Submission

No 38

# INQUIRY INTO CHILDREN AND YOUNG PEOPLE 9-14 YEARS IN NSW

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NSW
Carers
AUSTRALIA

6 May 2008

The Committee Manager
Committee on Children and Young People
Parliament House
Macquarie Street
Sydney NSW 2000

Dear Committee Manager,

Please find attached a submission from Carers NSW to the Inquiry into Children and Young People 9-14 years in NSW.

Carers NSW is the peak organisation representing around 750,000 carers of people with a disability, mental illness, chronic condition or frail older people. Carers are unpaid and are usually family members or friends of those they support to live in the community.

The submission provided identifies young carers as a specific group of carers in the 9-14 age group, and provides an overview of issues that young carers have raised with Carers NSW in regard to their support needs.

Thank you for the opportunity to provide comments.

If you require further information please contact Anita Smith, Policy Officer on 9280 4744, or anitas@carersnsw.asn.au.

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## Carers NSW submission to the Inquiry into Children and Young People 9-14 years in NSW.

*Prepared by Anita Smith, Policy Officer, Carers NSW*

### Introduction

About Carers NSW

Carers NSW is an association for relatives and friends who are caring for people with a disability, mental health problem, chronic condition or who are frail aged. It is the peak organisation for carers in New South Wales and the only state wide organisation that has carers as its primary focus.

Carers NSW is part of a national Network of Carers Associations and works collaboratively to lead change and action for carers. The core work of Carers NSW is to:

- Be the voice for carers in NSW
- Undertake research, policy development and advocacy
- Provide carer services and programs
- Provide education and training for carers and services providers

Our vision is that all carers in NSW are recognised, valued and supported by their communities and by governments.

Who Carers NSW represents

Carers NSW represents an estimated 750,000 carers across NSW (ABS, 2004).

A carer is someone who cares for a person with a disability, mental illness/disorder, chronic condition or who are frail aged. Carers can be parents, partners, brothers, sisters, sons, daughters, friends or children of any age. Carers may care for a few hours a week or every day. Carers are unpaid. They may receive incomes from a range of sources including wages or government pensions and benefits.

A primary carer is someone who takes on the main caring responsibilities of a care recipient. Australian Bureau of Statistics (ABS 2005) defines a primary carer as a person who provides the most informal assistance on an ongoing basis, to another person who is restricted by one or more core activities in the areas of communication, mobility and self care. A secondary carer provides informal care in a supporting role where either another family member or formal services provide the majority of care (Carers Association of South Australia Inc, 2001).

## Submission format

This submission provides information to the inquiry committee about a specific group of carers that Carers NSW provides direct support to, young carers.

This submission is provided to make the inquiry committee aware of this group of young people, identify their needs, and provide recommendations in supporting this group of young people in their caring role.

## Who are young carers?

A young carer is a child or young person 25 years or under who provides support for a family member who has a long term disability, mental illness, other illness, drug or alcohol problem. Young carers usually have more responsibilities than other young people their age.
The person they care for may be a parent, sibling, their own child, other relative or friend.

## How many young carers are there in Australia?

The ABS (2003) states there are approximately 347,700 young carers (5.2% of all people under 25) in Australia who provide support for a family member who has a disability, mental illness or other long term illness. 101,600 of these young carers are aged less than 15 years (representing 0.5% of all people under 15 years of age).

In NSW it is estimated there are currently 90,200 young carers (ABS, 2004). There is currently no available data of age breakdown of young carers in the 9-14 year age bracket. Carers NSW supports young carers as young as 7 years old.

There are currently 1502 young carers on our database.

## What do young carers do?

Young carers may undertake tasks ranging from cooking, cleaning, being responsible for finances, minding siblings and supporting the person with an illness or disability. Supporting the individual may involve personal care such as showering, emotional support, or medical support such as administering medication.

While each caring situation is different, the experiences and challenges of young carers and their families can be similar. Young carers often say that the emotional side of caring is the most difficult challenge. They can feel sad, confused and frustrated, as well as worry about their loved ones.

## Acknowledgement of young carers in *NSW Carers Action Plan 2007-2012*

In 2007 the NSW Department of Health implemented the *NSW Carers Action Plan 2007-2012*. The Action Plan outlines a whole of government policy commitment to recognising and supporting carers over the next five years. It includes strategies to increase the respect and recognition of carers, reach out to family members who may not see themselves as carers, improve services to carers and the people they care for, encourage agencies to view carers as partners in care and support carers to combine work and caring. The Action Plan specifically refers to identifying and supporting ‘hidden’ carers’ of which young carers have been identified within this group. The plan identified both the need to support young carers directly, as well as supporting parents who need care in their parenting role to reduce inappropriate levels of caring of young carers.

## Supports for young carers in NSW

Young carers are currently supported by both the Commonwealth and State governments.

Carers NSW Young Carer Project

The Young Carer Project at Carers NSW, funded by the NSW Department Of Ageing, Disability and Home Care (DADHC) and the Commonwealth Department of Families, Housing Community Services and Indigenous Affairs (FaHCSIA), was created to make a positive difference to the lives of young carers (25 yrs and under) and their families.
The young carer statewide project has been created to:

- promote the issues and needs of young carers through statewide community awareness programs;
- develop a young carer support network in partnership with relevant agencies, services and schools;
- coordinate a variety of young carer activities in the short-term;
- support referrals to local services who can assist young carers and their families;
- provide telephone support, information and referral for young carers and their families;
- develop and distribute other appropriate resources;
- review and evaluate existing young carer support activities.

The project undertakes the following activities to achieve its objectives: statewide camps, quarterly newsletter, telephone group counselling, face-to-face counselling, telephone support/information/referrals, interactive young carer website, development of regional networks, community awareness and education.

In 2005 FaHCSIA launched a range of initiatives to respond to young carers educational, emotional, social, information and respite needs. The initiatives included:

- Up to five hours a week of 'in home' respite to enable 'at risk' young carers to complete secondary school
- Two weeks of respite each year to enable young carers 'at risk' to undertake activities such as studying for exams, training or recreation
- Young carer information, advice and referral services including a telephone hotline, age-appropriate information and a website.

Injecting significant funds to increase respite availability to young carers who had been excluded from education, and funding to State and Territory associations has gone some way to further young carers and their families. However there continues to be a level of unmet need and lack of appropriate supports for young carers.

This program has recently undergone a national review, with the report still to be finalised. Carers Australia contributed a support paper on this review, with particular emphasis on the support needs of young carers. This support paper has been included as an attachment to this submission to provide additional and more detailed information about the support needs of young carers.

## Key Issues for young carers

Demographic changes in household structure places young people in a more likely position to take on a caring role. The percentage of one parent families with dependent children increased from 20.7% to 21.6% of all families with dependent children from 2000 to 2005.

This trend increases the likelihood of young people taking on significant caring roles within families as no-one else is available (ABS 2005; ABS 2006).

A number of research projects have been undertaken in both the UK and Australia, acknowledging young carers have a distinct caring profile and are a vulnerable group with specific needs in their caring role. In 2001 Carers Australia published a research report about young carers, which revealed the following:

- Young carers often fulfil the role of the carer because there is no one else to do it.
- Being a young carer can result in reduced life choices and future opportunities. Approximately 60% of young primary carers between 15-25 years are unemployed or not in the labour force, compared to 38% for the general population in this age group.
- Being a young carer can impact negatively on the young carer's health and well being. Many young carers have feelings of constant sadness, guilt, anger, fear and worry which can contribute to impaired psychosocial development.
- Being a young carer can impact negatively on their participation in school. Work or other community activities. Only 4% of young primary carers between 15-25 years are still at school, compared to 23% for the general population in this age group. Social impacts, including limited time to participate in social and leisure opportunities, reduced opportunities to develop friendships and relationships, reduced time to attend school or complete homework. Impact negatively on the young carer's participation in school, work or other community activities.

It is also important to note that whilst research has identified many negative impacts of caring on young carers, being a young carer can also have a positive impact on their lives. Many young carers experience pride in their role and the contribution they make to their family; the development of caring skills which could be used in future employment; maturity of the young carer due to the responsibility of their caring role; and development of close bonds between the young carer and the person they care for.

**Needs of young carers**:

One of the most significant issues for young carers is their participation in school and other learning institutions. Young carers report difficulty in attending school and completing homework due to the demands of their caring role. In addition cost of school fees, books and extra curricula activities can be prohibitive to participation at school for some young carers facing financial hardship.

The Commonwealth respite program mentioned above is one initiative that has been implemented to assist young carers to remain in education through provision of respite to allow attendance at school, time to do homework, and study for exams. Whilst the initiative is welcome, and addresses some level of unmet need, respite continues to be a key issue for young carers. Young carers identify that respite services need to be available when needed and in a form that meets the needs of the young carers and their family. Availability of, and access to specific respite services for young carers as well as better access to mainstream respite services will assist in the provision of respite for the individual needs of young carers.

In addition to respite there are other factors that limit access to education for young carers that also need to be addressed.

Access to education opportunities is also restricted by eligibility of Carer Payment and Carer Allowance. The Adult Disability Assessment Tool (ADAT) used to assess eligibility of Carer Payment and Carer Allowance does not reflect the needs of young carers. The ADAT limits eligible carers to 20 hrs per week of work or study. This limitation is prohibitive, particularly for young carers who are trying to juggle employment and their caring role, or for those who are completing primary, secondary or tertiary studies. This impacts on their future life choices as it does not encourage young people to seek further education or employment opportunities. Access to adequate income support for young carers and their families is essential in ensuring young carers have the opportunity and financial access to education.

There also needs to be a greater awareness of young carers within the school system, community care sector and general community. Young carers need to be identified as a specific group of carers at risk. Schools need to be better informed about and more supportive of young carers. Awareness training to school teachers is needed to assist school staff to identify young carers and support them to remain at school. Young carers identify needs such as flexibility in completing some school work at home rather than class attendance, and having someone to talk to about their caring situation (Institute of Child Protection Studies, ACU National, 2006).

Schools need to be more proactive in identifying and supporting young carers. Primary and Secondary school teacher information kits have been sent out by Carers Australia in attempt to raise awareness in schools about Young Carer identification, needs and issues. However, additional follow-up is required by the states in terms of implementing information and recommendations. Carers NSW would like to see participation of young carers in education, training and employment at rates approaching that of their peers who do not have caring responsibilities.

Young carers identify that there is little understanding from service providers and in the community about the role of a young carer and therefore what their support needs are. There needs to be a greater awareness of young carers and an understanding of the extent of the responsibilities they have. A survey of young carers conducted in the ACT (Moore, 2005) suggested that young carers and their families were not receiving supports because services did not respond to their need, they weren't of quality, they were not accessible and they were not well publicised which meant that many families did not know what they were entitled to or how to access supports.

Young carers identify the need for both widespread programs and services specifically targeted to young carers and their families, as well as identification of young carers and their families as a key target group for all mainstream services.  It is particularly important for mainstream services in rural and regional areas to acknowledge young carers and provide appropriate support due to the fact that there may be limited services specific for young carers in regional and rural areas.

The demand of the caring role also limits young carers access to social and recreational opportunities. Appropriate respite and support is needed for young carers to access social opportunities, as well as an increase in the availability of specific social and recreational opportunities that assist young carers to connect with each other, for example more peer support activities whereby young carers can meet or connect with other young carers to support each other and talk about their caring role.

## Conclusion

This submission has been provided to make the inquiry committee aware of young carers as a specific group of young people in need of specialised support, identify their needs, and provide recommendations in supporting this group of young people in their caring role.
The following recommendations are provided to better support young carers:

- Increase of specific respite services for young carers as well as better access to mainstream respite services.

- Increased financial support for young carers, including easier access to the Carer Payment and Carer Allowance, and incentives for young carers to remain in education or employment opportunities. Comment: is the second half of this recommendation better as separate recommendation. Agreed!
- Increased awareness and training programs to schools and school teachers about young carers and the supports they require to remain in school.
- Awareness and training to community care service providers about young carers and their needs, in order for services to have a better understanding about how to support young carers. This is particularly important in regional and rural areas where only mainstream service may be available to young carers.
- Increase provision of specific young carers social participation programs to provide young carers with linkages to support each other in their caring role.
- Additional funding in order to provide case management and service coordination to meet the ongoing and individual needs of young carers across the state.
- Review of respite services to reflect the ongoing needs of young carers and the difficulties associated with time-limited respite.
- Support for young carers should be considered in conjunction with support needs for their family situation. If the family was better supported the wellbeing of young carers will also be improved.

Carers NSW appreciates the opportunity to provide information regarding young carers to the Inquiry on children and young people aged 9-14 years in NSW.

If you wish to discuss these comments further please contact:

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# Young Carers Support Paper

## 1. Introduction

Carers Australia is the national peak body representing the 2.6 million family carers in Australia who provide care for people with disabilities, mental illness, chronic condition or who are frail.

Carers Australia's members are the Carers Associations in each state and territory, which deliver specialist information advice and counselling services to carers in the community. Carers Australia is informed about carer issues through its member Carers Associations and its participation in national and international forums.

Carers Australia believes that all carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education.

## 2. About young carers

### 2.1 Definition of young carers

Carers Australia uses the following definition of young carers:

> Young carers are children and young people under 26 years old who help care in families where someone has an illness, a disability, a mental health issue or who has an alcohol or other drug problem.

The person they care for might be a parent, a sibling, their own child, a grandparent or other relative, or a friend. (Some young carers have been identified by services as young as six years old.) They often provide care because they are the only ones at home available to fulfil this role. Most young carers are willing to take on this role and want to continue to provide care as long as they and their families receive adequate support and services that target both young carers and their families.

### 2.2 What do young carers do?

While every care situation is unique, young carers often perform tasks not normally undertaken by people their age. Responsibilities may include intimate care tasks, assisting with mobility and medication, looking after younger siblings, providing emotional support, completing housework or any other tasks that are required.

Young carers spend most of their time either directly providing care or thinking about the person they support.

### 2.3 Young carer facts

Data about young carers is limited. We know that there are more than 170,600 Australians under 18 years and 348,700 under the age of 26 who provide care to a family member who has a disability, or a mental or chronic illness (Australian Bureau of Statistics (ABS) 2004). Of these 41,400 under the age of 18 years and 90,200 under the age of 26 are primary carers. ABS classifies a primary carer as the person who provides the most informal assistance to the person needing care. The assistance has to be ongoing, or likely to continue, for at least six months (ABS 2004). Other young carers also provide care but do not have a primary or main carer role. (Note: ABS data does not include young carers under the age of 15 years.)

Approximately five percent of all people under 26 years of age in Australia are carers, and about 14 percent of all carers in Australia are young carers. The average age of young carers less than 18 years is 12-13 years. About three quarters of primary young carers are female. Young carers are representative of the general population in respect of their cultural and ethnic background. One third to one half live in the rural and remote areas of Australia where services that support families are, in general, poorly provided (ABS 2004).

Young carers are more likely to come from low income families and care for a parent, who often is someone with a mental illness.

Young carers experience disrupted school attendance because of their caring role. They are less likely to complete secondary or tertiary education than non carers. The school retention rate of young carers aged 15-25 years (ie young people moving into vocational or tertiary education) is four percent compared to 23 percent of the general population.

Many young carers see themselves as daughters or sons, brothers or sisters who are part of a family unit where a member or members have disabilities, or chronic, terminal or mental illnesses, rather than as a young carer of other family members. This may limit their access and referral to carer support services, particularly those established for young carers.

### 2.4 Impact of caring on young people

The caring role has the potential for significant negative effects on young carers, including reduced life choices and limited opportunities. The major factor for this outcome is their lower participation in secondary and tertiary education. This limits employment and career opportunities for young carers. Consequently, this will impact on the choices they have about their own future, and their financial wellbeing.

When families aren't well supported, children and young people can miss out on opportunities to go to school, do homework, spend time with friends, have a job or further their studies. They can experience high levels of stress and worry, feel confused and uninformed. Their physical and mental health can be affected as a result of caring without adequate support.

## 3. Support for young carers

### 3.1 The new Government’s Social Inclusion agenda

The new Federal Government has identified social inclusion as one of its major policy platforms. The ALP’s *Australian Social Inclusion agenda* stated:

> "The Australian economy has entered its 17th year of economic growth but now more than ever a social inclusion agenda is needed in Australia. Behind Australia's growth story lies the experience of Australians who, at the time of great prosperity, remain disadvantaged.
>
> Social exclusion is the outcome of people or communities suffering from a range of problems such as unemployment, low incomes, poor housing, crime, poor health and disability and family breakdown. In combination, these problems can result in cycles of poverty, spanning generations and geographical regions.

Deputy Prime Minister Julia Gillard stated recently that the social inclusion agenda must have two guiding principles – it must tackle the social exclusion of individuals and communities, and it must invest in the human capital of all our people, especially the most disadvantaged.

Many young carers and their families are socially excluded because of inability to complete, or difficulties with completing, secondary or post-secondary education and training, family low socioeconomic status, and exclusion from normal social activities because of affordability or accessibility because of caring responsibilities. (See section 2. About young carers.)

### 3.2 Young carer programs

The Australian Government provides funding for programs to support young carers through the Australian Government Department of Families, Community Services and Indigenous Affairs (FaCSIA). These were introduced in 2005 and include the Supporting Young Carers Initiative and the Young Carers 'at risk' Respite Program. The total program, announced in the 2004-05 Budget, was to cost $26.6 million over four years, of which $2 million ($500,000 per year) was allocated to the Supporting Young Carers Initiative. Carers Australia has been funded by FaCSIA to manage and deliver the program since February 2005.

The Young Carers 'at risk' Respite Program is provided through the Australian Government Department of Health and Ageing's (DoHA) Carer Respite and Carelink Centres.

Young carers can also access other carer services funded through the Commonwealth State Territory Disability Agreement, and non-age specific community care programs funded by the Australian Government Department of Health and Ageing.

### 3.3 Supporting Young Carers Initiative

Carers Australia coordinates this initiative through the state and territory Carers Associations. A national program coordinator, who is based at Carers Australia, oversees the initiative. Current funding allows for the employment of five full-time staff equivalent nationally. Carers Australia believes that these resources need to be increased to allow

- a greater community development role and support for existing young carer workers in their role
- family-centred assessment and case management options and
- greater brokerage of support services, including appropriate counselling.

The larger associations (Carers NSW, Carers Victoria and Carers Queensland) should be funded to employ 3 full time equivalent staff and the remaining associations, including Carers Australia, to employ 2 full time equivalents. This would bring total staffing costs for the Initiative to around $1.6m. A further $2m annually would be required for additional support and brokered services.

ANYCAT (Australian National Young Carers Action Team) is a national young carer network established to provide assistance to Carers Australia and the Carers Associations in the development of national, state and territory based Young Carer Programs. ANYCAT members comprise a young carer and the young carer program officer from each state and territory Carers Association, and it meets twice yearly face-to-face and by regular teleconferences. Additional funding should be allowed to provide education and training to the young carer members, particularly in their role as representatives of a wide diversity of young carers across the country. A further $20,000 per annum should be allowed for this.

The Initiative provides a range of age-appropriate services for young carers, such as information, referral and advice services including counselling. Further funding is required to increase the number of young carer kits produced to at least 10,000 per annum and to fund their distribution. Another $95,000 would be required. Provision should also be made for more copies of the secondary school resource to be printed and distributed and for a review of the existing primary school resource. Curriculum guides need to be developed for both primary and secondary schools to build on the resources currently in place. A strategy to successfully raise awareness of young carers in the post-secondary sector also needs to be developed, along with a supporting resource. A further $300,000 would be required for these initiatives.

The national website is currently undergoing reconstruction and should be live by early next year. Continuing funding will be required for a webmaster to maintain the website and to manage the interactive elements. The website will also be a major consultation tool with young carers, particularly for young carer policy development.

Since its inception:

- the number of young carers accessing initiative' services have continually increased since it began
- it has provided more than 82,800 single supports to young carers, service providers, schools and others
- around 8,380 young carers have received direct support as part of this initiative
- over 10,330 workers have received young carer training, information and support
- the young carer website and the NSW young carers website together have received close to 3,000 hits a day (Note: the young carer website is being upgraded through a FaCSIA grant.)

Carers Australia has advised FaCSIA that this initiative is under-funded because the demand for young carer services exceeds those that can be supplied under the current funding allocation. In addition to the funding outlined above, carers associations require funding to:

- reach and provide services to young carers and service providers in rural and remote regions
- reach and provide services to young carers outside secondary education, ie primary and post-school education and entering the workforce
- increase staffing level in Carers Associations to meet the increasing demand for young carer services, including education and training of young carers and service providers, particularly Respite and Carelink Centres
- have the capacity to respond to a national campaign to assist health professionals, service providers and educational institutions to identify, support and refer 'hidden' young carers

- the development and delivery of assessment and priority of access tools for all young carers across the range of carer services (Note: DoHA is developing a carer eligibility needs assessment (CENA) tool, which may be appropriate or adaptable for young carers; or age appropriate tools utilised by the Western Program in Victoria could be considered.)
- the development and delivery of a family case management model, which may include access to family support services and other specific services and resources to support all members in that family.

Carers Australia has also identified the need for research in five main areas:

- supporting young carers who care for someone with a drug and alcohol problem, eg analysis of, or testing of protocols between young carer programs and drug and alcohol support services
- supporting young carers in particular age groups: between the ages of 18-25 and under the age of 10 years
- transition policies from school to work and from home to independence
- support for young carers suffering grief and loss upon the death of their relative
- support for young carers who become a parent of a child with a disability.

Carers Australia would also like to see some longitudinal studies tracing the experience of young carers over a number of years, with an interval of say every four years, taking in the pre-adolescent, adolescent and young adult transitions.

In each of these areas research is required to explore the issues that face these young people and their families and what services need to be put in place to best support them. (Carers Australia is aware that some young carer research is being funded by FaCSIA.)

Carers Australia has also sought funding from FaCSIA to develop and further recommendations from the 2nd Young Carer Summit (2006) through a major national activity that incorporates academics, policy makers and young carers. FaCSIA is considering Carers Australia's proposal.

### 3.3 Young Carers 'at risk ' Respite Program

The Young Carers 'at risk' Respite Program has been operating for approximately two and a half years, and was established by the Australian Government to achieve better outcomes for young carers 'at risk' of leaving school prematurely because of their caring responsibilities. The program has two respite components – one for up to five hours at home respite per week during school term, and the other is two-week blocks of respite to undertake activities such as study, training or recreation.

It was designed to complement existing respite programs that are accessible by young carers. However, the program guidelines stated that current use of other respite programs by young carers is very low.

Around 500 young carers a year were expected to access each of the two components of the program. The FaCSIA Annual Report 2005-2006 indicated that 883 young carers accessed the respite component of the program in that year, which is nearly 90 percent higher than the projected figure.

While the demand for the program is high, it has inherent problems. These included:

- the restriction of the program to young carers in secondary education

- access by primary or main young carers only
- young carers are defined as being aged to 25 years but the program allows only for those aged up to 24 years
- respite is restricted to a maximum of a 12-month continuous period for an individual young carer, and the restriction in blocks of time and activities that can be supported.

  (Note: FaCSIA wrote to Commonwealth Carelink and Respite Centres in June 2007 indicating that the program was being reviewed and that more flexibility was allowed, including young carers aged 25 were covered by the program, as were young carers in primary education, and secondary carers could be considered as could an extension of the 12-month period in higher than usual need circumstances taking into the needs of the young carer and considerations of equity and accountability.)

The program guidelines assert that they are a 'living document' that may be amended from time to time to respond to changes in policy and service delivery, and Carers Australia calls on the Australian Government to be responsive to the recommendations in this paper.

## 4. Background to further respite policy development and delivery

### 4.1 Introduction

In 2006 at the 2nd National Young Carers Summit (which was attended by young carers, service providers and government delegates) respite was one of four key issues for which an action plan for the future support of young carers was developed.

The Summit focus on respite aimed to review different respite options for young carers and develop strategies to improve flexibility and access. The overarching outcome was to redefine young carers respite to become part of a broad support framework that assesses the impact the caring role is having on the young carer and the support services they require. Three main areas were identified:

- Access
    - impact of the caring role
    - restriction of respite brokerage funding to young carers in secondary school
    - dissemination of accurate information to young carers
- Coordination of services
    - consistent services
    - processes and systems for referral
- Eligibility
    - early intervention and assessment
    - time limits to brokerage
    - ongoing contact with families

Given that the Young Carers 'at risk' Respite Program is one of the programs being reviewed in 2007, it is appropriate to reflect on the recommendations from the Summit's action plan to inform the review.

### 4.2 Access

*Aim: Flexible support options are available to all young carers and their families, irrespective of location, financial and social circumstances, and phase of education*

### 4.2.1 Impact of the caring role

In any family, the burden of care can be borne more heavily by one member than another, but this can change depending on the individual circumstances. Many young carers are children, and while some young carers have sole care responsibility for their family member, it is more likely that young people do not have this sole care responsibility. Young people in this latter situation are considered to be secondary carers. Secondary young carers can also provide a significant amount of care that impacts on their life, particularly education. FaCSIA's advice of June 2007 indicates that the program guidelines can apply to secondary young carers on a case-by-case basis taking into account the needs of the young carer and considerations of equity and accountability. Prior to this advice the number of young carers that could benefit from assistance under the program was significantly reduced.

This group of young carers are particularly vulnerable as they are, in most cases, ineligible for other government assistance (eg Carer Allowance or Youth Allowance). Carers Australia believes that there is a need for an eligibility or priority of access tool to assist establish national consistency in the Young Carer 'at risk' Respite Program operation, particularly the definition of 'significant amount of care'.

### 4.2.2 Restriction of respite brokerage funding to young carers in secondary school

A program that only supports primary or main young carers at risk of leaving secondary school does not capture the whole respite support needs of young carers. In delivering a program such as this, it is vital that early intervention exists to reduce the educational risk associated with all young carers. To provide respite for a young carer in secondary school overlooks the need for intervention in primary school where the basic numeracy and literacy elements are learnt. Poor literacy increases the likelihood of a young carer entering secondary school below the appropriate academic level, and increases the likelihood of them prematurely leaving school. (Although, as indicated above, FaCSIA has advised that young carers in primary school are eligible under this program and this occurs in some situations.)

Young carers in post-secondary studies also require adequate respite assistance so they can complete their studies. It is inconsistent to only support a young person through one part of their education. In many cases the caring role does not decrease. In fact, over time the caring responsibility could increase as the condition of the person requiring care worsens.

It is logical that if this program successfully provides respite during secondary education it should also meet the family needs of young carers up until they reach the age of 26 if required.

### 4.2.3 Dissemination of accurate information to young carers

Depending on the region in which a young carer lives, the information that they receive about available support they can receive varies across the country. There is a large amount of duplication of information, which is a waste of resource funding. Carers Australia believes that there needs to be a consistent approach to information and support, with some variation for local content.

## 4.3. Coordination of services

*Aim: Improved coordination of services and communication at national, state and territory levels*

### 4.3.1 Consistent services

The Young Carers ‘at risk’ Respite Program is an Australian Government-funded program delivered by a wide range of respite services. Consequently, there is an inconsistent approach to the delivery of this program. This includes the interpretation of the guidelines by service providers to the information they give to young carers, and the direct support young carers receive. An example is a 10-year old young carer who receives respite support because they are not coping in primary school and the respite service has interpreted the guidelines that they are at risk of not completing their secondary education. Yet another 10-year old young carer in a similar situation who seeks support from another respite service provider is deemed ineligible because the guidelines were applied differently. Hopefully, FaCSIA’s recent advice will rectify the difference in interpretation.

There are many similar examples under the current program. Carers Australia believes that national, state and territory coordination and interpretation of the program guidelines is required to allow service providers to work collectively to improve and develop a nationally consistent approach to young carer support. This could occur through a role established within Carers Associations to coordinate, in collaboration with respite centres, development, improvement and consistency of practices. The Network of carers associations has developed a Good Practice Guide and a Young Carers Operations Guide which could assist with this work.

### 4.3.2 Processes and systems for referral

Processes and systems of referral are vitally important for young carers service – not only between the Young Carers ‘at risk’ Respite Program and the Supporting Young Carers Initiative, but also the referral process to and from other service providers such as:

- health and community services (doctors, community nurses, community health services, mental health services, and alcohol and drug services)
- government service delivery sectors (eg Centrelink) and other youth service providers
- education system
- employer groups.

A well-established and coordinated referral process and education program ensure that when other services identify a young carer there is a clear and consistent process for them to assist young carers to access respite and other appropriate support services. There also needs to be awareness raising of young carers and their identification in these services.

Equally important is the need to ensure young carer programs are referring family situations to appropriate family support services where they exist.

## 4.4 Eligibility

*Aim: Consideration to be given to the provision of respite that meets the individual family situation*

### 4.4.1 Early intervention and assessment

This is vitally important for the support of young carers. Appropriate support for young carers and their families can prevent the care situation getting to a point where the health and wellbeing of the young carer are at risk, quite apart from their education issues. They are susceptible to social and emotional issues, and financial stress. (Note: FaCSIA is funding young carer research that will provide evidence about these and other issues.)

It is important that all members of the family are engaged in needs assessments to ensure that the real need for the young carer and their family is identified. This will include the needs of the cared for person, the needs of each family member (including the primary young carer and secondary carers), and the needs of a family as a unit.

A focus on the needs of the care situation implies that the program (in combination with other programs) should have the capacity to deliver a range of support programs to support the continuity and well being of the family. However, the young carers program should focus on the young carer.

#### 4.4.2 Time limits to brokerage

The program guidelines indicate that respite brokerage funds are only to be made available on a short-term basis, and that they are to augment the formal service within a region, or to be an alternative means of funding the existing service system. However, there are very few of these alternative services for young carers.

While Carers Australia realises that there is an assumption that young carers will access the other respite services, the Young Carers 'at risk' Respite Program guidelines stated that take up of this respite is low. Therefore, Carers Australia believes that these limitations are unrealistic until barriers that prevent young carer take up of alternate respite are removed.

Young carers and their families are not all the same, and their respite requirements will be as different as the individual caring situation.

Most young carers and the person they care for in their family want to stay together, and residential care apart from each other is inappropriate. Respite and other carer services for young carers and their families need to be considered on a case-by-case basis. Young people's caring can, and in many situations does last the whole of their childhood and young adult years – well past a 12-month 'at risk' support period. The program restriction that respite is not to be used on an ongoing basis does not provide satisfactory support to young carers or their families who are not accessing other respite services.

#### 4.4.3 Ongoing contact with families

One of the strong recommendations that came up at the Summit was the need for a case management model to be developed for the ongoing support of young carers and their families. This not only ensures that the young carer has been through an assessment process, but it can also monitor and ensure that all the support needs of a young carer and referrals can be put in place for the young carer and their family. This also provides ongoing contact with the family and support services. A challenge is to determine where ongoing case management for the family may best sit, when a family is engaged with a number of different support agencies.

## 5. Recommendations

### 5.1 Supporting Young Carers Initiative

1. That the Australian Government provide additional funding to the Supporting Young Carers Initiative to adequately meet the needs of the initiative, as outlined in 3.2 above

2. That the Australian Government provide funding for young carer research on supporting young carers who care for someone with a drug and alcohol problem and how the resources of different agencies involved can be best used to support continuity of family functioning, supporting young carers between the ages of 18 to 25 and supporting those under the age of 10 years. There should also be a focus on supporting young carers through the periods of transition from school to work; from home to independence; and periods of loss and grief following the death of the cared for relative as well as the experience of becoming a young parent of a child with a disability. Longitudinal studies of young carers' experiences from pre-adolescent to young adult should also be undertaken.

3. That the Australian Government fund a national campaign to assist health professionals, service providers and educational institutions to identify, support and refer 'hidden' young carers to the program – provided however, that associations are sufficiently funded to have the capacity to respond to a resulting increased demand for services.

### 5.2 Young Carers 'at risk' Respite Program

1. That the Young Carers 'at risk' Respite Program guidelines are changed to:

- reflect that a definition of a young carer includes primary and other young carers whose caring role affects their attendance or learning at primary, secondary or post-secondary education and training institutions
- allow the delivery of supports to young carers who leave school because of caring responsibilities
- allow greater flexibility in relation to the target group of young carers while maintaining the integrity of the program's objective to minimise young carers risk of leaving school prematurely, to pursue post-school education and training and ultimately to encourage young carers to successfully enter the workforce
- allow greater flexibility of use of total available respite per family at the discretion of the case worker's assessment of respite needs.

2. That the Australian Government analyses other respite programs to determine if young carers are adequately accessing respite outside the Young Carers 'at risk' Respite Program, and to identify barriers to young carer take-up of these respite services

3. That the Australian Government provides funds to research and develop a tool that can assess the impact of the caring role on young carers, regardless of their caring status (ie primary or secondary carer)

4. That the Australian Government funds a training program to implement the assessment tool throughout respite and carer services

5. That the Australian Government funds a national young carer respite and services network through each state and territory Carers Association to provide opportunities for service providers to develop skills, knowledge and relationships through shared information and expertise

6. That the Australian Government funds the national young carers respite and services network to develop a best practice model that establishes a national referral system and process that suits all service providers, and that an education program is developed to train service providers in these processes

7. That the Australian Government encourages and funds strategies that implement the use of innovative technology to communicate nationally and at state and territory levels.  This could be established through the national young carers website

8. That the Australian Government funds the research and development of a family case management support model and training package that includes a whole of family approach; and that funding is available to implement this model in all young carer services.

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