

# **REVIEW OF THE RESPITE AND INFORMATION SERVICES FOR YOUNG CARERS PROGRAM**

**Final Report – Stakeholder Summary**

2008

## **Acknowledgments**

This work was commissioned by the Australian Department of Families, Housing, Community Services and Indigenous Affairs.

We would also like to thank the young carers who participated in the review, and the many key stakeholders from Commonwealth Respite and Carelink Centres and Carers Australia. We thank them for their time and insights and trust that their views are adequately represented in this report.

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## **Forward**

This report is a summary of the final evaluation report by ARTD Consultants of, what is now titled, the Young Carers Respite and Information Services Program. It was prepared by the Department of Families, Housing, Community Services and Indigenous Affairs to inform stakeholders about key findings and for feedback about how the program is being delivered nationally.

Following the evaluation, many changes were implemented for the 2008-09 financial year, including revised program guidelines and reporting requirements.

Our thanks to all those who participated in the evaluation and to ARTD Consultants for their valuable work.

# Executive Summary

This report presents the findings of an independent evaluation of the *Respite and Information Services for Young Carers Program*. The Young Carers Program has been implemented for three and half years (January 2005 to June 2008) with funding of \$26.6M from the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

The evaluation was conducted by ARTD Consultants, from October 2007 to March 2008 and is intended to inform the future directions of the program.

## **The Respite and Information Services for Young Carers Program (Young Carers Program)**

The Young Carers Program aims to assist young carers by supporting them to stay in education or training while continuing in their caring role. The program targets young carers who are completing their secondary education or the vocational education equivalent and are at risk of leaving school prematurely because of their caring role. Young Carers are defined as being at risk where, due to the caring responsibilities, they: frequently miss school; have no time to complete homework; feel very distracted when they are at school and experience limited connectedness with their school community and are considering leaving secondary school or equivalent education prematurely.

The program has two separate but related components: respite services delivered by Commonwealth Respite and Carelink Centres (CRCCs), located in 55 Home and Community Care (HACC) regions across Australia; and information, referral and advice services delivered by Carers Australia and their member Carers Associations.

## **Evaluation methodology**

The evaluation used a mixed methods approach combining qualitative case studies at ten sites across Australia (identified by State and Territory Offices as operating well); feedback from relevant stakeholders; a quantitative survey of Commonwealth Respite and Carelink Centres (CRCCs); and an analysis of documents and monitoring data reported in Carers Australia Quarterly Reports (2006/ 2007) and CRCC Quarterly reports for first quarter of 2007/2008.

In all, the ARTD consultancy team interviewed 82 program stakeholders sourced from CRCCs, Carers Australia and other local providers and agencies, and conducted three discussion groups at state network meetings of CRCC staff. ARTD researchers also visited eight CRCCs and two State Carers Association services.

We also consulted 91 young carer clients of CRCCs and Carers Australia through ten focus groups and 23 phone interviews.

The methodology was able to be applied effectively, but caution is needed in interpreting the results for young carers, in particular because of the positive bias introduced by sampling young people in contact with effective services or actively involved in Carers Associations networks. In addition, we are missing implementation data on 24% of CRCCs.

## **Key findings**

The Young Carers Program is an important program which provides services that are not readily available through alternate services.

Where young carers used the services for respite, information, referral and advice, they reported gaining important emotional and social benefits as well as being assisted to cope with their caring responsibilities and school work.

The Program was implemented as a traditional direct respite, information, advice and referral program, targeting young people which did not take into account the special circumstances and respite needs of young carers. As a result, some CRCCs adapted the service model to better meet the needs of young people, providing a flexible and broad range of indirect and direct respite services. Other services, particularly rural and remote CRCCs, struggled to implement the program.

### ***Respite services***

The respite services component met its target of assisting approximately 750 young carers a year, for the last two years of implementation. By the second year of the program, 1,100 young carers used respite services across Australia, up from an estimated 720 in the first year. Most young carers receiving assistance fit the main target group being high school age, 12 to 17 years. Nevertheless, 12% of young carers using services are primary school age and 5% are aged 22 to 25 years. Almost half of young carers using respite services have significant caring responsibilities, caring for a parent with a mental illness, a chronic illness or a disability. Many face complex family situations.

Implementation of the respite services has been characterised by diverse approaches and levels of commitment, driven by the poor fit between the service model framed in the Guidelines and the expressed respite needs of young people. CRCCs have faced difficulties identifying and accessing young carers and sometimes working with this unfamiliar client group. An important finding for the Review is that programs working with 'hidden carers', such as young people, need to provide sufficient resources towards raising the profile of carers in the wider community and also to services to find and access these carers. The operational/ brokerage split worked against such activity.

Service delivery has evolved over time to include outreach strategies, case management and a focus on indirect services, rather than direct services, although their direct respite does provide valuable assistance in specific circumstances. In practice, direct respite was only occasionally suitable for young people, and other services proved to be both more acceptable to young people and to offer a respite effect. Although young people appreciate the range of practical support in home and with school work they most value the personal support and advice they get from the service workers, whether they are based in CRCCs or State Carers Associations. Choice of respite options and flexibility in service delivery are key principles in providing effective respite services for young people.

CRCCs are working with other government agencies to provide support to young people. Workers may simply share information during meetings and/ or make cross-referrals and/ or coordinate support for the young person. Links may be through formal partnerships or informal relationships at the worker level, depending on the service model used by the CRCC. Examples of collaborative partnerships we found are with mental health services, Centrelink, youth services and schools.

Developing links with other services is an important strategy in planning for ongoing support for the young carer, particularly with the increasing complexity of referrals as the program becomes better known. Schools and health agencies have emerged as key referral agencies and the evidence shows there remains substantial work to be done to get the welfare of young carers to be recognised more broadly amongst school staff and health workers. Systems based approaches at the departmental level to direct policy and practice at the local level are necessary to bring about broad-based change.

### ***Information, advice and referral services***

Carers Australia and Carers Associations are successfully delivering information, referral advice services that broadly complement respite services to young carers. Information resources for young carers are widely used by Associations and respite services. However, the development of information resources and products has not been timely. As such, for the greater period of the Program, workers in contact with high schools have been without important resources to explain young carer issues.

A key issue for Carers Australia has been the administrative cost of distributing resources. Warehousing and distribution of information resources requires dedicated administration resources, which are not covered by the allocated funding. As a result, Carers Australia and their association members are seeking to recover distribution costs by charging services for bulk copies of the Young Carers Kit. However, this policy has not deterred CRCCs from obtaining kits, with 95% of CRCCs we surveyed using the Young Carers Kit as part of their services.

At the end of June 2007 the State and Territory Carers Associations had an estimated 1,528 individuals as registered contacts, that is, young people the Associations had provided direct support to. The young people had more than one contact with the service, so that 8,380 direct occasions of service had been provided including: 661 young people attended young carer camps or other recreational activities; 554 young people received face-to-face and telephone counselling, 413 supported referrals and 969 have been individually supported. In addition, Carers Australia and their members associations have distributed around 17,000 specific information resources to young carers and agencies.

Carers Australia report that they have had insufficient program resources to meet the demand for advice services, with counselling services being cross-funded by other programs.

Carers Associations have identified a need to raise awareness at the system or policy level with key agencies, such as education and health, and have put in place strategies with varying success at early stages. This approach is worthwhile as it validates and complements local partnerships between services and agency workers to identify and support young carers.

### **Outcomes for young people**

Most young people and service providers (97%) agree that the program can bring a range of tangible benefits for young people: improved emotional and physical well-being; practical assistance to carry out responsibilities. Service providers also reported that the program had helped some young carers cope better at school.

One important outcome for many young people is the acknowledgment that their role has had a marked impact on their feelings of self-worth and confidence. This has assisted some young carers to better cope with and manage their responsibilities. Participation in young carer networks and conferences has also been an effective strategy in improving self-esteem and empowering young carers.

Young people particularly appreciated being able to get emotional support and independent advice and help from an adult. There was a feeling that such support helped them share the burdens of responsibility and reduced their levels of stress. Active interventions by a worker to link them with services for the care recipient or arrange other assistance reduces stress and helps young people manage their responsibilities. Where offered, information about the care recipient's condition has also been valuable for some young people by assisting them to care for their parent or sibling.

Young people were largely satisfied with whatever level of respite or support they received from either CRCCs or Carers Associations and few identified problems with quality or unmet needs. There was a common attitude that any support was gratefully accepted, that services were generally responsive to their requests for support and that they had gained the help they needed. However, this feeling does not mean that the program has fully met the needs of young people involved or that it is meeting the broader service needs of young carers. FaHCSIA is currently funding a research study through the National Youth Affairs Scheme to identify demographic characteristics of young carers and where they are located, which will provide valuable information about the level of need for respite and support services.

### **Modifications to the program**

The report suggests ways the program might be modified to build on its strengths and incorporate what has been learnt about how to reach young carers, what is effective respite for young carers and good practice in delivering such services. In the short term, suggested modifications include revising the Program Guidelines, broadening the definition of young carers eligible for respite and allowing services to best meet the needs of young carers on a case-by-case basis, rather than rationing direct respite in specific forms.

The report also suggests modifications that could be made to improve practice and to increase the effectiveness of awareness raising activities, information distribution and referral.

In the medium term, the program could be refocused on carer support with direct respite as one option for support.

Service models could be further developed, especially for working with young carers from culturally and linguistically diverse backgrounds and from Indigenous backgrounds.

### ***Performance measurement***

Although CRCCs and Carers Australia are complying with reporting requirements, the current reporting regime is not providing reliable performance information.

Key performance indicators have been reported against inconsistently and have limited relevance to how respite services are being implemented. FaHCSIA has recently developed new standardised key performance indicators for 2008-09.

### ***Funding***

Overall, program funding for respite services has been more than adequate for most metropolitan and regional CRCCs, with just seven services (17%) having to establish waiting lists.



The findings suggest that program funding for respite service should stay at the current level with increased funding to remote/ rural areas and less funding for ineffective metropolitan services. A minimum amount of funding is needed to maintain viability and for a service to access young carers effectively. New funding strategies are needed to provide sufficient staffing resources for remote and rural services to access young carers.

The evidence suggests that funding for information, advice and referrals has not been adequate to meet increasing demand arising from the success of promotion efforts. In addition, the objectives of increasing awareness of young carers in the community and providing a state-wide information, referral and advice service appear difficult to achieve for a part-time worker located in each state and territory.

Increased funding will ensure sufficient resources are available, efficient resource distribution systems are in place and counselling places are funded to meet demand. Carers Australia is seeking a substantial increase in funding annually to allow additional services to be provided, for example, a greater community development role, family centred assessment and case management options and increased brokerage of counselling. Carers Australia should develop a detailed business case to justify new funding levels.

# 1 Introduction

This section briefly describes the Young Carers Program, and the aims and scope of the Review.

## 1.1 Young carers

Caring for people with disabilities is an important feature of contemporary Australian society. One in five people in Australia report having a disability<sup>1</sup>. The Australian Bureau of Statistics defines disability as,

Any limitation, restriction or impairment which has lasted or is likely to last, for at least six months and restricts everyday activities.

The Program Guidelines define primary young carers as:

...someone up to 25 years of age who is the main provider of care and support for a parent, partner, child, relative or friend, who has a disability, is frail aged or who has a chronic mental or physical illness or alcohol/ drug dependence.

A substantial number of young people are carers in Australia, with 170,600 young carers aged up to 17 years and 348,000 young carers aged up to 25 years.<sup>2</sup> From a population perspective, 3.6% of young people aged up to 17 years are carers and 9% of young people aged 18-25 years. Around half the primary young carers are aged up to 17 years, and 80% aged between 18-25 years are female.<sup>3</sup>

The available data reveals the profile of young carers<sup>4</sup>:

- between one-fifth and one-half live in rural or remote areas<sup>5</sup>
- young carers are usually representative of the general population in terms of cultural background
- most young carers live in NSW, Victoria and Queensland
- more than one half of primary young carers are caring for a parent, and that parent is likely to be a mother and a sole-parent household
- it is estimated that one in four young carers are providing care for a person with a mental illness.

The responsibilities of caring have been shown to limit young people's opportunities. Young carers tend to leave school earlier than their peers, and are less likely to be in the labour force or employed. For example, in 1999 only 4% of primary young carers aged between 15-24 years were still in education, compared to 23% of other young people.<sup>6</sup>

Many carers are hidden, that is, they are unaware of available services or models of care or choose not to access government services. Young carers are often part of this group.

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<sup>1</sup> 1998 ABS Survey of Disability, Ageing and Carers.

<sup>2</sup> ABS Survey of Disability, Ageing and Carers 2003.

<sup>3</sup> Quoted in Cass, B. 2007. Youth Studies Australia, Vol 26, NO. 2 p 47.

<sup>4</sup> 1998 ABS Survey of Disability, Ageing and Carer (DAC)

<sup>5</sup> Sources differ regarding where young carers are located. The 1998 ABS Survey of DAC say one-third to one half young carers live in rural/ regional areas. The 2006 ABS Census of Population and Housing quote 19.2%

<sup>6</sup> ABS 1999.

## 1.2 The Young Carers Program

The Young Carers Program was developed as a measure for the 2004/ 2005 budget as a result of *Carers Australia, The Young Carers Research Project: Final Report, DFAC, 2002*. The report showed that young carers have fewer life choices and opportunities than other young people because their responsibilities impact on their ability to complete school and on their physical and mental health. The report also identified the need for policies and programs designed specifically for young carers.

As part of the Government's initiatives to support carers, the four-year \$26.6 million Respite and Information Services for Young Carers Program assists young carers by supporting them to stay in education or training while continuing in their caring role. The Program targets young carers who are completing their secondary education or the vocational education equivalent and are 'at risk' of leaving school prematurely because of their caring role. Young Carers are defined as being at risk where because of the caring responsibilities they: frequently miss school; have no time to complete homework; feel very distracted when they are at school; experience limited connectedness with their school community and are considering leaving secondary school or the equivalent education prematurely.

The Program aims to support over 500 young carers, for each respite component, aged up to and including 25 years.

The Program has two separate but related components:

### **Respite services**

The major component of the Program is provided through the national network of 55 Commonwealth Respite and Carelink Centres (CRCCs). The CRCCs are funded by FaHCSIA to deliver in-home respite through brokerage arrangements with service providers and supplementing other support programs. The 2007/ 2008 budget for the respite services is \$6.9 M.

Young carers can access: up to five hours at-home respite per week during school term to complete secondary education or vocational equivalent, and a two-week block of respite care a year to undertake activities such as studying for exams or training. The respite block can be used flexibly to support young carers through stressful periods associated with full-time study. The intended outcomes for young carers are improved school attendance, educational outcomes and employment skills.

The objective is to:

- help young carers better manage or balance their education and caring responsibilities. It is a targeted measure and seeks to supplement existing programs, not replace them.

CRCCs are regionally-based not-for profit organisations whose primary funding comes from the Department of Health and Ageing to deliver the National Respite Program and a range of other disability and respite programs. The CRCCs have been funded by FaHCSIA under the Young Carers Program to reflect the expected young carer population (2003 ABS Survey of Disability, Ageing and Carers).

CRCCs target resources within their region of operation, with a diverse pattern of service delivery and a variety of arrangements with local service providers.

## **Information, referral and advice services**

Carers Australia is responsible for the dissemination and development of age-appropriate information, referral and advice services to support young carers. This includes a young carers website (<http://www.youngcarers.net.au>) currently being re-developed and a recently launched high school education kit. State Carers Australia Associations provide advice and support services, including counselling and referrals. The objective was to develop nationally consistent information products.

The objectives are to:

- support young carers in their caring role by providing them with a clearly identifiable and accessible point of contact for information, referral and advice services
- support young carers in their caring role by providing co-ordinated and age-specific information
- provide young carers with access to timely age-specific counselling and support services
- increase awareness of young carers and their issues within the community, including but not limited to: government departments, schools and medical practitioners
- increase the rate of identification by young carers seeking assistance and support.

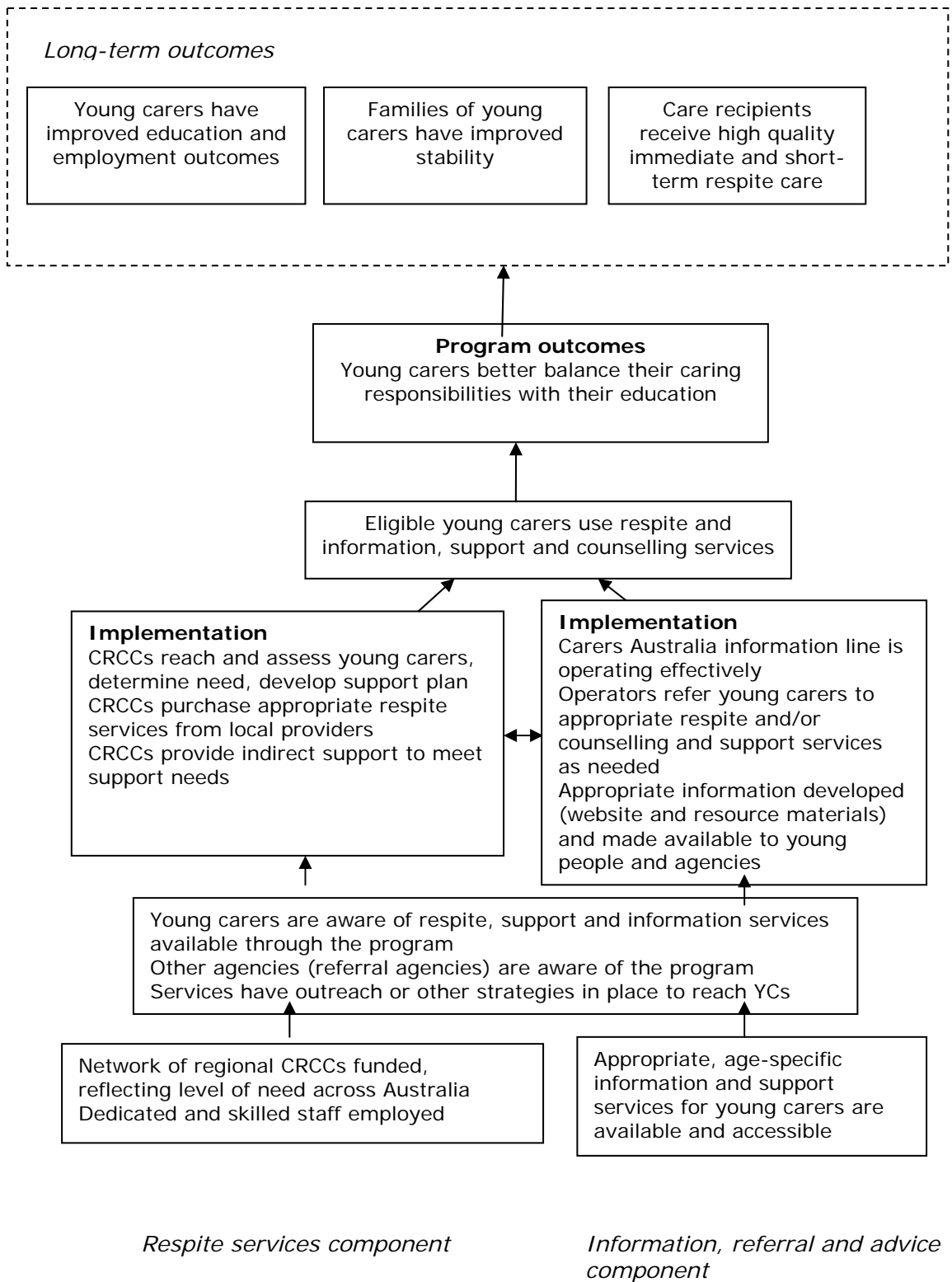
## **Program logic**

The Program logic represents the different levels of outcomes the Program sets out to achieve, and the relationships between them (Figure 1.1). It shows how the implementation of the Program contributes to the Program outcomes and in turn to the long term outcomes for young carers, their families and care recipients.

The Program logic highlights that for young carers to utilise respite services, they need to be aware of support through the Program, and be engaged with a CRCC, while the CRCC needs to have relationships with appropriate service providers.

The Program logic shows how the two streams of the Program are intended to contribute to the Program outcomes. They function in parallel but also with the many interactions between them. For example, both CRCCs and CA may aim to reach young carers with information, depending upon the local context and the circumstances of the young carers

**Figure 1.1: Program logic for Respite and Information Services for Young Carers Program**



## **1.3 Scope and objectives of the Review**

The purpose of the Review is to assess the effectiveness and efficiency of the Program to inform decisions about possible improvements and future directions.

The scope of the Review is the implementation of the Program since the 2004-2005 Budget provision, with a greater focus on the last year of implementation (2006-2007) and on the respite component.

### **1.3.1 Key evaluation questions**

The Review aims to answer a range of key questions.

#### **Effectiveness of implementation**

The overall implementation questions are:

- *What and how much has been done and how well has it been done?*
- *How could the Program be modified to better meet the information and respite needs of young carers?*

#### **Program outcomes**

The overall results questions are:

- *Does the Respite and Information Services for Young Carers Program assist young carers to better manage their education and caring responsibilities?*
- *Does the Program assist young carers to access suitable support and advice?*

#### **Appropriateness of funding methods**

The overall funding question is:

- *Is the level and method of funding adequate to ensure the Program is delivered effectively?*

#### **Adequacy of performance indicators**

The overall Review question is:

- *How relevant are the existing performance indicators, and what alternate indicators would better reflect the effectiveness of Program delivery?*

## **2 Review methodology**

This section provides an overview of the methods used to collect evidence for the Review.

### **2.1 Approach**

This Review used a mixed methods approach combining qualitative case studies at ten sites, feedback from relevant stakeholders, a survey of CRCCs, analysis of documents and analysis of monitoring data from 2007/ 2008 CRCC Quarterly Reports and Carers Australia Quarterly reports from 2005 to 2008.

In all, we interviewed a total of 82 Program stakeholders from CRCCs, Carers Australia and other local providers and agencies and conducted three discussion groups at State network meetings of CRCC staff. ARTD researchers also visited eight CRCCs and two State Carers Associations.

We talked to 91 young carer clients of CRCCs and Carers Australia, through ten focus groups and 23 phone interviews.

The methodology was able to be applied effectively, but caution is needed in interpreting the results for young carers, in particular because of the positive bias introduced by sampling young people in contact with effective services or actively involved in Carers Association networks. In addition, we are missing implementation data on 24% of CRCCs.

## Summary of data sources, data collection methods and sample sizes

Data source	Method	Sample size
July - Sept 07 CRCC FaHCSIA Quarterly reports	Analysis of nos. YCs participating	55 reports
Carers Australia Quarterly reports from 2005/ 2006 financial year to 2007	Analysis of monitoring data (reported six-monthly)	6 reports
Program stakeholders	Field visits	8 sites, one in each State/ Territory
CRCCs	Written survey	42 Response rate=76%
CRCC managers at case study sites	Semi-structured face-to-face interviews	8 managers
CRCC managers: remote and rural sites	Semi-structured telephone interviews	5 managers
CRCC manager: urban site with low-level implementation	Semi-structured telephone interview	1 manager
CRCC managers Qld and Vic	Discussion groups	2 groups
CRCC Young Carers Program Coordinators/ CRCC workers	Semi-structured face-to-face interviews	9 workers
Victorian CRCC Young Carers Program Coordinators/ CRCC workers (incs one State Carers Association Young Carers Program worker)	Discussion group	9 workers
Local respite service providers/ referral agencies	Semi-structured face-to-face interviews and telephone interviews	27 workers
School teachers	Semi-structured telephone interviews	8 teachers
Young carer clients of CRCCs	Focus groups	8 groups and 53 YCs
Young carer clients of CRCCs	Semi-structured telephone interviews	14 YCs
Young carer clients of Carers Australia	Focus group	2 groups, 15 YCs
Young carer clients of Carers Australia	Semi-structured telephone interviews	9 YCs
National DoHA officers	Semi-structured face-to-face interviews	3 staff
National FaHCSIA officers	Semi-structured interviews	5 staff
State and Territory FaHCSIA officers	Semi-structured telephone interviews	8 officers
Academics	Semi-structured telephone interviews	2 academics
Carers Australia National Office Senior Executive	Discussion group	2 groups, 5 staff
Carers Associations of Qld and Vic	Discussion group	2 groups, 10 staff
YC State Coordinators	Semi-structured face-to-face interviews	2 coordinators
YC State Coordinators	Discussion group	1 group



## 2.2 CRCC survey

The purpose of the survey was to collect systematic independent data on the extent the respite component of the Program has been delivered and the profile of clients. The data were also intended to help fill the gaps caused by the limited nature and inconsistent reporting of monitoring data about the Program.

All 55 CRCCs were mailed a self-completed written survey including a pre-paid reply-paid envelope. Up to three rounds of reminder follow-up telephone calls were made to non-respondents.

Forty two CRCCs returned the survey; a response rate of 76%. Although we are confident that the survey results reasonably represent how the Program is being implemented for young carriers, they may introduce positive bias in terms of services provided.

The survey was piloted by two services prior to being finalised.

The survey covered:

- Information about administration of the Program (Qs 1-4)
- Information about the number and profile of Young Carers Program clients (Qs 5-8)
- Services for young carers (Qs 8-13)
- Access to respite services (Qs 14-18)
- Links with Carers Australia and use of resources (Qs 20-21)
- Promotion of service (Qs 22-25)
- Funding and Guidelines (Qs 26-27)
- Benefits of the Program (Qs 28-29).

## 2.3 Field visits to case study sites

The purpose of the field visits was to provide in-depth information on the effectiveness and efficiency of the Program in specific contexts, to complement the broader data analysis. The visits also provided an opportunity to get feedback from young people about their experiences with the Program, and explore how well these services are meeting young people's needs and whether the Program is benefiting them.

The case study sites:

<b>Location</b>	<b>CRCC Respite services</b>
Rural	Mid North Coast (Macksville, <b>NSW</b> ) Australian Red Cross - South West Region (Bunbury, <b>WA</b> )
Metro	Community Based Support South (Moonah, <b>Tas</b> ) Carers ACT (Canberra, <b>ACT</b> ) South and East Metropolitan ( <b>SA</b> ) Northern Region ( <b>NT</b> )
Regional	West Morton/ South Coast (Gold Coast, <b>Qld</b> ) Barwon Health (Newcomb, <b>Vic</b> )
<hr/>	
<b>Carers Australia Information and Support Services</b>	
Carers Queensland	
Carers Victoria	

Three locations that illustrate emerging findings have been written up as case studies (section 3).

During these field visits, data were collected from:

- **young carers**, either as part of a focus group facilitated by ARTD or through one-to-one interviews, depending on the young person's preference. Young carers were selected at random from client lists of CRCCs and invited by letter from the CRCC to participate in the research. For one group (Victoria), the young people were selected at random from clients caring for a parent or family member with a mental illness; for a second group (NSW), the young people were selected at random from clients caring for recipients with a physical disability. All other groups had a mix of care recipients with mental and physical health issues. The invitation letter explained the reasons for the research and offered a \$55 incentive payment for participating. All young carers and their parent or guardian formally consented to participating in the research. Of the 91 young people invited, 61 participated, a response rate of 67%. All groups were conducted at CRCCs (the Carers Qld and Carers Vic groups were conducted at the State Carers association offices) and many young carers were transported to the groups by CRCC workers
- **CRCC service managers/ Young Carers Program coordinators and/ workers at all sites.** ARTD researchers interviewed CRCC stakeholders face-to-face using semi-structured interview guides. These interviews took between 45 mins and three hours to complete
- **Local respite service providers and referral agencies.** ARTD researchers interviewed CRCC stakeholders face-to-face or by telephone, using semi-structured interview guides. The service providers were recommended by the CRCCs
- **School welfare officers or school principals.** Because of the timing of the visits in school holidays, school stakeholders were interviewed by telephone after the field visits. The informants were selected by the CRCCs on the basis of having worked with the service
- **State Carers Associations** – face-to-face interviews were conducted with CEOs; Program Coordinators; Young Carer Counsellor; Education Officer.

## 2.4 Other qualitative data collection

The purpose of these interviews/ discussion groups was to collect information on the effectiveness of implementation of both the respite and information components of the Program, that is, the perceived impact, utility of the funding model and fit with national policy and other funding programs from key Program stakeholders.

Qualitative data were collected from a range of stakeholders:

- **National Office FaHCSIA Carers Branch, Mental Health Branch and Youth** – interviews conducted using semi-structured interview guide
- **DoHA officers** - interviews conducted using semi-structured interview guide
- **FaHCSIA State and Territory officers** - telephone interviews with eight officers, one from each State and Territory – interviews conducted using semi-structured interview guide
- **CEOs/ Senior Managers CRCCs** - discussion groups at State Program Management Meetings:
  - Brisbane, 14 November 2007
  - Melbourne, 22 November 2007
- **Victorian Young Carers Program Coordinators** - Network Meeting, 22 November 2007
- **Carers Australia National Executive** – discussion with the CEO, Young Carers National Coordinator, Project Manager and Business Manager. Carers Australia also provided a written submission for the Review.

- **CRCC managers** of three remote, three rural and one metropolitan site where Centres have experienced difficulties delivering the Program – interviews using semi-structured interview guides
- **State and Territory Carers Associations Young Carer Coordinators** – discussion group, 29 November 2007, Australian National Young Carers Action Team (ANYCAT) National Meeting in Melbourne
- **Young Carer representatives on ANYCAT** – focus group conducted during National Meeting, 29 November 2007
- **Young carer clients of Queensland and Victoria State Carers Associations** – mix of telephone interviews and focus groups. Carers recruited through the Associations
- **Key academics** - Professor Ken Pakenham, School of Psychology, University of Queensland and Dr Bettina Cass, Social Policy Research Centre, University of NSW, conducted using a semi-structured telephone guide.

## 2.5 Analysis of monitoring data

CRCCs report six-monthly to the Department of Health and Ageing (DoHA) as part of the National Respite Commonwealth Program minimum data-set, and quarterly to FaHCSIA. The quarterly reporting requirement for the Young Carers Program commenced in the current financial year.

No monitoring data was available to the Review from the DoHA minimum data-set. In addition, Program-specific data for the Program is not available from the data-set, as there is no identifier used.

Over the period of the Review, only complete data for the first quarter of the 2007/2008 financial year was available from CRCCs. Carers Australia reports for the first and second quarters were available. Prior to the 2007/2008 financial year, client data were reported through DoHA Narrative Reports, and complete records of these data were unavailable. It was therefore not possible to analyse client records across the three years of the Program.

ARTD combined the records from all quarterly reports and produced a summary report by State, region and nationally. The analysis included average hours per client; average hours per occasion of service and average hours per client per week. The reporting has limitations; it does not capture the amount of indirect services accurately, and it is difficult to calculate the total number of clients because the reporting does not distinguish between ongoing and new clients.

Carers Australia quarterly reports provides summary reports of State Carers Associations' activity levels.

The Review did not have access to quantitative data on school attendance rates for individual young carers accessing services, or long-term school retention rates or employment outcomes.

## 2.6 Literature scan

ARTD reviewed twelve documents to glean information about young carers support needs and models of good practice for delivering respite and carer support.

Most of the documents were provided by FaHCSIA and others were identified through key stakeholder interviews.

The documents reviewed and a summary of key information found are shown in Appendix 1.

## **2.7 Research**

ARTD conducted limited research across State department for equivalent models of Young Carer program using literature available on websites and contacting a small number of key policy officers. The results were summarised and are documented in Appendices 1 and 2.

### 3 Implementation of respite component of the Program

This section assesses how well the respite component of the Program has been implemented, and presents evidence about how many and which groups of young carers have participated in the Program and where they are located. It addresses the key evaluation questions:

- *How much has been done?*
- *What and how well has it been done?*

Case studies of service delivery in three HACC locations: West Moreton South Coast Queensland; the Top-End Northern Territory; and Barwon South West, Victoria, are documented at the end of this chapter.

#### 3.1 Participation rates

Overall, the Program has met its target of approximately 750 young carers<sup>7</sup> being assisted a year, in 2006/ 2007 and 2007/ 2008, but not in 2005/ 2006.

Between July 2005 and February 2008, CRCCs assisted an estimated 720 to 1,200 young people each year<sup>8</sup>. The numbers of young carers being assisted has increased over time as CRCCs have developed practice models and promoted their services.

In the 2006/2007 period, half of the surveyed CRCCs assisted up to 20 young carers over the 12 month period, while a small number of services assisted 75 or more young carers. One third of CRCCs had between 0 and 10 clients.

#### Numbers of young carers assisted by 42 CRCCs by financial year and State/Territory

State	2005/2006	2006/2007	2007/2008*	Total
VIC	297	326	297	920
NSW	191	319	333	843
QLD	119	225	182	526
SA	38	48	63	149
WA	21	47	64	132
TAS	1	1	15	17
NT	2	5	6	13
All	669	971	960	2600

Source: CRCC Survey. \*July 07 to Feb 08.

CRCCs based in Victoria, NSW and Queensland have assisted the most numbers of young carers, with Victoria and Queensland showing the highest average number of young carers assisted per CRCC during 2006/07.

<sup>7</sup> Target is 500 young carers per respite block, which FaHCSIA estimates is 750 individual young carers

<sup>8</sup> Complete monitoring data on participation rates for all CRCCs is not available. Estimation based on survey results and average number of clients assisted per CRCC, extrapolated to account for missing data.

## Average number of young carers assisted in 2006/2007

State	N(YC)	N(CRCC)	Average per CRCC
VIC	326	6	54
QLD	225	7	32
NSW	319	13	25
SA	48	3	16
WA	47	10	5
Tas	5	2	3
NT	1	1	1
All	971	42	23

### 3.2 Characteristics of young carers being assisted

CRCCs are successfully accessing the main target group of the Program. Survey results show that most young carers receiving assistance are high school aged, that is, between 12 and 17 years of age.<sup>9</sup> One third of the young carers are aged between 15 and 17 years, 12% are from culturally diverse backgrounds and 7% identify as Aboriginal or Torres Strait Islander. CRCCs report that they are increasingly being referred young carers less than 12 years of age.

#### Demographic characteristics of young carers assisted in 2006/ 2007 by 42 CRCCs

Characteristics of young carers	n	%
Aged <12 years	116	12%
12–14 years	254	26%
15–17 years	349	36%
18–21 years	119	12%
22–25 years	53	5%
Total	971	100%
CALD	120	12%
Identify as ATSI	67	7%
Studying at vocational equivalent of school	50	5%
Have a disability	27	3%
Refugees	4	<1%

During 2006/07, one third of young carers looked after care recipients with a mental illness and just under a quarter cared for someone with a physical disability. A significant minority of young people were also caring for family members who are chronically or terminally ill (15%) or have an intellectual disability (11%).

The proportion of young people caring for recipients with particular conditions varies somewhat between CRCCs and is influenced by the success of promotional activities and existence of referral protocols between the CRCC and agencies. For example, the Barwon Young Carers Program has close ties with a program that works with children of parents with a mental illness, and many of their referrals come from this program.

<sup>9</sup> Demographic data collected for 2006/2007 year only.

### Type of disability of care recipients (young carers in 2006/2007)

Number of YCs assisting person with...	N	%
Mental illnesses	331	34%
Physical disabilities	224	23%
Chronic or terminal illnesses	145	15%
Intellectual disabilities	104	11%
Multiple disabilities or health problems	81	8%
Dysfunction caused by severe alcohol or other drug use	16	2%
Other (specify)	38	4%

The majority of young people were caring for a parent (61%) with a significant minority caring for a sibling (20%).

### Who young carers are caring for

Care recipient	No. YCs	% YCs
Parent	593	61%
Sibling	195	20%
More than one care recipient	76	8%
Grandparent	33	3%
Extended family	4	0%
Friend	0	0%

### 3.3 Extent the Program was delivered

The Program has been inconsistently delivered by CRCCs, with some services having few if, any clients and others successfully engaging with young carers. Seven services have established waiting lists because demand exceeds capacity on occasions (section 6.1). Where the Program has been delivered effectively, CRCCs have provided more indirect respite services to best meet the respite and support needs of young carers rather than direct, in-home respite (section 5).

All of the remote CRCCs and most rural services receiving relatively small amounts of funding struggled to implement the Program and had few clients (see section 6), This is serious implementation failure given that the 1998 ABS data shows between one-third and one-half of young carers live in rural or remote areas.

There was insufficient funding to dedicate enough resources to establish the Program. Remote and rural CRCCs face other particular challenges to implementing new programs. Many have small numbers of staff working across program areas and limited ability to cover the large geographical areas covered by their service. Rural and remote CRCCs also have difficulties recruiting suitably qualified staff. Centre managers we spoke to commented that they had no or only small travel budget and no funding from the Young Carers Program to do so. Some Centres do not provide outreach; rather they work through health teams, such as aged care assessment teams to identify respite clients. Other remote services provide mobile respite services. Remote and rural CRCCs also have few other services to refer young people to, a small pool of suitable in-home respite providers and face high costs of providing respite. For example, it can cost \$13,000 to transport someone from a remote area into Darwin for respite. A WA CRCC commented that the lack of

family networks amongst non-Indigenous families in remote areas means that when something goes wrong the families leave the area.

Some large metropolitan and regional services that received sufficient funding to employ Program-specific workers have also failed to deliver the Program effectively. One Metro CRCC indicated that it was difficult to spend the brokerage component, as most of the services they provide are indirect. Indirect services are generally inexpensive compared to paying for direct in-home or out-of-home respite. The CRCC also stated that few agencies or key stakeholders are aware of the Program.

Another important factor influencing the extent to which the Program has been implemented is that the Guidelines are not easily applied to complex family situations (section 3.8.) For example, changeable family circumstances make it difficult to identify a primary carer and families face a range of problems. In many circumstances, other siblings (secondary carers) may also need respite and support (not allowed by the Guidelines). Some CRCCs do support secondary carers and identify one child for reporting purposes, while others do not.

### 3.4 Accessing young carers

Identifying young carers is a key barrier to providing respite and support for this group. Almost all (90%) of CRCCs reported that they found it difficult to identify young carers in their region, with half (49%) finding it very difficult.

#### Identifying young carers

How difficult is it to identify YCs in your region?	n	%
Very difficult	20	49%
Moderately difficult	17	41%
Not difficult	4	10%
TOTAL	41	100%
No data	1	

Source: CRCC Survey, Feb 2008.

#### 3.4.1 Attitudinal barriers to young carers' participation

How young carers and their families view the young person's caring role is a barrier to young people participating in the Program. Many young people and their families simply do not initially recognise the Program as being "for them".<sup>10</sup>

The classification 'young carer' is not a term readily used by families where young people have taken on a caring role. Young people do not identify themselves as "young carers". Young carers and their families commonly regard young people taking on caring responsibilities as being a normal response to their family situation. As Bettina Cass says, 'Care is embedded within a normative framework of obligation and responsibility'<sup>11</sup>. Identification of a young person as a primary carer appears to be even more problematic in Indigenous families, where extended families are the norm and the caring role is shared amongst the extended family members.

Young people also perceive that being classified as a carer sets them apart from their peers as being different. They have fewer opportunities to socialise and may suffer social isolation. For example, some young people report being teased or bullied about their parent's disability. Around one third of CRCCs estimate that

<sup>10</sup> These findings are confirmed by Australian research.

<sup>11</sup> Cass, B. 2007. Youth Studies Australia vol 26 No. 2.



between 1–10% of young carers known to them refuse respite assistance. One CRCC estimated that 50% of young carers referred to their service refuse assistance.

CRCCs also report that some parents are unwilling to allow young carers to be supported under the Program.

CRCCs also indicated that some parents feel the Program has the potential to undermine their parental authority. Others are said to fear judgement by outsiders of their parenting and to have a strong desire for privacy. CRCCs also report they sometimes encounter a lack of trust in government agencies and a fear of intervention, such as the children being removed from the home. We found that some CRCCs appear to have an insufficient knowledge about their child protection responsibilities. Assessing whether a child is at risk from a child protection perspective is one area where CRCCs are seeking more clarity.

Other CRCCs say parents simply lack understanding of how the Program could benefit their child and conversely, do not recognise that their children may be disadvantaged through their caring role. Parents also sometime express the view that the family is already adequately supported by other respites services.

There is also a low awareness of difficulties faced by young carers amongst some key agencies in contact with young people. For example, the case studies highlight some teachers' lack of awareness of problems young carers face in completing homework and attending school regularly because of their caring responsibilities. Carers Associations have strategies in place to educate key agencies and report some progress in this area but also that they have insufficient resources to make widespread changes in this area over a short time period (section 4.2.3).

### 3.4.2 Strategies used to promote the respite services

CRCCs generally recognise that in order to access hidden young carers, respite services must be promoted to relevant agencies likely to be in contact with young people such as schools, general respite services and health workers. The services must 'reach-out' to young carers as young carers are unlikely to actively seek out respite services. Using outreach strategies is a feature of an effective service model, when measured by identifying clients and successfully meeting their needs (Case studies 1 and 3). CRCCs that do not use outreach strategies effectively have fewer clients compared with other services.

CRCCs use a variety of methods for promoting their service to young carers. Most report using agency network meetings (98%), visits to service providers (81%), giving presentations to community groups (83%) and schools (81%). Three-quarters of CRCCs use brochures for promotion.

#### CRCCs' promotional strategies

Resource	n	%
Agency network meetings	41	98%
Visits to service providers	36	86%
Community presentations	35	83%
Visits to schools	34	81%
YC brochure	31	74%
CRCC forums	29	69%
YC poster	28	67%

Self developed brochure	28	67%
Local newspaper	19	45%
Other	19	45%
Radio	14	33%
Self developed poster	11	26%
Self developed website	5	12%
Carebus	3	7%
Self developed DVD	2	5%

Source: CRCC Survey. Multiple responses permitted.

The most successful promotional activities are said to be agency network meetings (55% CRCCs nominated), and visits to service providers (50%). Young Carers Program workers attend interagency meetings to raise awareness of young carers and also participate in reference groups for other services. Examples of service providers targeted for visits by workers include youth pathways officers, local councils and mental health services. One CRCC in Tasmania is promoting the service via Centrelink. The CRCC has an agreement with local Centrelink Office (Carer Support Position) to send a package of young carer resources including information about the service to all young people under 25 (on their database) who are receiving a Carers Allowance or Carers Payment.

Just over a third of CRCCs nominated visits to schools (38%) as a successful promotional strategy. CRCCs have sent letters to schools, presented at staff meetings and developed posters for display in school premises, with varying levels of success. Nevertheless, just under two-thirds (64%) of CRCCs said that school staff were willing to engage with the Program on the most recent occasion they approached a school.

In South Australia, schools became more engaged in the Program when young carers' issues were recognised at a policy level within the Education Department. One Tasmanian Centre changed their approach after being told that the schools don't have young carers. The worker described the profile of a young carer more explicitly (late getting to school, misses school), and referrals increased. In Darwin, the young carer worker has used a range of strategies to engage school counsellors and class-based teachers (case study 2).

Interviews with CRCCs reveal that some young carer workers lack skills or knowledge of school networks/systems and find it difficult to engage schools. Others report that some teachers lack knowledge of and interest in young carers' issues and have other more pressing student welfare priorities.

### **CRCCs rating of schools' willingness to engage with the Program on the most recent occasion they were approached**

<b>Rating</b>	<b>N (CRCCs)</b>	<b>N %</b>
Unwilling	3	8%
Willing	23	64%
Very willing	10	28%
<b>TOTAL</b>	<b>36</b>	<b>100%</b>
No data	6	

CRCCs generally agree that in order to change attitudes towards supporting young carers amongst young carers and their families and some service agencies, it is necessary to do more to promote community awareness of young carers' issues and available services for them. There was a common view that a national

marketing campaign about the role of young carers is needed and a national brand (logo) for the Program. A Qld CRCC has developed a sample logo for the Young Carers Program. Carers Australia has developed a logo for information materials for Young Carers but CRCCs see the logo as belonging to Carers Australia and not available for general use by respite services.

The information materials developed by Carers Australia are about young carers rather than services for young carers. The lack of information about the Program itself is seen as gap. As a result, CRCCs have developed their own brochures about the respite services for young carers.

### 3.4.3 Referral pathways

According to CRCCs, young carers hear about the service mainly through their teachers or other school staff, through friends or family, or through disability, youth and other health services. Some families are already involved with other programs under the CRCC, which has resulted in referrals to the Young Carers Program. In remote services, it is common for a referral to come through a CRCC because the family is known to the service. One CRCC in Tasmania is using Centrelink as a referral agency and a Victorian CRCC both makes and receives referrals from a project funded under the Children of Parents with Mental Illness Program.

The young people confirmed the evidence from CRCCs, finding out about the Program through school counsellors, parents, via another respite service and hospital social workers. Few contacted a CRCC service directly, with an adult generally doing so on their behalf. Young carers were motivated to consent to support because they wanted help for themselves or the person they care for and because the social activities appealed to them (section 5).

Interviews and discussion groups revealed that referrals tend to be informal, either by phone or email, if a service is unclear about the appropriateness of a referral they will speak to the Young Carers Program worker directly. One Queensland CRCC has formal processes in place to ensure referrals are appropriate and that referral agencies understand who is eligible for the service. Without formal processes there is a risk referrals will not be made. For example, one community stakeholder we spoke to knew about the Program but did not have details about who and how to make referrals and, as a consequence, had not made any referrals.

#### Main ways young carers hear about the service

<u>Response</u>	<u>N</u> <u>CRCCs</u>	<u>%</u> <u>CRCCs</u>
Teachers or other school staff	18	43%
Friends or family	18	43%
Disability services	16	38%
Youth services	15	36%
Other health services	15	36%
CRCC advertising	13	31%
CA State office staff	11	26%
Other	10	24%
CA local branch staff	6	14%
Mental health providers	6	14%
Centrelink	6	14%
CA website	5	12%
CA brochures eg YC kit	2	5%
Drug and alcohol services	2	5%

Source: CRCC Survey, Feb 2008. Multiple responses permitted.

CRCCs stated that referrals are increasingly complex as the Program gets better known by “first-to-know” agencies.

### 3.5 Service delivery

A detailed description of how the respite services are being delivered in three separate locations can be found at the end of this section in the case studies. This section provides an overview of how respite services are being implemented.

#### 3.5.1 Operation

The way the service is delivered reflects the amount of funding CRCCs are given to implement the Program. The service may be delivered by a dedicated worker/s with support from other staff from time to time or become part of a generalist respite worker’s duties, depending on available funding.

The number of full-time equivalent (FTE) staff designated to work with young carers ranges from none to 2.5 FTEs, with 43% of services operating with one FTE staff member or less.

The survey results show that 58% of CRCCs have one staff member working directly on the Young Carers Program, a third of CRCCs have two staff and a small number have three staff. A quarter of CRCCs have two staff members working indirectly on the Program, while a third of CRCCs have four or more staff working indirectly on the Program.

Just over half of CRCCs (58%) report that they require staff who are working directly with young carers to have formal qualifications, ranging from certificates to degrees, and sometimes stipulating the area of qualification, for example, welfare, social science, youth work, education.

There is also a broad range of ways brokerage funding is being used from brokering direct respite support to brokering organisations that provide skills-based camps or tutoring. For example, it is not uncommon for CRCCs to broker out tutoring and domestic assistance. One service in Tasmania brokers all services both indirect and direct through 43 partnerships with other services. Services also broker out direct respite with a substitute carer coming into the home to provide time to complete homework or out-of-home care.

#### 3.5.2 Types of services provided

CRCCs offer a wide range of services including a mix of indirect and direct respite services, with indirect services being more commonly provided than direct respite services. The mix of services has evolved over time and been driven by the expressed needs of young carers and by what is age appropriate and fits their family situation. Young carers have demanded indirect rather than direct respite services seeing these kinds of services as giving them respite from their caring roles (see 3.5.4 and section 5). CRCCs also differ in approaches used and mix of services offered.

#### Figure 3.1: Example of case management approach

A CRCC cited a case where two young carers were missing a lot of school because they were caring for a parent with motor neurone disease. The children were sole carers and there was minimal involvement from HACC. The CRCC worker organised 24 hours of respite; arranged for the older child to combine distance education with going to local school; sent both children to a camp; liaised with other support agencies and helped coordinate these and linked the children with the school welfare officer.

Where cases are complex, some services are using a case management approach and developing care plans for the young person. Workers meet with the young person and their family and assist young people to coordinate services for themselves and the care recipient<sup>12</sup>, negotiate with school, refer young people to other services including counselling and Centrelink, assist young people to manage household responsibilities, and link the care recipient in with services if appropriate. CRCCs indicated that many young people need intensive support and/ or a long period of support, and that it can take some time to engage the young person and their family and engender trust.

Over 80% of CRCCs provide domestic assistance (house cleaning and cooking meals), and more than half (60%) reported that this was the most frequently accessed support. A similarly high proportion of CRCCs offer assistance with referrals to other programs for ongoing support. Two-thirds of CRCCs report providing transport, home visits and tutoring for young carers.

A majority of services provide phone call check-ins (emotional support), activities during school holidays, social support and material assistance. Just over half offer Young Carer Camps. Examples of the kinds of social activities and material assistance provided are camps; movie tickets/ vouchers; payment of fees to join sporting clubs; purchase of school uniforms and books; payment of school fees and driving lessons.

Along with domestic assistance, the most frequently accessed supports for young carers are tutoring (48%) and social support, such as social groups (29%). Around one fifth of CRCCs report young carers frequently access transport services.

### Services provided by CRCCs to young carers

<b>Response category</b>	<b>N CRCCs</b>	<b>% CRCCs</b>
Domestic assistance	35	83%
Assistance with referrals to other programs for ongoing support	33	79%
Transport	29	69%
Home visits	29	69%
Tutoring	28	67%
Phone calls/ check-ins	27	64%
Activity days during school holidays	27	64%
Social support (e.g. sports groups)	25	60%
Material support (e.g. school books; school uniforms; gym fees)	25	60%
Young Carers Camps	22	52%
24-hour blocks of respite at assignment or exam times	21	50%
Peer support with other young carers	21	50%
Counselling	21	50%
Skills development (e.g. cooking; budgeting; stress management)	20	48%
Week blocks of respite for recreation, family holidays, camps	20	48%
Case management	20	48%
Other*	16	38%
Mentoring	13	31%

Notes: Multiple responses permitted. \* Other services offered to young carers include anger management, financial advice, driving lessons, vouchers for respite options, Family Day Care, Centrelink support, medical alarms, home and garden maintenance, shopping.

<sup>12</sup> For example: Assisting young people to receive Carers Allowance or care recipient to get medical services.

### 3.5.3 Use of and appropriateness of respite packages

The Program offers two kinds of direct respite packages: blocks of respite which may be provided as 24 hours, one-week or two-week blocks or five hours respite per week during school term. Although young people use direct in-home or out-of-home respite less frequently than other services and these services are not always appropriate, they do provide valuable assistance in specific circumstances.

Young people were said to prefer using the five hour respite as tutoring or domestic assistance rather than as in-home care, where a temporary alternate carer looks after the care recipient. Examples of ways direct in-home respite is used are to provide non-nursing support so that young people can attend after school activities, attend tutoring at school or another location or go to the movies. In-home support may also have the desired outcomes of providing companionship for the care recipient.

Block respite is rarely used as a two-week block, with the preferred use as 24-hour blocks. Just four CRCCs indicated they had used two-week blocks of respite. CRCCs commonly said that young people did not request the two-week blocks and they were unable to use this and regard this kind of respite package as being inappropriate for young people, given their family situations and age. CRCCs indicated young carers more often need shorter and more frequent assistance. Fewer than 10% of CRCCs indicated that direct respite in the form of 24-hour blocks is used frequently. An example of the use of 24-hour block funding is having an adult stay overnight as an alternate carer when a care recipient has been recently discharged from hospital.

There was a common view that allocating and rationing direct respite under one of two ways of delivery inhibits services' ability to be flexible and meet carers' needs. Although half of the survey respondents agreed that five hours respite per week during school terms was sufficient to meet the needs of young carers, only one third agreed that two-week blocks of respite are sufficient.

Direct in-home respite is not always appropriate because young people prefer respite as time out in recreation or to socialise, and some are reluctant to trust other people to care for their family member, particularly when substance abuse or mental illness is involved. CRCCs also report that some parents see direct respite as an insult to their parenting skills or fear others might question their parenting abilities and are unwilling to have 'strangers' in their home. In addition, respite packages are designed around school terms and respite needs are year round.

#### **How CRCCs use block funding**

<b>Block respite</b>	<b>n</b>	<b>%</b>
One two-week block	0	0%
Two one-week blocks	4	11%
24-hour blocks	19	50%
Flexible as needed	8	21%
No requests	7	18%
<b>TOTAL</b>	<b>38</b>	<b>100%</b>
No data	4	

Source: CRCC Survey, Feb 2008.

### 3.5.4 Links with other government services for young carers

Case studies reveal that many CRCCs work with other government agencies to provide support to young people. Workers may simply share information during meetings and/ or make cross-referrals and/ or coordinate support for the young person. Links may be through formal partnerships or informal relationships at the worker level, depending on the service model used by the CRCC. Examples of collaborative partnerships were found with mental health services, Centrelink, youth services, schools.

Developing links with other services is an important strategy in planning for ongoing support for the young carer. Particularly with the increasing complexity of referrals as the Program becomes better known. CRCCs commonly observed that more young people are presenting with complex family situations.

However, CRCCs report that finding alternate support for young people can be very challenging, particularly if there are insufficient resources to employ dedicated workers to develop those links. In rural and remote areas CRCCs may have an additional difficulty, with few suitable youth specific or culturally appropriate services to refer young people to. Other CRCCs report they face difficulties finding suitable counsellors to refer young people to and, in particular, a lack of youth-specific counsellors and/ or male counsellors. A common challenge in getting ongoing support from other agencies is that these that tend to be one-issue focused.

Another common challenge is that it can be difficult to obtain HACC services for young people who are not recognised as being eligible for HACC services. Young people value domestic support via the Program and CRCCs are frustrated that it is difficult to refer young carers to get ongoing domestic support. On the other hand, some CRCCs report that HACC may already be supporting the families of the young carers.

The National Respite Program (NRP) encompasses young carers, but in reality there is fairly limited funding for young carers under that Program. The main targets are carers of the frail aged and to a lesser extent carers of those with disabilities. The Department of Health and Ageing Guidelines state that when considering priority for services for young carers, CRCCs should consider whether the young carers are eligible for FaHCSIA funding – this may mean that young carers outside the definition could miss out on services.

Links with Carers Association's information and counselling services are discussed in section 4.4.

### **3.6 Compliance with and appropriateness of Guidelines**

Although CRCCs have endeavoured to comply with the original Guidelines, it is apparent that there are occasions when CRCCs have interpreted the Guidelines differently in order to be flexible and meet the respite needs of young carers. In fact, 84% of CRCCs who responded to the survey agreed that the Guidelines need to be modified. They commented that the original Program Guidelines are not always relevant or applicable to complex and changing family situations.

In mid-2007, FaHCSIA informed the CRCCs that the Guidelines were to be interpreted more flexibly so that young carers included 25 year olds and young carers in primary education could be assisted through the Program, assessed on a case-by-case basis, and that an extension of the 12-month limit could be considered, if needs were high. CRCCs strongly supported this approach.

CRCCs are providing services to young carers at primary school struggling to keep up with schooling because of their caring responsibilities, under the rationale that in

the long term, they are at increased risk of leaving school early (12% of all cases). CRCCs reveal that in some instances young carers are without any other supports.

Case studies reveal that CRCCs are supporting some young people for longer than the 12-month limit, where required. Most CRCCs disagree with a 12 month limit, commenting that limiting respite for young carers is inappropriate because it fails to recognise the often on-going nature of the caring role and concomitant ongoing need for respite services and the lack of alternate sources of respite.

CRCCs are also providing services to 17% of young carers aged 18–25 years stating that some young carers in tertiary education need respite and lack alternate sources of support. Given the stated lack of alternate support available and the apparent need there is a case for including this group in the program.

STOs and CRCCs also report that, ‘the main provider of care definition is being applied quite broadly in some areas and narrowly in others.’ As a consequence, it appears most CRCCs are, on occasions, taking on client referrals for secondary or alternate carers who they consider may also be at risk of leaving school early. Some young carers although not the main carer, also take on significant caring responsibilities.

Stakeholders (CRCCs and Carers Australia) argue that the scope of the Program should be broadened so that it can prevent and ameliorate mental and physical health problems arising from their caring responsibilities and not narrowly focus on school retention. The Program also misses out young carers who have already left school and are not pursuing vocational education.

### 3.7 Elements of effective practice

The evaluation and the brief review of literature have revealed key elements necessary to engage young carers and meet their respite needs.

These elements are:

**Choice:** offer a range of services, both indirect and direct and allow young carers to choose activities and services that will best meet their respite and support needs. The issues faced by young carers may be complex or simple, as young carers have variable family situations and caring roles. As one young person commented, ‘Organisations should realise that every carer is different because the people they care for don’t have the same thing’. Available services could include: recreational opportunities; personal support (informal and formal counselling); domestic assistance; tutoring; and in-home respite.

**Outreach and networking with key ‘first-to-know’ referral agencies:** it is necessary to work with key referral agencies including schools, health services and disability services to access young carers. Young carers commonly do not think of themselves as carers, nor do they know where to go to for extra support and rarely actively seek help.

**Establish formal referral and intake procedures:** to ensure that referral pathways work efficiently and effectively and so that referral agencies are assured young people are being supported as needed.

**Use a case management approach [case planning]:** to identify young carers’ needs and ensure that appropriate services are provided and on-going support needs are identified and strategies in place to provide these.



**Take a whole family approach:** consult with the young person's family when planning respite services and assist the carer and other siblings where possible. Engagement of parent/s and family is important in meeting young person's needs.

**Offer intensive personal support (where needed):** young people value independent advice and emotional support highly and such support assists young people to manage their caring responsibilities (respite effect).

### 3.8 Conclusions

Implementation of the respite services has been characterised by diverse approaches and levels of commitment, driven by the poor fit between the service model framed in the Guidelines and the expressed respite needs of young people. CRCCs have faced difficulties accessing hidden young carers and sometimes working with this unfamiliar client group. Service delivery has evolved over time to include outreach strategies and a focus on indirect services, rather than direct services, although there remains a place for these. Flexibility in service delivery is a key principle in providing effective respite services for young people.

The original Guidelines were based on a traditional concept of respite, where a respite effect would be achieved when the caring role is formally provided by others on a temporary basis. In practice, direct respite was only occasionally suitable for young people and other services proved to be both more acceptable to young people and to offer a respite effect. A service model, based on using a case management approach and taking into account the family situation is evolving and we recommend that key elements of effective practice – outreach, case management, a family approach, formal collaboration with key referral agencies be incorporated into all CRCC's service delivery. We also recommend that the Guidelines be broadened to allow young people to be supported for more than 12-months and that the definition of "Young Carer" include alternate, part-time main carer or secondary carers as well young carers at primary school and in tertiary education. FaHCSIA should also consider removing the "rationing" of direct respite services to provide further flexibility in service delivery.

A majority of young carers using respite services have significant caring responsibilities, caring for a parent with mental illness or a chronic illness or disability. Many face complex family situations. As such, the Program needs to build on and encourage partnerships with support agencies. For example, stronger links might be developed with the program for Children of Parents with Mental Illness and mental health services at the local service level. Workers may need specific training about mental health issues. Health professionals, in contact with people with mental illnesses and chronic conditions, such as General Practitioners, nurses and social workers will be important sources of referrals.

Another key partner agency is the education sector. Although CRCC workers and Carers Australia are actively promoting young carer issues to schools, the evidence shows there remains substantial work to be done to get the welfare of young carers recognised more broadly amongst school teachers and counsellors. The development of information materials such as the Young Carers Kits is one strategy. However, experience in the health promotion field shows that a broader range of approaches are needed to get new health and welfare issues addressed in schools. One of these lessons is that schools are focused on educational outcomes and it is necessary to demonstrate how the student welfare affects education or links with the syllabus. The evidence is clear that the welfare of young carers does affect educational outcomes. Systems based approaches at the departmental level to direct school welfare policy at the local level are necessary to bring about broad-based change. In the health promotion field, studies have shown that bringing about changes in policy needs a long view and to involve the sector as active

partners in the process. At the local level, professional development is important, as is working closely with key school staff members.

## Case Study 1: Gold Coast

### Context

This Young Carers Program is located in a coastal tourist region, the Gold Coast in Queensland. The community serviced by the Program is fairly transient, and many people move to the area with no family support. The area has only a small number of Indigenous people and people from CALD backgrounds.

The young carers we talked with in this case study area reported that they perform a variety of support functions, including: practical help, such as housework, shopping and cooking; looking after younger siblings; taking care of medications; and organising hospital and doctor's appointments. Young carers reported mixed experiences with dealing with school as young carers:

*'I was in trouble with teachers as I never got my homework in.'*

*'I had teachers saying that just because your mum is going to die is no reason not to do work. I would get expelled from school because I'd get into fights with teachers.'*

*'All my teachers were really nice about it, as soon as my mum was in hospital teachers knew and were really supportive, [they] said I didn't have to go to school if I didn't want to.'*

*'If I missed school they would sit down with me the next day and help me do the schoolwork.'*

Young carers

Blue Care (The Uniting Church in Australia Property Trust) has auspiced the Young Carers Program for two years. The Program employs a full-time project officer to promote the Young Carers Program, respond to referrals to the Program and assist young carers to access services for support. Over the last three years the service has assisted 37, 51 and 41 carers in each year respectively.

The project officer's case load is currently around 50 young carers, with around a third classified as high need. Currently 75% of the young carers are female, and 25% are male. A profile of the ages of young carers accessing the service in 2006/07 is provided in the table below:

Age range	% young carers 2006/2007
<12 years	16%
12 – 14 years	37%
15 – 17 years	37%
18 – 21 years	8%
22-25 years	20%
All	100%

About half of the Young Carers Program clients are from low socio-economic backgrounds, with the bulk of the families being either split, single or blended families. The Program coordinator commented that it has been difficult to access the Indigenous and CALD communities.

Other CRCC staff are occasionally involved in the Young Carers Program, for example a female Carer Support Officer has provided support when a female is needed (e.g. single parent father needed support when his daughter was going through puberty and he was unsure how to handle that). This female Carer Support Officer has also attended young carer excursions.

Blue Care manages the CRCC in the West Moreton/ South Coast (Gold Coast) Region, which includes the Young Carers Program. The funding for the Young Carers Program at the Gold Coast represents a small part of the overall funding the CRCC South Coast receives, accounting for 8.9% of the total CRCC South Coast budget. The CRCC coordinator reported that the CRCC subsidises the Young Carers project officer's wage with funding from other sources, as the Young Carers Program funding received from FaHCSIA is insufficient to cover a full-time wage. A full-time staff member is required to meet the ever increasing numbers of young carers on the Gold Coast.

### **The service delivery model**

Key functions of the service delivery model are:

- Outreach and promotion activities
- Formal referral and intake processes
- Case management.

#### Outreach and promotion activities

Program staff report that locating young carers can be challenging, particularly as young people often do not recognise their own status as being a 'young carer' until they are identified as such by a service or the Young Carers Program. Therefore, promotional and outreach activities are considered to be an important aspect of the Program delivery, supporting the identification of young people who will benefit from the support the Young Carers Program can provide.

The outreach and promotional activities undertaken have been targeted towards the development of a greater understanding and awareness of the Program amongst other agency stakeholders, such as schools, as well as broader community awareness.

Promotional activities include:

- visiting secondary schools and primary schools, and some private colleges
- providing all school guidance officers in the region with a 'Young Carers kit' developed by the local Young Carers Program
- attending school guidance officers' meetings twice a year, and presenting a young carer case study
- attending monthly interagency meetings, where up to 200 services attend, many of which are youth services
- placing young carer stories online
- disseminating young carer brochures in libraries
- promoting the Young Carers Program on the radio
- highlighting the Young Carers Program in the annual report of the Program's auspice, and in general auspice advertising
- incorporating Young Carers Program information in other promotional tools, e.g. local support services card.

The Program plans to target future promotion to GPs.

There is evidence that the outreach and promotional activities have been effective:

- external agency stakeholders report that schools have a greater awareness of the Young Carers Program and the needs of young carers
- the Program has received referrals from a range of agencies and individuals
- young carers we interviewed reported finding out about the Young Carers Program through a variety of sources, including: their school counsellor; teacher's aide; their parent; their parent's carer; their parent's psychiatrist; a nurse at the hospital their parent attends; and through the local representative at Carers Queensland.

*'[our organisation is] starting to become more aware that there are young carers'.*

Stakeholder from a family support organisation

Program staff identified challenges when undertaking outreach and promotional activities. Some private colleges approached resisted engagement, reporting that they do not have any young carers. Staff addressed this by providing information to support these schools' identification of young carers. It was also reported that the production of promotional materials has been expensive and time-consuming. It was suggested that cost savings may be achieved across the Programs if promotional materials were developed centrally and made available to CRCCs.

### Formal referral and intake processes

The Program has consistently had four to five referrals to the Program every month for the last few months. Referrals come from a range of sources, including local MPs, local representatives of Carers Queensland, school guidance officers, from within the CRCC, parents of young carers, and young carers referring other young carers.

Referral calls made to the CRCC are handled by an Intake Officer who passes on appropriate referrals to the Young Carers project officer. All referrals are responded to within 24 hours.

Following the receipt of a referral from a stakeholder agency, the Young Carers project officer meets with the referring agency to discuss the family's background and support needs. The Gold Coast Young Carers Program has developed protocols to guide this process, which include gaining consent from the family for the meeting to take place.

The project officer then undertakes a home visit with the young carer and their parent(s)/ guardian to inform them about the support that is available under the Young Carers Program. The Gold Coast Young Carers Program has developed a booklet, *Guide to Service Provision*, to support this.

Effective and sensitive engagement of parents is considered to be important to the success of the Program's engagement with the young carer, and the delivery of the Program to them. The Program staff discussed the complexities of providing respite, with some parents seeing it as an insult to their parenting, and others worried that the Department of Child Safety will remove their children. From a safety aspect, all parents appreciate meeting the project officer so they know who their children will be speaking to and seeing.

*'You're dealing with a package – carer and care recipient – and you have to be sure you don't step on the parenting role; if parents feel threatened that you're questioning their parenting ability, they'll step back'.*

Program staff

### Case management

This Young Carers Program has adopted a case management approach, key features of which are:

- the development of a care plan
- regular contact with the young carer to monitor progress and provide emotional support
- regular communication and referrals between agency stakeholders
- exit planning.

If the young person decides to join the Young Carers Program, a care plan is developed with the young carer. The care plan identifies the young carer's support needs, along with the services and support that can be provided to address them. If the young carer is in crisis mode, the project officer can organise immediate support to address the pressing issues, for example pay bills, supply food, and then they focus on supporting them as young carers.

The realisation of the case plan often requires multi-agency delivery of services, with the project officer brokering services from a range of other agencies. The project officer makes referrals and advocates to these agencies on behalf of the young carer. Services purchased to support young carers include:

- **Practical support:** such as domestic assistance, school equipment, transportation of the care recipient
- **Emotional support:** some young carers have been referred to various counselling services
- **Educational support:** including tutoring
- **Social support:** most of the young carers have been on young carer camps and/or been involved in other activities such as kayaking, mountain climbing, craft activities.

The Program may also access services through a Church-based organisation, such as food (e.g. all the young carers we spoke with had received a Christmas hamper), part payment of phone bills, and is active in attracting donations from a range of organisations, e.g. clothing, computers.

Direct respite is generally provided only in terminal or chronic cases.

There have been instances when the project officer has also linked other members of the family to appropriate support services to address issues the parents are facing, but for which they are not currently receiving support.

The project staff commented they are satisfied with the quality of the service providers they use, and have memorandums of understanding in place which outline the expected service delivery. The project worker has regular communication with the referring agency and stakeholder agencies engaged in delivering the care plan, to monitor delivery and keep them informed.

*'Communication between us is important so we're doing the best thing for the family'*

Stakeholder from a family support organisation

The care plan developed by the project officer includes an exit plan. Examples of exit strategies include: linking a young carer into the Army Reserve; supporting a young carer in achieving an apprenticeship; and, linking a young carer with a job at a boat company. Project staff commented it would be preferable to follow a young carer until they exit high school, regardless of the age at which they entered the Young Carers Program (i.e. for more than 12 months if appropriate), as it is sometimes difficult to know where to refer young carers when they approach that crucial point heading into their senior years at high school.

The Young Carers project officer stays in regular contact with those young carers in his current case load. Young carers reported that they appreciated the emotional support provided through regular contact with the project officer.

*'The Young Carer worker rings me once a fortnight and I talk to them about any problems I may have – I've rung them twice to talk about problems I'm having'*

Young carer

### **Links with Carers Queensland - Information and Support Service**

The Young Carers Program workers reported having limited contact with the main State Carers office. However, they have close ties with the regional office, working on joint activities and referring to each other's service frequently.

The Program has received Carers Queensland 'Young Carer Support Kits' for young carers when they have asked, however they would like to be able to have a stock of kits so that they could give them to the young carers' families at the first visit.

### **Impact of the Program on young carers**

The Program aims to help young carers better balance their caring responsibilities with their education, and ultimately, to improve education outcomes and family stability.

Stakeholders report many positive benefits of the Program:

#### *Social connectedness and respite from caring role*

Young people reported having fun at the young carers camp and participating in social activities.

Stakeholders identified the benefits of young carers attending activities, and reported that camps *'take the young people out of their comfort zone, build self-esteem and confidence'*. They also reported that they have *'seen parents relax as they've seen their children [young carers] enjoy themselves in activities run by the Young Carers Program'*.

Stakeholders also said they have seen young carers make new friends through the Young Carers Program.

*'Through meeting other young carers, young carers know they are not alone.'*

Program stakeholder

### Educational benefits

Young people reported feeling more confident about managing their school studies as a result of receiving tutoring.

*'I was having trouble with Maths and the tutoring made me understand.'*

*'I feel more confident, I was always down as teachers put me down, [the tutor] helped me learn more words so I would do better on spelling tests.'*

*'I talk to the Young Carers worker re how to deal with teasing'*

Young carers

### Mental health benefits

Young people appreciated the emotional support, and being able to talk to someone outside the family about their caring role and the difficulties they face:

*'All I ask for is someone to talk with, and the Young Carers Program worker is really good and he's interested in my school activities as well, he's a really great person.'*

*'Knowing the Young Carers Program worker is there and I can talk to him and he pops around and if I need anything he's there.'*

*'When I'm having a bad day, I ring the Young Carers worker to talk to him'*

Young carers

### Support with caring responsibilities

The Program was also reported as having wider benefits for the whole family, ranging from practical outcomes as a result of domestic assistance, to reducing stress for the care recipient and other family members.

## Case Study 2: Darwin

### Context

This Young Carers Program is located in the heart of Darwin in the Northern Territory (NT). The Program services 75% of the population of NT (200,000). It extends across an area over 800,000 kilometres from the east and western borders, to the islands off the top of NT and as far south as Elliot, 400 - 500 kilometres north of Alice Springs. One of the challenges for the Program is a large area to cover and small population.

Most of the young carers we spoke to supported a family member with some form of intellectual disability, including autism, dementia, ADHD or global delay. Some of the young carers supported multiple family members. For example, one young carer helped their mum who had a physical disability, their grandmother with dementia and their sister with autism. Often the caring is shared amongst siblings. These young carers helped with various family supports, including practical support (such as getting siblings ready for school, cooking, cleaning, bathing and showering), and developmental support (developing communication skills, managing behaviours).

In Darwin, the Young Carers Program is under the auspice of Carers NT. There are two sections of Carers NT, the CRCC and the Carer Advisory Service which provides carer counselling, education and training for carers and service providers. This co-location of services is considered to enable seamless service provision to the young carers it supports.

The number of young carers assisted by the Program for Darwin is relatively low compared to other Young Carers Programs, but is reflective of the funding available.

Program funding can pay for a Young Carers Program staff member for one day per week. The demand for young carers' assistance, and the complex needs of the young carers in the Program, has led Carers NT to supplement the funding from FaHCSIA to deliver a holistic and enhanced service to support young carers in 2007/08. Not having a designated worker resulted in low identification of young carers due to a lack of experience and misunderstanding of Program Guidelines amongst general staff.

Additional funding has been drawn from the NT Government's funding for carers, a proportion of the respite funding received from Department of Health and Ageing (DoHA) and small grants. The additional funding enables the employment of a full-time young carer worker to coordinate the Program.

The move to the full-time young carer worker is reported to have led to a more successful approach as the service can be promoted and relationship development can occur with young carers.

### The service delivery model

The co-location of the CCRCC and the Carer Advisory Service has informed the service delivery approach implemented in Darwin. In particular, the co-location has facilitated easy and timely referral of young carers for specialist services such as counselling, education and training.

Key activities undertaken by the Darwin Young Carers Program are:

- Outreach and promotional activities to raise awareness of the Young Carers Program, and support external agencies' identification of young carers in need of assistance
- Intake and referral processes to identify young carers to the Program
- Brokerage of services to address young carers' needs
- Provision of emotional support to young carers by the young carer worker
- Research activities to inform Program development.

#### Outreach and promotion activities

The Program has been constrained in its ability to promote itself largely due to limited funding. However, Young Carers Program workers have been able take a much more active role in promotion since the funding for the Program was increased and the creation of a full-time position. A staff member comments, *"We advertise via our networks rather than public ads."*



Promotional activities include:

- distributing Carers Australia kits to schools
- speaking to counsellors
- promotional activities in secondary schools during Carers Week
- convening social activities and networking opportunities
- visiting other services to educate them about young carers.

The coordinator reports that service providers engaged in these activities are often surprised that the need to support young carers is an issue, and that the caring role has such an impact on the young people who are carers.

It was clear from conversations with some of the young carers that the Young Carers Program worker had made significant inroads to building a relationship with the younger carers' schools. The young carer worker had visited schools in the weeks preceding the 2006 Carers Australia Young Carers Summit and selected young carers to represent their school at the Summit. The worker has assisted some schools to establish young carers groups. One young carer comments:

*'We had a young carers group which met every Tuesday for a whole year...sometimes just the young carers would show up, sometimes you could bring your friends along and then they would get to know what young carers were.'*

Young Carer

The co-location of the CRCC and Carer Advisory Service appears to have enhanced young carers' access to the Program. A number of the young carers' first contact with the Program was via events conducted during Carers Week facilitated by Carers NT Advisory Services. The broader activities of the CRCC also act as outreach services for the Young Carers Program. For example, some of the young carers involved with the Young Carers Program have previously been involved in Carers NT through Croc shops (Croc shops provide fun activities for the siblings of children with a disability with an underlying theme, such as feelings).

Key issues and challenges associated with promotional and outreach activities include:

- Service providers are not acknowledging that young carers exist, as conveyed in the following comment from Program staff:

*'People choose to say these things don't happen. Some perceive 'young carers' as being in an abusive relationship.'*

Young Carers Program staff

- There are challenges associated with reaching young carers supporting a family member with a mental illness. The staff member from a youth drug and alcohol service that had seen young carers commented that young carers do not realise how much caring for someone with a mental health problem is different to a physical disability.
- One of the young carer's tutors suggested that the eligibility criteria for the Program could be better communicated to stakeholders and young carers, as a girl they had tutored did not know she was eligible for free tutoring until late in her schooling.
- Program staff also reported some challenges in identifying and supporting young carers, particularly in relation to accepting financial support via the Carer payments and Centrelink. They comment:

*'Young carers don't want to get paid to do this, it's out of love. It's their expected role. They don't realise they have special needs.'*

Young Carers Program staff

#### Formal referral and intake processes

The Young Carers Program worker has developed referral relationships with a variety of 'first point of contact' services, including Carpentaria, an early intervention service, and schools. Formal referral processes have been set up for agencies wishing to identify a young carer in need of assistance.

All referrals are received via Carers NT general respite and they are subsequently forwarded to the Young Carers Program worker at weekly intake meetings. Referrals have been received from counsellors, mental health, the Aged Care Assessment Team (ACAT) and self referral. However, a major avenue for young carer referrals is informal via the general respite intake for carers. Staff report, *"We operate as an individualised service not a call centre and we try to meet with them face-to-face...Mum rings regarding her own problems or difficulties with the child with the disability and we become aware of their siblings with carer needs."* The young carers are normally invited first to a social activity, such as going cart racing, which is paid for by Carers NT through applying for small grants of funding.

One challenge identified by Program staff is that the funding for the Program needs to last all year. This means Program staff are under pressure to space the introduction of new young carers into the Program across the year, rather than take them all at once. However, rather than use waiting lists, the service tries to overcome this issue by supporting the young carers with other Carers NT services using alternative funding sources.

#### Brokerage of services

A broad range of services is required to respond to the complexity of issues present within young carers' families. A young carer's needs are determined through a review of the referral information and an initial meeting with the young carer and their family. Young carers' needs are monitored through regular contact between the Young Carers Program worker and the young carers, as well as through ongoing communication with referring agencies and brokered service deliverers. Some of the more formal features of a case management model were not present, such as use of case plans and exit strategies.

The young carer worker spends a small amount of time brokering respite and other services, with the main focus of their time being spent on information provision, emotional support and education. Services and assistance brokered to support young carers include:

- **Financial support:** Material aid such as: school fees; computers (contribution to a portion of the cost); funding for hockey trips; purchase of school uniforms; purchase of mobile phones
- **Educational support:** Tutoring
- **Social/recreational support:** trips to Zone 3 (an outdoor recreation centre)
- **Direct respite:** There are two young carers receiving support for palliative care
- **Referrals to drug and alcohol services:** A local youth drug and alcohol service had received complex referrals for young carers with drug and alcohol issues supporting a family member with a mental illness.

A major challenge identified by the Program staff has been meeting the needs of young carers in Indigenous communities. A staff member comments:

*'We know indigenous communities have young carers but we don't have the resources to meet their needs.'*

Young Carers Program staff

#### Emotional support

The young carer worker has regular telephone and face-to-face contact with the young carers to provide emotional support. One young carer commented that the worker would on occasion support them in their home:

*'Just to have dinner with them or really just be there for them... someone to be there just to join in and make a night not seem like all the other nights and have someone there just for a night.'*

Young carer

### Research

The service is also taking some proactive steps in championing young carer issues. For example, another part of the young carer worker's role is to develop infrastructure to allow the service to do research into resilience training programs for young carers, this is done in association with Charles Darwin University's Faculty of Social Work.

### **Links between Carers Australia Information and Respite Services**

The CCRCC is co-located with Carers NT, providing young carers with seamless access to Carers NT services, including counselling, education and training. Program staff commented that the CCRCC and Carer Advisory Service are in the same building and that the young carer worker attends the staff meetings of both services.

### **Impact of the Program on Young Carers**

Stakeholders report many positive benefits of the Program:

- Social connectedness
- Respite from the caring role
- Educational benefits
- Mental health benefits
- Stronger families.

#### *Social connectedness and respite from caring role*

Program staff report that the respite reinvigorates the young carers and they see that they need to look after themselves to have multiple roles. A few young carers reported making new friends and feeling more able to confide with their friends their caring responsibilities. Some of the young carers evidently had a very close supportive relationship with the Young Carers Program worker.

Comments by young carers also illustrated that the Young Carers Program worker facilitated social connectedness for young carers, as expressed in the following comment:

*'If you need to call someone and you don't know what to say... She'll ring that person for you.'*

Young Carer

Young carers reported greater social connectedness from participating in young carer events, such as the Young Carers Summit, including the recognition that they are not alone as young carers.

#### *Educational benefits*

Young carers reported educational benefits, such as exemptions from schoolwork if needed. One young carer said that although they never used home work exemptions it was helpful knowing that they had that option if they got busy with caring.

One of the young carers received a computer to assist with study. Previously, they had to use the library computers to complete their homework. Program staff report that the young carer is in Year 11 so it has made a big difference for them now at home.

Some areas identified by stakeholders for improvement included the need for better communication between teachers, the tutor and the Young Carers Program staff. For example, the Young Carers Program worker had not followed up some young carers' progress with their tutoring. Tutors also commented that some young carers needed help with motivation to stay committed to the tutoring, reporting that one young carer had not turned up during scheduled tutoring sessions.

*Mental health benefits*

Stakeholders noted emotional growth as some of the benefits from the Young Carers Program. For example, one young carer's tutor reported that the young carer got a sense of satisfaction from writing.

*Stronger families*

Parents realise that the focus is normally on their child with the disability, and that the young carer also has needs.

## Case Study 3: Geelong

### Context

This case study has been taken from the Geelong Young Carers Program. Geelong is the largest regional city in Victoria, (population approximately 197,000).

The young carers we talked with undertake a variety of support tasks, including:

- **practical** – such as helping with shopping, washing clothes, doing the dishes, cleaning, cooking, driving
- **looking after siblings** – such as *'getting my brother ready for school'*
- **medical support** – for example, attending the doctor with their parent, and organising medications.

Although most of the young carers felt that being a carer has not impacted on their experiences at school, a small number commented on teachers not being sympathetic when they have been late to school. One young carer summed up the difficulty in balancing schoolwork and her caring role:

*'I got pulled up for wagging and stuff and like 'I'm at home with mum' and they're like 'well everyone cares for their mum' and I'm like 'well you don't understand'. I don't want to be treated differently but ... it's not like I've purposefully put off my homework. So it did get really hard at school.'*

Young carer

Barwon Health delivers the Young Carers Program across the Barwon South West Region. The Program has a full-time Young Carers Program worker located in the Geelong main office, and a 0.2 position located in rural South West of the region in Warrnambool. The Young Carers Program worker position began as a 0.5 role, but two years ago it became necessary to make the position full-time. A manager from Barwon Health oversees the Program, with 10% of their time devoted to the Young Carers Program.

Over the last three years, the service has assisted 48, 62 and 56 young carers in each year. Project staff commented they have no difficulty in locating young carers, with the full-time Young Carers Program worker currently having a case load of 50-60 young carers. Most of the young carers we spoke with have been involved with the Program for two to three years.

The majority of the young carers are caring for someone with a mental health issue, and most are from single parent families. A significant proportion of young carers assisted by the Geelong Young Carers Program (19%) are aged less than twelve years.

Age range	% YCs assisted in 2006/07
<12 years	19%
12-14 years	15%
15-17 years	42%
18-21 years	16%
22-25 years	8%
total	100%

### The service delivery model

Key functions of the service delivery model are:

- Promotional activities
- Intake and referral procedures
- Case management.

#### Promotional activities

The Program has focused on building awareness amongst agencies/ services and schools in the Geelong area to support the identification of young carers who could benefit from the Program.

- **Promotion to agencies/services:** representatives of the Geelong Young Carers Program attend local interagency meetings and visit other services, particularly youth, and mental health services. The workers recently had a stall at the launch of a new

initiative called 'Headspace' (the National Youth Mental Health Foundation).

- **Promotion to schools:** the Young Carers Program has targeted a geographical spread of schools, and plans to visit two to three new schools each year. The Young Carers Program worker has also been involved in school open days, recently hosting a stall at a college open day. One school advertises the Program to other staff within the school and through notices on the student bulletin.

The Geelong Young Carers Program is currently developing promotional activities that target young people, supporting self referrals. Workers recently held a focus group with young carers to design a promotional tool that would appeal to young people. The result was the development of a 'flag' pen containing information about the Young Carers Program. The pen will be officially launched and distributed to young carers and schools.

The Young Carers Program worker is yet to undertake promotional activities that specifically target the CALD community. They consider that such activities will require additional resources because young carers in CALD communities are not identifying themselves as young carers.

There is evidence to suggest that the promotional activities to agencies/ services are supporting the identification of young carers, with referrals being received from a range of agencies/ services such as health services (including mental health) and palliative care. However, Program staff commented that despite their promotion of the Program to schools, they have not received many referrals from schools. The young carers we spoke with found out about the Young Carers Program from either a local health service with which they were involved, or from their mother.

#### Intake and referral processes

The Geelong Young Carers Program has formal intake and referral processes. All referrals to the CRCC are taken by the Intake and Response Team, and appropriate referrals are passed on to the Young Carers Program worker. The Young Carers Program worker follows up the referral with an initial discussion with the referring agency, followed by a written contract. The worker then meets with the young carer and their parent to explain the Program and their role.

During the initial stages of contact, the Young Carers Program worker provides the young carer with emergency contact numbers and a Carers Australia kit. If appropriate, the Young Carers Program worker asks what school the young carer attends and, with the young carer's permission, makes contact with the school's welfare officer to organise appropriate support the young carer may need, e.g. counselling.

The initial stages of contact with the young carer and their family can take some time, as trust needs to be established and the young person needs to understand and recognise their role as a young carer and their need for support.

Stakeholders reported satisfaction with the thoroughness of the referral process.

#### Case management

The Program uses a case management approach, including: assessing a young carer's needs; providing planned support and indirect respite services for young carers to meet their needs; and, reviewing and monitoring of the care plan.

At the outset an assessment is undertaken of the young carer's needs using the SCoTT tool (Initial Needs Identification and Care Planning) and the Carer Identification Form. The Young Carers Program worker then develops a care plan with the young carer to address their identified needs. The care plan is reviewed every three months. Young carers whose parents are very ill and receive limited family support are provided with 'intensive packages', which involve more regular contact.

A key approach used by the Geelong Young Carers Program is a voucher system, whereby young carers are provided with vouchers (in denominations of \$5 and \$10) which can be redeemed at businesses throughout the region, e.g. restaurants, respite services, recreational activities. For example, a young carer may use the vouchers for direct respite to enable them to undertake a social activity, e.g. a respite worker taking the young carer to the cinema. The vouchers are given to young carers according to their need, established

through their needs assessment and development of their care plan. If a young carer wants to do an activity that is not covered by the vouchers, the Young Carers Program worker will aim to organise it.

Other support includes:

- **Practical support:** help with cleaning and cooking; organising driving lessons; taking carers to and from school; budgeting
- **Educational support:** linking young carers into the St Vincent de Paul Society, which has paid for school books and school excursions; liaising with a school to help out with school fees; arranging tutoring
- **Emotional support:** linking young carers with the Carers Australia counselling service; the Big Sister Big Brother program; an educational group for young people living with mental health issues; arranging a young carers forum with guest speakers talking on subjects such as 'looking after yourself' and 'stress and anxiety'; peer support days
- **Social support:** holding activity days each term, one for younger young carers under the age of 12, and the other for over 12's; linking young carers in with young carer camps held in conjunction with other Young Carers Programs; belly dancing classes; music tuition.

The Young Carers Program worker also produces and sends a newsletter to all the young carers, and emails young carers about any appropriate information or notice of upcoming activities.

The young carers talked about how quickly the Young Carers Program worker organises the support they request, and they reported that there is nothing they have asked for that the worker has not been able to help with. They also commented that they appreciated the Young Carers Program worker consulting with them about what they would like to do:

*'On the group day, she asked us to request or give her ideas of what we'd want to go and do instead of her setting out something and us not liking it. We can all suggest things we want to do'*

Young carer

A respite service, with which some young carers are linked, aims to use young respite workers to go out with the young carers and tries to use the same worker with the young carer for each outing.

Project staff reported that they are satisfied with the experience and skills of the services to which they broker:

*'We have regular liaison with the providers we use. We use the respite services that Carer Respite [within the CRCC] uses, they are of high quality.'*

Program manager

The Geelong Young Carers Program adopts a holistic approach to working with young carers, by ensuring that case management is undertaken in the context of wider family needs and the young carer's role within the family. Young carers have been supported with household management activities (such as budgeting, cooking and cleaning) where their parents have been unable to undertake these tasks. If a case manager from another agency or program delivered by the CRCC is already involved with a family, the Young Carers worker organises (with the permission of the young carer and the care recipient) for themselves and the other case manager to visit the family together in order that each worker is aware of how they are working with the family. In addition, if considered appropriate, the worker links the parent being cared for into appropriate services.

*'You can work with the young carer, but it's difficult to ignore the rest of the family's needs'*

Program worker

### **Links with Carers Australia Information and Support Service**

The Program has not had any referrals from Carers Victoria, but has referred young carers to Carers Victoria for counselling. One young carer commented that the counselling provided by Carers Victoria was very useful:

*'Yeah, it was good. It helped me. I had trouble at the end of Year 12 so I went there then, and now everything's just blown up again and so I'm going there for another 6 [sessions]'*

Young Carer

The Young Carers Program workers have contact with Carers Victoria at regular respite manager meetings and Young Carers Program worker meetings. The staff commented that, at first, they could not access the Carers Australia Young Carers Kits directly as they had to go through Carers Australia to obtain them, however now they can access them directly, and have stock available on site.

A few young carers we spoke with had accessed the Young Carers website, and commented it was fun and easy to access and they particularly liked the story about being a young carer. One young carer suggested an improvement:

*'It has an info page for primary school and secondary now, and that's all in really difficult words so I think they need to have an info page to us about us, rather than to the teachers about us and stuff'*

Young carer

The Program is currently planning a joint promotional activity with Carers Victoria in Youth Week promoting the Young Carers Program.

### **Impact of the Program on young carers**

Program staff reported that the Young Carers Program was meeting young carers' needs in the Geelong area because they have chosen to deliver assistance in a flexible way in accordance with the needs of the young carers. The key benefits of the Program, identified by the Young Carers Program workers, are:

- young carers meet new friends, reducing their isolation
- young carers participate in social activities which they may not normally have the chance to do because of their caring role
- young carers are more accepting of their status as a young carer, and may be more comfortable about telling more people about their role
- tutoring has helped young carers cope better at school
- less stress on the family through support such as domestic and financial assistance.

The Young Carers Program workers encourage feedback from young carers on what they think of the support and respite that has been provided to them. In general, the feedback has been very positive, and this was corroborated by the young carers we spoke with. The young carers identified a range of benefits from their engagement with the Program:

*'I get to meet other young carers – good to know that I'm not the only one and they know what I'm going through as well'*

*'Just time to get away from everything'*

*'My school didn't really know about my issue so I advocated it at my school ... I think it's gotten better.'*

Young carers

A young carer also commented that the Young Carers Program worker had taught her not to be ashamed of what was happening in her life. A school stakeholder commented on the positive support provided by the Program to a student she had referred.

*'The student found it very supportive and very helpful. It gave her "time-out to be a kid". The student received support that was flexible, user friendly and tailored to her needs.'*

School stakeholder



## **4 Implementation of the information, referral and advice service**

This section describes how the information, referral and advice services component, called the “Supporting Young Carers Initiative” has been delivered by Carers Australia and the State and Territory Carers Association.

A brief case study about how Carers Victoria’s Young Carers project operates is provided at the end of this section.

### **4.1 Background**

Carers Australia is the national peak body for carers and is responsible for carriage of the Young Carers information, referral and advice service. The organisation comprises eight State and Territory Carers Associations (members) and regional offices within the Associations. The organisation operates with funding from government, private sources and donations from the general public.

The Commonwealth Department of Health and Ageing funds Carers Australia and the State and Territory Carers Associations to provide information, specialist advice and training for all carers and the service sector. These funds also cover services for young carers, but prior to the Young Carers Program were insufficient to fund specific activities promoting the availability of information and advice services to young carers.

### **4.2 Development and distribution of information resources**

Carers Australia was funded to develop and distribute resources via the State and Territory Carers Associations.

Specifically, Carers Australia was contracted to reprint and distribute the Young Carers Information Pack and other resources; establish information networks with other NGOs working with young carers; maintain and update the Young Carers website and maintain and facilitate meetings of the Australian National Young Carers Advisory Team (ANYCAT). Carers Australia has also organised and conducted two National Young Carers Summits, where young carers meet to discuss the role of young carers and how respite and support needs can be met.<sup>13</sup>

The State and regional based information, referral and advice services for young carers are sub-contracted to the State and Territory Carers Associations.

The designers of the Program intended that high quality information products be available nationally, in a timely way. The information was primarily to be distributed through State and Territory Carers Associations to young carers and their families but was also meant to be a resource for respite services and other agencies in close contact with young people.

A key issue for Carers Australia has been the cost of distributing resources. Warehousing and distribution of information resources requires dedicated administration resources, which are not covered by the allocated funding. As a result, Carers Australia and their Association members are seeking to recover distribution costs by charging services for bulk copies of the Young Carers Kit. This policy has not been a general deterrent for CRCCs, with 95% of CRCCs we surveyed using the Young Carers Kit as part of their services (section 4.4).

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<sup>13</sup> Report on 2006 Summit is available.

There have been other minor issues regarding distribution of resources, such as the Young Carers Kits being in short supply at times. The re-development of the website is sub-contracted and proceeding according to the agreed time-frames.

### 4.3 Delivery of State and Territory based services

State and Territory Associations are sub-contracted by Carers Australia to provide State/Territory level advice, information and referral services, including counselling services for young carers. One of the requirements from Carers Australia is that the Associations employ a part-time Program coordinator wage or 20 hours staff time a week.

In all States and Territories, young carers also have access to existing information infrastructure for carers, such as the 1-800 Advisory Line and counselling and education. Queensland provides a specialist young carers counselling service.

Some State and Territory Carers Associations also receive funding for young carers from State and Territory Governments and corporate sponsorship. The amount of these funds varies considerably. These extra funds have allowed the Associations to expand their activities to better promote young carer needs. In particular, Associations with funding for respite as well as for information, referral and advice are able to offer more direct support for young carers and a broader range of services.

The four State and Territory Carers Associations co-located with respite services (ACT, NT, SA and Victoria) have had opportunities to share information, cross-refer and to varying extents coordinate services for young people. Carers ACT and Carers NT offer a coordinated service for young people (see Case Study 2, section 3 and Case Study 4, section 4).

#### 4.3.1 Information and referral services

At the end of June 2007, the State and Territory Carers Associations had an estimated 1,528 individuals<sup>14</sup> as registered contacts, that is, young people to whom the Associations had provided direct support. The young people had more than one contact with the service, so that 8,380 direct occasions of service have been provided, including: 661 young people have attended young carer camps or other recreational activities; 554 young people have received face-to-face and telephone counselling; 413 supported referrals; and, 969 have been individually supported.<sup>15</sup> In addition, Carers Australia and their member Associations have distributed around 17,000 specific information resources to young carers and agencies.

#### Number of young carers receiving information and referral services provided using Young Carers Program funding since 2005<sup>16</sup>

Service	2005	2006	2007	Total
Telephone counselling	30	12	17	59
Counselling - total	190	279	75	544
Attended camps	110	257	3	370
Participated in day activities	109	158	24	291
Case coordination	14	85	107	206
Provided personal support	35	290	127	452

<sup>14</sup> Source: Carers Australia April to June 2007 Progress Report, Demographic data page 3.

<sup>15</sup> Source: Carers Australia April to June 2007 Progress Report, page 2. Report states that these contacts are usually several contacts for an individual but accompanying graph presents as number of young carers.

<sup>16</sup> Table does not include web-statistics as data provided is insufficient to interpret usage or satisfaction with website

Supported referrals to respite	11	65	20	278
Supported referrals (other)	0	112	23	135
Brokerage	10	49	1	60
Individual support - total	151	317	460	969

Source: Carers Australia quarterly reports. Note table does not include young carers receiving counselling under other funding sources, either external or internal.

### **No. information packages distributed over three years**

<b>Service</b>	<b>2005</b>	<b>2006</b>	<b>2007</b>	<b>Totals</b>
YC Information packs	523	4,420	1013	5,956
Pocket packs	56	8,334	2,576	10,966

There has been a steady increase in contacts over the three and half years from approximately 300 young carer direct contacts in 2005, to 1,500 at the end of June 2007.<sup>17</sup> Participation levels, where a young person is provided with a direct service, have increased five-fold since the Program's inception.

The profile of young people accessing Carers Australia information and advice services differs somewhat from those using the respite services provided by CRCCs. Carers Australia has a broader target group, offering information and advice to all young carers regardless of age or whether or not they are secondary carers or deemed at risk of leaving school. Young carers registered with State and Territory Carers Associations tend to be younger, more likely to be caring for siblings and for a family member with an intellectual disability than those using respite services. For example, 20% of young carers using respite services care for a sibling and 11% care for someone with a disability, compared to 45% of Carers Australia registered young carers caring for a sibling and 25% for a person with a disability.

Another strong difference is that just over a third of young people using respite services are caring for someone with a mental health issue, compared with 21% of Carers Australia registered Young Carers. It is apparent that CRCCs are reaching a higher need group than Carers Associations.

#### **4.3.2 Awareness raising and policy development activities**

Given the limited available time (three days a week), project coordinators have largely concentrated on raising awareness of young carer needs and the support services available amongst key referral agencies in contact with young people. Much of the effort has been concentrated on metropolitan or regional areas close to capital cities, although project officers also participate in State-wide agency networks, wherever possible.

Another common strategy has been to build the capacity of individual workers through training about young carers' needs, and by facilitating service provider networks. The new young carers' operational guide may support these activities.

<sup>17</sup> Carers Australia notes that participation figures include all services provided to young carers, some of which are funded by NSW Department of Disability and Home Aged Care or general funds from donations or the National Respite Program.

## Summary of Young Carer coordinators' awareness raising and policy development activities

State	Main activities
NSW	<p>E-news bulletin and newsletter to relevant agencies            Partnership with CRCCs, capacity building and networking            Facilitate Young Carers State Network            Networking with key agencies and joint promotional activities            State website has a page for young carers</p> <p><i>Activities complemented by DADHAC funded Young Carers Program (Appendix 2)</i></p>
Vic	<p>Policy development for child protection for Carers Victoria            Community development with government agencies including networking/            advocacy with Centrelink, education department            Facilitate service provider network            Facilitate Young Carers State Network            Membership of youth networks            Service provider training            State website has a page for young carers            Development of resources, e.g. DVD</p>
Qld	<p>Service provider training, e.g. professional development course for counselling young carers            Networking and policy development with State Government agencies            Facilitation of regional services for young carers, e.g. recreational opportunities            Skills training of regional Carers Queensland workers            Funding applications for additional projects            Promotion and awareness raising amongst service providers            Facilitate Young Carers State Network</p>
SA	<p>Ambassadorship Program            Facilitate Young Carers State Network            Presentation to community groups, teachers, government agencies            Facilitate Young Carers State Network</p> <p><i>Activities largely metro based</i></p>
WA	<p>Networking with key government agencies            Development of resources for service providers, e.g. DVD <i>Dreams for Life</i>            Skills development for young carers            Facilitate Young Carers State Network</p>
Tas	<p>Development of resource kits            Joint promotional and awareness raising activities with CRCCs (planned)            Distribution of resources to service providers and hospitals</p>
ACT	<p>Development of resources            Awareness raising activities with government agencies and schools (presentations and meetings)            Facilitate Young Carers State Network            Partnership with CYCLOPS (ACT Young Carer Program)</p> <p><i>Worker also provides direct support and case management for young carers</i></p>
NT	<p>Integrated model that combines respite and information funding            Outreach and awareness raising with schools, education department and education networks</p>
National	<p>Promotion to school sector and other agencies: distribution of school resources to all secondary public and private schools in Australia; distribution of primary school resource to all primary schools; advertisements in the Curriculum Corporation EQ Magazine for 12 months; Young Carers National Summits</p>

Young Carers project coordinators have also worked at the policy level with State Government agencies such as education to get young carer issues recognised at a system level, with limited success. Associations commonly report that more work is needed to get young carer welfare needs recognised by State and Territory education authorities and for the development of appropriate policies for schools.

We have no systematic evidence about the broader results of the State and Territory awareness raising activities except that referrals from agencies have increased since the Program's inception. One Association indicated that most enquiries about young carers to the 1-800 number come from agencies and parents, and that workers' knowledge of young carer issues has improved. As a result, more young carers are being identified and recognised by services and schools and so are getting supported. Other Associations report increased knowledge and awareness amongst the agencies they have worked with, and a flow of referrals. On the other hand, project coordinators also commented that some services remain resistant to acknowledging the role and issues faced by young carers, with young carers being denied services. In common with CRCC stakeholders, Carers Australia project coordinators noted that few agencies provide case management services for young carers with complex needs.

#### **4.4 Links between information, advice and referral and respite services**

The two components of the Program, information and respite, are intended to be closely linked and complement one another. Carers Associations provide appropriate specific information resources for young carers and agencies, which may be used by CRCCs as part of service provision. The Associations also provide counselling services for young carers who may be referred by CRCCs. Associations may also refer young people for respite services to CRCCs. In some instances there may be overlaps in services, for example it is not possible to separate information provision from offering respite services, and both components provide recreational opportunities for young people and personal support. To be effective, links between the two components should be strong.

We found moderately strong links between CRCCs and the State and Territory Carers Associations, although the strength and frequency of links varies by State and by CRCC. The strongest links between CRCCs and the Carers Association are in South Australia, Victoria, NSW and Queensland. NSW, Victoria and Tasmania Carers Associations report they are actively seeking partnerships with CRCCs to provide joint activities and share information. The Carers Associations in NT and ACT also auspice the respite services and offer integrated information and respite services.

Two thirds of CRCCs indicated they have frequent contact with their State and Territory Carers Association about young carers. However, two CRCCs stated that they never or rarely contact Carers Associations.

**Table 4.5: Frequency of contact between CRCCs and State and Territory Carers Associations about young carers**

<b>State</b>	<b>Frequently</b>	<b>Sometimes</b>	<b>Never or rarely</b>	<b>TOTAL</b>
SA	100%	0%	0%	100%
VIC	83%	17%	0%	100%
NSW	77%	23%	0%	100%
QLD	67%	33%	0%	100%
WA	50%	40%	10%	100%

NT	0%	100%	0%	100%
TAS	0%	0%	100%	100%
All	66%	29%	5%	100%

Source: CRCC Survey Feb 08. Note, the Carers Association combined services in ACT and NT did not complete surveys.

Most CRCCs use Carers Australia information resources, particularly the Young Carers Kit (95%) and the High School Kit for Teachers (50%). However, some CRCCs reported difficulties ordering bulk kits for dissemination to clients and that it was necessary to refer young carers to Carers Associations to source kits directly themselves.

### CRCCs' use of Carers Australia resource materials

Resource	n	%
Young Carers Kit	40	95%
High School Kit for Teachers	21	50%
Primary School Kit	14	33%
Don't use CA resources	1	2%

Note: May use more than one resource.

Some CRCCs actively refer young carers and their families to Carers Associations for specialist counselling and to attend State-wide recreational camps. One NSW CRCC refers all young carers to the Carers Association for information, recreation opportunities and if required, counselling. A small number of the young people we spoke to who were actively involved in Carers Association social activities or counselling services had been referred by a CRCC.

Conversely, Carers Associations are referring young carers to CRCCs when they fit the Guidelines of being a primary carer at risk of leaving school and are the appropriate age. Just over one quarter of CRCCs indicated that a Carers Association is a major source of referrals for their service. Nevertheless, there are barriers to referrals from Carers Associations to CRCCs. CRCCs have different intake and referral processes and offer varying services, which makes it difficult to assess whether a referral is appropriate. In addition, there are no Program resources describing the respite services to help explain the service to young people and their families. Carers Associations are seeking a greater consistency of intake and referral processes amongst CRCCs and generic information about the respite program. This is a need echoed by CRCCs, who also identified a need for a national brand for the Program.

Another important issue is that the target group for the two components differs somewhat. Carers Associations have a broader target group than CRCCs, providing information and advice for young carers of all ages, and do not exclude secondary carers. As a consequence, a significant proportion of their clientele are not eligible for respite services. For example, one Carers Association stated that only 3% of the young carers on their books are primary carers, or do not fit the Guidelines in other ways. Consequently, they make few referrals to CRCCs.

The type of contact between CRCCs and Carers Associations also appears to be influenced by the networking and capacity building efforts of Carers Associations. Carers Associations with effective networking and capacity building strategies appear to have stronger links with CRCCs in general, across a wider range of activities. For example, the Gold Coast Regional Carers Association office has a close relationship with the local CRCC. The worker refers young carers to the local CRCC and is involved in joint activities.

## **4.5 Conclusions**

Carers Australia and Carers Associations are successfully delivering information, referral and advice services that broadly complement respite services to young carers. However, the demand for counselling and advice services is greater than supply and cannot be met effectively under current Program resources. To progress this further Carers Australia would need to develop a business case that demonstrates how much funding is needed to provide what suite of services.

There remains a need for Program-wide information resources to be available, and for a coordinated approach to distribution of such resources. Information resources for young carers are widely used by Associations and respite services, however the development and distribution mechanisms need to be improved and better resourced to improve dissemination to respite and other key services.

Carers Australia has identified a need to raise awareness at the system or policy level with key agencies, and has put in place strategies with varying success at this early stage. This approach is worthwhile as it validates and complements local partnerships between services and agency workers to identify and support young carers.

## **Case Study 4: Implementation of the information, referral and advice service by Carers Victoria**

### **Service delivery**

Carers Victoria offers a 1-800 number for general information and advice, telephone and face-to-face counselling services and a website. Young carers are able to access these services, and some counsellors are experienced in assisting young people.

Carers Victoria has produced a range of resources and information specifically for young carers and service providers with funds from five philanthropic organisations, e.g. a DVD "Just care for us", service provider brochures, identification cards for young carers and a CD-Rom for young carers. The Carers Victoria website has detailed information for young carers, families, teachers and service providers with links to both the national young carer website and other relevant websites. A CCRC respite service for young carers in the Western metropolitan region is co-located at Carers Victoria.

A young carer or a family member contacting Carers Victoria will be offered use of the 1-800 Carer Advisory Service, a chance to register as a young carer, and the opportunity to be sent information materials. Young carers are generally also connected to the respite Young Carers worker co-located at Carers Victoria, or are referred to the nearest respite centre.

Carers Victoria indicated that not many young carers ring Carers Victoria directly; it is more likely to be a service provider or family member calling on their behalf.

Referrals to a counsellor generally come through a service or a parent. Counselling is offered via telephone, face-to-face with a counsellor, or may be brokered to external providers if the young carer is located in a rural area. Carers Victoria notes that there has been limited uptake of the counselling service by young carers.

The two co-located services for young carers, respite and information services, have a long-standing collaborative relationship, exchanging and sharing information, cross-referrals and doing joint promotional activities. The respite service had 85 young carers in 2006/2007.

The young carers we interviewed were involved in VYCAT and ANYCAT and in the State Government Mentoring program for young carers. Young carers had been linked in with respite services, and attended young carers' lunches and other social activities. They also had regular contact with the Young Carers worker to talk through issues.

Since 2005, 802 young carers have received a service from Carers Victoria. A total of 123 young carers have received counselling – 60 cases were in-house and 63 brokered out.

### **Young Carers project officer activities**

FaHCSIA funding is used to employ a Young Carers project officer for 20 hours per week or 0.5 FTE. The project officer focuses on developing awareness of young carer issues amongst key government agencies, in particular the education sector, and promoting solutions to identifying young carers and addressing their needs. One key strategy is to be actively involved in formal agency networks and presenting at forums where young carers' issues can gain maximum exposure. The Young Carers project officer hopes to expand her promotional activities to the health system, with the aim of raising the awareness of young carers. The project officer is currently contributing to the development of child safety, wellbeing and protection policies for Carers Victoria.

Examples of the awareness raising and promotional work undertaken include:

- promotion to educational networks - the Young Carers project officer targets State-wide networks and State-wide conferences of school networks, e.g. presenting information on the Young Carers Program to the Catholic Education Office, Department of Education Student Wellbeing networks, networks of school nurses etc
- coordination and resourcing of the Victorian Service Provider Network for interested stakeholders which meets twice a year and receives regular updates via e-bulletins. This network continually grows and has about 90 members currently, from a wide range of services, e.g. schools, respite services, Young Carers Programs, youth agencies, government departments



- meetings and other promotional activities with key agencies and services, e.g. Melbourne City Mission, mental health services, PATS program, CanTeen, Association of Services for Children with a Disability
- distribution of resources to services, e.g. the Young Carers Kit, posters, brochures,
- participation in many State-wide conferences and forums attended by key agencies, e.g. youth participation forums, School Counsellor and Student Wellbeing Conference, Families affected by Drug and Alcohol problems network
- participation in the Victorian Carer Services Network (VCSN). The network shares information, networks, engages guest speakers to inform professional development, tracks trends, issues, service gaps and program delivery across Victoria
- young carers have a double page spread in the quarterly Carers Victoria newsletter and are encouraged to contribute to it
- Youth Week 2008. Carers Victoria, in conjunction with the VCSN, is running a series of advertisements in newspapers about young carers.

The project officer is actively involved in young carer network groups but generally does not provide any direct support to individual young carers; this role is provided by the respite service Program worker. The project officer participates in tele-conference meetings with the ANYCAT group, and has established a young carers' network in Victoria (VYCAT). VYCAT was established as an outcome of the 2006 Young Carers Summit. This group of 18 young carers is committed to being involved with Carers Victoria, acting as both a reference and recreational group. VYCAT meets four times a year and is also involved in projects as they arise, for example some network members have presented to teachers at schools, and some members are part of the selection group for a yearly Rotary young carer scholarship fund.

### **Outcomes**

We have no systematic evidence about the results of the Carers Victoria project, for example improved knowledge of issues or changes in practices of key service agencies. Carers Victoria commented that more agencies are aware of young carer issues as a result of the project activities, for example that:

- more young carers are being identified and recognised by services and schools and this means they are getting supported
- young carers are being linked in with other young carers
- young carers and their families are receiving relevant information to support the balance between their care responsibilities and other parts of their life
- young carers are getting support from counselling and respite services tailored to their needs. Carers Victoria offers Media Training to young carers, and yearly scholarships to support their education. The Victorian State Government currently funds a two year Mentoring program for young carers.

From the young carers' perspectives, they are very positive about their experiences, particularly as it has helped them understand their role and provided them with emotional support.

*'Initially learning I was a young carer, that it's a normal thing, not abnormal.'*

*'Good to know that there's a group of people there to support me if I'm struggling and it's usually because of my caring role, there is reassurance, and the knowledge they give you which really empowers you.'*

*'All the staff at Carers Victoria are empathetic and caring.'*

Young carers suggested that more information should be available in the media and at schools about young carer issues, and what support is available. One young carer thought that belonging to a support group of other young carers would be helpful.

## 5 Outcomes for young carers

This section summarises evidence whether the Program has assisted young carers to access suitable support and benefits for young people. It answers the key evaluation questions:

- *Does the Program assist young carers to access suitable support and advice?*
- *Does the Program assist young carers to better manage their education and caring responsibilities?*

Respite is traditionally conceived as a type of service, where formal service provision takes over the care-giving role from the carer temporarily, to provide a break from caring responsibilities. Respite is also conceptualised as an outcome 'respite effect', where a carer gains emotional and practical benefits from a range of supports or services. It is using the later understanding that we have framed our discussion about outcomes for young carers.

Because the young people we spoke to had often accessed services from both CRCCs and Carers Associations and because services overlap we have discussed impacts of the Program as a whole.

### 5.1 Young carers' access to suitable support and advice

Young people we spoke to were largely satisfied with whatever level of respite or support they received from either CRCCs or Carers Associations, and few identified problems with quality or unmet needs (section 5.3). Young carers were largely motivated to take up assistance<sup>18</sup> by the need for a break from caring or get help to cope with their responsibilities. There was a common attitude that any support was gratefully accepted and that services were generally responsive to their requests for support and that they had gained the help they needed.

Some young carers used one service, for example, attending camps or domestic supports and others a full range of services, including receiving personal support from the worker. It is clear that young people receiving intensive personal support were very satisfied and that this type of support is highly valued by young carers who require it. Such support is needed for young carers who have primary care responsibilities, little family or outside supports and face complex problems. Many CRCCs do not offer this intensive support as the case management approach is seen as being outside the Program Guidelines.

Those young people who had accessed limited support, such as attending camps or getting domestic help, viewed these services as meeting their needs for a break and practical help.

Young people actively involved in Carers Australia networks and conferences also had very positive experiences and some were actively taking advantage of opportunities to take leadership role in the community.

It is likely that a young person whose needs were not being met or who is dissatisfied would simply drop out of the service or decline to be involved at all. Nevertheless, young carers did raise issues about the quality and availability of direct respite care. One young carer felt the respite facilities were not of an adequate standard; another that using nursing homes is inappropriate for the age of the care recipient (poor) and another that the formal processes in place made it

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<sup>18</sup> Most young people we spoke to were linked to services by adults, schools counsellors, teachers, parents, social workers and did not actively seek assistance themselves.

difficult to organise direct respite. A few young carers who attended camps run by Carers Associations were unaware that in-home direct respite was available.

## **5.2 Perceptions of benefits for young carers**

Most young people and service providers (97%)<sup>19</sup> agree that the Program brings a range of tangible benefits for young people – improved emotional and physical well-being and practical assistance to carry out responsibilities. Those CRCCs who were unable to see benefits felt that resources limited the potential impact of the Program and for young carers, that their limited involvement had little impact on their lives.

### **5.2.1 Caring responsibilities**

One important outcome is that the acknowledgment of the role of young carers and their situations has had a marked impact on young people's feelings of self-worth and confidence, which has assisted some young carers to better cope with and manage their responsibilities. Participation in young carer networks and conferences has been an effective strategy in improving self-esteem and empowering young carers.

Young people particularly appreciated being able to get emotional support and independent advice and help from an adult. There was a feeling that such support helped them share the burdens of responsibility and reduced their levels of stress. Active interventions by a worker to link them with services for the care recipient or arrange other assistance reduces stress and helps young people manage their responsibilities. Where offered, information about the care recipient's condition has also been valuable for some young people by assisting them to care for their parent or sibling.

Getting a break from their responsibilities was also seen as an important benefit for young people and for their families. Direct and indirect respite has given many young people a chance to socialise, participate in school life and 'just be themselves and enjoy being a kid'. One common strategy is to offer camps for young carers. Camps give young people the opportunity to share experiences with others in similar situations, which has reduced social isolation and increased feelings of being connected. Young people described feeling normal and less alone knowing others shared the same experiences and can understand the situation they face. Some young people said they had made friends as a result of participating in camps and other social activities and said they had fun. Young people also said that their parent/s are happier and less stressed because they know their child is getting an opportunity to socialise and enjoy themselves. Domestic assistance was also said to reduce stress on the family as a whole. These benefits fit with recent conceptualisations of respite being a service that provides benefits for the carer and the care recipient within the context of family relationships.

### **5.2.2 Coping with school**

For some, the assistance has also mitigated the impact of caring on their ability to engage with school. Young carers described instances where tutoring had improved their school marks and helped them catch up on work. One young carer ascribed his decision to stay at school to assistance from his support worker. CRCCs cited cases where young carers who might otherwise have left were staying at school. There were also cases where the young person is now more likely to interact in class or make long-term life goals.

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<sup>19</sup> Survey results: 64% CRCCs strongly agree and 33% agree that the program provides tangible benefits for young carers.

## Summary of young carers' perceptions of the benefits of Program by type of assistance provided

Type of assistance	Benefits reported by YCs	Issues/ comments
Direct respite e.g. in-home or out-of-home care	<p>Gave time to study, do exams, homework or work</p> <p>Break from responsibilities and opportunity to socialise and participate in recreational activities</p> <p>Reduced stress on carer and or other family members</p>	<p>Mixed experiences with respite: e.g. 1 person not satisfied with out-of-home respite facilities (unhygienic) and bad experiences meant not used again; e.g. 2 respite worker very nice and trustworthy</p> <p>Level of reluctance to use direct respite, unwilling to trust others with care</p> <p>Formal processes a barrier, too much paperwork, too hard to organise</p> <p>Poor knowledge of available services – unaware that direct respite available or in-home respite available or that able to access these more frequently</p>
Personal support by caseworker e.g. emotional support; negotiation with teachers and other agencies on young person's behalf; coordination of services for care recipient	<p>Helps them cope with responsibilities and solve problems, understand their situation</p> <p>Reduces young person's stress levels knowing they have access to help and someone who understands, can negotiate on their behalf with school or other agencies</p> <p>Relaxation of deadlines for homework, greater understanding and latitude given by teachers for absenteeism or lateness to class</p> <p>Reduced stress on parents because young person being assisted</p> <p>Family more connected (one person)</p>	<p>Highly valued</p> <p>Regular contact common</p> <p>Support commonly initiated by parent or school counsellor or social worker</p> <p>Need to be sensitive about respecting parental roles and responsibilities</p>
Practical assistance e.g. cleaning, cooking, shopping and gardening services; financial advice	<p>Reduces stress for whole family</p> <p>Reduces financial stress (one young person was able to remain at school after getting advice)</p> <p>Frees up time to study or socialise</p>	
Tutoring	<p>Helps young people understand/ catch up on subjects and perform better</p> <p>Increases confidence at school</p>	
Recreational opportunities	Provides a break from responsibilities and chance to be a normal teenager	Camps need to cater for range of age groups

Type of assistance	Benefits reported by YCs	Issues/ comments
e.g. camps and day activities; movie vouchers	Having fun, making friends  Reduces feelings of social isolation, chance to mix with others in similar situations, understand issues and feelings	Cost/ transport problems in getting to camps
Counselling	Reduced stress, improved feeling of self-worth and better understand situation	Long-term relationships with support worker seen as more valuable than short-term counselling by some
Information provision e.g. website and Young carers pack	Good information, useful  Helped understand role and that not unusual to care for others	Generally low level of awareness or use of website amongst focus group participants  Need to know you are a young carer to find website  Website seems aimed at younger carers (17 yr old)  Common for young carers to have been given information pack
Leadership opportunities e.g. membership of Networks; public speaking; attending conferences/ summits	Empowering, improved self-confidence, reduced feeling of social isolation  Opportunity to improve services for other young carers, influence policy	Highly valued by those involved

CRCCs and young people's perceptions of benefits align well. However, the evidence of benefits is limited and may have a positive bias in that it is partly based on the experiences of current clients of CRCCs identified as being examples of effective services. These services have adapted their practices and services to meet identified needs (sections 3 and 4). Systematic evidence, such as client exit surveys on satisfaction with services and outcomes, is needed to confirm that benefits are being widely obtained.

### 5.3 Unmet needs/ suggested changes

The extent of unmet expressed needs amongst young carers is difficult to assess on the current evidence. Few young people expressed unmet needs.

When asked about what changes are needed to services, young carers commonly mentioned that more could be done to bring about awareness of their issues amongst teachers and hospital staff. Lack of understanding amongst teachers and fellow students of young carers' issues remained a common challenge for young carers. Young people commonly described incidences of bullying by other students or intolerance by teachers of late arrival to classes, absenteeism, and not completing or handing homework in late. Young carers did see improvements in attitudes where a worker had intervened on their behalf or presented to teachers. A few young people had talked to their class about their role, which helped others understand their problems. The main education resource for secondary teachers

about young carers was distributed to all public and private schools in September 2007. Every secondary public and private school in Australia was sent a copy (approximately 2900 schools). The kits arrived at the schools to coincide with their first week in term four. The package also contained a CD of the Reading, Writing and Responsibilities Research on which the resource was based. " This resource may go some way to educating teachers about young carers' roles and the impact on participation in school.

One unmet need that emerged was the availability of easier to understand information about the care recipient's disability or medical condition. Young people want information to help them understand what they are dealing with.

A few young carers also mentioned specific changes to services, such as making the Carers Allowance more accessible and forming support groups for young carers. Young carers in one group viewed the Carers Allowance as being virtually impossible to get because the eligibility criteria are unreasonable.

Some young people would have preferred activities be arranged for the whole family. Young people also felt it is important that others in their position know about the services and want the Program to be well promoted.

## 6 Funding

This section discusses the adequacy of funding for the Young Carers program. It addresses the key evaluation question:

- *Is the level and method of funding adequate to ensure the Program is being delivered effectively?*

### 6.1 Respite services

#### 6.1.1 Current situation

The respite services component is funded at a level of approximately \$23.9M for the period January 2005 and July 2008, with funds allocated across 55 CRCCs annually, with \$6.9M in 2007-08.

The funding is allocated as two streams: operational (40%), which includes administration expenses, staff wages, promoting the service, outreach activities or carer support activities; and brokerage (60%), which includes purchasing respite packages from formal or informal sources, making payments to help young carers access respite and contract a support worker to provide a service.

The current funding allocations for individual CRCCs are based on the method used by the Department of Health and Ageing and takes into account the 2003 Australian Bureau of Statistics (ABS) Carer Population Data adjusted by Home and State and Territory Community Care Region (HACC) regions and the estimated numbers of young carers based on ABS data.

In 2007/2008 financial year, the amount of funding allocated to individual CRCCs for the Young Carers Program ranges widely, with the median amount of funding for a service of \$100,000.

#### 6.1.2 Adequacy of funding

Overall Program funding has been more than adequate for most metropolitan and regional CRCCs, with seven services that had waiting lists. Just over half of the services indicated that demand for respite services does not exceed their capacity to provide services. When this situation does occur, the most common response is to make referrals to other services. Three CRCCs claimed to be subsidising the Program, specifically the wages of workers.

However, in remote and rural areas, the allocated funding has been insufficient to establish the Program. In addition the 40:60 operational/brokerage split has hindered the effective delivery of the Program by making fewer funds available for the indirect respite and carer support.

In May 2007, the program area was advised that there may be underspends for the program for the 2006/2007 financial year. CRCCs were advised that unspent funds from 2006-07 may be retained on condition that it is used to meet the commitments of the funding agreement (letter to CRCCs June 07). CRCCs were subsequently asked to submit action plans to reduce underspends by considering more flexible service delivery options. Funding variations were executed with individual CRCCs that had action plans approved

All of the remote CRCCs and most rural services receiving relatively small amounts of funding struggled to implement the Program. Remote and rural services

indicated that the small amount of funding resulted in CRCCs having insufficient staff resources to actively promote the Program or access young carers using outreach strategies. The lack of funding for dedicated resources was exacerbated by the split of the funding into operational and brokerage components. Only the operational component funding (40%) is available for activities to promote the service and so access young carers.

Other CRCCs also reported difficulties spending the brokerage funds because many young carers are not seeking direct respite services (see section 3). As a consequence, some CRCCs report mainly using the operational funding and underspending the brokerage component. One large regional service with a large young carer client base stated the CRCC cross-subsidises the salary of their young carer worker, whilst being unable to use brokerage funds. Information on how the two funding streams were spent was not available for the evaluation, so it is not possible to analyse what proportion of the underspend is actually brokerage. However, responses from the survey show that just one third of CRCCs think that the funding allocation of 40% operational funds and 60% brokerage funds works well.

It is difficult to assess the level of funding based on need and potential demand for services and this is outside the scope of the Review. It may be that there are fewer young carers needing respite and support than anticipated under the funding formula or that CRCC's strategies to access young carers are ineffective. However, the need for support depends on each young carer's circumstances, with some young carers facing complex issues and having high support needs and others less so. Need for respite may also be episodic.

In assessing what level of funding is adequate, it is instructive to compare funding levels and client numbers. CRCCs with funding around the median of \$100,000 appear to be operating most effectively, in that they are accessing between 20-60 young clients. Funding at this level allows a dedicated worker to be employed, which is essential to identify and access clients. Services receiving less than \$50,000 (the remote and rural services) have few if any clients and it is apparent that the level of funding is inadequate to promote the service and identify young carers.

For respite services targeting 'hidden carers', such as young people, to be successful, FaHCSIA needs to commit sufficient operational resources towards raising the profile of carers in the wider community and also to finding and accessing these carers at the local service level.

## **6.2 Information, referral and advice services**

### **6.2.1 Current situation**

The information and support service component is funded at a level of approximately \$500,000 per year and is intended to build on the existing infrastructure of the Commonwealth Respite and Carelink Centres including the 1-800 Advisory Service and the National Carers Counselling Program. At the State and Territory level the funding pays for a part-time Program coordinator.

### **6.2.2 Adequacy of funding**

In their submission to the Review<sup>20</sup>, Carers Australia claim that the Young Carers Support Initiative is underfunded and the demand for the information, referral and advice services cannot be met under current resources. State and Territory

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<sup>20</sup> Young Carers Support Paper, December 2007.



Associations all indicated that current resource levels limit the scope of activities and hence their ability to raise the profile of young carers amongst the community and key agencies. Carers Australia indicated that funding does not cover postage and other distribution costs for resource kits, and these can be considerable. Some stakeholders complained that the Young Carers Kits are in short supply.

Carers Australia is seeking an increase in funding to allow additional staff, and:

- a greater community development role and support for Young Carers Program workers in their role
- family-centred assessment and case management options
- greater brokerage of support services, including appropriate counselling
- education and training of ANYCAT members
- an increase in the distribution of Young Carers Kits and review and distribution of other resources.

We have little systematic data that measures unmet demand to allow us to assess Carers Australia claims for being under-resourced. The success of promotion efforts has meant there are more young carers seeking assistance. In addition, the objectives of increasing awareness of young carers in the community and providing a state-wide information, referral and advice service appear difficult to achieve for a part-time worker located in each State and Territory.

## 7 Performance measurement

This section discusses the adequacy of performance measurement processes and key performance indicators. It addresses the key evaluation question:

- *How relevant are the existing performance indicators and what alternate indicators would better reflect the effectiveness of the Program?*

### 7.1 Respite services

#### 7.1.1 Current situation

CRCCs report data against two performance indicators for the Young Carers Program, “the number of young carers receiving five hours respite a week” and “the number of young carers receiving two week blocks of respite”.

These monitoring data are part of CRCCs’ reporting requirement across multiple Program funding streams from the Commonwealth, including: National Respite Funding from DoHA, and the three FaHCSIA respite programs.

The DoHA reports are six-monthly and include reporting minimum data-set.

FaHCSIA requires quarterly monitoring data reporting, using the same template for all three programs and against performance indicators. FaHCSIA also requires CRCCs to provide: annual plans; triennial plans; a progressive financial statement after six months and an annual financial statement after 12 months. All reports are initially assessed by STOs, who liaise with CRCCs to clarify data and also provide summary reports to the national office.

#### 7.1.2 Issues

Although CRCCs are complying with reporting requirements, the current reporting regime is not providing reliable performance information.

Key Performance Indicators (KPIs) have been reported against inconsistently and have limited relevance to how services are being implemented. The KPIs do not capture indirect respite, a large part of support being provided. Nor do they provide any information about the outcomes of services provided or the quality of services.

Services are reporting indirect respite activities inconsistently within the current format. Feedback from CRCC managers revealed that some CRCCs fit all current activities in the format, and in other cases activities go unreported. CRCCs are forced to be “creative” in fitting in their activities under the reporting format. In addition, services report the number of clients each quarter in receipt of the two respite packages but not whether one client is receiving both packages. CRCC’s attitudes to FaHCSIA’s quarterly reporting requirement for young carers were generally positive as they view the task as necessary and of acceptable scope. However, many viewed the suite of reporting requirements as being somewhat ‘over the top’ for a small program, especially within the context of reporting across multiple programs. Smaller services, with staff working across programs, find it especially onerous to report hours spent on each program.

CRCCs are seeking reporting that is less frequent, with many preferring six-monthly periods, streamlined and relevant to the Program activities. CRCCs suggested that the annual planning template and reporting format could be aligned.

At present, there is no feedback loop for monitoring data which would motivate and encourage staff to report accurately and consistently.

From FaHCSIA's perspective, there is also limited useful data obtainable from the DoHA reporting process. The minimum data-set does not currently allow clients supported under the Young Carers Program data to be identified separately. Consequently, it is also not possible to assess how much respite is provided through the National Respite for Carers Program, and how much is done under the Young Carers Program funding.

Reporting processes and requirements for CRCCs should be reviewed in conjunction with changes in the performance indicators. CRCCs should be asked to report against the new performance measures, and the Department could consider aligning reporting time-frames with DoHA.

### **7.1.3 Alternate performance measures**

The Department is developing alternative indicators at a program level that will better capture the performance of the Program as it is being implemented now, including intermediate indicators that measure the quality of services from the perspective of young people. The proposed new KPIs for the Program are:

- *No. of young carers assisted over 12 months*
- *% clients satisfied that the services they received were appropriate to their needs*
- *% of clients assisted from Indigenous or CALD background*

If the Program is re-designed, new indicators may have to be developed.

## **7.2 Information, referral and advice services**

### **7.2.1 Current situation**

Carers Australia reports against three performance indicators: "number of young carers seeking information, referral and advice services including counselling continues to increase"; "young carers not previously on the books of Carers Associations seek assistance"; and, "information products continue to be requested and distributed to young carers".

The indicators for the information, referral and advice services are relative rather than absolute indicators, and seek to capture whether additional FaHCSIA funding has increased Carers Associations' capacity to support young carers.

Carers Australia collates data and performance information from Carers Associations and reports every three months (Quarterly Reports). Every second report includes monitoring data collated across all States.

### **7.2.2 Issues**

Carers Australia is complying with reporting requirements. The collation of monitoring data provided by Associations, and performance information is appropriate and an efficient use of limited administration resources. The six-monthly interval for reporting monitoring data is also appropriate. Carers Associations are able to provide these data and the time period allows sufficient time for data to be collected and collated.

The performance indicators for the information, referral and advice service are providing some useful performance information about outputs, even though they ask for similar and overlapping information. Carers Australia has provided data that shows the increase in the number of carers seeking assistance over time through State and Territory Associations.

Improvements should be made to the presentation of data, with the client as the unit of analysis. The Department and Carers Australia should agree on data specifications that will meet the needs of both organisations and fairly represent activity levels.

### **7.2.3 Alternatives**

New indicators to measure the performance of the information, referral and advice service could include an indicator that captures the number of young carers assisted and their profile and what kind of assistance is being provided. A second indicator might measure the amount of key resources being distributed and where. A third indicator could measure satisfaction with information and advice provided.

## 8 Modifications to the Program

The suggested modifications are based on evidence about what is working and what factors are influencing how the Program has been implemented.

### Revisions to Guidelines

- *Maintain the flexibility in the Guidelines* – this is a strength of the Program and has allowed services to provide respite and support to meet the needs of young carers.
- *Allocate funding either as 60% operational and 40% brokerage split or as a lump sum that providers can use to meet their own needs for operational and brokerage.* Many CRCCs are unable to fully spend the brokerage funding and need a higher proportion of operational funding to ensure they have dedicated staff to promote the service to referral agencies, access young carers and provide personal support to the carer. Young carers are special cases because they are hidden and have different/ additional respite needs compared to adults and may not have the ability to relate to services. Preferred respite is a mix of indirect respite, personal support, social and recreational opportunities, practical help with domestic duties and direct respite. Indirect support is cheaper than formal in-home or blocks of direct respite.
- *Remove rationing of direct respite, that is the requirement to provide a maximum of five hours a week or 14 days block a year, so that individual needs can be met effectively on a case-by-case basis.* Also remove the restriction of providing respite in school terms only.
- *Allow services to also support secondary carers and primary school aged children, where appropriate.* Secondary carers often also have extensive responsibilities, and roles within the family change depending on the circumstances and task. Feedback from schools indicates that they find the concept difficult to interpret and difficulty in distinguishing the roles and can be a barrier to referrals.
- *Allow respite services to be provided for longer than 12 months.* Although support needs vary and can be episodic, carer responsibilities remain whilst young people are at school. There are limited other services that can provide appropriate ongoing support for young carers.

### Program development

- *Strengthen information sharing amongst CRCCs young carer workers.* For example, state-wide Young Carer Worker Networks or web-based information sharing wikis.
- *Improve the dissemination of young carer resources by funding Carers Australia to distribute bulk information to CRCCs and schools.* Also develop a brochure on CRCC 'respite services' for use by Carers Australia and the services.
- *Increase efforts to raise profile of young carers, particularly amongst key professionals, especially school teachers and school community.* Possible strategies are to conduct a media-based public information campaign; build on Carers Associations' existing awareness raising activities with key agencies in contact with young carers.

- Re-focus the Program as carer support for all young carers, not just those deemed at risk. All young carers need support because of their vulnerability and lack of experience and burden of responsibilities, which put them at increased risk of not completing their secondary education. Such an approach is more suited to special circumstances of young carers, than direct respite packages. Brokered respite would be one option for support.
- *Develop a model of service for providing a respite effect for young people.* The model should take into account the need to provide personal support where appropriate but remain sensitive to parent's rights. Elements might include: case management approach, understanding family situation and family focus, role for indirect and direct respite, formal referral and intake processes and case coordination with other agencies involved with family; the development of standard reporting tools; form letters; exit planning formats; assessment tools.
- *Take a systems based approach to developing school policy on young carers* with the aim of all States and Territories implementing policies to ensure student welfare and encourage retention at school.
- *Develop guidelines/ policy regarding child protection issues and young carers* for use by respite workers in direct contact with young carers.
- *Expand referral pathways to cover first-to-know agencies* as potential sources of referrals e.g. schools, GPs, Centrelink, Youth networks.
- *Develop formal links with other relevant programs at State and Federal level,* specifically Children of Parents with Mental Illness Program (one third of young carers receiving respite care for a person with mental illness); Centrelink and the National Illicit Drug Strengthening Families Program.
- *Develop models of working with CALD and ATSI's.* These groups have not been effectively reached by the current Program.

### **Funding levels and performance measurement**

- *Increase funding to remote/ rural areas.* The evidence indicates that a minimum amount of funding needed for a service to access young carers effectively.
- *Improve reporting processes,* collect data on number of clients and demographic profiles, types of services provided and satisfaction with respite services.
- *Link new performance indicators with reporting requirements.*

# Appendix 1 Project Reference summaries

## 1. Supporting Young Carers: a practical guide to effective service delivery

**Author:** Brown, Jeremy

**Institution:** Raw Energy

**Year:** 2006

**URL:**

<http://www.youngcarer.com.au/downloads/Supporting%20Young%20Carers%20-%20A%20Practical%20Guide%20to%20Effective%20Service%20Delivery.pdf>

- **Abstract**

- The Raw Energy Young Carer Support Program (Raw Energy) was established in September 1999 to support young people in a caring role. Young Carers are defined by the Raw Energy Program as people between the ages of five and eighteen who provide care or support to a family member with a disability, chronic illness or diagnosed mental illness. Based on knowledge and experience gained from seven years of direct contact with young carers, the paper provides an insight into the unique service delivery model developed and implemented by the Raw Energy Program. The issues that exist for young carers such as identification, education, respite, health and wellbeing, definition, eligibility and impacts of the caring role are discussed as well as an in-depth description of the service strategy developed in order to address these needs. The aim of this paper is to provide a practical guide to what the Raw Energy Program has demonstrated as an effective method of service delivery for young carers. The outcomes achieved by this model will be listed in detail. Central to these services is the underlying philosophy that the service provided by Raw Energy is based on mutual trust, respect, and commitment; and driven by the ideas, feedback and ever changing needs of young carers.

- **Impact of Caring on Health**

- Examples of impacts of caring on young people's health:
  - Lack of physical activity - low energy levels
  - Poor diet
  - Lack of engagement at school
  - High stress levels
  - Weak immune system - sick often
  - Depression
  - Poor personal hygiene.

## 2. Global Perspectives on Children's Unpaid Caregiving in the Family. Research and Policy on 'Young Carers' in the UK, Australia, the USA and Sub-Saharan Africa

**Author:** Becker, Saul

**Year:** 2007

Global Social Policy 7(1) pp.23-50

- **Abstract**

- The article provides the first cross-national review and synthesis of available statistical and research evidence from three developed countries, the UK, Australia and the USA, and from sub-Saharan Africa, on children who provide substantial, regular or significant unpaid care to other family members ('young carers/ caregivers'). It uses the issue of young carers as a window on the formulation and delivery of social policy in a global context. The article examines the extent of children's informal caregiving in each country; how young carers differ from other children; and how children's caring has been explained in research from both developed and developing countries. The article includes a review of the research, social policy and service developments for young carers in each

country. National levels of awareness and policy response are characterized as 'advanced', 'intermediate', 'preliminary' or 'emerging'. Explanations are provided for variations in national policy and practice drawing on themes from the globalisation literature. Global opportunities and constraints to progress, particularly in Africa, are identified.

- **Young carer support needs**
  - Higher levels of disposable income could help minimise the quantity and intimacy (not by choice) or the caregiving
- **Impact of Caring on Health**
  - Young carers report more injuries than non-carers
- **Models of service/ good practice**
  - In the UK and Australia there is growing recognition of the need for a "whole family" approach to disability and caring.

### **3. Stop to Listen: Findings from the ACT Young Carers Research Project**

**Author:** ACT, Youth Coalition of ACT; Moore, Tim

**Year:** 2005

**URL:** <http://www.youthcoalition.net/documents/projects/Young%20Carers%20Research%20Project/Stop%20to%20Listen.pdf>

- **Abstract**
  - The research project, funded by the ACT Department of Disability, Housing and Community Services through the Carers Recognition Grants Program, sought to discover more about the lived experiences, needs and goals of young carers in the ACT in an attempt to identify more responsive and accessible service delivery.
- **Impact of Caring on Health**
  - Caring can have positive effects on mental and emotional health such as raised self-esteem, stronger family relationships and increased skills
  - Possible negative effects include fatigue, greater chance of injury, limited social and recreational opportunities.

### **4. A Current Perspective: What services and young people say about best practice and gaps for young carers in Australia**

**Author:** Kroehn, Anna; Wheldrake, Kate

**Institution:** National Youth Roundtable 2005-2006

**Year:** 2006

**URL:** [http://www.thesource.gov.au/involve/NYR/pdf/current\\_perspectives.pdf](http://www.thesource.gov.au/involve/NYR/pdf/current_perspectives.pdf)

- **Abstract**
  - The report is the final component of the work that Anna Kroehn and Kate Wheldrake undertook as their project for the National Youth Roundtable 2005-2006. The National Youth Roundtable 2005-2006 consists of 30 young people from around Australia who met in Canberra from the 1-9 September 2005. The purpose of this research is to provide examples of policies and procedures working in practice in Australia at the current time. As well, the research recognises that a lot more needs to be done to assist young carers and their families, and aims to assist the Commonwealth Government and Carers Australia to identify the gaps in service provision for young carers.
- **Young carer support needs**
  - Young carers mentioned the difficulty of receiving financial assistance (Carers Payment and Carers Allowance from Centrelink). They also mentioned the lack of continuity in respite care (would like to have the same person provide care consistently)



- **Models of service/ good practice**
  - Best practice respite is flexible, tailored to the needs of the family. Recreational activities are also helpful
  - Best practice emotional support is through groups and one-on-one counselling
  - Best practice peer support is in groups providing creative outlets as well as recreation and identity development
  - Best practice information services are age-appropriate and relevant to young carers
  - A whole family approach includes service providers meeting with and consulting with the whole family through home visits and family activity days.

## **5. A Teachers Guide to Help Young Carers**

**(adapted from Carers NSW School Information Package)**

**URL:** <http://www.carers-sa.asn.au/yc/teachers.html#1>

- **Abstract**
  - The Guide, formulated by Carers Australia, provides information, aimed at helping teachers understand the special needs of young carers and the challenges that they face, especially at school. The guide focuses on identifying, understanding and assisting young carers.
- **Young carer support needs**
  - Young carers need to be recognised. Many young carers will not identify as such for various reasons. They need an open door and support that is attentive as well as relevant
  - Young people need "time out" - respite from caring for the sake of social and personal development, rest and relaxation.
- **Impact of Caring on Health**
  - Lack of support can cause negative outcomes for young people:
  - Emotional/ psychological distress
  - Nervous exhaustion
  - Loss of childhood
  - Sleep deprivation
  - Interrupted education through absenteeism
  - Inability to concentrate and meet learning objectives at school
  - Deteriorating health, i.e. back and joint pain
  - Restricted education, employment and life opportunities
  - Isolation.
- **Models of service/ good practice**
  - When caring responsibilities are shared, and support and assistance is given, caring can be a positive influence and provide positive outcomes for young people.

## **6. Reading, writing and responsibility: Young Carers and Education: research report**

**Author:** Moore, Tim; Morrow, Ros; McArthur, Morag; Noble-Carr, Debbie; Gray, Jamie

**Institution:** Institute of Child Protection Studies, Dickson, ACT, 2006

**URL:** [http://www.acu.edu.au/\\_data/assets/pdf\\_file/0005/47678/RW\\_and\\_R-YoungCarersEducation.pdf](http://www.acu.edu.au/_data/assets/pdf_file/0005/47678/RW_and_R-YoungCarersEducation.pdf)

- **Abstract**
  - The purpose of the report is to develop an understanding of the needs and experiences of young carers in education, and to inform the development of school-based supports for young carers and their teachers. The aims of this research were to: (i) identify the major issues

and concerns of young carers in the education system, including the barriers to them achieving satisfactory outcomes in education and receiving appropriate supports and services (including external referrals); (ii) identify the information needs of teachers and other school staff in appropriately supporting young carers within the school environment; (iii) identify strategies to meet the information needs of teachers and the support needs of young carers within educational settings.

- **Young carer support needs**
  - Young carers in school requested better financial assistance and/or tutoring services in order to help them keep up with students without caring responsibilities.
- **Impact of Caring on Health**
  - Many young carers report that a lack of sleep has had a big impact on their general wellbeing and restricts them from connecting to social opportunities such as school and friends.
- **Models of service/ good practice**
  - Researchers report that school can be seen as a place to escape the harsh conditions of the home-life and responsibilities, for young carers, into 'normality'
  - Young carers requested better understanding of their situation from teachers and that teachers actively seek to help young carers as they are many times too embarrassed or preoccupied to seek help
  - Young carers mentioned that school is the optimal place for dissemination of information about disability and caring, both for carers and peers
  - Young carers mentioned the need for flexibility in school assessments - including the ability to earn vocational accreditation based on caring work (as is done in some schools), enabling carers to drop non-compulsory units.

## **7. Young carers and education: identifying the barriers to satisfactory education of young carers**

**Author:** Moore, Tim

**Journal:** Youth studies Australia, Vol: 24, Iss: 4, 2005, 50-5

**URL:**

<http://search.ebscohost.com/login.aspx?direct=true&db=anh&AN=19083327&site=ehost-live>

- **Abstract**
  - As a consequence of the deinstitutionalisation of people with disabilities and the ageing of the population in the past 25 years, the number of young people fulfilling the role of carer for a relative has increased. The difficulties faced by young carers are considerable, not the least of which is their unequal access to a satisfactory education. The paper discusses the socio-political, ideological and practical barriers that prevent young carers from achieving their potential in the education system, and suggests some reforms that would improve outcomes for these young people.
- **Young carer support needs**
  - Carers Australia and the ACT Young Carers Network assert that the most vital need for services is "ongoing, flexible and coordinated respite for young carers" which would free the young person to pursue schooling, leisure and social activities away from home.

## **8. 2nd National Young Carers Summit - 2006: Report**

**Author:** McEvoy, Adam

- **Abstract**

- From 31 August to 1 September 2006, Carers Australia hosted the 2<sup>nd</sup> National Young Carers Summit at Sea World Nara resort on the Gold Coast in Queensland. The Summit brought together young carers, service providers and government representatives to focus on the further development of the work that has already been done in supporting young carers. The report provides an overview of the activities undertaken and ideas discussed at the Summit by all participants.

- **Young carer support needs**

- Information must be disseminated into the community so that young carers will identify as such, and thus receive acknowledgment and support from the wider community
- Respite services must be flexible and tailored to the needs of the young carer and their care receiver, as well as take into account the personal impact of the caring role.

- **Models of service/ good practice**

- Federal, and State and Territory Government departments work collaboratively to identify both their role and responsibilities in supporting young carers. They should also commit to funding young carers and support services that are adequate and viable.

## **9. Hopping off the roundabout: Supporting young Carers in Western Australia**

**Author:** Moore, Tim; Morrow, Ros.

**Institution:** Carers WA

**URL:**

<http://www.carerswa.asn.au/supportforyou/documents/YoungCarersRoundtableReportLowres.pdf>

- **Abstract**

- With over 40,000 young carers in Western Australia, the Young Carer Roundtable aimed to build on the recommendations from the National Young Carer Summit 2006 so that better ways to support this group of young people can be developed. The Roundtable participants have come up with range of recommendations for the key areas of identification; education; respite and whole of government. These will now need to be prioritised within a strategy which can be recommended to government. Carers WA will work with key stakeholders to this end.

- **Young carer support needs**

- Young carers in school require more flexibility in study and assessments as their caring responsibilities many times exclude them from participating successfully and fully.

- **Models of service/ good practice**

- Young carers, as well as teachers and education staff argue that linkages between community organisations, service providers and schools should be built and/or strengthened in order to provide better personalised and complete solutions for young carers. Such linkages would also help in identifying young carers
- Respite services should be tailored to the needs of the individual carer in consultation with them in order to provide optimum reduction of stress/ fatigue (best outcome of respite)

- Increasing and encouraging interagency and inter-departmental collaboration to produce a flexible and comprehensive "whole of government" solution.

## **10. Principles of Practice for working with young carers and their families**

**Institution:** UK Young Carers Initiative

**URL:** <http://www.youngcarer.com/showPage.php?file=1111523736.htm>

- **Abstract**

- An information page, written by the UK Young Carers Initiative, aimed at providing professionals working with young carers and their families a better understanding of young carers and best practice principles for effective and sensitive work.

- **Models of service/good practice**

- For a holistic approach to the support of young carers, children's voices and feelings must be heard and taken into account. Children should be informed that they have a choice whether or not to take on a caring role
- Inter-agency communication is very important to completely meeting the needs of young carers and their care recipients
- Due to the fact that young carers are often 'hidden carers' and do not identify as carers, it is important to develop pro-active agency practice that will encourage young carers and their families to ask for support.

- **Other relevant information**

- There is a need to safeguard children by minimising instances of children taking on inappropriate caring responsibilities
- It is important to raise community awareness of the challenges that young carers face. This, among other things, helps to ensure that young carers have the same access to education and career choices as their peers.

## Appendix 2 – Summary of similar programs

### 1. 'Young Carers Project' – NSW, DADHC

- Program was set up by volunteers in 1996 and conducted by Carers NSW. In 2000, Carers NSW secured funding from DADHC and extra and ongoing funding 2003. First annual camp in 2003
- Some financial assistance from local Rotary clubs
- Project role: Support young carers' personal and emotional wellbeing and social and educational participation, and increase awareness by education, health, community service providers about the needs of young carers. Key activities:
  - Camps
  - Quarterly newsletters and monthly e-bulletins
  - Talk-link (telephone group counselling)
  - Face-to-face counselling
  - Telephone support/information/referrals
  - Interactive Young Carers website
  - Support to regional young carers networks
  - Community awareness, training, education.
  - Action plan - "develop and implement government agency strategies to support young carers in a coordinated cross agency approach, consistent with principles of the NSW government's young policy. Source: NSW carers action plan 2007-2012
- Resources for principles, school counsellors, year advisors: "Being a carer, Being a student, Being a kid: Supporting students who are carers". Information booklet/pack.
- In the NSW Carers action plan 2007-2012 there is a focus on "hidden carers" one type of which is young carers.
- In a 2003 evaluation of the DADHC Young Carers Program, Jane Elkington & Associates found that the program was "amongst the most developed, most multi-strategic approach in Australia and the world". The evaluation noted that a major strong point of the program were camps, which has grown in size and been identified as an important source of support and information for young carers and were generally well received by young carers and their parents and guardians. Other aspects of the program which were noted as well-received included Tele-Counselling Groups and information packs for schools. A major gap in service (in the scope and aim of the program) which was identified was the challenge of creating a smooth transition for the young carer to the role of adult carer at age 18.

#### Sources:

- Senior Policy Officer - Carers, Office for Ageing
- NSW Carers action plan 2007-2012 (NSW Health)
- Carers NSW annual report 2005-2006  
([http://carersnsw.asn.au/storage/pdfs/annual\\_report\\_2005\\_2006.pdf](http://carersnsw.asn.au/storage/pdfs/annual_report_2005_2006.pdf))
- Report on the Review of the Young Carers Program; Jane Elkington & Kate Hunter, 2003.

## 2. Children of Parents with a Mental Illness

[COPMI](#) (Children Of Parents with a Mental Illness) is a program funded by the federal Department of Health and Ageing and run through the Australian Infant Child Adolescent and Family Mental Health Association since 2001 with the aim of "promoting better mental health outcomes for children of parents with a mental illness". The program does not focus on the carer status or responsibilities of the child but rather aims to help all such children cope successfully with the complex situation of having a parent with a mental illness.

The program provides mainly online information and referral services for children of parents with a mental illness as well as their teachers and families (e.g. The program also works to promote public awareness of the issues encountered by COPMI families.

### Sources:

- Project Manager, COPMI Initiative - Australian Infant Child Adolescent and Family Mental Health Association, Ph: (08) 8367 0888
- COPMI Website: <http://www.copmi.net.au/>
- AICAFMHA website: <http://www.aicafmha.net.au/>

## 3. CYCLOPSACT

[CyclopsACT](#) (Connecting Young Carers to Life Opportunities and Personalised Support in the ACT) is a program funded by the ACT Government and run by Anglicare, aimed at providing both information and support services for young carers in the ACT. In relation to information services, CyclopsACT works with young carers, to provide them with a better understanding of their position, rights and best practice information, and with community services, clinicians and schools to provide the wider community with a better understanding of the challenges that young carers face and the best ways to provide support for them.

The program has been working with schools in the ACT to help form in-school peer support groups for young carers. There are currently 23 such groups operating that have received training and support from CyclopsACT.

The brokered services provided by the program are limited to indirect respite, such as transport when necessary, school books and recreation. The program also provides 'individual support' that is not planned in the young carer's case, mostly for emergency situations.

CyclopsACT has a strong working relationship with the Young Carers Program run by Carers ACT, involving cross referral (in both directions) to ensure the provision of necessary services for young carers which may not be available under one of the programs. The two organisations work together in relation to information services as well, producing joint materials and co-presenting at professional seminars. CyclopsACT currently employs two workers to provide case management services for young carers (limited to 10 hours per week each). Such managed cases are also coordinated with the Carers ACT Young Carers program to ensure the complementary nature of the services provided by both programs.

### Sources:

- CyclopsACT Website: <http://www.cyclopsact.org>
- ARTD – Interview with CyclopsACT, ACT, February 2008.

#### 4. Raw Energy – SA, HACC

[Raw Energy](#) is a State program funded through the Home and Community Care Initiative and provided through the South and East Metro Commonwealth Carer Respite Centre. The program provides various services to support young carers, including information and referral services, personal support and case management, recreational support activities and a young carer mentorship program. The CCRC also provides services for young carers through the Young Carers Program and the two services are coordinated to avoid overlaps. The two different programs also have separate workers and a separate volunteer base. Traditionally, the Raw Energy program was mainly “fun-focused”, however staff have recently begun reorienting the program towards activities which are fun but with a focus on life-skills education.

Sources:

- Raw Energy website: <http://www.youngcarer.com.au/index.htm>
- ARTD – Interview with South and East Metro Commonwealth Carer Respite Centre, South Australia, February 2008.