



Institute of Child Protection Studies

RESEARCH REPORT

Reading, writing and responsibility: Young Carers and Education

April 2006

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A report by Tim Moore, Ros Morrow, Morag McArthur, Debbie Noble-Carr and Jamie Gray of the Institute of Child Protection Studies, ACU National for the ACT Department of Disability, Housing and Community Services

April 2006

ISBN: 192123900X

Institute of Child Protection Studies
Signadou Campus
Australian Catholic University
PO Box 256
Dickson 2602
Australian Capitol Territory
icps@signadou.acu.edu.au
Phone 02-62091225
Fax 02 62091216
Website <http://www.acu.edu.au/icps/>

Research Team

This research project was conducted by the Institute of Child Protection Studies, ACU National. The project team consisted of :

Tim Moore (ACU National)
Ros Morrow (Curtin University)
Morag McArthur (ACU National)
Debbie Noble-Carr (ACU National)
Jamie Gray (Young Carer Consultant)

This report was produced by the Institute of Child Protection Studies, ACU National with funding from Carers Australia.

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ISBN: 1 921239 00 X

Acknowledgements

The Institute of Child Protection Studies (ICPS) would like to thank the following people and organisations for assisting in the development of this report:

Adam McEvoy and Mary Reid (Carers Australia)
National Young Carers Reference Group (Carers Australia)
State and Territory Carer Associations
Frances Moore (www.webquestdirect.com.au)
Jeremy Brown (Raw Energy, Carer Support and Respite Centre Inc, SA)
Sue Roche and Fiona MacGregor (ACT Department of Education and Training)
Katie Acheson and Judith Sands (CYCLOPS ACT)

Across Australia, teachers, school counsellors and psychologists, welfare officers and Education department staff participated in the project by offering advice to the research team, by completing surveys and participating in focus group interviews. The research team would like to thank those who offered their time, experience and knowledge.

In particular, we would also like to acknowledge the generosity, wisdom and insight of all the children and young people who participated in the project. It is hoped that this report will shed some light on their experiences at school and will lead to greater understanding and support within the community.

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Case Study: Michael¹

Michael is 16 years old. When Michael was 13, he was in a car accident with his mother, Jane. Both Michael and Jane were rushed to intensive care where they stayed for some months – during which time Michael’s father moved to another city to start ‘a new life’.

Michael sustained some internal injuries but recovered over time. Jane, however, had considerable damage to her brain – leaving her partially blind and unable to walk. After leaving hospital, Michael became her primary carer and helped her around the home or, as Michael puts it, “became her legs and her eyes”. Though challenged physically, Michael still sees his mother as providing for him “like all Mum’s do – she still makes sure I’m OK, tells me to do my homework and clean my pigsty room”.

Michael finds it hard at school sometimes. Getting up early and going to bed late has taken its toll on Michael physically and though he knows that his Mum is alright at home by herself “can’t but worry about what’s going on, can’t stop thinking about if I did everything she needs”.

Michael is a self-proclaimed ‘loner’. He says that many of his friends don’t understand what’s going on at home and, shares stories of others who ‘turned their backs’ on him when his mother was unwell – “they called her ‘retarded’ and just stopped talking to me’. Though he thinks he’s good at hiding his feelings from people at school, he does sometimes feel upset and alone. He gets particularly angry when people talk disrespectfully about others with disabilities or illnesses, because ‘it’s like they’re talking about my Mum’.

Michael has had some great teachers who have supported him throughout the years. One particular teacher, Mrs O’Dwyer, has helped explain his situation to other teachers, has stuck up for him when he hasn’t got his assignments in on time, or when he’s been in fights because other students have paid out on his mother. However, some of Michael’s other teachers have just seen his caring ‘as an excuse’ – believing that he’s ‘just lazy’. This upsets Michael and has kept him from seeking help when he needs it most.

Michael would love to go to a school where people were taught about illnesses and disabilities and where they were challenged about the way they treated others. He would like teachers to understand his situation - not to give him special treatment – but to listen when he needed to talk or offer some flexibility when times were particularly tough. Some help at home would also take the pressure off and tutoring might help him catch up when he is behind.

¹ “Michael” is an amalgam of young carers who participated in this research project and was developed to illustrate the main issues that young carers face in their education. Though he does not exist as a single entity, each of Michael’s experiences is based on a real life situation.

1 Introduction

1.1 Purpose

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.

1.2 Aims of the Project:

The aims of this research were to:

- 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);
- Identify the information needs of teachers and other school staff in appropriately supporting young carers within the school environment;
- Identify strategies to meet the information needs of teachers and the support needs of young carers within educational settings.

1.3 Background

Over the past twenty years there has been a growing awareness of the existence and needs of children and young people with care responsibilities for family members and friends. During this time, policy makers and service providers have developed a greater understanding of the ways that caring for a relative or friend may impact, both positively and negatively, on the health, wellbeing, participation and livelihood of these children and young people.

In 2002, Carers Australia commissioned a report to draw together current knowledge of this relatively hidden group and discovered that care being provided by young people was widespread and that the impacts of providing care without support were often significant.

Amongst these findings, Carers Australia observed that only a small number of young carers aged 15 to 25 were engaged in education and that this was not because young carers did not place value on their learning, but that because a range of barriers kept them from attending and achieving within the school setting.

Such findings were reiterated in 2004 at the First National Young Carers Summit where young carers of all ages and from across Australia reported great difficulties in fully participating in schools, and subsequent research projects in Victoria, Western Australia and the ACT.

In 2005, the Commonwealth Department of Family and Community Services launched a range of initiatives to respond to young carers educational, emotional, social, informational and respite needs. Injecting significant funds to increase respite availability to young carers who had been excluded from education, and funding Carers Australia to develop a suite of services and supports through its Carer Association networks, the Australian Government attempted to rectify the situation and to further support young carers and their families.

This report has been commissioned by Carers Australia to inform the development of resources for teachers and young carers in schools as part of their broader young carer supports.

1.4 What we know about young carers in Australia

Who are young carers?

For the purposes of this report, young carers are defined as:

children and young people who care or help care in a family affected by the illness, disability, mental health and/ or drug or alcohol issues of one or more family members or friends.

Young carers may thus be caring for a parent, a sibling, a grandparent, another relative or a friend. In most cases, young carers care for someone with whom they co-reside, but some young carers care for someone who has been hospitalised or who lives elsewhere (Carers Australia 2002; Carers Association of South Australia 2003; Moore 2005). Sometimes young carers care for more than one relative at a time, or relatives with more than one condition. Most often,

young carers care for a single parent who is most likely to be their mother (Carers Australia 2002).

As their relative or friends' conditions range significantly, so therefore do the range of care tasks that young carers assume. However, most young carers report that they are responsible for household tasks, providing personal care and emotional support to their relative, supervising younger siblings and advocating for services.

Critics of the 'young carer movement' argue that all children and young people assume such responsibilities (Olsen 1996). However, recent research suggests that unlike their peers who may cook or clean the house sporadically and with support and supervision from their parent, young carers most often assume primary responsibility for care tasks and complete them with little or no guidance or assistance from others (Gays 1998; Moore 2005; Morrow 2005).

Young carers report caring from as young as five years of age, however those under 18 are mostly aged between 10 and 13 years of age (Carers Australia 2002). Both boys and girls care and may be the second, third or fourth family member to assume primary care responsibilities for their relative or friend (Moore 2005).

Research in Australia and the UK has clearly shown that young carers provide similar types of care to relatives as do adult carers (Dearden and Becker 2002; Moore 2005). Many young carers provide the majority of care to their relative or are solely responsible for their care needs. Young carers care for relatives for an average of 6 hours per day and may have cared or continue to care for up to 14 years (Gays 2002; Moore 2005; Morrow 2005).

The extent of young caring in Australia

In Australia there has not yet been a rigorous exploration of the number of children and young people with care responsibilities. However, Access Economics (2005) suggests that approximately 169 900 children and young people under 18 and a further 177 800 aged between 18 and 25 are carers.

Some writers have argued that this figure grossly underestimates the real young carer population, particularly as 600 000 children live in families affected by parental alcohol or other drug issues (Odyssey Institute of Studies 2004) a further 840 000 children live with a parent with a physical or intellectual disability (Goggin and Newell 2005) and at least 27 000 live with a parent with a psychotic disorder (Cowling, McGorry et al. 1995). This is not to suggest that all of the 1.5 million children with a parent with such conditions will automatically assume care responsibility for their relative but that the real number of those who care may be greater than previously anticipated.

Why do young carers exist?

Children and young people have always provided care to sick, ill and disabled family members (Becker 2005). However, over the past three decades the numbers of people within our community who are frail aged and in need of personal assistance has grown dramatically (NATSEM 2004); as has the number of people living within the community who have disabilities, chronic illness, mental health issues and/or alcohol and other drug misuse (Dalley and Finch 1988; Braithwaite 1990; Carers Australia 2002). At the same time, there has been an increase in divorce rates (ABS 2001), a breakdown of the extended family and higher participation of women within the workforce, which has meant that traditional supports have been reduced. Coupled with the fact that people living with illnesses, disabilities, mental health issues and the aged do not currently receive adequate supports, children and young people are now more likely to take on considerable care responsibilities than in the past (Moore 2005, p17).

For writers such as those from the UK Young Carers Research Group, (Dearden and Becker 2002, p1) the most significant factor in determining which children care and what level of responsibility they assume is the availability and effectiveness of health and social care support for their ill or disabled relative. They assert that,

The causes of a young person's caring are to be found in the complex interplay between medical and social determinants, not least the 'disabling' barriers engendered in much contemporary social welfare and social services policy, organisation and practice (Aldridge and Becker 1993).

In her work with the Victorian Carer Services Network, Julie Nankervis (2005, p4) also found that a number of factors, outside the control of parents, families or of children, 'either gradually or suddenly thrust [children] into significant care responsibilities'. These included:

- The onset or worsening of a parent's condition which increases care needs;
- The overall severity of the condition, nature and intensity of emotional and practical care required;
- The size and composition of the family, including number of children and the absence of two parents in the household due to work demands or relationship breakdown;
- The availability of older siblings or other relatives (such as grandparents) to care;
- The number of individuals requiring care in the immediate and extended family;
- The connectedness or isolation of the family in their community;
- The lack of appropriate and accessible formal services to provide treatment and care of their relative;
- Cultural expectations which govern who provides informal care or acceptability of external assistance;
- The family's capacity to pay for external help or assistance that would reduce caring tasks.

How does caring impact on a child or young person's life?

Children and young people with care responsibilities argue that their caring has had both positive and negative impacts on their lives, their relationships, their families, their participation and their future outlook. Previous research projects have found that caring affects:

How they see themselves: Most young carers report that their caring has impacted on the way they think about themselves, who they are and how they fit into the world around them. Many feel proud of the fact that they can help care for someone they care about, rather than watch them from afar (Moore 2005).

Their health and wellbeing: Though some young carers feel that caring has made them more active and motivated, many young carers feel that the physical strain of caring impacts on their general health (Gays 1998; Gays 2002). Large numbers also report feeling stressed, anxious, depressed and overwhelmed by their care responsibilities, though others share feeling hopeful, proud and resilient (Dearden and Becker 1998; Cree 2003; Moore 2005). 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 time with friends (ACT Young Carers Network 2000).

Skills development: Many young carers believe that through caring they have developed new skills and capacities that they will use throughout their lives, including the ability to meet the care needs of a relative, managing a household, negotiating with professionals and providers, budgeting, household chores and, to varying degrees, self care (ACT Young Carers Network 2000; Halpenny and Gilligan 2004; Moore 2005):

How does caring affect families?

Young carers also often report that caring has had an impact on their family dynamics, functioning and finances:

Family connectedness: Caring can place significant stress and strain on families, particularly when family members experience compassion fatigue and unresolved frustration, anger and anxiety. However, many young carers report that they feel more connected with other family members when they take on care responsibilities together (Halpenny and Gilligan 2004).

Financial security: With significant costs associated with health care treatment, medication and social support, and a low capacity to access employment or social security payments, many families experience financial difficulties (Carers Australia 1997). As a result, many young carers either do without bare essentials, or in some cases, have turned to begging and/or crime to fulfil their families' needs (Moore 2005).

Safety: Young carers often report situations when they feel unsafe. Often alone with their relative, many feel overwhelmed by the responsibility – particularly when their relative is prone to seizures, or when they display challenging behaviours (Odyssey Institute of Studies 2004; Moore 2005).

Homelessness and criminality: Recent research suggests that children and young people in families affected by illness, disability, alcohol or other drug use and/or mental illness are at greater risk of homelessness than their peers (Mallett, Rosenthal et al. 2005; Youth Coalition of the ACT 2005). As mentioned, as a result of poverty, young carers can also be at greater risk of criminality:

How does young caring impact on young carers' participation at school?

Often responsible for significant care responsibilities in the home, young carers report that their opportunities to participate in the community and with friends are frequently restricted. As well as having limited opportunities to participate in education, young carers tell us that their caring has had impacts on their:

Social life: With significant care responsibilities within the home and a reluctance to have visitors for fear of adverse reactions, many children and young people feel socially isolated from their peers (Moore 2005; Morgan 2006). However, many young carers report that when they are linked with other children and young people in similar situations to themselves they form strong and long-lasting relationships (Nankervis 2005; Morgan 2006).

Employment: A majority of young carers are not able to participate in the workforce (Carers Australia 2002). Many believe that they have many qualities and skills that would make them employable, but that their caring is 'a full-time job in itself'. In the future, many young carers report hoping to work in a caring profession (Moore 2005).

How does caring affect young carer's futures?

Many young carers feel that their caring responsibilities would continue to impact on their lives for some time – regardless of whether they continued to care or not.

Transitions into adulthood: Through their caring, young carers develop skills and gain independence that can assist them in the future (Carers Australia 2002). However due to the restrictions on their education and their capacity to connect with the community around them, transitions to adulthood can be difficult (Frank, Tatum et al. 1999; Halpenny and Gilligan 2004).

Outlook: Many young carers report feeling hopeful and optimistic about the future. They believe that having dealt with adversity that they are more equipped and capable of dealing with future difficulties and challenges (Halpenny and Gilligan 2004; Moore 2005).

Caring into the future: Many young carers are resigned to the fact that they will be caring for some time to come (Halpenny and Gilligan 2004). They believe that this will impact upon the work that they will be able to do, the relationships they will be able to have, and the way they will be able to participate in the wider community. Many young carers are also aware that they will one day relinquish their care responsibilities – either as a result of their cared-for relative's death, or their transition into other care arrangements (Frank, Tatum et al. 1999).

Their own health and wellbeing: Many young carers are aware of the long-term impacts that caring can have on their lives. Others are concerned about their own susceptibility to illnesses and conditions and that of their future children (Moore 2005).

2 What we know about young carers and education

Important international research carried out by Dearden and Becker examined the experiences of young carers with a particular focus on their educational experiences. In a 2002 meta-analysis of existing research, they found that although not all young carers experienced difficulties, **most** reported that their caring had negatively impacted upon their education. Young carers experienced a range of educational difficulties as summarised in Table 1 below.

Table 1: Key educational difficulties identified through UK research on young carers

Difficulty	
Absence	May be regular, protracted or occasional May result in referral to educational welfare services
Lateness	May be persistent or occasional
Tiredness	May be identified by lack of concentration, lack of attention, falling asleep
Difficulty joining extra curricular activities	Due to time constraints as a result of caring
Bullying	May be a direct result of caring/family disability but may be unrelated
Restricted peer networks in school	May have little in common with same age peers, may be mature beyond their years, may be a result of time constraints due to caring
Poor attainment	May be reflected in lack of qualifications, low grade qualifications or underperformance
Homework / coursework	May be poor quality, not submitted on time or at all This may be persistent or occasional
Anxiety	Concern over ill/disabled relative
Behavioural problems	May result in referral to educational psychologist or child and adolescent psychiatrist

(from Dearden and Becker 2002, p5)

The Australian research into young carers is a developing body of knowledge. However a significant gap remains in understanding the young carer's experience within the education system. The next section describes the particulars of the research project before examining what young carers in Australia say about their experience with the education system.

3. The project

The project comprised of two parts: one that focused on young carers themselves and another that focused on teachers and other school staff.

Part One: Talking to Young Carers

The research team developed the project in a way that attempted to maximise the input of young carers themselves. The active and purposeful engagement of young carers in the research was driven by ICPS's commitment to consumer participation and also the recognition that research is often more responsive and credible when those who are being studied are provided a range of opportunities to participate in the research (Oliver 1992).

As such, the team met with the National Young Carers Reference Group, which included young carers from each state and territory, prior to the commencement of the project and employed a young carer to help advise the development of the research. This young carer consultant helped design the research questions, conducted a number of the interviews and was invited to provide feedback on the final report. Although ICPS would have preferred to have had the consultant conduct all interviews, time constraints and organisational issues prevented this occurring.

How young carers were recruited

Young carers were recruited from across Australia through existing programs, primarily state and territory carer associations.

Young carers were contacted by workers from these programs who explained the purpose of the project before inviting the child or young person to participate. A letter was then sent to the young carer and their parent/s, explaining the project in more detail and seeking written consent from both parties.

Young carers who returned their consent form to the program were referred to ICPS and an interview was organised and conducted.

The sample for the study was purposive in nature (Shaugnessy & Zeichmeister, 2003), meaning the sample comprised participants who specifically met the selection criteria for the study. The criteria for inclusion in the study were:

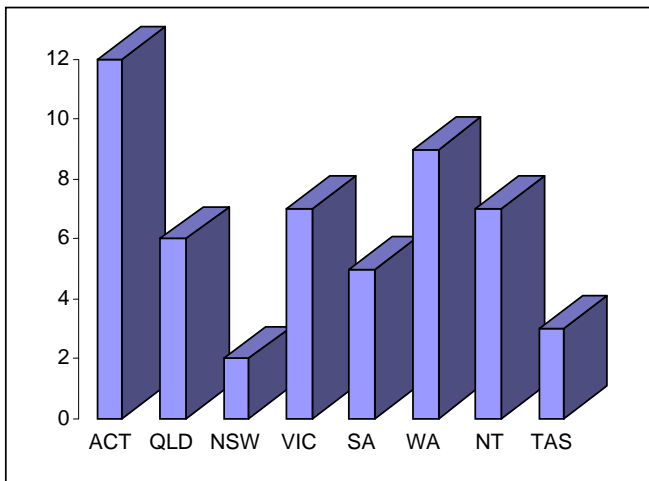
- Aged between 12 and 21;
- They had been identified as young carers; and
- They were affiliated with a carer organisation.

In an attempt to attract a broad group of children and young people, referring organisations were encouraged to identify young people of different ages, from different cultural or linguistic backgrounds and those with varying care responsibilities.

Young carers who participated in the interviews

Fifty-one young carers participated in the study. Telephone interviews were conducted with 44 of the young carers and the remaining 7 participated in a Focus Group Interview. There were 22 males and 29 females; the mean age of the group was 16. The sample included young carers from every state in Australia. The details of the number of young carers from each state are presented in Figure 1.

Figure 1: Young carers by state



Young carers ranged in age from 12 to 21 with over 80% of respondents being under the age of 18. Those over 18 were either still completing their education or reflected on the time that they spent at school in earlier years.

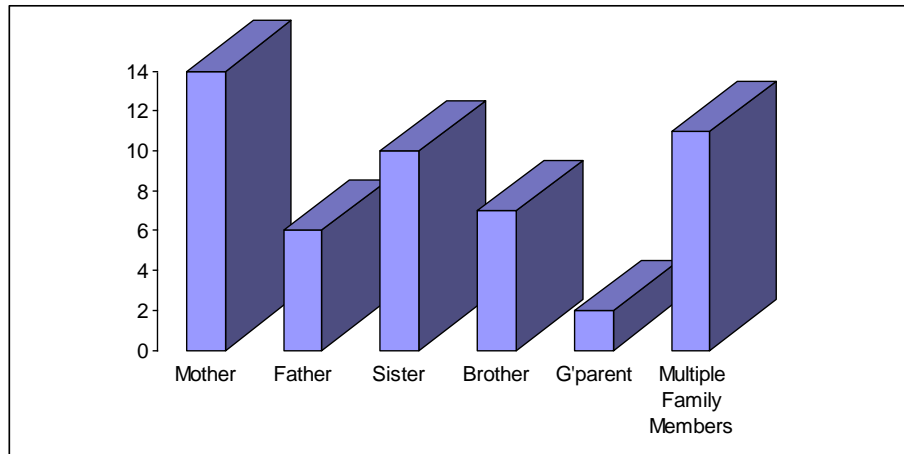
Figure 2: Age of respondents

Age	Number of young carers
12	2
13	2
14	8
15	11
16	6
17	11
18	7
19	3
21	1
TOTAL	51

Profile of who they care for

The largest proportion of young carers cared for their mother, (28%) followed by their brother (20%). Figure 3 below indicates who the care recipients were.

Figure 3: Who young carers care for



The role of primary carer fell to 21 of the young carers. Young carers cared for relatives with physical, intellectual and sensory disabilities, with acquired brain injury, neurological conditions, mental illness and alcohol and other drug dependence.

The young carer interviews

A structured interview format was designed for the study. Interviewers were recruited and trained and were given guidelines to follow when conducting the interviews. The interview schedule for the telephone and Focus Group Interviews had 4 sections. A copy of the interview schedule is found in Appendix 2.

Section 1 comprised of 9 questions which asked about the young carer. For example, their age and which year they were in at school, who they care for, how many hours a week and how long they have been caring.

Section 2 focussed on issues directly related to school and included 6 questions. The questions allowed for information to be gleaned about the young carer's education achievements. It also encouraged the young carers to share information about those who knew and supported them. This section presented an opportunity for young carers to identify and discuss some of the issues which occurred at school and impacted on them physically and emotionally (e.g., bullying).

Section 3 allowed for consideration of psychological factors (feeling tired and lacking energy, not sleeping, worrying and being angry) and educational factors (the inability to find time to complete homework, having poor grades as a result of caring). The final issue to be considered related to lack of participation in their communities and difficulties in activities of daily life as a result of caring (e.g., not having friends home, no time to participate in after school activities, financial restrictions). This section required a response of Strongly Agree (5) to Strongly Disagree (1), a high score is indicative of a young carer's life being significantly affected by their role and responsibilities.

Section 4 asked the young carer to share information about what has helped them with their schooling and could help other young carers in the future.

Part Two: Talking to teachers and school staff

Teachers and other school staff were also engaged in the research process. Researchers were particularly interested in their current awareness of the existence and needs of young carers in schools and any strategies that they had previously identified to support this group of students.

How teachers were recruited

The questionnaire was emailed to 20 individuals within organisations (e.g., principals and student services officers) and individuals known to the research team. Telephone contact was made with staff within the education sector (e.g., Peel Inlet Education Office and Victorian Education Department) in an endeavour to increase the participation rates. This number gave the research team access to 66 educational professionals throughout Australia. Responses were received from 13 (a 21% response rate). The option was given for the questionnaire to be completed on line or by telephone interview. This was done in an effort to increase participation.

Education professionals who participated in the survey

Of the 13 questionnaires returned there were 5 males and 8 females. Of the 13 there were 9 from the ACT, 2 from the Northern Territory and 1 from Western Australia and South Australia. Five of the respondents were teachers, while the remaining 8 included a deputy principal, 3 student support officers employed in schools, 3 school counsellors and school psychologists and a special teacher's assistant.

The structure of the school survey

The school survey comprised four sections. The first section asked the teacher or other school staff member about their role and teaching experience. The second section was concerned about the young carers that staff had identified in their time at school and how they perceived caring had impacted on the young person's life. The third section asked staff about how they had responded in the past and the fourth with ways in which the school had or could possibly respond to young carers within existing and potential programs and structures.

Project challenges

The research team encountered a number of challenges in identifying and recruiting teachers from across Australia to participate in the study. Firstly, the project commenced late in the school term of 2005 and continued into early 2006. This meant that most teachers were either busy finalising assessment, on holidays or preparing for a new school year.

Secondly, though the research team had ethics approval from both the Australian Catholic University and Curtin University, each state and territory education department had their own internal process that needed to be completed before the research could commence, as did each of the Catholic and Independent school bodies. Such processes took up to 8 weeks to complete and, in a number of cases, could not be completed during the Christmas holiday shut-down.

Thirdly, many teachers who were invited to participate believed that they could not complete the survey because they had not identified young carers in the past and therefore felt unable to respond.

“I am really sorry but I don’t have any knowledge about the children who are the subject of your survey” and “As the t/librarian I am unaware of some students who MAY [sic.] Be young carers, but I don’t have nearly enough information to answer the questionnaire. Sorry.”

The research team acknowledges that due to the small size of the sample it cannot generalise about the way that teachers think or have responded to young carers in schools. However, responses that were received provided the team valuable views and insights into the issue.

4. What we learned about young carers in schools

4.1 Why young carers value school

In 2001, Carers Australia found that only 4% of young carers aged 15 to 25 were engaged in the education system – compared with 23% of the broader youth population. Carers Australia discovered that it was not because young carers did not place value or importance on having an education but it was due to reasons often outside of their control.

If young carers left school early it did not seem to reflect their ideals about the importance of education.... It was just their only option. (Carers Australia 2002, p44)

Many of the young carers who spoke to the research team reported that school was important to them.

I loved everything about school. I loved all my teachers, I loved the structure it gave to my day, I loved the fact that I could hide in my homework when I got home, I loved all of the support I got at school and I loved the fact that I could escape everyday to school and have another part of my life - rather than just my home life. (Female young carer, 18years)

In particular, young carers valued school because it:

- Offered them respite from their home lives;
- Provided them opportunities to connect with other young people (particularly those in a similar situation to themselves) and to develop a sense of belonging;
- Was a place where they could receive support and information from people who were understanding and caring.

Young carers also appreciated the opportunity to learn and to experience new things.

Time out from caring

Young carers reported that going to school was beneficial because it gave them an opportunity to leave the family home and have time out from their care responsibilities – without having to feel as much guilt as they would otherwise.

*We don't have a life – if we're looking after whoever you're looking after - at school you can have a life.
(Female young carer, 15years)*

Many young carers also reported that school gave them respite not only from their home situation, but also from the roles they assumed. They told us that they appreciated being 'lost in an ocean of others' where they did not have to be differentiated by the values, expectations and responsibilities that they assumed at home.

Made me able to make friends without them knowing of my caring role so they knew me first and could focus on other things. (Female young carer, 16years)

It's not the best place, but it's a place to get out and have a normal life. (Male young carer, 15years)

Writers such as Aldgate (1990), Gilligan (2000) and others (Bancroft, Wilson et al. 2004) report that schools can thus be an escape from the harsh realities of a young person's life – a safe haven where they can immerse themselves in 'normality' and break away from an exclusively 'in need' identity. School can also provide young carers with stability from what Couzins describes as the "burden of uncertainty and dislocation associated with chaotic family lives" (2004).

Young carers appreciated this, and believed that during their 'time out' they could take time to reflect on who they were and what was important to them.

If you're always looking after someone else all the time, it's hard to work out who you are: what you like to do, where you'd like to go. (Male young carer, 15years)

Connecting with others

Often socially isolated, young carers in this study reported that school provided them with an opportunity to connect with their peers, with other young carers, with adults they trusted and with the wider community.

I go to school it's like a getaway and I like to see my friends and sometimes I don't actually get to get out of the house to see my friends. (Female young carer, 15years)

I like seeing my friends and being in familiar surroundings. You can have a break away from home. You can muck around with friends at lunch time and stuff. (Female young carer, 12years)

The value of such connections with others and the sense of belonging that these connections instil in young people have been identified by writers such as Resnick et al (1993) who emphasise schools as being “the primary source of connectedness with adults, and with the broader community”. At the same time, schools provide young people with a sense of membership and purpose amongst their peers (Gilligan, 2000, p41) and, in doing so can encourage them in their academic performance, motivation and overall emotional wellbeing. Connectedness to peers and with schools reconnects young people to their communities and its supports (Prime Minister's Youth Pathways Action Plan Taskforce, 2001).

Young carers in the study also felt that school provided them with a place where they could achieve. For some this was important because achieving raised their esteem, their self confidence and their sense of achievement.

It was great to have something that I could do well. I knew I was good at being a young carer but sometimes that feels like it's a bit lame. You need people to notice you doing well, to have people say 'you're doing a good job' – and you don't usually get that as a young carer. Yeah, your relative probably thanks you all the time – but people like from respite and that come in and never seem to see you or tell you that you're doing a good job. Everyone needs that sometimes. (Male young carer, 15years)

Deen (1995) argues that this is important to students, particularly those ‘at risk’ as schools present ‘a secure space for students who experience being respected as persons and find an environment that stimulates and values their intellectual, social and emotional possibilities’. Having a sense of worth and ‘mastery’ has shown to be crucial in whether young people stay connected with and achieving in education (Brendtro and Ness 1983; Brendtro, Brokenleg et al. 1990; Brendtro and Shahbazian 2004; CYCLOPS ACT 2005).

Receiving support and information from others

Young 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.

I had a bit of an issue with a few of my friends who were cutting themselves and they came to me cos they knew I would understand [because of Mum] so I went to one of my teachers, because I wouldn't go to a counsellor because they make you do things you don't want to do, so I went to a teacher I trust... she said 'I most likely don't understand what you're going through but I see where you're coming from' and she tells me what I could do to get away from that stuff and I actually listened to what she said and it really worked. (Female young carer, 15years)

Schools and teachers should assume an invaluable role in identifying and supporting problems for young people early in the course of the issue – as Gilligan asserts, ‘because of their day to day contact with individual children, during school term, teachers and other staff are particularly well placed to observe signs of abuse, changes in behaviour or failure to thrive’ (Gilligan 1998, p15). Schools are therefore in a valuable position in that they can identify problems and offer support early (McArthur and Winkworth 2005).

Teachers have also been shown to have a great capacity to provide support, guidance and mentorship to children and young people, particularly those experiencing adversity. A favourite teacher can, as Werner and Smith suggest, ‘become not just an instructor for academic skills, but also a confidant and positive model for personal identification’ (in Gilligan 1998, p14). Many young carers appreciated having such a person in their life.

Having someone there was so important. They didn't have to even do much – but knowing that someone was there made all the difference. (Female young carer, 14 years)

As well as being supported by teachers, young carers particularly appreciated meeting and sharing with other young people in similar situations as themselves. With a deep understanding and empathy, young carers felt that they could trust others and valued the opportunity to get advice and strategies from others who could relate to their situation.

All of my friends are good, but one of my friends is actually also a young carer – it's good to have another person that understands your situation, we are a bit closer because we can talk to each other and understand. My other friends are good because they know that I can't come out because I am helping out at home. (Female young carer, 15 years)

Schools were also seen as a great place to receive information about different types of illnesses, disabilities, mental health issues and drugs and alcohol was seen as a positive function of schooling. In addition, young carers reported that schools could sometimes provide them with information about services in the community that could support them and their families.

To get information – to find out more... What supports are around, how to get help. (Male young carer, 15)

A number of young carers also felt that schools were a place where they could share their experiences, find support and get help from others in similar situations as themselves and to challenge stigma and discrimination.

I think also, that if you're at school with other young people, you can spread the message. You can be like an information booth – telling people about things. (Male young carer, 17 years)

Learning and experiencing new things – for now and the future

A large number of young carers appreciated their schooling because it gave them an opportunity to enjoy finding out new things, be exposed to new experiences and knowledge and for being offered a broader world view than just their family life.

Education is my main priority – then socialisation. (Male young carer, 15years)

A chance to broaden my horizons, a chance to learn something my parents can't teach me... (Female young carer, 19years)

Many young carers felt that having an education would help them find employment and bring money into the home. For some this was important because they believed that they would always be caring and that having a job and being able to adequately provide for their families and meet the additional costs of health care and respite would be important.

Planning for the future. You want to get qualified so if you want to take on more of a role, to be able to pay for things, you can. (Female young carer, 16years)

4.2 Young carers and school attendance

Research in Australia and overseas has shown that young carers often have poor attendance at school. In the United Kingdom, Galloway and others found that poor school attendance was found in over 50% of children who had care responsibilities for their parents (Halpenny and Gilligan 2004; Becker 2005) while Australian studies found that only 4% of primary young carers aged 15 to 25 were engaged in study, compared with 23% of the general population (Carers Australia 2002, p42). Other educational research in Australia has shown that 'family problems', including children's caring, are the major reason for poor school attendance in Australian schools (Marsh 2000) and have highlighted it as a significant issue for schools and educational systems.

In these studies, poor attendance included being late to school, having to leave school during the day, and missing out on school completely (Dearden and Becker 2002; Becker 2005) and was usually attributed to young carers having to care for relatives at home with little or no support from the service system (Moore 2005).

In this study, young carers almost 50% of respondents (n=24) reported that they had some difficulty in attending school – either because they missed school days, were late or found it difficult to get to school when caring for their relative. These results are summarised in Table 2.

Table 2: Young carers and attendance

Issue:	Agree that it is an issue		Strongly agree that it is an issue		Total	
	N	%	N	%	N	%
Missing school	8	16	11	22	19	38
Being late for school	12	24	12	24	24	48
Missing transport	7	14	6	12	13	26

Although there were only a small group of teachers who participated in the study a majority of them felt that caring had significantly impacted on the attendance of students with care responsibilities and was often the first thing that they noticed.

Some writers have been reluctant to draw a causal connection between a young person’s care responsibilities and their poor school attendance asserting that caring may be just one element in a configuration of stressors such as poverty, isolation and social exclusion (Dearden and Becker 2002; Halpenny and Gilligan 2004). However, as many young carers live within families who are at greater risk of experiencing each of these elements, it may be asserted that the likelihood of poor attendance is higher for these children and young people.

Young people in this study suggested that when their attendance was poor it was because of:

- The level of care responsibility they assumed;
- The lack of services available to support them and their relative, and
- Family issues such as poverty and isolation.

The level of care responsibility young carers assume

By their very nature, young carers assume significant care responsibilities within the home. In this study, young carers reported caring for an average of 27 hours per week, with more than 50% of respondents reporting that they cared for more than 30 hours – as seen in Table 3.

Table 3: Hours caring

Number of hours	Number of young carers
0-5	1
5-10	6
10-20	11
20-30	11
30-40	16
40+	5

Of the young carers who participated in the study, 21 of the 51 self-reported that they were the person in the family who was the main provider of care to their relative. Others reported that they shared the responsibility with other family members or friends, often suggesting that they cared for similar amounts of time and assumed similar responsibilities to others.

It is shared between me and my Dad, but my Dad works night shift and the nights are the worst time for my Mum’s illness. (Female young carer, 18years)

It is not surprising, then, that 38% of the young people reported that they missed school and a further 48% said that they were sometimes late for class because they were caring for a relative before school.

I used to walk most of the time anyway, but still I was late because I had to stay home and break up a fight or deal with my mum crying. (Female young carer, 17years)

Young carers reported that teachers, other school staff and peers may not be aware that they were absent or late to class because of their responsibilities at home.

I used to get told off when I would turn up late and then I would lie about why I was late and I used to say stupid shit all the time, to try and avoid saying the real reason. (Female young carer, 17years)

A lack of services

Young carers tell us that the main reason that they are unable to attend or to remain at school is because they are needed at home to care for their relative. Without appropriate or responsive levels of in-home support and respite, many young carers do not believe that they can, in good faith, leave their family members at home. This is disappointing, particularly as Dearden and Becker state:

the provision of services... seems to decrease the level of caring provided by children... and to increase their community participation. (1998, p69)

In an ACT survey, it was found that only 10% of young carers could identify supports provided to their families that reduced their care responsibilities and enabled them to participate within the community and, in particular, their schooling (Moore 2005).

The study 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 because they were not well publicised which meant that many families did not know what they were entitled to or how to access supports. The study also found that many families were reluctant to seek assistance because they were afraid of how a child's caring may be perceived, they were wary about outside intervention or because they were not aware of how caring was impacting upon their child's health and wellbeing. The findings of this study are summarised in Table 4:

Table 4: Barriers to Service Support

What kept families from accessing services	Percentage
Service design issues	58
Services do not respond to the family's needs	28
Families had bad experiences in the past	20
Services weren't of high enough quality	10
Access issues	34
Services are too expensive	18
No transport available	8
Services are too far away	8
Service promotion issues	48
Families unaware of what services are available	30
Families don't know how to access services	18
Reluctance within the family	96
Families felt they could cope without outside help	42
Families did not access for privacy reasons and fear of scrutiny or inappropriate intervention	22
Other family members prefer help from within the family	20
Family members felt guilty for receiving outside help	20

(Moore 2005, p25)

Poverty

In Australia, two of the most financially vulnerable groups within the community are families where a member has an illness or disability and sole parent families. As many young carers live in families that fit into both of these groups, it has been argued that they make up “one of the most vulnerable and financially disadvantaged groups in Australian society” (Carers Australia 2002).

With other family members often unable to work, and due to the increasing costs of medical and primary health care treatments, respite and in-home support, writers argue that many families struggle to meet basic living requirements (Carers Australia 1997; Carers Association of South Australia 2003). Instead, many families rely on inadequate government pensions that do not cover the extra costs incurred by families where disability or illness is present. Carers Australia found “that subsistence on income support payments, even with planned budgeting, [is] not possible on a longer term basis without relief from some of these expenses” (Carers Australia 1997).

In this study, 55% of young carers agreed with the statement that their families struggled financially because of the associated costs of caring for a relative with an illness, disability, alcohol or other drug or mental health issue. As a result, many suggested that their participation in their schooling was limited.

We have to pay for a walking stick for my Mum, for medication. Cos Mum costs a lot of money so sometimes it's hard. (Female young carer, 14years)

I know when Mum ended up in a wheelchair I had to take over with the bills and I would have no idea what I was doing. A bill would come for \$200 and I'd pay it all and another would come for another \$200 and I would like be 'I don't have enough money because I paid the other one. (Female young carer, 16years)

Living in poverty has been shown to be a significant barrier to young people's participation and achievement in education (Webber and Hayduk 1995). Unable to pay for basic school requirements such as school uniforms, text books, stationery and transport, many young carers report experiencing difficulty as a result. Punished with detentions and extra homework, excluded from participating in extracurricular activities and unable to keep up with work without text books and educational supplies, many young carers believe that their financial disadvantage had a significant impact on their schooling (Aldridge and Becker 1993; Carers Australia 2005; Moore 2005). Young carers in this study agreed.

We can't afford anything. We don't even have enough food sometimes – so how can I ask for money to go on an excursion or a camp or something. I just tell the school mum's too sick for me to go – but it's really cos we can't afford it. (Male young carer, 15years)

Young carers asked for more support with the costs of caring because they believed that while their families could not cover basic necessities around the home, they could not afford added expenses tied to education and learning.

More money because I don't qualify for carers allowance for them, which makes it hard financially to do all the things that we need. (Male young carer, 16years).

In an ACT study, young carers reported that such punishment and public shaming had led to them to steal their educational supplies, or in some cases, to disengage from the education system completely (Moore 2005).

4.3 Young carers and school achievement

Article 28 of the UN Convention on the Rights of the Child (United Nations 1989) states that children have a right to education. Article 29 follows by stating that education should be directed to developing children 'to their fullest potential'. As such, the Convention calls for schooling to not only provide children with basic learning, but also the skills, capacities and resources to develop their personality, talents, and mental and physical abilities. For schools to appropriately support young carers they must therefore look not only at the young person's attendance but also their capacity to achieve at school. This section focuses on the issues facing young carers at school that affect their achievement.

Young caring and the positive impacts on education

Some young carers (n=17) believed that their caring had had positive impacts on their education and their experiences at school. Some shared stories of when they had taken advantage of their knowledge about health, illness, disability and issues affecting people in the community:

When I was in high school we did a project on things to do with cerebral palsy – so I had a home advantage. (Female young carer, 18years).

Others felt more motivated with their schooling, asserting that they worked hard so their parents were proud of them and had ‘something to live for’.

I made an effort for Mum. It was something that made her happy so I worked hard so she'd get that buzz. (Female young carer, 15years).

Yes, it just helped me have an escape from life. I felt proud about going to school. Because I am one of only a few people in my family to have completed Year 12. My family was stoked. (Male young carer, 18years)

Some young carers were motivated knowing that many young people in their situation did not achieve at school and therefore worked hard to prove to themselves that they could.

Knowing that only 6% of young carers had finished their education inspired me to finish – for the other young carers. Mum pushed me as well. (Male young carer, 16years)

I made myself a commitment that I'd actually do something – not make my sister's life my life – to not let it keep me back. I had a goal and I worked to it. (Male young carer, 17years)

Other young carers were aware that they may need to care for their relative for some time into the future and therefore needed to get an education so that they could get a good job to adequately support their families.

It made me determined to do well so I can get a good job and more money in case I have to continue caring for someone or someone else. (Female young carer, 16years)

A number of young carers also felt that because of their exposure to issues in their families they were motivated to work in human services and worked hard at school to enable their entry:

It has given me motivation and a thing to aim for, because I want to work in that field (disability) and also knowing that you have to work hard in case you have to support the person in the future (my younger brother) so I know it is important to get a solid foundation. (Female young carer, 16years)

It has meant I am the sort of person who thinks about issues such as mental illness and disadvantage etc and therefore I am interested in a lot of these things. It has opened up a whole lot of new doors in terms of mental health advocacy (I do a lot of public speaking and work in this area). (Female young carer, 18years)

Young carers and the negative impacts on education

In this study 44% of young carers suggested that they felt that they had not achieved as highly as they believed they could due to the pressures of caring. They identified a range of reasons for why this was the case. These included:

- Physical and emotional issues;
- Not having time to complete homework and catch up with schooling;
- Having a school system that was inflexible and unresponsive to their needs, skills and experiences.

Physical and emotional issues

Young carers in the sample reported that they missed sleep (54%) and felt tired and lacked energy at school (78%). Sometimes this was because of the significant care responsibilities they assumed or because they were up late attempting to complete school work.

I get up at 6:30. By 7:30 I'm getting everyone's breakfast. Get back from school at 3 and help around the house. Cook tea. I got to bed about 11. (Female young carer, 15years)

The homework – the knowing that I'm going to have to look after my sister tomorrow night so I'm not going to have time to do my homework so I'm going to have to stay up late to do it tonight. (Male young carer, 17years)

Other young people (82%) reported that they worried about their relatives at home, and therefore found it difficult to concentrate at school.

Knowing that my Mum was stressing out as well and had to cope by herself. (Male young carer, 17years)

I know sometimes I missed stuff in class because I was worried about if Mum was taking her medication and that sort of thing. Sometimes I wouldn't hear what they just said in class. (Female young carer, 16years)

I can't really describe what it was that stressed me out, but I was always anxious about what was going on at home. (Male young carer, 17years)

With a number of care tasks to be completed before going to school, young carers often reported not having enough time to have breakfast or to pack their lunch (n=24). Not having adequate food or nutrition has been shown to have a detrimental affect on children and young people's capacity to learn and to otherwise achieve at school (Reid 2000). Table 5 outlines the factors young carers stated were the outcome of their caring.

Table 5 Factors impacting on physical/emotional achievement

Issue:	Agree that it is an issue		Strongly agree that it is an issue		Total	
	N	%	N	%	N	%
Lack of sleep	11	22%	15	29%	26	54%
No breakfast or lunch	10	20%	14	27%	24	47%
Feeling tired and lacking energy	23	45%	17	33%	40	78%
Worry about home	23	45%	19	37%	42	82%

Lack of flexibility and responsiveness

Writers in the education sector have clearly shown that to be engaging and accessible, the school curriculum must be relevant and where possible, reflect and have practical implications for the lives of students (Slee 1991) and prepare them 'for living independently, for managing relationships and for prospective employment' (Prime Minister's Youth Pathways Action Plan Taskforce 2001).

In particular, it has been shown that marginalised young people are 'more likely to engage in educational programmes that address their real issues, tacit knowledge and intuitive life skills' (Prime Minister's Youth Pathways Action Plan Taskforce 2001, p90).

Slee continues by arguing that those schools with high drop out rates 'do not, through their curricula, establish a climate of acceptance of students in different or difficult circumstances [and that this] social ostracism leads to many feeling little option but to leave school' (p25).

Young carers have been shown to be a group of children and young people with significant knowledge, skills and experiences. Often the primary carer, young carers are responsible for the medical, personal, emotional and physical needs of their relative or friend and thus must develop skills and expertise to ensure their safety and well-being. Similarly, they are often responsible for the upkeep of the family home – for budgeting, shopping, cooking, cleaning, banking, purchasing services and supervising other siblings - these are responsibilities that require the development of specific skills and expertise. It is therefore unfortunate that these skills and

competencies developed through their caring are often not recognised within mainstream educational settings.

However a small group within the larger sample identified times when their schools had provided them with vocational education accreditation in areas such as disability work, community work and advocacy. This proved to be invaluable to the young carers not only because their skills were being validated but also because it meant the school could be more flexible in allowing students to drop non-compulsory units.

I know one young carer who wants to become a nurse and she looks after her Mum and it would be great if she could get recognition – cos she's got half the skills already, she knows how to do it – but some recognition of her skills, to help her in would be awesome. Its not like she's getting something she doesn't deserve – she's just getting recognition of her skills. (Male young carer, 17years)

I suppose last year I wasn't really doing well in Maths and not liking it, I was having a bit of trouble so the principal said that I was allowed to drop a subject this year if that helped me. (Female young carer, 16years)

Difficulty with managing caring and schoolwork

Young carers in this study reported that they found it difficult to juggle their care responsibilities and their school work and that this sometimes impacted on their educational outcomes.

But I have noticed that I used to get good grades in Yr 9 and 10, but last year I failed 2 subjects because I had to take a lot of time off school when my Mum was in hospital and then when I was living with my Grandmother that wasn't a great situation, so it affected my grades in those subjects that I used to be really good at. (Male young carer, 17years)

It's hard to keep on top of everything. Every time you think you're gonna catch up something happens at home and you're behind again. It's almost funny – you have to laugh. Cos you're always trying to juggle everything and you're always gonna be hit with disappointment. You've gotta laugh or you wouldn't cope with it. It's so frustrating. I used to get pissed cos I knew I wasn't getting what I should grades wise but

you have to just deal with it. A bad mark is better than no mark, you know. (Female young carer, 16years)

In particular, young carers reported difficulty in completing their homework and keeping up with schoolwork that they had missed because they had either been at home caring or because they had found it difficult to concentrate in class. Teachers also identified student's inability to complete homework as being an issue.

When they were at school they struggled to complete work, often appeared tired and never completed homework. (High school Teacher)

As mentioned above, around 45% of young people (n=22) reported that they felt that their grades at school were not as good as they could have been because of their caring responsibilities. It is important to note that some young carers felt that their caring was only one of a number of factors that kept them from achieving.

The subjects I failed were Maths and Chemistry and I usually do well in them, if I had had someone to help me out it would have really helped I think. (Male young carer, 17years)

I didn't do that well but it wasn't just because of my caring. I'll say 3 [out of five] though cos it definitely did have an impact – there was other things going on but they wouldn't have been as big an issue if wasn't caring at the same time. (Male young carer, 17years)

In this sample, six young carers reported that because of their poor attendance and achievement they had repeated a year at school. Another four stated that they had been close to failing a school year in the past but had worked hard to keep up with others.

I fought against it, in primary school they wanted to keep me back a class (I think it was my parents mainly worried that I wouldn't cope with going to high school) but I didn't want to be kept down again, so I fought against it and it didn't happen. It has been very hard for me and this has a lot to do with my brother. (Male young carer, 14years)

Kids who have caring responsibilities – they have to drop out sometimes. It's not "I don't want to go to school anymore" but it's I just can't. (Male young carer, 17years)

Though young carers often struggled with their education, it should be noted that only a small number (n=7) strongly felt that they could not see any value in engaging in their schooling. This is a similar finding to previous studies completed by Carers Australia (2002) and Canberra young carer service, CYCLOPS ACT (2005).

Table 6: Issues affecting achievement (time and value)

Issue:	Agree that it is an issue		Strongly agree that it is an issue		Total	
	N	%	N	%	N	%
No time for homework	13	25%	15	29%	28	54%
Difficulty keeping up	12	24%	14	27%	36	57%
Grades are not as good	12	24%	10	20%	22	44%
Difficulty in seeing value of education	6	12%	7	14%	13	26%
Repeating a school year²	n/a	n/a	n/a	n/a	6	11%

4.4 Young carers and participation

Over the past twenty years there has been a recognition within the educational literature that schools are beneficial not only because they provide young people with academic development but also because it allows them to develop socially (Resnick, Bearman et al. 1993). As such, young people learn, not only from classes and books, but also from their interactions with others.

As mentioned above, young carers place great value on going to school as it provides them an opportunity to engage with their peers and with strong, stable and trusting adults.

² Note: Young carers were not asked to rank how true the statement “because of my caring I have had to repeat a school year” but were asked to respond “Yes” or “No”.

Although almost 60% of the young carers felt like they were the only ones at their school who were carers, many also reported that they greatly valued opportunities at school to find and spend time with others in a similar situation as themselves. Having others who understood what young caring was like and who could offer support and advice and could empathise with their situation was incredibly important to many of the young carers.

It was good because I had friends with parents in the same situation as my Mum because I could talk to. We had a balance of understanding. (Male young carer, 18years)

All of my friends are good, but one of my friends is actually also a young carer – it's good to have another person that understands your situation, we are a bit closer because we can talk to each other and understand. My other friends are good because they know that I can't come out because I am helping out at home. (Female young carer, 15years)

Young carers reported that often when they met other young carers at school they could also share information about illness and disability, services that were useful and strategies to deal with tough times.

Yeah a friend, he knew through high school too, I guess its good to have someone know, and he is sort of going through the same thing, so we sort of understand what each other are going through. (Female young carer, 17years)

Letting other people know – one of my mates, he had a brother with Down Syndrome. He took it on 'like no big deal – it's the way life is'. But knowing that he can do more. That there are services are out there – and there's things that you can just get away from. To let him know that he's not alone. (Male young carer, 17years)

However, through the research it was discovered that young carers' participation in school and their social development was sometimes hampered for reasons associated with their care responsibilities and family dynamics. Issues arising from the research include:

- Lack of time to socialise with friends after school;
- Difficulties in engaging with others who understand;
- Losing friends because of home life;
- Bullying and harassment;
- Feeling uncomfortable and unsafe;
- Expressing anger and other emotions negatively.

Lack of time to socialise with friends after school

Many young carers report that they find it difficult to participate in school let alone to participate in after school activities such as sporting teams, music or drama groups or other school-based programs. Being able to participate in extracurricular activities has shown to be important not only for student's social development but also for their achievement in school and their future civic participation. In a study completed in the United States, for example, researchers found that students who participated in activities after school were more likely to stay engaged with their schooling, to attend college, to vote, and to volunteer later in life (Zaff, Moore et al. 2003). Norwegian studies have come to a similar conclusion, finding that children from 'non-harmonious homes' who participate and receive positive recognition for their participation in hobbies or other activities are less likely to have behavioural problems and that this is a significant factor for the overall health and wellbeing (in Gilligan 1998).

Although they saw it as being important, 66% of young carers in this study felt that they were unable to participate in activities outside of school hours because they were needed at home. Young carers also reported that it was difficult to have friends over to their houses because of their relative's condition and, in a number of cases, their behaviours.

My brother acts really weird around my friends, it's very disturbing – if they have been over at my house he is always weird and head butts them or kicks them, so that is really hard. (Female young carer, 15years)

As a result, their capacity to spend time with their peers was limited.

Difficulties in engaging with others who understand

Young carers often found it difficult relating to other young people and receiving support from them when times were difficult. Young carers felt that this was because they did not have things in common, or because friends could not fully empathise with the magnitude of their situation or the challenges they were confronting.

People didn't really understand and they didn't want to take on other people's issues – so I was a bit of an outsider. (Male young carer, 17years)

You get ditched by your friends. You'd get upset and it wasn't about boys and they wouldn't understand. (Female young carer, 15 years)

My friends know [that I'm a young carer] but they don't understand. They say "My aunty's got a disability" or "I know someone like that" but they don't really understand what it's like for me. What's really going on. They think they do but it's different. They don't know what it's like to care for someone, to worry and to always have to look after him. The whole pressure. (Female young carer, 12years)

Losing friends because of home life

A large number of the young carers reported that they had lost friends not only because they were unable to spend time with them but also because the friends were either afraid or they discriminated against people with disabilities and, by default, their carers.

They found out by accident. My friends were over and met my Mum. From then on I was the "crazy kid", the outcast. When it got around, I lost every friend I ever had. (Female young carer, 18years)

I was at my school for a year and a half and had lots of friends and I didn't tell them about my brother or stuff. And then they found out he had a disability and they all ditched me. (Female young carer 17years)

Young carers felt that this was because there was a lack of understanding of disabilities, illnesses, alcohol and other drug and mental health issues in the community. For many this led to feelings of isolation and 'not fitting in'.

You're excluded from everything – not ever being asked to be part of things... You'd have to be asked to be included... So you'd always be alone. (Male young carer, 17years)

Bullying and harassment

Bullying has been identified as one of the major issues affecting children, young people and schools in Australia today (Tattum in ACT Legislative Assembly 2001; Kids Help Line 2004). In this research project, young carers were asked about times when they had been bullied because of their relative's condition or the fact that they were caring for them. 40% of young carers could identify times when they had been directly teased or assaulted.

Mum parks in the disabled car park and we get crap for that though. (Male young carer, 16years)

I used to get bashed... my dad being in a wheelchair. I had to stick up for myself so I got in a lot of trouble. In my primary school there was no support whatsoever, and because of my father's disability I got picked on – so up to Year 10 no one would really talk to me. I just had to learn to deal with it myself. But because I coped with people giving me crap, people started to respect me more and they knew they could come up and talk to me about stuff because I'd been through stuff and they respected that. (Female young carer, 17years)

Very much so. I was picked on because my family wasn't right. People said that I'd been abandoned by family. I was shoved into lockers. The teachers decided to tell everyone so they all knew and that was crap. I was absent from school and they told everyone and they started teasing. (Female young carer, 18years)

Young carers also reported times when their family members had been teased or harassed and how this affected them also.

They used to come up and say you've got a 'spasticated' brother and like throw things at my brother and they were really hurtful. Sticking up for him was hard because most the time they wanted to beat the crap out of him – sometimes he didn't know what he was saying back to them – so I had to stand up for him and keep him out of trouble. I got roped in because of that and got hurt myself. (Female young carer, 17years)

Those who had been teased said that it made their life at school incredibly difficult and, in some cases, led to them moving schools.

It was the last thing you need after going to school from being up all night and looking after people and you go there to have some time out – just 6 hours off - and then its just as bad or worse as at home. (Male young carer, 15years)

In year 1 I was moved to another school because the bullying got so harsh. I was beat up and teased because of my sister and the school didn't do anything about it. So I just moved schools. It happened again so I had to move again. I stopped telling people about what I was doing because it wasn't safe. (Female young carer, 15years).

Although it was beyond the scope of this project to compare young carers and other young people's experiences of bullying at school, a number of young carers reported that they thought they were bullied more and more harshly than their peers because of their family situation.

Feeling uncomfortable and unsafe

As well as being directly bullied or harassed, young carers reported that they felt personally attacked when students or teachers spoke derogatorily about people with illnesses or disabilities and that this compounded other school stressors. Of the sample, 75% reported that they felt uncomfortable about the way that people at school spoke about others with illness, disabilities, alcohol or other drug or mental health issues.

All through high school, people including my friends talk about Junkies and Druggos, and it upset me because mum was using needles, and was addicted to speed. Something needs to be done. (Female young carer, 17years)

Many young carers reported that it wasn't that people necessarily targeted comments at them or their families, but that negative language impacted upon them anyhow, and isolated them and made them feel uncomfortable identifying themselves as carers.

It was never really stuff aimed at me, just general comments about mental illness and stuff, it is just not something that you want to hear. (Female young carer, 15years)

Young carers mainly spoke about how other young people participated in these negative behaviours, but also of times when teachers had either engaged in the discussions or had failed to step in and respond.

Yeah, teachers often would just sit back and say nothing or, even worse, laugh about how people were talking. What message is that sending? That it's OK and that no-one really cares? Well I care and it really hurt me when I knew they were talking about people like my Dad... It was worse when teachers said stuff like "schizo" or whatever or made dumb noises like they were disabled or something... How can things change and how are you meant to ask for help if even the teachers don't give a shit? (Male young carer, 15years)

They argued that schools needed to actively respond to these cultures.

They should stop other kids from being nasty and paying out people about their disability or about your family. Because thats not nice. They call you names and that's quite hurtful. (Female young carer, 12years)

Feeling unsafe and uncomfortable, many of the young carers felt like they didn't quite 'fit in' and reported that they would not disclose their home situation to their peers or to school staff for fear of how this might impact on their lives.

Expressing anger and other emotions negatively

52% of the young carers who were interviewed reported that there were times they felt angry and upset about things that were going on at home and they took this out on others at school or acted out in class as a result.

Sometimes I'd just fire up for nothing and I didn't know what I was doing. When I look back but it was always when stuff was going on at home that I wasn't coping with. I was always so scared and angry and emotionally screwed up that I had to let it out and people just got in the way and I took it out on them. (Male young carer, 14years)

Of these, some reported that because they were under stress they responded badly to bullying or harassment.

I bashed a couple of them because they knocked my dad. (Female young carer, 16years)

I got sick of the bullying and said if you don't stop this I'm going to have to hurt you'. I had to show them that I was crazy. It wasn't the best idea but at the time it was the only way I could stick up for myself. By having the whole school think I was crazy they'd stay away from me and they wouldn't pick on me. (Female young carer, 21years)

Yes, I have been in a lot of fights because of things people have said that upset me and made me angry. (Female young carer, 16years)

It is interesting to note that both male and female young carers reported such behaviours.

Table 7: Issues impacting on participation at school

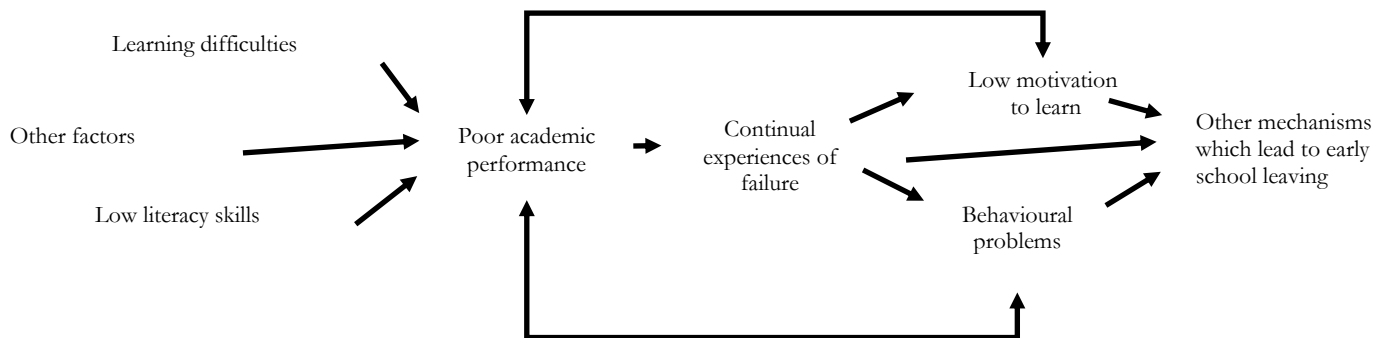
Issue:	Agree that it is an issue		Strongly agree that it is an issue		Total	
	N	%	N	%	N	%
Can't participate after school	18	35%	16	31%	34	66%
Feel like only one who cares	14	27%	16	31%	30	58%
Hard to make/keep friends	14	27%	12	24%	26	51%
Bullying and harassment ³					23	45%
Feel uncomfortable with way people talk/act	11	22%	27	53%	38	75%
Take anger/upset out on others	14	27%	13	25%	27	52%

4.5 Linking attendance, participation and achievement

In 1997, the National Youth Affairs Research Scheme found that a significant precursor to early school leaving for young people was poor academic performance, regardless of whether this poor performance was related to learning difficulties, inadequate skills or other factors (Brooks, Milne et al. 1997). Basically, they asserted that if students did not achieve at school, their self esteem was often bruised and their motivation to participate in education severely minimised. This is shown in Figure 5.

³ Note: Young carers were not asked to rank their experiences of bullying or harassment but were asked whether they had experienced bullying at school.

Figure 5: Relationship between poor school achievements and early school leaving



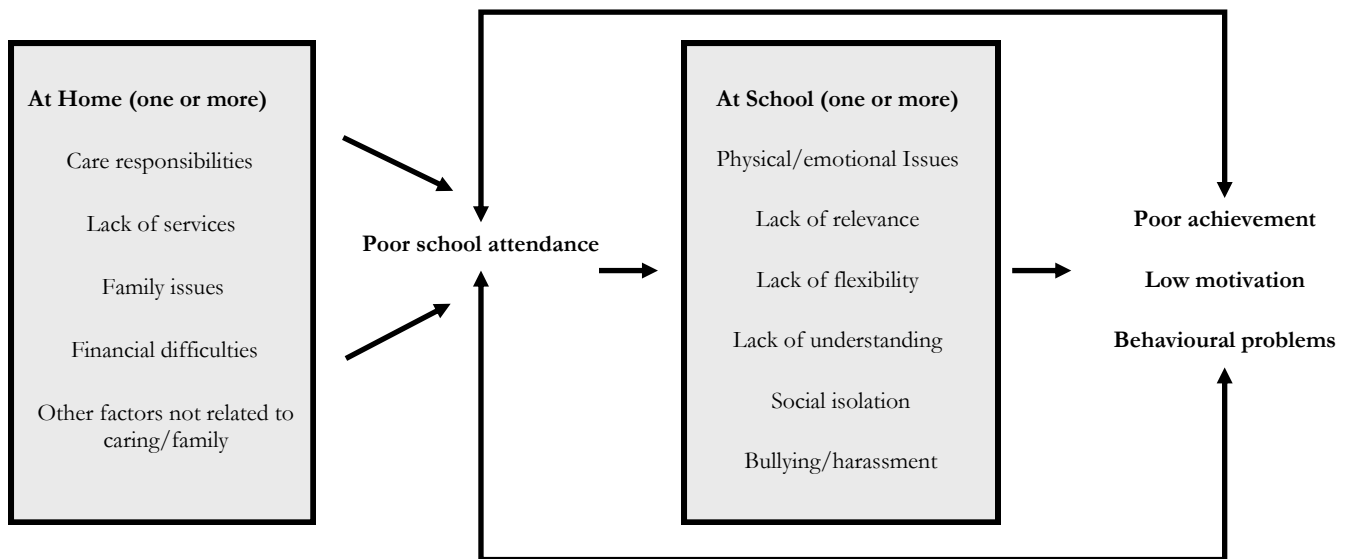
(from Brooks, Milne et al. 1997, p17)

It may be argued that having a number of other stressors in their lives, young carers are at even greater risk of poor attendance, performance and early school leaving:

I'm in the top 5% of Australia but I'm in all the low classes because I've missed so much school and am behind. It's annoying because I should be doing better but I just don't have enough time to do it. (Female young carer, 12years)

The stressors that have been discussed above are highlighted in Figure 6. As noted, however, it is important to realise that not all young carers will experience these stressors or have negative outcomes in their education.

Figure 6: Relationship between caring factors and achievement



5 What young carers want and need from the school system

Young carers and teachers were asked about the ways in which schools were currently supporting students with care responsibilities as well as what they believed teachers should know and do to better support young carers in schools.

5.1 How teachers support young carers

Teachers were asked about how they and their schools had supported young carers in the past. A majority of the respondents indicated that their main course of action was to refer the young person to the school counsellor/school psychologist or the special needs team. A proactive approach which was adopted by a number of teachers and student services officers was to request and organise “meetings with parents, teachers and principal to share concerns about issues...”

Another approach after a young carer was identified was to arrange for external study and extensions on assessment dates. One teacher approached the issue by moving away from the more traditional approaches and implemented a “journal book (for all students) to allow them

the opportunity to write about any problems they were having”. The journal was not handed into to the teacher respecting the young carer’s privacy and possible lack of desire to self-identify

Teachers were asked about the formal strategies their schools implemented to assist young carers. Responses were extremely varied and ranged from “standard policies and procedures under the umbrella of Student Wellbeing and Child Protection” to “We have special programs for all the students...” and “Contact with external agencies such as the Behaviour Department within the education system and DCD [the Department of Community Development]. Overall the strategies that emerged were informal and developed on a “case by case” basis. One teacher highlighted how his school adopted an eclectic approach by employing many strategies including: flexibility and assistance with school work, involving community agencies to provide respite, transport and food. The school also ensured young carers had timeout “in the medical room where students can catch up on their sleep if they need to”.

Education professionals were asked how they would go about developing an in school program for young carers. Four distinct issues emerged:

1. **Education** - This related to educational factors and the identified need to establish a good “relationship between staff and students.” The educational process required flexibility For example the development of “special curriculum” for young carers that recognised their experience.
2. **Personal Care and Development** - Interaction with community organisations and counsellors was identified as important a focus on young carer’s self care and social skills development “...(this would) assist these Young Carers in socialisation and normalisation”. A number of teachers emphasised how young carers need the time and space to be involved in “...something fun and creative”
3. **Program Development** - A theme which emerged strongly, not only in this particular section of the questionnaire, was the idea that programs should be suitable for all students and not only for young carers.

4. **Financial Assistance** – The need for financial assistance for study was raised and the difficulties young carers face in accessing entitlements from Centrelink..

Teachers stressed the need for information to enable them to identify young carers at school. Participants suggested that “Information on what a carer actually is and what these situations might be like” would be useful as would “a checklist and key signs to recognise carers”.

The respondents were asking for something which could help them detect the early warning signs. Some respondents actually provided information which could be used to identify young carers.:

- When a student comes to school with the same clothes on for weeks;
- When a student is bumming food of [sic] other students;
- When a student starts selling stolen items at school to buy food or credit for a mobile;
- When there is a noticeable change in school work;
- Once a student starts to truant.

Others wanted information about “The support already given to the carer; the needs of the carer. i.e. home support, agency support, educational program, personal development, need.....” Others wanted to know what community organisations there were that could assist, citing the need for information about key contacts and resource people.

Concerns were also raised about the issue of confidentiality and the need for “Guidelines about approach [sic] the parent/s about concerns.”

The extension of this question was what information teachers and other staff would find useful to support young carers in school. A variety of ideas were given and these included; skills based training, academic assistance and support; recognition, list of resources and information pack, emotional support and finally holidays and respite.

Teachers were asked how information could best be disseminated to other teachers. They identified information sharing through Professional Development Programs, online resources and Education department information packs. More generic comments included “general public awareness is crucial”.

5.2 What young carers want teachers and schools to know

A large number of young carers in Australia have not and do not identify themselves to teachers or other school staff as being young carers (Morrow 2005). In this study, 39 of the 51 young people suggested that someone at school knew that they were caring, but only 17 said that the person who knew was a teacher. Five of the young people felt that ‘everyone’ knew but did not specifically identify teachers.

Nearly everyone knew. I didn't want to keep it from people. If people wanted to talk about it they could. If they didn't that was cool too. (Male young carer, 18years)

11 young people suggested that no-one at their school knew that they were young carers.

I don't share this information with people too readily because I have been careful who I tell I haven't had any bad experiences with people. (Female young carer, 16years)

Many young carers report that because teachers and schools do not know that they have care responsibilities at home they are unable to adequately or responsively support them. When they had identified themselves, a number of the young carers reported positive outcomes: teachers seemed more understanding, were more willing to be flexible and helped them find the supports that they needed. However, a majority of the young carers shared negative outcomes including the loss of anonymity, receiving inappropriate responses, disbelief and breaches of confidentiality. For some these negative outcomes outweighed the benefits.

In a way I just thought that I shouldn't have told anyone. I put way too much more into it than I should have – told more than they needed to know. The benefit of people knowing wasn't worth the looks, or the calls or the in-your-face stuff. (Female young carer, 21years)

In this section, we will discuss some of these experiences as well as some of the factors that influence whether or not young carers will identify themselves within the school community.

The benefits of identifying

Young carers told us about times when they had shared their home situations with a teacher or other staff member and this had been beneficial. Some reported that their teachers were considerate, that they comforted them, supported them and gave them advice when appropriate. Others suggested that the simple fact that someone at school knew about their situation was both validating and comforting because their home life was no longer a secret.

You have a chance to vent issues with them and tell them what's happening. (Female young carer, 16years)

I never needed to talk to her. But it was kinda good she knew. (Female young carer, 12 years)

Young carers recognised that because of the stresses and strains they were under they sometimes responded badly to situations at school, got into fights with other students or were generally distracted and unable to concentrate. Others shared times when they were upset, afraid or otherwise emotionally unwell. During these times, young carers reported that it was useful to have a teacher who understood what they were going through and who could help them find resolutions.

It has helped because if I got so upset that I just had to walk out of class I could go straight away. And I didn't have to explain all the time, it was just enough that people knew my Mum had a mental illness and this meant that I found it hard to cope sometimes. (Female young carer, 15years)

It was important to me to know that everyone understood why I behaved the way I did sometimes and to know that I wasn't just chucking tantrums, or that I just had a short fuse for no reason. Sometimes at

school I would start crying for no reason or react badly to something someone said and it was important that people knew what was going on behind the scenes so they understood my behaviour. (Female young carer, 18years)

Again, many of the young carers did not necessarily expect or hope that teachers would actively become involved in their situation, but were pleased because it meant that they were potentially more understanding. Other young carers, however, found that sharing their experiences lead to a greater flexibility from teachers in assessments and in their class work more generally.

Sometimes teachers were a bit more flexible. They didn't really know what was going on but they knew that something was up so they let you have an extension or something and that's good. (Male young carer, 17years).

Last year (in Yr 11) it was helpful that my teachers knew because if I was late for a deadline they would consider my home life and maybe give me more time to complete my work. Although this year I am being treated a bit more independently and left to my own, but that is probably good, because it is Year 12. (Male young carer, 17years)

The costs in identifying

There were a number of reasons why respondents thought that they and other young carers would not identify themselves as young carers, to teachers. Some speculated about negative responses while others shared experiences where teachers had responded badly or when their identification had led to negative outcomes.

A number of children and young people suggested that when they identified themselves as being a young carer they were no longer hidden from view, from scrutiny and from unwanted intervention. This was upsetting for those who valued their privacy and their ability to blend into the crowd.

They don't want to be treated any different. Some people don't like to be given slack in class – they just want to be treated normally. (Female young carer, 15years)

I don't want people to know. School is the only place where people don't look at me weird, where they don't treat me like I'm any different, like I'm someone to pitied or something. I like no one knowing because then it's about me and not about what I do at home. (Male young carer, 15years).

I wouldn't want teachers to know, it's just a private thing that you keep to yourself. (Male young carer, 16years)

Some young carers felt that they did not want teachers to know because they feared unwanted sympathy and over-scrutiny, and felt it might leave them open to what they deemed unhelpful responses such as child removal.

That was one thing I always hated, if a teacher found out about my situation it was like 'oh that poor girl blab blab,' it wasn't 'how can I do anything to help you. It was oh that poor girl she must have a terrible life. But I don't have a terrible life – I just don't know what I'm doing. (Female young carer, 17years)

We didn't tell anyone cos we [Dad and I] were worried they'd think he wasn't looking after me or make me do stuff kids shouldn't have to do. I didn't want people to know – I didn't want to be taken. (Female young carer, 15years)

Their home situation, for example. Parents might not want people to know they have an illness/disability and that they are not coping at home and that this is affecting their kids. So I think if you decide to tell or not it has a lot to do with the home situation. (Female young carer, 18years)

Young carers also reported that they would not identify because their confidentiality and trust had been broken in the past. They reported times when teachers and counsellors had shared their home lives with others, including other students, without their permission and without considering what may be the negative consequences including bullying from other students.

Some of my teachers were a bit nosy, asking specific questions about my Mum that was not necessary for them to know. And also some of them would bring it up in front of other people, like other students that

maybe didn't know my situation and the teachers would refer to stuff like me having to help my Mum go to bed etc. It was not so good when that happened. (Male young carer, 16years)

I hate the counsellor, because she broke my confidentiality once and they always want you to come back. I'd never trust anyone again. (Female young carer, 15years)

Others felt that identifying was not really that beneficial for them because, in the past, teachers have seemed to either not know what to do or not care about their situation.

They were shocked and said they were there for me and stuff but I could tell they were uncomfortable and that they didn't know what to do. They didn't bring it up again and neither did I so... you know, what was the point? (Male young carer, 15years)

But educationally it does not really help because they are not really sympathetic about handing in work late etc. If you have what they think is a good reason then it may help, but this is not usually the case. (Male young carer, 16years)

Others shared experiences of when the advice or support they received was not useful and were then sceptical about what value there was in sharing information again.

Once I told the deputy principal what was going on (it was when my Grandmother was always telling me delusional stuff and I was worrying about it) and all he said was that I could make a speech in front of everyone at my school and see if anyone else was in my situation and that is all he offered at that time. I did not want to do that. (Female young carer, 15years)

A number of young carers believed that there was no benefit in having others know that they were caring because they were doing well at school and because they didn't believe that they needed any additional support.

Maybe they think that they're fine and don't need help and they might feel a bit embarrassed – it's a bit embarrassing because their relative isn't normal – they might get laughed at. (Female young carer, 12years)

For me it was because we are so used to being on our own that we don't want others to be involved. We are used to coping on our own. We want them to back off. (Female young carer, 18years)

Many children and young people with care responsibilities have not heard of the term 'young carer' or do not feel that it represents their life because of the types of supports they provide, the level of caring responsibilities they assume or because of cultural expectations within the family (Morrow 2005). Other young carers report that they never knew that their family experience was different to others and have therefore have not shared their situation.

I think my thing was I didn't know I was carer, it was just second nature to me, I didn't know the difference. I grew up thinking my family was like everyone else's, except they used to talk about mine. (Female young carer, 17years)

Lots of young carers don't know that they're young carers. They think that "I'm just looking after my brother" but they don't know they're a carer or what's round. (Female young carer, 13years)

The implications for schools

Previous research has stressed the value of providing teachers and other school staff with the skills to identify young carers in their classrooms (Frank 2002; Carers Association of South Australia 2005; Morrow 2005) and, in more recent times, been heralded as the key way to support them within schools. However, the vast majority of young carers in this project felt that until schools could counter the negative consequences such as bullying and peer rejection and provide them with useful and concrete supports, they would not feel comfortable in people knowing about their home lives. This discovery, which confirms research conducted by Banks et al (2001) and others, is important because although it does not challenge the need for schools to be more aware of which students in their schools are caring, it does suggest that identification cannot and should not be the only strategy that schools adopt to support students with care responsibilities.

In fact, it may be argued that though important, identification of students should only occur after schools have developed a series of strategies and policies to address their needs. With such preparation, schools can provide young carers with planned and well co-ordinated supports that enhance their school experience rather than putting them at risk of further isolation and concern.

To better support young carers, schools should also attempt to promote caring as a positive experience, to encourage help-seeking behaviours amongst students and to counter negative school cultures that reinforce stigma that may lead to peer rejection or bullying. This should occur at a whole-of-school level and should engage the commitment of all staff to ensure that it effectively permeates all aspects of the school community. Young carers in this study argue that if this occurs more children with care responsibilities will come forward to seek support.

What young carers want teachers to know about young caring

As well as knowing that they exist, young carers wanted teachers and other school staff to know about what caring entailed, how it impacted on their lives and particularly on their schoolwork, and how they might better support them.

Teachers don't understand that with a lot of young carers – that you have a lot more responsibilities – that you go home, you clean up, that you make sure that your mum or whoever has eaten, make sure that things are ready, that things are clean and everything and that by the time your ready to do your homework its 12 o'clock and its time to go to sleep, And you get up and do it all over again. (Male young carer, 15years)

The young carer's responses are summarised in Table 8:

Table 8: What young carers want teachers and schools to know

<p><i>That young carers exist and that they assume significant care responsibilities:</i></p> <ul style="list-style-type: none"> • <i>young carers usually are not lying when they share their experiences</i> • <i>young carers will sometimes need flexibility in their attendance and assessment</i> • <i>young carers will often feel tired, anxious and distracted</i> • <i>not all young carers will identify themselves as carers</i> • <i>not all young carers know that they are young carers</i> • <i>sharing information about their home life can sometimes be difficult</i>
<p><i>That caring is a normal experience:</i></p> <ul style="list-style-type: none"> • <i>a large number of children and young people help care for a family member</i> • <i>young carers do not want to be treated differently to others</i> • <i>young carers are not usually being “exploited” by their parents</i> • <i>caring does not always negatively impact on a young carers’ education – sometimes there are even positives</i>
<p><i>That young carers need understanding:</i></p> <ul style="list-style-type: none"> • <i>young carers may need some ‘space’, especially when they are feeling stressed or tired</i> • <i>young carers are bullied and harassed because they are caring or because of their relative’s condition</i> • <i>young carers do not feel safe or comfortable in what they consider a hostile environment</i> • <i>young carers do not always want sympathy, but they often do need concrete support</i>
<p><i>That young carers have a range of skills and experiences:</i></p> <ul style="list-style-type: none"> • <i>that need to be valued and validated</i> • <i>that can be applied at school</i> • <i>that might be recognised through vocational education</i>
<p><i>That young carers need support:</i></p> <ul style="list-style-type: none"> • <i>young carers need someone ‘safe’ who will listen and support them</i> • <i>young carers need someone to advocate for them at school</i> • <i>young carers need someone to ask them if they are alright</i> • <i>young carers needs someone to help connect them with supports</i>
<p><i>That young carers need their privacy:</i></p> <ul style="list-style-type: none"> • <i>young carers do not like people knowing about their situations – particularly if there is a chance of negative consequences</i> • <i>young carers are happy for supportive teachers to share their situation – but only for the purposes of increasing understanding or for engaging supports</i> • <i>young carers will often not identify if they are afraid that their privacy will be broken</i>

5.3 What young carers want schools to do

Participants in this study acknowledged that particular teachers in particular schools were working extremely well with young carers. In fact, some young carers reported that school was their safe haven and that teachers provided them with the security and support that they needed. However, some young carers asserted that this support usually relied on an individual teacher rather than a school strategy or commitment.

Young carers identified a range of things that they believed schools could do to better support them with their education. Although diverse, responses fell into thematic areas:

- increased opportunities for personal support and advocacy;
- integrated promotion and understanding of diversity; and
- flexibility in school delivery.

To achieve these, young carers called for more teacher training and professional development.

Personal support and advocacy

In an ideal world, young carers felt that all teachers would have an understanding and some compassion for their situation and that of their peers. However many young carers reported times when they felt unsupported and invalidated by teachers:

I'm sick of them saying "We don't get paid enough to care" – they said that all the time to me – well they do get paid to look after us so they should care. (Female young carer, 18years)

Many young carers felt that having someone within the school that was available for them to talk to was important. Some believed that this should be an identified teacher with specific skills and experiences while others felt that it should be someone they personally felt comfortable with. Either way, young carers valued having someone who listened to them, who was empathetic (rather than sympathetic) and who helped them resolve their problems.

Young carers - they're not different – they just need to be approached in a different way, given some leniency towards work and not to just push them because they don't know how to approach them. Come up to them one-on-one and say that they're there if they want to talk about it so that the young carer goes "there's this teacher who is there who will listen – there's at least one teacher who'll listen or help me out if I need it" – that's good for young carers whether they take it up or not. (Male young carer, 17years)

A number of the young carers believed that this person should actively support them because they did not feel comfortable approaching people for assistance or advice.

Because I come from a European background – whatever happens in the family stays in the family. So I was afraid to say something – because of that big rule. I just hoped someone would ask me what was going on so I could answer them and tell them what was going on. If they asked I couldn't get in trouble – it would be wrong to lie. (Female young carer, 18years)

If I need help though I usually just sit there, sometimes I am just tired and I am really bad with asking for help. (Male young carer, 15 years)

Having a specified support person was valued by young carers who felt they needed an advocate within the school to support them when times were difficult and to mediate with other teachers who may not be as understanding.

One of my teachers – the only one who knew or cared I was a carer - had a conference and we sat down she explained my Mum's illness to the people who were bullying me and told them what was going on. Mental illness was a scary thing to a lot of people. They didn't understand. So someone telling them made a big difference. They all stopped and said sorry, that they didn't realise what was going on or how it was for me. And it stopped. (Female young carer, 18years)

The only 2 teachers who cared had to fight against the rest of the teachers who didn't want a bar of it. At the end it was much easier. (Male young carer, 15 years)

Young carers also felt that schools could support them in identifying other young people in their schools who had care responsibilities. When they did know someone in the same situation as themselves, young carers reported feeling less isolated, less ‘different’ and more connected to the broader community. Young carers thought that school-based support groups, study teams and buddy programs were therefore beneficial.

When I was younger they used to have these groups where you could get together with other young carers and meet other girls who were carers so you spend time with them like going to the movies— that was fun. It was just good to have a break to do something you want to do – to just have a laugh – with people who are going through the same things as you. (Female young carer, 12years)

It would make it hard if they knew, one person is easier to talk to then lots, But maybe a group after school to talk to others in a similar position... That could work maybe. (Female young carer, 17years)

Integrated promotion and understanding of diversity

To achieve greater understanding, young carers called for curriculum to be developed and integrated into mainstream classes to address the lack of awareness and empathy they believed led to these pervasive cultures.

More awareness: A lot of people don't know about illnesses. You know, they think that people are just 'crazy', a lot of people also think that schizophrenia passes on from one generation to another...that is why no-one says anything about being a young carer. (Female young carer, 19years)

Provide information for other school members on mental illness and caring issues etc. So that there is not such a misunderstanding and just getting the general awareness up of these issues. There should be talks at lunchtimes about different conditions so they understand things better. (Male young carer, 18 years)

They believed that this would be useful not only for young carers but also for the broader school community.

More education for everyone at school on disabilities and mental illness so that they understand better – for the teachers and the kids. There is still a lot of stigma that is around about mental illness so people need to have a better understanding. (Female young carer, 16years)

In health ed we never spoke about mental illness except depression – and then it was just sex ed. Its just as important that people know about stuff not just sex. – things that are important in your life. (Female young carer, 18years)

Young carers also felt that schools would be an optimal place for the dissemination of information about illnesses, disabilities, mental health issues and drug and alcohol use, young caring and available services. They felt that it would be useful for libraries to stock books that were readily accessible and for newsletters to include information about young carers and what support was available and how to access it.

I found it difficult to find information. I had to rely on young carer camps to get the stuff I needed or my mum's friends who had kids themselves who could explain stuff to me. (Male young carer, 18 years)

They should have notices on the notice board about where you can go, who you could ring if you need some help or someone you could talk to. (Female young carer, 12years)

Flexibility in school delivery

Due to the sometimes erratic nature of caring, many respondents argued that they found it incredibly difficult to keep up with their schoolwork and to meet assignment deadlines – no matter how organised they tried to be. Many young carers shared stories of when particular teachers had been flexible, but felt that such flexibility needed to be built into school policy so that they didn't have to explain their situation or fight for help each time they needed it:

We don't want to teachers to go 'don't worry about it' just to give you more time. (Female young carer, 14years)

Pass me automatically! No – seriously, make it easier for me to catch up and support me in my learning and more time to be helping me out and more time for assignments and stuff. More flexibility. (Male young carer, 16years)

In particular, young carers called for schools to allow them opportunities to resit exams, to resubmit assignments and to be more flexible about when and how units could be completed. For example, a number of young carers felt that if schools adopted a ‘complete’/‘not yet complete’ style of assessment they could reattempt units rather than fail them automatically thus missing out on completing year 10 and year 12 certificates as a result.

I was forced to do Human Biology or I would fail VCE [Victorian Certificate of Education], or if I failed English I'd fail my whole thing. I wanted to achieve a two-year education that I could follow on to uni, but the strictness that they apply to it, to everyone, not just young carers is over the top, it's extremely hard too when you consider the fact that only 6% of young carers complete their tertiary education. (Male young carer, 17years)

I am doing a personalised SA Certificate of Education - they have modified it so that I can get my certificate in a year instead of over 2 or 3 years. And a subject at my last school called “Community Services” covered disability and child care etc. this was good for me. (Male young carer, 16years)

Through their caring, many young carers have developed significant skills and expertise that they believe could be recognised by schools and integrated into assessment tasks. Some young carers shared experiences of when their schools had provided them with vocational education accreditation in areas such as disability work, community work and advocacy. This proved to be invaluable to the young carers not only because their skills were being validated but also because it meant the school could be more flexible in allowing students to drop non-compulsory units.

I know one young carer who wants to become a nurse and she looks after her Mum and it would be great if she could get recognition – cos she's got half the skills already, she knows how to do it – but some

recognition of her skills, to help her in would be awesome. Its not like she's getting something she doesn't deserve – she's just getting recognition of her skills. (Male young carer, 17years)

I suppose last year I wasn't really doing well in Math and not liking it, I was having a bit of trouble so the principal said that I was allowed to drop a subject this year if that helped me. (Female young carer, 16years)

Home schooling was raised as a useful alternative to education for young carers who felt unable to leave home. Some young people were hesitant and felt that home schooling would reduce their ability to spend time outside of the home, and their opportunities to socialise with others and to be exposed to different experiences. However those who were engaged in home schooling (n=4) believed that it was the most useful option for them.

It would be too hard for me to go to school for 6 hours a day and look after my mother at the same time. My Mum needs 24 hour a day care. I help out with a lot of meals. It is very dangerous for her to stand up for too long. It's worked out in hours to help Mum. I can take a break from it. (Male young carer, 15years)

Alternate education programs had been used by a number of young carers who described them favourably. They particularly appreciated the flexible learning options, because strict school attendance wasn't required and units could be completed over a number of months or years.

The school I go to is a school that takes on older kids to finish high school, so my school has been good. If I need time off they understand and they give me my schoolwork to do. (Female young carer, 17years)

A large number of young carers felt that they would benefit from a system where they could take advantage of school-based, home school and distance education modes of learning. Although acknowledging organisational complexity, many felt that it would enhance their capacity to do well at school.

Ideally you could do it at school, at home and by mail. It means you could still catch up with your friends and do normal classes but you could also do work at home. I'd hate to have to do it all by myself – because it would get too lonely and I'd need someone to kick me up the ass and make sure I was doing it. (Male young 16years)

Maybe doing some of your courses by correspondence but instead of all of them so you can still get out of home to see your friends. (Female young carer, 16years)

For those students at school, young carers felt that sometimes they needed 'time out', particularly if they were stressed, tired or needing space. Young carers suggested having a special room for young carers where they could access a phone to call home, and where they could get support if necessary. This was particularly important for those young carers who found it difficult managing their anger and needed somewhere to 'chill out'.

They give me some time to cool down. They ask me if I need to go home, to have some space. (Female young carer, 14years).

Sleep – maybe if the person was at school and needed a sleep then they could go to sick bay and have some time out. I'd be up till 5 with my sister throwing up and I'd go to school exhausted and I needed sleep. (Male young carer, 18 years)

They could give you time out to walk around the school for a bit – because then you get to walk in the quiet and the fresh air and think about stuff while you're walking around. (Male young carer, 12 years)

As well as flexibility in the way education was delivered, young carers called for schools to be more accommodating of their needs more generally. In particular, young carers raised concerns about not being allowed to have a mobile phone at school – feeling that for their own peace of mind, and in some cases, their capacity to leave the home, access to a phone was essential. The ability to leave the school grounds during free periods and lunch breaks was also raised, as was being able to make up detentions over a week instead of in one single period.

Being able to use your mobile at school to check on things at home at lunch time I got into so much trouble every time I did that – I used to do it every day – I used to get detention because I wanted to call my mum at lunch time. The rule was no mobile phones at school at all. I got detention almost every week. (Female young carer, 15years)

I need to know that I can leave school to go help Mum. Otherwise I really can't go at all – and that's bad for everyone. More flexibility in rules is important. (Male young carer, 15years)

Responses to the question “What do you think schools should do to better support young carers” are summarised in Table 9:

Table 9: What young carers would like their schools to do

<p>Support for young carers:</p> <ul style="list-style-type: none"> • <i>support groups where young carers can meet and develop friendships</i> • <i>existing programs be expanded to become more inclusive of young carers (i.e. cross-age tutoring, special education settings, one-on-one educational support)</i> • <i>provide ‘time-out’ and other young carer-friendly spaces on site and allow young carers to have space and time when needed</i>
<p>Curriculum:</p> <ul style="list-style-type: none"> • <i>curriculum developed that reflects the experiences of people with conditions and their families, challenges stigma and promotes diversity</i> • <i>self-care, ‘caring’ and help-seeking skills integrated into mainstream programs</i>
<p>Delivery:</p> <ul style="list-style-type: none"> • <i>schools work with community education programs (including VET) to provide a variety of delivery modes (including home schooling, distance education, take-home work)</i> • <i>schools work with young carers to credit pre-existing skills and experiences in nationally recognised packages (such as Certificate IV Disability Work) to enable time off from study</i>
<p>Policies and programs:</p> <ul style="list-style-type: none"> • <i>policies reviewed to make sure that they are inclusive for young carers (i.e. no mobile phones etc)</i> <p><i>Training for teachers:</i></p> <ul style="list-style-type: none"> • <i>on issues affecting children and young people (including caring)</i> • <i>on illnesses, disabilities, mental health, alcohol or other drug issues</i> • <i>on how to minimise stigma, discrimination and harassment of people with conditions and their families</i> • <i>on how to create a supportive school environment for all young people</i> • <i>on how to best support young carers in schools</i>

External supports that could help young carers

Although young carers felt that schools could provide them with valuable assistance, many reported that they also needed practical support outside of the school grounds to enable them to fully participate and achieve in their education.

Respite Care

For those with significant care responsibilities, additional in-home support for their cared-for relative was identified as being essential. These young carers believed that only if they were able to relinquish a number of their care tasks, particularly those that were required during school hours, could they attend school and do so without guilt or concern.

It would be good if there was someone there to look after them and make sure that they're safe and stuff... because my Dad once set fire to the oven so I was worried he may do that again... but if I knew he wouldn't hurt himself it would be fine. (Female young carer, 16years)

Respite provided to cared-for relatives outside the home was also sought by most young carers in this study, particularly that which was:

- provided by staff with skills and experiences (so that young carers could have some time off and feel safe and secure about their relative)
- provided at times that met the young carer and their relative's needs – including during peak exam times and after school (so that young carers could do homework), and when young carers felt they were not particularly coping
- provided freely or cheaply to ensure that all young carers could access
- provided in a way that met relative's needs by responding to their age, their capacity and their likes and wishes.

I think it's good for both parties. You want – not so much get rid of her – but you want to get out [of home] without having to feel selfish and that. My sister loves where she goes she does. At school they do horse riding and shopping... it's good for both parties. (Male young carer, 16years)

Also respite is really good as well, I can get time away on weekends and that makes it easier to concentrate at other times. (Female young carer, 17years)

Respite is a huge thing. I was offered respite just before exam time which I thought was just great... If there was maybe respite for the young carer, giving them more a surrounding where they can relax and study in a comfortable environment where they could do what they needed. (Male young carer, 17years)

Although they valued such respite, only a small number of young carers identified times that they had received such support. Many shared stories of being ‘knocked back’ from services because they did not fully meet eligibility criteria, because services did not take into consideration their whole-of-family support needs, because they were too expensive or otherwise inaccessible.

Respite is really hard. There's too many restriction on it – when it's available, what you can do, how much it costs – and it gets too much. It's not worth worrying about – it's too much hassle for too little. (Female young carer, 14years)

Young carers were particularly frustrated in their attempts to access the newly developed “Young Carer At Risk” respite program.

Because my Mum helps care for my little brother I can't get that respite. But they didn't listen. I look after him too, and my little sister who's got an intellectual disability and my Mum half the time who's got chronic fatigue. I'm the one who does most stuff and they knocked me back then they knocked Mum back cos she's on disability and so we get nothing. No one will work with us. (Male young carer, 16years)

You shouldn't have to fight for help all the time. They are supposed to be helping but by the time you fight for what you need you're so stressed out you can't even get it. (Female young carer, 14years).

Some young carers also reported feeling anxious about their relatives accessing respite services and, in a number of cases, this was due to the recent media attention on abuse in care.

When it came to the point of getting respite, you'd always be fretting – you'd be worried about whether she was ok, being looked after properly. It might be good for young carers to be able to check out the place where they'd go so that you'd feel better. The workers there would help get the monkey off my back just for that the weekend. (Male young carer, 17years)

You hear about people being bashed and abused in respite and you're always thinking 'could that be my Mum, could it happen to her?' You're never really sure. They have to fix those places up and look after the staff so they're not stressed out and take it out on people [who are receiving respite]. If they don't fix stuff up then there's no point us getting time off cos we're just worried the whole time. And you come back home more stressed than you were before you started. (Female young carer, 14years)

Young carers therefore asked for more quality respite which could both give them time out but also the sense of security and confidence they needed to make the most of the opportunity for rest.

Financial support

Many young carers reported that although their families were financially disadvantaged, they were currently not receiving any financial assistance either through government benefits or emergency programs. As such, young carers sought access to income support and access to education support schemes that would help them meet the costs of their education.

More money because I don't qualify for carers allowance for them, which makes it hard financially to do all the things that we need. (Male young carer, 16years).

We can't afford anything. We don't even have enough food sometimes – so how can I ask for money to go on an excursion or a camp or something. I just tell the school mum's too sick for me to go – but its really cos we can't afford it. (Male young carer, 15years)

Tutoring

Young carers called for extra tutoring – either at school at special learning centres, or after school so that they could catch up on homework or missed lessons. Some young carers felt that

this should be provided in the young person's home so that they could 'keep an eye on things', while others felt that this would be too distracting and would not be a good use of resources. Either way, young carers felt that extra educational support would be useful.

Tutoring is one thing. Like something at a community centre whether ... you can just sit there and someone will come to help you. Workers at community centres and youth centres – like a tutor but not a tutor... (Male young carer, 18 years)

Some tutoring at home so they don't have to juggle as much – they can do homework and look after their relative at the same time. Tutoring's a big one – the main thing. (Male young carer, 17 years)

Access to computers and IT

Many young carers reported that they found it difficult to study and to achieve in their schoolwork because they could not afford a computer or have access to the internet. Unlike peers who could spend extra time at the library or at school, young carers had to be at home and could not therefore use public facilities as readily as their peers. Those who had been sponsored by a local carer association appreciated home access.

I don't have a computer so if I'm going to do my homework I need to go down to the library but if Mum's not well then I can't go which means I can do my homework and then I get in trouble. (Female young carer, 14 years)

Having a computer changed my life. I could do everything I needed for school – and it opened up a world to me too – I could sit on the computer and chat with other people. It was great because I was doing better at school and felt like I wasn't alone. (Female young carer, 15 years)

6 Conclusions

This research project attempted to provide a greater understanding of the experiences and needs of young carers in schools. Like other studies, it discovered that most young carers highly valued their education and worked hard to achieve satisfactory outcomes. It also found that many young carers believed that as well as meeting their educational needs, school provided them with respite from their home situations, with a sense of ‘normality’ and belonging and the opportunities to develop socially with their peers.

Young carers in this study reported that there were a number of factors that acted to restrict their access to education and their capacity to fully participate and achieve within it. Issues such as poverty and social isolation were compounded by a lack of appropriate and responsive services and acted to keep many children and young people from attending school.

Physically tired and emotionally drained, many young carers reported that keeping up with their schoolwork was a major challenge. Others spoke of the fear, anxiety and stress associated with caring and the shame and guilt they experienced when leaving their family members at home. With these “monkeys on [their] backs”, young carers reported difficulty concentrating in class.

Within the school gates, many young carers often faced stigma and misunderstanding which, in a large number of cases, led to them being bullied or losing friends. Others felt ‘alone’ and disconnected within schools that discouraged diversity and attacked family difference.

Inflexible timetables and assessment processes were identified as key barriers to successful schooling, as did a lack of understanding and empathy from teachers who did not appreciate the nature of caring or the way it impacted on a young person’s life.

Although faced with such challenges, all of the young carers placed great value on their schooling and, in many cases, the support they received from those who did understand, who did believe them and who actively worked with them to find solutions. Young carers identified a

range of ways in which their schools had helped them navigate their way through the challenges while offering ideas on how they might improve and greater support others in similar circumstances.

Throughout the research project it became clear that though there has been some attention within the media and within popular discussions, many teachers and schools remain relatively unaware of the existence and needs of young carers in schools. It is hoped that this report will complement and inform the development of resources for teachers and schools to increase their awareness and capacity to respond to the needs of this important target group.

References

- ABS (2001). *Marriages and Divorces Australia*. Canberra, Australian Bureau of Statistics,.
- Access Economics (2005). *The Economic Value of Informal Care*. Canberra, Carers Australia.
- ACT Legislative Assembly (2001). *Assembly Inquiry into Young People Not Achieving Satisfactory Outcomes in Education*. Canberra, ACT Legislative Assembly.
- ACT Young Carers Network (2000). *Submission to the Inquiry into Young People Not Achieving Satisfactory Outcomes in Education*. Canberra.
- Aldgate (1990). "Foster children at school: success or failure?" *Adoption and Fostering* **14**.
- Aldridge, J. and S. Becker (1993). *Children who care: Inside the World of Young Carers*. London, UK, Young Carers Research Group, Loughborough University.
- Bancroft, A., S. Wilson, et al. (2004). *Parental drug and alcohol misuse: Resilience and transition among young people*, Joseph Rowntree Foundation.
- Becker, S. (2005). *Young Carers: Evidence and Messages from UK and Australian Research*. Carers: The Next Generation, Adelaide, Carers South Australia.
- Braithwaite, V. (1990). *Bound to Care*. Sydney, Allen and Unwin.
- Brendtro, L. K., M. Brokenleg, et al. (1990). *Reclaiming youth at risk : our hope for the future*. Bloomington, Ind., National Educational Service.
- Brendtro, L. K. and A. E. Ness (1983). *Re-educating troubled youth : environments for teaching and treatment*. New York, Aldine Pub. Co.
- Brendtro, L. K. and M. Shahbazian (2004). *Troubled children and youth : turning problems into opportunities*. Champaign, Ill., Research Press.
- Brooks, Milne, et al. (1997). *Underage school leaving: A report examining approaches to assisting young people at risk of leaving school before the legal school leaving age*. Hobart, Tasmania, National Youth Affairs Research Scheme.
- Carers Association of South Australia (2003). *Developing a Whole of Government State Carers Policy in South Australia: Discussion Paper*. Adelaide, Carers Association of South Australia.
- Carers Australia (1997). *Caring Enough To Be Poor: A Survey of Carers' Income and Income Needs*. Canberra, Carers Australia.
- Carers Australia (1997). *A question of responsibility*. Canberra, Carers Australia.
- Carers Australia (2002). *Young Carers Research Report: Final Report*. Canberra, Department of Family and Community Services.
- Carers Australia (2005). *Young Carers Summit Report 04*. Canberra, Carers Australia.
- Couzins, J. (2004). *The role of the school in supporting children. Children of parents with mental illness*. V. Cowling. Melbourne, ACER Press.
- Cowling, V., P. McGorry, et al. (1995). "Children of mothers with psychotic disorders." *Medical Journal of Australia* **163**.
- Cree, V. (2003). "Worries and problems of young carers: issues for mental health." *Child and Family Social Work* **8**.
- CYCLOPS ACT (2005). *Making Education Work Project*. Canberra, unpublished.
- Dalley, G. and J. Finch (1988). *Ideologies of caring : rethinking community and collectivism*. Basingstoke, Macmillan Education.

- Dearden, C. and S. Becker (1998). *Young Carers in the UK: A Profile*. London, Carers National Association.
- Dearden, C. and S. Becker (2002). *Young Carers and Education*. London, Carers UK.
- Deen, N. (1995). "Schools make people grow: notes on the supportive school." *Pastoral Care in Education* 13.
- Frank, J., C. Tatum, et al. (1999). *On Small Shoulders: Learning from the Experiences of Former Young Carers*. London, The Children's Society.
- Gays, M. (1998). *A Comparative Study of Aged-related Domestic Labour Between Young Carers and Young People*. *Faculty of Health Care and Social Studies*. Luton, University of Luton.
- Gays, M. (2002). *Lifetime of Caring: ACT Schools-based Young Carers Survey*. Canberra, Marymead Child and Family Centre.
- Gilligan, R. (1998). "The importance of schools and teachers in child welfare." *Child & Family Social Work* 3(1).
- Gilligan, R. (2000). "Adversity, Resilience and Young People: the Protective Value of Positive School and Spare Time Experiences." *Children & Society* 14: 37-47.
- Goggin, G. and C. Newell (2005). *Disability in Australia: Exposing a Social Apartheid*. Sydney, UNSW Press.
- Halpenny, A. M. and R. Gilligan (2004). *Caring Before Their Time? Research Perspectives on Young Carers*. Dublin, National Children's Resource Centre,
- Kids Help Line. (2004). "Info Sheet 7: Bullying." 2005, from <http://www.kidshelpline.com.au/upload/4038.pdf>.
- Mallett, S., D. Rosenthal, et al. (2005). "Young people, drug use and family conflict: pathways into homelessness." *Journal of Adolescence* 28(2): 185-199.
- Marsh, P. (2000). "Truancy or absenteeism? A school governance perspective." *Queensland Journal of Educational Research* 2004(16).
- McArthur, M. and G. Winkworth (2005). "Breaking into schools: Creating high quality human services in educational contexts." *Children Australia* 30(1).
- Moore, T. (2005). *More than Words: Supporting Young Carers and Their Families*. Canberra, Youth Coalition of the ACT.
- Moore, T. (2005). *Reading Between the Lines: Talking to Children and Young People about their experiences of Young Caring*. Canberra, Youth Coalition of the ACT.
- Morgan, R. (2006). *Being a Young Carer: Views from a Young Carers Workshop*. Newcastle upon Tyne, Office of the Children's Rights Director, Commission for Social Care Inspection.
- Morrow, R. (2005). *A profile of known young carers and identification and snapshot of the ones who are hidden*. Perth, Curtin University of Technology.
- Nankervis, J. (2005). *Time out for studies and life: A Practice Guide and Worker Resource for the Young Carers at Risk Respite Program*. Melbourne, Victorian Carer Services Network.
- NATSEM (2004). *Who's going to care? Informal care and an ageing population*. Canberra, Carers Australia.
- Odyssey Institute of Studies (2004). *Nobody's Client Project: Identifying and Addressing the Needs of Children with Substance Dependent Parents*. Melbourne, Odyssey House.

- Oliver, M. (1992). Emancipatory Research: A Vehicle for Social Transformation of Policy Development. First Annual Disability Research Seminar University College, Dublin, National Disability Authority and The Centre from Disability Studies.
- Olsen, R. (1996). "Young Carers: Challenging the Facts and Politics of Research into Children and Caring." Disability and Society **11**(1): 41-54.
- Prime Minister's Youth Pathways Action Plan Taskforce (2001). Footprints to the Future. Canberra, Department of Education, Science and Technology.
- Reid, L. (2000). "Associations Between Participation in the National School Lunch Program, Food Insecurity, and Child Well-Being." The Social service review.
- Resnick, M., P. Bearman, et al. (1993). "The impact of caring and connectedness on adolescent health and well-being." Journal of Paediatrics and Child Health **29**.
- Slee (1991). How Young People See School: This is no Ship of Fools. Preventing juvenile crime : proceedings of a conference held 17-19 July 1989, Australian Institute of Criminology.
- United Nations. (1989). "Convention of the Rights of the Child." Retrieved 27 October 2005, from www.unicef.org/crc/fulltext.htm.
- Webber, C. and K. Hayduk (1995). Leaving school early. Canberra, Galilee Inc.
- Youth Coalition of the ACT (2005). Telling It How It Is: Listening to Young People about Youth Homelessness in the ACT and the Services that Support Them. Canberra, Youth Coalition of the ACT.
- Zaff, Moore, et al. (2003). "Implications of Extracurricular Activity Participation During Adolescence on Positive Outcomes." Journal of Adolescent Research **18**(Winter).

Appendix 1: Quantitative Data

	Mean	Std Dev
Psychological implications		
Because of my caring I sometimes don't sleep well	3	1
I sometimes feel tired and lack energy because of things I do at home	4	1
I sometime worry about things going on at home, and that makes it hard at school	4	1
Because I'm caring, sometimes I feel angry or upset and I get in trouble for taking it out on other people at school (through fights or mucking up in class)	3	2
Sometimes I feel like I'm the only one who cares at my school	3	1
Overall mean 18 (Range 1 to 25)		
Educational implications		
Because of my caring I sometimes miss school	3	2
Sometimes I am late for class because of my caring	3	1
Because I'm caring, I sometimes don't have time to do my homework	3	1
Because I'm caring sometimes I find it hard to catch up on schoolwork	3	1
I think my grades at school aren't as good as they could be because of the pressure of caring	3	1
Overall mean 16 (range 1 to 25)		
Daily activities: how caring impacts		
Because I'm busy before school, I sometimes don't have breakfast or pack lunch	3	2
Because I'm bust at home, sometimes I miss my transport to school and find it hard to get there	3	1
I sometimes can't participate in things after school because I need to be home	4	1
Sometimes I can't afford things at school because we have to pay for things tied to my relative's condition (like medication, home help, doctors appointments etc)	3	2
Because of things at home, sometimes I find it hard to make or keep friends at school	3	2
Because of my caring, I don't really see the value of going to school at the moment	2	2
Overall mean 22 (Range 1 to 35)		

Appendix 2: Information Letter (Young Carers)

Australian Catholic University Limited
ABN 15 050 192 660
Canberra Campus (Signadou)
223 Antill Street Watson
Australian Capital Territory 2602 Australia
PO Box 256 Dickson
Australian Capital Territory 2602 Australia
Telephone 6209 1229
Facsimile 6209 1216
www.acu.edu.au

**INFORMATION LETTER TO PARTICIPANTS
YOUNG CARERS AND EDUCATION PROJECT**

Dear Young Carers and Parents,

I am writing to invite you to be part of a study that the Australian Catholic University is conducting that focuses on young carers and education.

This project aims to find out what support young carers need, whether they are getting this, and what might be done to resolve the situation.

The project will include some one-on-one phone interviews and some focus groups. These will be conducted by a youth researcher, Tim Moore, and / or a young carer aged between 18 and 25 who has been trained to help with the research.

The researcher will ask questions about what young carers do, what the main issues are for them around their education, what support they've had in the past, what help they might need, and what might be done better to support them. All the questions are open, and young carers can choose to answer them or not.

The phone interviews usually take around 30 minutes to fill out. Sometimes they might be shorter or longer, depending on how young carers answer. Interviews may be audio-taped so that we will have an accurate account of the information you give us— these tapes will be destroyed after the project is completed.

The Australian Catholic University is gathering this information for Carers Australia so that they can put together resources for teachers and schools. The information will be made available in a report that will be developed for the community so that they have a greater understanding of your needs also.

The survey is completely voluntary – participants can choose to be involved or not as well as choosing what questions are answered and which are not. At any stage, your child can also decide to no longer participate – without having to give a reason.

In our study, everything that is shared with researchers is confidential. This means that we will only use information for the purposes of our report, and only with permission. The only time when confidentiality might be breached is if we are concerned about the safety of a child.

If you have any questions about the survey or would like to know how you might participate, you can contact::

Tim Moore
Australian Catholic University
(02) 6209 1229
t.moore@signadou.acu.edu.au

or

Dr Morag McArthur
Australian Catholic University
(02) 62091225,
m.mcarthur@signadou.acu.edu.au

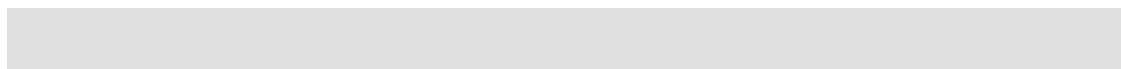
This project is conducted with the approval from the Human Research Ethics Committee at the Australian Catholic University. If, during the course of the research, you have any complaint about the way that you have been treated or if you have a query that you think has not been dealt with by the project researchers, you may contact:

Human Research Ethics Committee Chair
Research Services
Australian Catholic University
Strathfield Campus
Locked Bag 2002
STRATHFIELD NSW 2135
Ph: 02 9701 4159
Fax: 02 9701

If you are interested in participating in this survey, please complete and sign both copies of the attached Consent Form and return to [INSERT DETAILS OF YOUNG CARERS WORKER AT STATE / TERRITORY CARERS ASSOCIATION]

Yours sincerely,

Dr Morag McArthur
Australian Catholic University



Appendix 3: Young Carers Questionnaire

Young Carers in Education Survey Phone Interview

Notes for Starting the Interview:

Introduce Yourself

SAY SOMETHING LIKE: Hi, I'm [] and I'm doing some research with the Australian Catholic University on young carers in schools.

Tell them something about yourself. For example how old you are, where you live, who is in your family (etc) and why you're interested in doing this project (ie your own experience of being a carer etc). This helps build trust and makes the process more of a two-way discussion.

1. *Explain the project*

SAY SOMETHING LIKE: What we're hoping to find out is what school is like for young carers, what helps them to do well, what challenges they sometimes have to deal with and what they think would make things better for them.

We're doing this because we believe that young people themselves have a lot we can learn from and we want to hear about your opinions and experiences.

2. *Explain the nuts and bolts*

SAY SOMETHING LIKE: We understand that you live or used to live in a family where someone had an illness, disability or alcohol or other drug issue and we would greatly appreciate it if you could give us your time and thoughts.

The interview will take around 45 minutes and we will be asking questions about your own experiences and opinions and what you think needs to be done better help young carers at school.

Because we value your input, we'll send you a movie ticket as a thanks for your time.

3. *Explain what will be done with the information and that it is confidential.*

SAY SOMETHING LIKE: The information that you give us in this interview will only be used in a report for Carers Australia. Everything you say will be kept confidential – except if we are worried about your safety.

When the report is written up we will do everything we can to make sure that no one who has participated can be identified or cause problems for young people?.

4. *Explain what you want from the participants*

SAY SOMETHING LIKE: We only want you to answer the questions that you feel comfortable answering and only when you have the information to answer the questions about yourself and your own experiences.

Don't worry if there is something that you can't or don't want to answer – it's OK.

5. Check to see if they are happy being interviewed

SAY SOMETHING LIKE: Is that all OK? Do you have any questions about what we're doing?

Answer any questions they have.

6. Check to make sure that they have filled out their consent form

7. Clarify a few things:

SAY SOMETHING LIKE: During the interview we'll sometimes talk about 'caring' and being a 'carer'. This is the official language for helping your relative who is sick, ill, disabled or with a alcohol or other drug problem. If you have any questions about it as we're going along, stop us and ask.

PRE-INTERVIEW CHECKLIST

- Introduced yourself and the project
- Explained that the survey is voluntary
- Checked to see if there are any questions about the consent
- Received signed consent form (including parents signature for under 14)

ABOUT YOU:	
<i>SAY SOMETHING LIKE: I'd like to start by asking you some questions about you. We're gathering this information so we know what types of young people participated in the survey.</i>	
1. How old are you?	
2. Are you male or female?	
3. What is your postcode?	
4. What school year are you in?	

About Your Family	
<i>SAY SOMETHING LIKE: Now I'd like to ask about the person or people you help care for (or, for those who are no longer caring, those they used to care for) and how much caring you do.</i>	
5. How many people in your family do you care for?	
6. Who in your family do you care for? (what is their relationship to you – Mother, father, sister, brother, aunt, uncle, friend etc)	
A	
B	
C	
D	
E	

7. In what year did you begin caring?	
8. How many hours a week would you usually help care for your relative?	
9. Are you the person in your family who does most of the caring for your relative?	

About School

In this section we're going to ask you about your time at school, whether you've told anyone about your caring, and what that was like for you.

10. What do you like most about school?	
11. Does anyone at your school know that you are a young carer?	NO
11 (b) If yes, who?	
12 (a) If someone does know, how has this been good for you?	
12 (b) If someone does know, how has this been not so good for you?	
12 (c) Why do you think some young carers might not want people at school to know that they are young carers?	
13. Have you ever been bullied because someone in your family has an illness / disability / AOD or mental health issue? If yes, what happened?	
14. Have you ever had to repeat a school year because you've been behind as a result of your caring?	YES / NO
14(b) If yes, how many times have you had to repeat?	

About how young caring affects your time at school

In this section, we want to know how you think caring has impacted on your time at school, how much time you're there, and how well you do. I'm going to read a statement and I'd like to you to rate out of 5 how true the statement is for you. 1 means you strongly disagree with the statement, 5 means you strongly agree with the statement.

	Strongly disagree 1				Strongly agree 5
1. Because of my caring, I sometimes don't sleep well					
2. Because I'm caring, sometimes I miss school					
3. Sometimes I'm late for class because I've been caring at home					
4. Because I'm busy before school, I sometimes don't have breakfast or pack lunch					
5. Because I'm busy at home, sometimes I miss my transport to school and find it hard to get there					
6. I sometimes feel tired and lack energy because of the things I do at home					
7. I sometimes worry about things going on at home, and that makes it hard at school					
8. Because I'm caring, sometimes I feel angry or upset and I get in trouble for taking it out on other people at school (through fights or mucking up in class)					
9. Because of my caring, I sometimes don't have time to do my homework					

10. Because I'm caring, sometimes I find it hard to catch up on schoolwork					
11. I think my grades at school aren't as good as they could be because of the pressures of caring					
12. I sometimes can't participate in things after school because I need to be home					
13. Sometimes I can't afford things at school because we have to pay for things tied to my relative's condition (like medication, home help, doctors appointments etc)					
14. Sometimes I feel like I'm the only one who cares at my school					
15. Because of things at home, sometimes I find it hard to make or keep friends at school					
16. I sometimes feel uncomfortable because of the way people at school talk about people with disabilities, illnesses, mental health or alcohol or drug problems					
17. Because of my caring, I don't really see the value of going to school at the moment					

Some young carers tell us that caring has had a positive impact on their schooling – like feeling more motivated to do well, like having a better attitude, or being more focussed. How true is this for you (1 to 5) and in what ways has caring had a positive impact FOR YOU.	
--	--

What might help <i>In this section, we'd like to know what has helped you with your schooling or what you think might help you and other young carers in the future.</i>	
17. What things does your school do that helps you with your schooling?	
18. What do you think teachers should know to make school better for young carers?	
19. What do you think schools should do to make it better for young carers?	
20. What help could young carers get outside of school to help them with their education? (including help for your relative, help catching up with school, help dealing with things that stress or worry you, time out etc)	



Appendix 4: Consent Form (Young Carers)

Australian Catholic University Limited
ABN 15 050 192 660
Canberra Campus (Signadou)
223 Antill Street Watson
Australian Capital Territory 2602 Australia
PO Box 256 Dickson
Australian Capital Territory 2602 Australia
Telephone 6209 1229
Facsimile 6209 1216
www.acu.edu.au

I, (parent / guardian) I
information provided in the *Letter to Participants*. Any questions I have asked have been answered to my
satisfaction. I agree that my child/ren, nominated below, may participate in this activity, realising that I can
withdraw my consent at any time. I agree that research data collected for the study may be published or
may be provided to other researchers in a form that does not identify my child in any way.

NAME OF PARENT / GUARDIAN:

SIGNATURE:

DATE:/...../2005

NAME OF CHILD (1).....

NAME OF CHILD (2)

SIGNATURE OF RESEARCHER:

PARTICIPANT ASSENT FORM (for participants under 18 years of age)

I, (participant) have had the information in the Letter to
Participants explained to me and all the questions I have asked have been answered to my satisfaction. I
understand that I do not have to participate in the survey, that I don't have to answer questions I do not
want to, and that I can finish at any time that I like without having to give an explanation.

I agree that any information that is collected for this study may be published in a report or shared with
other researchers in a form that does not identify me in any way.

NAME OF PARTICIPANT

SIGNATURE:

DATE:/...../2005

If you have any queries about this consent form, please contact Tim Moore on (02) 6209 1229 or
email t.moore@signadou.acu.edu.au



Appendix 5: Teacher's Information Letter



Participant Information Sheet

In Australia, only 4% of primary young carers are involved in secondary education (CA 2000). Of those engaged, two-thirds report that caring has had a negative impact on their capacity to achieve, and that this is compounded by issues within their school, including a lack of awareness and recognition, of flexibility or capacity to respond effectively (Moore 2005). Carers Australia have been contracted by the Commonwealth Department of Family and Community Services to develop an information resource for high schools in an attempt to increase satisfactory outcomes for young carers in their education.

The aim of this project is to develop a greater understanding of the needs and issues confronting young carers in education, and to identify strategies schools may use to better support them.

Central to this is our need to understand the requirements of teachers and other school support staff to assist them in appropriately supporting young carers within the school environment.

Your participation is voluntary and your anonymity is assured. All information will be maintained by the researcher at Curtin University of Technology and be treated confidentially. You maintain the right to withdraw from the study at any time and any decision to do so will not affect the research in any way.

Research approval has been granted in the ACT by the ACT Department of Education and the Catholic Education Office.

The project team is Dr Morag McArthur and Tim Moore from the Institute of Child Protection ACU and Dr Ros Morrow Curtin University of Technology Perth. Ethics approval has been granted by ACU Canberra and Curtin University of Technology.

Ros is conducting the interviews with staff in the education sector for the project.

If you would like to *discuss your participation* in the study you can contact Ros:

Email: r.morrow@curtin.edu.au

Work: (08) 9266 3036

Mobile: 0417 095 725

You can complete the **questionnaire electronically or on by telephone**. Please contact Ros to arrange a time for the interview.

Questionnaires can be completed **online and emailed** to Dr Ros Morrow or mailed to:

Dr Ros Morrow Curtin University of Technology GPO Box U1987 Perth Western Australia 6845

If you would like to receive a copy of results of this study, detach and return the personal detail slip at the end of this information sheet separate to your survey.

This is probably the most important survey you have been asked to complete. Please take time to complete it.

Thank you for taking the time to read this letter and I look forward to receiving your completed survey.

Regards,

Ros Morrow

Dr Ros Morrow MAPS



Name: _____

Address: _____

If you prefer an electronic copy please provide your email address:

Appendix 6: Teacher's Survey



Institute of Child Protection Studies

You can complete this questionnaire and return by email to r.morrow@curtin.edu.au or alternatively you can contact Ros to arrange for a telephone interview to be conducted (W (08) 9 266 3036 or M 0417 095 725)

YOUNG CARER QUESTIONNAIRE

This section of the questionnaire requires information about you and the role that you have within the education system.

INFORMATION ABOUT YOU

Q1. Male Female

Q2. Location: City Post Code Country Post Code

Q3. What is your role? (e.g.,Teacher, Student Services, Pastoral Care, Social Worker, Psychologist, Counsellor).

If you are a **teacher** could you **please go to question 4** if you have **another role** could you go to **question 5**.

Q4a. Do you teach in a Primary of Senior High School District High School
 Other (please specify)_____

Q4b. What year students do you teach? _____

Q4c. How long have you been in your role? _____

Q5a. Do you work in Primary School or Senior High School

Q5b. How long have you been in your role? _____

ABOUT YOUNG CARERS

Definition

“Children and young people who care or who help care in a family affected by the illness, disability, alcohol or other drug or mental health issue of one or more family members”

Young carers might care for a parent, a sibling or a relative with intimate care (such as washing, bathing, dressing, changing dressings), with personal support (such as monitoring to make sure that they are emotionally well, that they are safe, that they have what they need) for mobility (getting around the home and the community), for household work (such as cooking, cleaning) and supervision and support of other family members (particularly children).

Not all children who have a family member with an illness, disability, alcohol or other drug or mental health issue are young carers – but a large number of them are.

Q6. Approximately **how many** children and/or young people can you identify in the following age ranges as young carers using the above definitions?

Q7.

5 to 8 years of age		9 to 11 years of age	
12-15 years of age		16 to 18 years of age	

Who do they care for? (please tick multiple answers if appropriate)

- Parent(s) Sibling(s)
 Grandparent(s) Other (specify)

Q8. It has been suggested that children and young persons who carer miss out on school, social activities and demonstrate specific behaviours that are different to others the same age. Please take a few moments to reflect on the issues given below and mark **X**/highlight the most appropriate in relation to the children/young people you have identified.

Miss school		Report being bullied	
Late for school		Report to the sickbay/visit the nurse	
Need to contact home during school/work hours		Quiet and withdrawn	
Don't interact with other children/young persons		Demonstrate anger and/or frustration	
Seem to be depressed		Emotionally Upset (e.g., crying)	
Unhealthy behaviours (e.g., smoking, using drugs)		Suffer from eating disorders	
Don't participate in after school activities		Homework doesn't get completed	

Tired and lack energy		Report not sleeping well	
They worry		Aren't able to concentrate	
Is there anything else you would like to add?			

ABOUT YOUNG CARERS IN THE SCHOOL

Q9. We would like you to think back to when you first became aware of a child who cared. Can you share with us how this occurred, what made this young person different from their peers? (e.g., tired, depressed, sad, isolated, not completing homework, being bullied)

If you are a teacher please answer question 10, if you have another role could you go to question 10a.

Q10. When you found out that a young person was caring what did you do? (e.g., refer to student services, school psychologist or give additional assists in class)

Q10a. When you established that a young person was a carer what steps did you take to help the young carer? For example if you are a counsellor did you meet with the young carer on a number of occasions and help develop strategies to help them cope? Have you ever discussed issues about a young carer with other staff members?

Q11a. Does your school have any formal strategies in place for young carers? For example help with school work?

Q11b. Does your school have any formal strategies in place for other students that young carers could take advantage of?

Q12. You are at the coalface you probably have a good idea of what would and would not help these young people. If you were given the opportunity to develop a program for young carers how would you go about it?

Q13. What information do you believe teachers and other staff within the education sector would find useful to

A} identify and

B} support young carers in schools?

Q14. How could this information be disseminated to ensure that it reached everyone? (e.g., online, professional associations, education department, group training sessions)?

Q15. Is there anything else you would like to share with us?

