service	This is the first service I contacted Carers ACT to use	I have used this service in the past	I was aware of this service prior to attending today but have not used it
	Audiovisual items				1
	Lending services			1	3
Counselling	Qualified professionals				1
	Individual counselling services		2	1	1
	Family counseling services				1
	Conflict resolution				1
Support Groups	Support Groups offered by Carers ACT each month include the:				1
	After caring				1
	Carers of people with a disability				1
	Male Carers				1
	Inner North Carers				1
	Northside Carers				2
	Southside Carers				1
	Tuggeranong Carers				1

Writing for Carers was the first service I contacted Carers ACT to use.

Attachment A: Network of Carers Associations Program Logic and the Guide for Good Practice (National Network of Carers Associations, July 2007) including Map of Carers ACT issues against Program Logic and Guide for Good Practice.

Carers ACT Identified Issues	Guide to Good Practice	Program Logic
How Carers first heard about Carers ACT	1.1 Access to services 1.3 Addressing barriers to access 5.6 Communications and Marketing	<p>Processes: Intake and assessment Communication and marketing</p> <p>Services: Carer information, resources and publications Community education</p> <p>Intermediate Outcomes: Carers have better access to services for carers and family members.</p> <p>Ultimate Impact: Carers enjoy improved health, wellbeing, resilience and financial security.</p>
Are people members of Carers ACT and what do they see as the benefits of membership? What would they like to see as the benefits?	5.4 Carer representation	<p>Input: Carer and member input</p> <p>Processes: Developing the membership base</p> <p>Immediate Outcomes: Associations build a strong membership base Active participation of carers in Associations</p> <p>Intermediate Outcomes: Strong National Network and carer movement</p> <p>Ultimate Impact: Caring is recognized as a shared responsibility of family, community and government.</p>
Perception: what do people believe is the role of Carers ACT? In what ways can Carers ACT support and better support Carers?	1 Carer centred services 2 Rights and participation of carers as clients 3 Range of carer services and support 4 Working with specific carer populations 5 Community influence and service system change	<p>Processes: Service delivery Research and policy development</p> <p>Outputs: Services Carer information, resources and publications Carer education and training Community education etc.</p> <p>Immediate Outcomes: Carers</p> <ul style="list-style-type: none"> • feel understood, connected and supported • have better coping skills • have increased knowledge and life skills

		<ul style="list-style-type: none"> • have time out and reduced stress • have better access to services for carers and family members <p>Intermediate Outcomes: All listed</p> <p>Ultimate Outcomes: Both</p>
Do Carers believe they have better access to services and support in their role of Carer since contacting Carers ACT?	Effectiveness of 1, 2, 3, 4, 5 above	<p>Intermediate Outcomes: All</p>
Service usage: Which services are Carers aware of? Which have they accessed in addition to their initial contact and service?	<p>1.1 Access to services</p> <p>1.2 Initial contact and referral</p> <p>1.5 providing individualized and coordinated support</p> <p>1.7 Brokering service solutions</p>	<p>Processes: Service delivery</p> <p>Outputs: Services Carer information, resources and publications Carer education and training</p> <p>Immediate Outcomes: Carers</p> <ul style="list-style-type: none"> • feel understood, connected and supported • have better coping skills • have increased knowledge and life skills • have time out and reduced stress • have better access to services for carers and family members <p>Intermediate Outcomes: All</p> <p>Ultimate Impact: Both</p>
Can the group name five key things Carers ACT can do better in supporting Carers in 2008-09?	7.4 Evaluation and action research	<p>Processes: Innovation and quality improvement</p>

Attachment B Conduct of the Focus Group
CARER FOCUS GROUP – 2 MAY 2008

CONDUCT OF FOCUS GROUP

PURPOSE: To seek feedback from family Carers who have accessed a variety of Carers ACT services and to inform the 2008-09 Business Plan process, specifically to identify areas where we can improve our service delivery.

KEY ISSUES: The key issues identified by Carers ACT are:

8. How Carers first heard about Carers ACT
 - a. How was their first contact experience?
 - b. How is their on-going contact experience?
 - c. How would Carers rate the type of response they received when contacting Carers ACT for assistance? (Identify service entry point)
9. Are people members of Carers ACT?
 - a. What do they see as the benefits of membership?
 - b. What would they like to see as the benefits of membership?
10. Perceptions:
 - a. What do people believe is the role of Carers ACT?
 - b. What ways can Carers ACT support and better support Carers?
11. Do Carers feel understood, connected and better supported as a result of contact with Carers ACT? If this is not the case, what needs to happen for them to achieve this outcome?
12. Do Carers believe they have better access to services and support in their role of Carer since contacting Carers ACT?
13. Which services do Carers use?
 - a. Which other services and supports of Carers ACT are they aware of? (in addition to the one(s) they initially contacted)
14. Can the group name five key things that Carers ACT can do better in supporting Carers during 2008-09?

They map into areas in

- The Guide to Good Practice (National Network of Carers Associations, July 2007) and
- Network of Carers Associations Program Logic. (Attachment A.)

METHODOLOGY

Stages and work	Running sheet
1 Preparation: <ul style="list-style-type: none"> • Set date, time and venue • Recruit Carers for the focus group 	Preparation <ul style="list-style-type: none"> • May 2, 12 – 2pm, Belconnen Premier Inn • As per Dee’s email to Kirsten. Contacting

<ul style="list-style-type: none"> • Prepare the session <ul style="list-style-type: none"> ○ Welcome, confidentiality statement, program ○ Introductions and purpose ○ Main topics <ul style="list-style-type: none"> ▪ Written questions and individual responses ▪ Group discussion and responses ○ Capturing information ○ Report headings and timing 	<p>about 30 Carers with the aim of getting about 12 to agree and having a group of 8-10 on the day. (11 April to 30 April)</p> <ul style="list-style-type: none"> • Carol to prepare in detail (11- 30 April) <ul style="list-style-type: none"> ○ Dee and Kirsten to comment on and add to preparation ○ Carol to finalise and prepare <ul style="list-style-type: none"> ▪ Handouts: survey questions ▪ Butchers paper ▪ Powerpoint if needed ○ Carol to agree roles and responsibilities with Kirsten early in week beginning 28 April
<p>2. Conduct the focus group</p> <ul style="list-style-type: none"> • Follow the running sheet • Ensure high comfort levels so that all participants can speak • Ensure all topics are dealt with <ul style="list-style-type: none"> ○ Individually (in writing) and ○ By the group in discussion • Ensure there is no influence from facilitators • Ensure all recording of group discussion is factual, inclusive and visible • Confirm and summarise • Thanks and next steps for use of information. 	<p>Carol and Kirsten conduct the focus group and record the information. Carers are welcomed, provided with lunch, requested to provide anonymous demographic information (e.g. which services they use, when they first approached Carers ACT, etc.) Each topic is addressed and carers have time to reflect on their own experience, write or tick relevant comments on the topic and then join in a whole group discussion about the topic.</p> <ul style="list-style-type: none"> • Carol facilitates the discussion and both Carol and Kirsten record comments • Carol confirms comments on the topic and Kirsten summarises /corrects record <p>After each topic has been addressed the final questions are posed and a list of five improvements for 2008-09 constructed. The meeting closes with explanation of the use of the information, Carers confidentiality, and thanks for participation.</p>
<p>3. Report First draft to Kirsten 9 May Kirsten's comments and input Final Draft for discussion with CEO in week beginning 12 May Final Report for Carers ACT 16 May</p>	<p>Carol prepares draft report from written information and records of discussion Carol sends draft to Kirsten to ensure information accurately and appropriately reflects the group's discussion. Carol prepares final draft report for CEO and Carol, Kirsten and CEO review the report to ensure the language is clear and appropriate. Carol finalises report and gives it to CEO.</p>

FOCUS GROUP SESSION DETAILS

12 NOON

Welcome individuals and seat them. Ensure they take lunch and drinks from the buffet. They may complete the demographic information at this time or later.

12.10PM WELCOME

Welcome the group. Carol introduces Carol Flynn from Carol Flynn and Associates and Kirsten from Carers ACT and respective roles.

Thank the group for giving their time to be a focus group. Explain the selection process and the confidentiality of their attendance, individual information, and views.

Explain the purpose of the focus group; the program of work for the session including the topics; and the report which will be given to the CEO and how it will be used in the Business Planning process for 2008-09.

Each participant introduces themselves and some of the Carer ACT services they use or have used. At this time they may say up to three things they think Carers ACT do well currently. These will be listed.

12.20PM: TOPIC DISCUSSION

Work begins on the topics. Each topic is dealt with seriatim. With six topics, each will receive about 15 minutes.

- On each topic the Carer has a series of survey questions (see draft questions attached) to record their personal opinions and thoughts with a space for free comment. This individual thinking and writing is done first.
- Then the topic is discussed by the group and the range of experiences/ views are recorded. The discussion is guided by the survey questions and by the facilitator. Views are recorded clearly on butchers' paper and this is hung on the wall for later additional thoughts.
- At the end of the topic discussion, the views are confirmed and summarized.

At the end of discussion on all topics, the views are re read, confirmed, amended and summarized.

1.45PM: IMPROVEMENTS LIST

Then the group addresses the five key things Carers ACT can do better in supporting Carers in 2008-09.

These are written individually first (and may have been noted during the previous discussions) and then aggregated before being prioritized and edited.

1.55PM THANKS AND NEXT STEPS

The focus group comes to a close with:

- Thanks for attendance with appreciation of the value of their contribution
- Reminder of the next steps, that is the report and its use in Business Planning by the Board, Executive and staff of Carers ACT

- Reassurance of the confidentiality of their views and suggestions.

2.00PM CLOSE

REPORT

After the focus group, all the individual and group recorded materials will be collated and typed up. Carol will use the materials to develop the Report. The Chapter headings in the report are:

1. Executive Summary
2. Methodology
3. Results of Focus Group
 - a. Topic Headings 1 - 6
 - b. List of improvements
4. Attachments
 - a. Questions
 - b. Raw recorded data without any identifiers.

The final Report will be presented on 16 May 2008.