

Submission Number: 45

Date Received: 13/02/09



**Combining school and work
Supporting successful youth transitions**

**Young carers
'Under the radar'**

January 2009

Carers Australia is the national peak body representing those Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

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Title: **Combining school and work: supporting successful youth transitions**
Date: February 2009
On behalf of: Carers Australia

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Introduction

Our submission draws the Committee’s attention to a group of young Australians who have a range of skills and abilities that have been developed through the provision of **unpaid** care in families where someone has an illness, a disability, a mental health issue or who has an alcohol or other drug problem.

Research consistently shows that family carers forfeit employment opportunities, experience isolation, loneliness and social exclusion to the detriment of their own quality of life. If young carers are to reach their full potential and enjoy the same opportunities as other young Australians, it is critical that the government acts now and provides them with adequate support through their schooling years so they can make a successful transition to employment.

The impact of this caring role on their education and the transition to work can be quite significant. Some young carers are spending more than 30 hours per week in their caring role – almost equivalent to full time employment.

We believe there is a link between this Inquiry and the current Inquiry into Better Support for Carers. Carers Australia would ask that the Committee liaise with Annette Ellis and her committee members before finalising any recommendations. In November last year Carers Australia held a Young Carers Forum to examine and discuss issues of concern to young carers. Ms Ellis was a panel member on the education session. She noted that the Committee had travelled the country listening first hand to carers’ stories as part of their Inquiry. In relation to young carers she said:

..“the lack of recognition, the lack of understanding, the lack of opportunity for complete educational outcomes, because of the role of caring, the lack of understanding by their peers as to the role and the pressure that they’re facing in what they’re doing were clear messages.”

Ms Ellis added “I’m pretty confident that we’ll be able to say something pretty constructive in how we believe it should go forward from here for young carers.”

The Hon Jenny Macklin acknowledged the efforts of young carers during her official opening of the Young Carers Forum:

“If I can say to all of you who are here today, you are very, very special young people, extraordinarily special young people, compassionate and committed way, way beyond your years. One of the things that’s so wonderful about you is that you really are the voices of so many other young carers who every day get on with the job of caring for the people whom you love and they love.

...Many of you are trying to manage your schooling and some of you are trying to manage your university courses as well while you’re undertaking your caring responsibilities.

...I hope that you learn some ways that you might be able to improve your juggling efforts meeting all of the different responsibilities you have but I also hope that as a result of you all coming here to Canberra, we’re able to do a better job because we listen and take on board what you’ve got to tell us.”¹

During the Forum, young carers were encouraged to tell their stories and share their thoughts. Some of these stories are outlined below.

It seems part of these things of identification and respite is actually about gearing young carers to be able to continue doing this for a really long time and I don't want to. Apparently according to social workers, I've been doing this since I was eight and I think it's really important that at this forum we actually emphasise to young carers that at some point they're going to stop being carers and have to get on with their own lives. There's actually a really fundamental problem there. It's important to support young carers and recognise them and tell them that they're doing a great job. But it's also really important to actually try and dismantle why it is that so many young people are having to take up these caring roles.

I'm 16 and I'm in year 10 at high school. I care for my older sister who has schizo effective disorder and my dad who has several heart conditions, diabetes, sleep apnoea and various other assorted problems that come along with those. I love going to school, the social side of school is also a great chance to get away from the caring role. I love learning and I want to do lots in my life so I think an education is vitally important for every student and that young carers should have the opportunity to receive equal education opportunities as every other student in Australia.

Yes school is a bit of respite for me. Especially when I was in year 7 my sister was particularly ill and she was being cared for 24/7 at home, so being able to go to school was my chance to get away from everything at home and I was able to really focus on my studies. That was my chance to get away to concentrate on something else and not have to worry as much on the problems at home.

Having teachers who understand what your role is and what young carers do and why you may not be able to get work in on time or why you may need to leave the classroom because you just can't think anymore is important. And having people that want to take the time to understand, that generally can give you an extension or offer you a bit of assistance because they know that you've got something else going on at home is important.

So the education of the teachers and making teachers aware of what young carers are, I think is vitally important. I know they say they don't have a lot of time, but just for them to know what a young carer is and what a young carer does, and so they are kind of aware of what their life is like. The teachers then may be a bit more understanding and emphatic.

A young carer learning for the first time she was a young carer:

Yes, I just said to the teacher, oh, I've just been looking after my mum and she just hasn't been too well and I didn't even finish telling what her situation was and instantly she just, took me into her office and she actually put me on the phone to Abe, who's left now, and he just said, Oh, I need to come and see you and I need to come and see you now. Yes, he came down to my house the next day and sat down and we had a chat so that was good. It was incredible, it was so good and I think the circumstances – I was so broken, like 16 years old and even though it had only just been me caring for my mum for six years, it was my life that I'd been living with and facing such hardship.

About Carers Australia

Carers Australia is the national peak body representing those Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Through its members, the state and territory Carers Associations (the Network) there is a unique infrastructure Australia wide. The Network delivers specialist information, advisory and counselling services to carers in 60 sites around Australia.

Carers Australia is informed about carer issues through its member Carers Associations and its participation in national and international forums.

Carers Australia believes 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. Unfortunately, research clearly indicates that many carers are disadvantaged socially, physically and economically.

About Young Carers

A vulnerable and 'at risk' group

Young carers are a group of young Australians under 26 years of age who provide **unpaid** care in families where someone has an illness, a disability, a mental health issue or who has an alcohol or other drug problem. They are required to perform the same caring tasks as older carers including providing emotional support and assisting with mobility, the provision of medications, housework and intimate care tasks. The time spent caring can be as much as 30 hours per week – almost equivalent to full time employment. Young carers have to juggle their caring responsibilities and their schooling.

Naturally, young carers see themselves as daughters or sons, brothers or sisters who are part of a family rather than a “young carer”. A general lack of awareness and focus on the needs of young carers, within schools and among other professionals, means their needs can go unnoticed.

We do know that it is very difficult to accurately estimate the numbers of young carers across Australia due to the numbers who are ‘hidden’ in our community. However, current figures suggest that there are:

- 348,700 under the age of 26, and of these 170,600 are young carers under the age of 18
- 132,000 are primary carers – that is they provide the most care.²
- approximately 105,500 carers are under the age of 15³.
- one-third to one-half of young carers live in rural and remote areas of Australia where services that support families are, in general, not adequate.

Characteristics of young carers

Young carers are a diverse group with different needs and levels of vulnerability. In Australia it has been found that:

- young carers have been identified by services as being as young as 6 years of age
- females are only slightly more likely to become young carers than males
- young carers are generally representative of the general population in their cultural background
- young carers spend most of their time providing care or thinking about the person they support
- over half of young primary carers are caring for a parent who is more likely to be a mother and the family is also likely to be a sole-parent household
- approximately one quarter of young carers provide care for a person with a mental illness.⁴

Identification of young carers

Identification is a major issue for young carers. There are a number of reasons why young carers are not being identified, or choosing not to identify themselves, including:

- a complex range of social and cultural values, beliefs and attitudes
- a general lack of awareness by government, key professionals in sectors such as health, welfare, community care, education and disability and the wider community
- the perceived stigma of being associated with disability or illness
- the wish not to be labelled by others
- the fear that child protection services could see them as 'at risk' and remove them from the family.

Australia is not alone. In most countries community awareness of young carers is very limited, even among those in the health, education and social service professions who have most regular contact with the families of young carers. The idea that young people, even children under age 10, are undertaking caring responsibilities goes against general societal norms where children should themselves be looked after, rather than looking after someone. As a result those administering adult services often fail to recognise that a young person is taking an active caring role in the family, often excluding them from discussion about patient treatment or services for the family and, as a result, their particular needs are ignored.

Increasing identification of young carers requires legislative frameworks of equity and fairness with developed welfare support, community awareness and respect. It also requires clear pathways of referral to supporting organisations for those most likely to be in contact with families. Additionally there is a need for disparate service organisations to take a 'whole of family' approach to support.

At the official opening of the Young Carer Forum, the Hon Bill Shorten, Parliamentary Secretary for Disabilities and Children's Services expressed concern about the role of young carers in society:

"I'm sure many people don't realise how many young carers there are and how hard you work because a lot of what you do is under the radar. You fly so close to the ground that, in fact, you just don't get picked up in a lot of the debates in the news and everywhere else. Sometimes some of you and others not here are so busy that you don't even realise that you fit into this category of being a young carer... The thing which really affects me when I read about you is the social isolation. You have a right to have friends, to have fun but your responsibilities make you mature beyond your years and you don't put up your hand and ask for anything special. You do need a hand sometimes."

Impact of caring

The caring role has the potential for significant negative effects on young carers, including reduced life choices and limited opportunities. 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. As a direct consequence of their caring role, the majority of young carers are at risk of all or some of the following:

- socio-economic disadvantage
- isolation
- low levels of health and emotional wellbeing
- impaired psychosocial development
- limited friendships
- low participation and attainment in school and employment
- difficulties in making the transition to independence
- significant lack of opportunity and choices.⁵

Impact on education

Education and the transition from education to employment are significant issues for young carers. Many find that their caring responsibilities significantly disrupt or curtail their education.

An examination of the experiences of young carers in education in 2006 illustrates many of the issues they face. The researchers found that school was valued highly, in terms of being a place where they could achieve, where they could connect with their peers and with adults they trusted, and as a place of respite from their caring duties. Nevertheless many experienced difficulties:

- almost half had attendance difficulties, being late or missing days altogether

- more than half had found it difficult to keep up with homework
- a number had to repeat a year
- almost half concluded that they had not achieved as highly as they believed they could due to the pressures of caring.⁶

What was seen by some as an inflexible and unresponsive school system contributed to their difficulties. Many had not told schools that they were carers, preferring to maintain their privacy, and cited negative consequences of identifying as a carer, such as bullying and peer rejection, and school staff who did not understand and some who broke their confidences. When young carers perceive this as the culture around them they are unlikely to identify themselves as carers at school.

Where the culture was perceived more positively carers valued schools as 'a locus for support'. Teachers who were understanding, counsellors who were available to talk, friends who offered assistance were all identified by young carers as things they appreciated about school.⁷ Some schools had taken proactive and positive action, meeting with parents, arranging for external study or extension of assessment dates, involving community agencies to provide respite, transport and food. For some, their schools were 'a safe haven'.

The statistics below demonstrate the impact of caring on education and the transition to employment:

- only 4 per cent of primary carers between the ages of 15-25 years are still in education compared to 23 per cent of the general population in that age group⁸
- 60 per cent of young primary carers aged 15-25 are unemployed or not in the paid workforce compared to 38 per cent of the general population of the same age group.⁹

And, there is an even higher risk of not making the transition from education to employment for young carers from Indigenous or multicultural backgrounds as educational participation rates are much lower for these groups.¹⁰

These figures clearly indicate that young primary carers are at a much higher risk than the general youth population of not making successful transitions into employment and gaining financial stability and independence.

Despite the fact that 3.5 per cent of young people aged under 18, and 9.2 per cent of those aged between 18-24, are carers many educational institutions and teachers are not aware they have young carers in their classes. They may not recognise absenteeism, incomplete or late homework, or lack of concentration by a student as the result of caring responsibilities. Many young carers may also have difficulty in participating in after-school activities, often being needed at home or being unable to pay for additional activities.

One of the main problems is that many teachers and school administrators are concerned only with the child's scholastic progress. Erratic attendance or incomplete homework is often perceived either as misbehaviour or as reducing the child's chance of success. Children may not always be able to control their school attendance or give sufficient time to their homework, yet will usually be held responsible by their school.¹¹

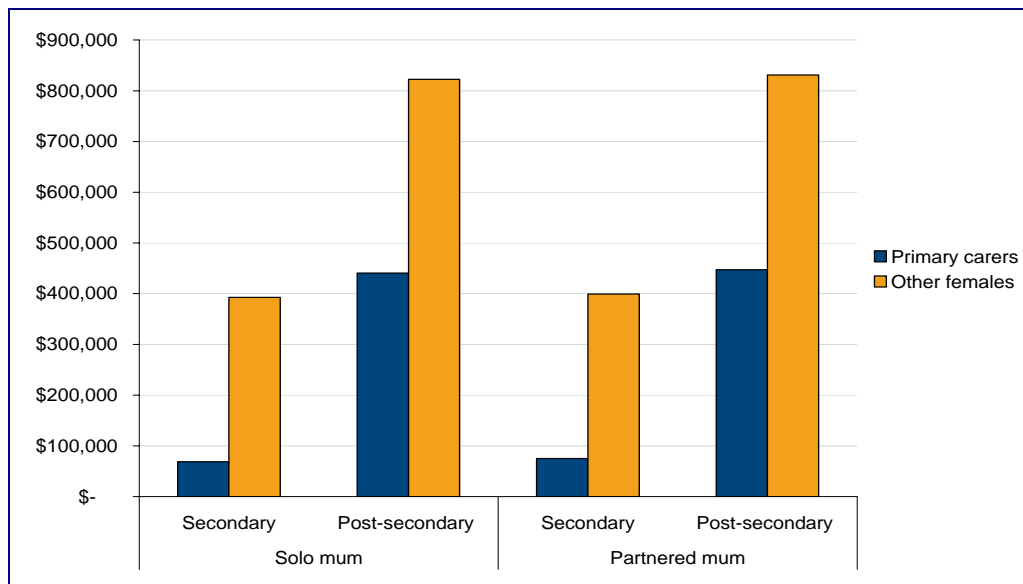
Links between education and long-term earning capacity for carers

In 2008 Carers Australia commissioned the National Centre for Social and Economic Modelling (NATSEM) to look at the impact on the long-term earning capacity of carers. The research looked at two groups of female carers - women aged 30 years with two or more children, who are primary carers caring for their child with a disability and women aged 50 years, who are primary carers caring for their male partner with a disability.

Although these groups were not young carers, the research presents a worrying picture for carers who do not have qualifications above secondary school.

Findings from the research show that women, aged 30 years, with two or more children, caring for a child with a disability and whose highest level of education is less than or equal to completion of secondary school are expected to earn less than \$100,000 (2006 dollars) over their working life. Women sharing the same characteristics but without the primary caring responsibility will earn four times that amount over their working life. While women with post-secondary level education also show a difference in individual income earned over their working life, the difference between primary carers and those without caring responsibilities is double (about \$400,000 vs \$800,000) as opposed to the four fold difference observed with those with lower levels of education.

The table below shows the gross individual income over the working life from wages and salaries for 30 year old women with two or more children – primary carers of a child with a disability versus other females.



Source: Model estimates using HILDA Wave 6 data file.

Recognising young carers' skills, abilities and experiences

Carers acquire skills and abilities over the course of their caring role. These skills and knowledge may be able to be recognised and attributed toward more formal qualifications through the recognition of prior learning or recognition of current competencies. The areas that relate to employability skills¹² where young carers are likely to have had experience include:

- **communication:** listening and understanding, sharing information, being assertive, empathising, negotiating, establishing and using networks
- **teamwork:** working with people from different backgrounds, applying teamwork to a range of situations
- **problem solving:** identifying problems and solving them, developing and implementing solutions
- **initiative and enterprise:** being creative, generating a range of options, translating ideas into action
- **planning and organising:** managing time and priorities, being resourceful
- **self-management:** taking responsibility, articulating own ideas and visions, evaluating and monitoring own performance
- **learning:** using a range of mediums to learn, being open to new ideas and change
- **technology:** operating equipment.

Young carers are likely to have had to liaise and negotiate with GPs, pharmacists and other health professionals, service providers, teachers and government agencies including Centrelink. Some young carers feel they are often not recognised as carers 'by adults in authority'.

Flexible and innovative approaches to schooling

Establishing flexible approaches to education for young carers is crucial. However, in the first instance, schools, teachers and counsellors should be aware that there will be young carers in their school. Currently some schools do this well while others are not as proactive in identifying young carers.

In our 2009-10 Budget Submission we made a number of recommendations around raising awareness of young carers in schools. In particular we have recommended that the Australian Government undertake a national school awareness and training program to ensure schools and teachers have the knowledge needed to understand and support young carers throughout their education.

To achieve this recommendation we identified three components:

- update and disseminate resources for primary and secondary schools – to be available in a range of formats
- undertake a comprehensive scan on good practice models of young carer support in educational institutions

- establish, as a matter of priority, a ‘young carer education taskforce’ that includes young carers and representatives from the Commonwealth, all states and territories and peak organisations to develop nationally consistent policies, procedures and guidelines for young carer education support.

Support required by young carers

Young carers support needs will be different from other young people who do not have caring responsibilities. To address the barriers to successful educational outcomes, young carers require respite, counselling, domestic assistance and feeling confident that the person for whom they are caring will be ‘OK’ whilst they are at school.

Currently the Australian Government funds the Young Carers Respite and Information Services Program. The program has two components - the Young Carers Respite Program delivered through the Commonwealth Respite and Carelink Centres (CRCC) that provides young carers with access to age appropriate support and respite services and an information, advice and referral component managed by Carers Australia.

The respite program initially targeted primary young carers in secondary school. However, following an evaluation the guidelines were amended in 2008 to include secondary carers and also carers in primary school where their education was assessed as being jeopardised by their caring role.

The information, advice and referral component provides peer support groups for young carers, and employs a number of young carer workers to provide age appropriate information, referral and advice services, including counselling.

Both these components are seriously under-funded and do not meet the needs of all young carers. In our 2009-10 Budget Submission, we recommended a substantial increase in funding for this program.

What young carers want

Young carers have identified a number of priorities they would like addressed. These priorities are fundamental to young carers continuing their education in a safe and supportive environment. Young carers want:

- young carer-friendly practices in all schools and tertiary institutions
- teaching staff to receive training about the impact of caring especially in relation to their attendance at school and the ability to do homework in times of difficulty
- schools to provide a safe environment for them without stigma or bullying from those who do not understand disability or ongoing illness

- confidentiality from those they talked to about their caring role and support to help them connect to services
- opportunities to meet other carers in support groups
- access to flexible delivery methods such as on-line learning
- a curriculum that covers caring skills and self care
- recognition of prior learning for their caring activities.

National Carer Framework

Carer legislation, carer policies and action plans have been introduced in most states and territories and some overseas countries as a vehicle for enhancing and embedding recognition of carers and in some cases conferring rights or provisions within existing legislation. We believe that it is now time to develop a national carer framework.

The rationale for why we need to protect carers' rights and ensure equality of opportunity is multi-dimensional. It's about social justice, basic human rights, freedom to make life choices, community expectations, and protection and reciprocity in family relationships.

Carers Australia believes that all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have 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. These rights should be mandated in legislation.

A national carer framework has three elements:

1. A National Carer Act – the overall legal framework for the recognition and support of carers
2. A National Carer Strategy – the vision, outcomes and principles
3. A National Carer Action Plan – short to medium-term agenda, long-term goals, timelines, activities and future directions including future funding

National Carer Act

Recognition of the role and contribution of carers should be supported by appropriate national legislation to acknowledge their vital contribution to Australian society and to protect their rights as carers. As we have mentioned, most Australian states and territories have adopted a carer policy, carer action plan or Carer Recognition Act to underpin carer policy and programs within their jurisdiction, and to set a legislative standard for the treatment of carers by government services.

A National Carer Act should guide interventions and protect rights in a number key areas:

- carer recognition
- mandated involvement as partners in health and community care services
- participation and rights at work
- choice in caring
- children and young carers are protected against inappropriate caring
- access to certain key supports and entitlements.

National Carer Strategy

A national Carer Strategy should set out the government's the vision for carers, the outcomes and principles. This strategy should complement the national disability strategy and any other relevant strategies. The principles should be based on relevant UN Conventions and should include principles that address Australia's values as a society.

National Carer Action Plan

The National Carer Action Plan should set out timelines, activities and funding to meet the National Carer Strategy vision and outcomes and comply with carer legislation.

As an example, it should detail mechanisms and plans to ensure young carers are fully supported in their caring role, are protected against inappropriate caring and are assisted through education and the transition to employment.

Conclusion and recommendations

Young carers are an ‘at risk’ group of young Australians who often slip ‘under the radar’. Their long-term earning capacity can be adversely affected by their caring. It is essential that all schools and learning institutions recognise that young carers will be in their classrooms. We believe that young carers are entitled to the same educational opportunities as all young Australians. We also believe young carers should have a choice to care without fear of discrimination or feeling guilty.

Our beliefs are in line with the first two principles of the ALP’s 2007 National Platform for Education¹³ that affirm:

1. All children have the right to high quality education so that they can live fulfilling and rewarding lives. It is the responsibility of government to protect that right.

2. This responsibility entails investment in raising standards at all levels of education. It includes guaranteeing that all Australians have access to the full range of learning outcomes so that students and trainees can fully develop their capabilities, as well as the intellectual and social skills they need to gain the maximum benefit from citizenship.

Other principles of particular relevance to young carers include:

28. Labor recognises the importance of the middle school years and the need for specific encouragement, support and inspiration for young adolescents at school.

37. Labor will continue to give priority to equity in schooling, for students and groups of students who are currently not participating fully in schooling or who require additional support to reach their potential.

44. Labor’s commitment to all young people and their families is to guarantee access to valued learning to Year 12 of schooling or its equivalent in other areas of education and training.

Recommendations:

Our recommendations are in line with the recommendations in our 2009-10 Budget Submission and our submission to the Inquiry into Better Support for Carers. We recommend that the Australian Government:

- undertake a national awareness raising campaign to promote self-identification by young carers and to increase awareness of young carers on the part of service providers, health professionals and educational institutions. Campaign material should be age, gender and culturally appropriate
- establish an ongoing ‘Young Carer Scholarship Program’ aimed at assisting young carers through secondary education, TAFE courses and university degrees
- expand and invest more funding in the existing support programs targeting young carers to better meet growing demand and broadening their reach
- strengthen the voice of young carers in decision making and planning that affects them through a structured program to support their representation

- provide ongoing funding for a 'professional development, leadership program' to support young carers as ambassadors and mentors
- invest in a national carer framework as a matter of priority.

We also recommend that young carers' skills, abilities and experiences be attributed toward more formal qualifications through the recognition of prior learning or recognition of current competencies.

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