

## Getting it right for young carers in the ACT

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### History

The focus on young carers is a relatively new area of work that has developed and grown mostly over the past decade, although Aldridge & Becker (1993) argue that the phenomenon itself can be traced back through history. It has been suggested that young carers' needs have often been overlooked in the past, as professionals have tended to focus on the family member with a disability, without appreciating the young carer's separate needs (Community Care 1995).

Awareness of young carers as a social policy issue has stemmed largely from the United Kingdom, through the work of the Young Carers Research Group (YCRG) based at Loughborough University, and the Carers National Association (CNA). Australia as a whole is beginning to recognise the needs of young carers, with work starting in the ACT within the last three years.

It can be argued that in the past there was a greater expectation that children should work, and take care of family members. This is particularly relevant in light of the history of childhood, and the notion of childhood as a social construct, rather than a biological condition. On the other hand children are a minority group whose secondary status has been codified in many social institutions. Separate laws govern their lives. Adults may feel that childhood is an 'age of innocence' (Newman 1996) and that children need protection. Social policy in relation to children commonly emphasises not their rights, but their needs. They have been described as victims of 'structural inconsiderateness' (Kaufmann in Mayall 1998) whereby policies in many areas of social life disregard their interests. Within the family, children have traditionally been understood as dependants (Moore 1999).

### Who are young carers?

There are many definitions and categories of who is a young carer, and what they should be doing to be considered a young carer. These differing definitions usually relate to a particular research focus, or eligibility criteria for a service.

However for the purpose of this paper, a young carer is a child or young person under the age of 18, who looks after, or helps to look after a relative with an illness and/or a disability. Some young people may also be looking after friends or neighbours.

What is crucial to this definition is that they are looking after someone *with an illness and/or a disability*. The definition does not include young people who baby-sit, or who take responsibility for younger siblings if both parents are working full time. But it would include young people looking after siblings, if who would 'normally' look after siblings was unable to, due to disability/illness.

Similarly the definition does not include young people looking after their own offspring. If their children themselves had a disability, then these young people would be considered *parent carers*.

## Identification of young carers

It is widely acknowledged that it is difficult to identify young carers (Aldridge & Becker 1993; Frank 1995; Reibelt 1998; CAA 1997). One major barrier to measurement is that families see caring as a private family matter, and not subject to government scrutiny (Reibelt 1998). Young people and their families do not readily identify with the term 'young carer'. It has no relevance to them. They may simply perceive themselves as looking after someone usually a family member, rather than 'caring'.

It has been suggested that families may mask the fact that a child is a carer, (YCRG 1994). This study found that families are fearful of statutory interventions about their child/ren being taken into care. Professionals working with families may not be aware that parents play down a child's caring role because of these fears. Young carers will adopt this attitude out of family loyalty, which contributes to their non-identification.

Professionals are also failing to engage young carers in a discussion on what their caring role entails (YCRG 1994). This neglect may well be due to constraints of time and resources and lack of knowledge about the existence of young carers. Agency workers may deny young carers status for philosophical reasons – neglect to ask; don't physically meet young carers so rely on parental information; underestimate or downplay role of young carer. Developing appropriate services and support from the onset of an illness or disability may help many young carers and their families. Regular contact with professionals means that someone is aware of the situation and is in a position, in theory at least, to offer some support.

## Effects of caring

Young carers are young people first, and many of their peers will be involved in similar household duties. The performance of household tasks is viewed as preparation for independence, and part of a 'normal' childhood experience (Gays 1998), yet the responsibility of caring has accelerated the transition from childhood to adulthood for many young carers, making them 'wise beyond their years'.

Having a relative with an illness or disability in the family means that the whole family is impacted. However, this does not necessarily mean that children are carers (Morris 1997), and if they are, their caring role is not always onerous or 'damaging'. Positive effects of looking after someone include feeling proud in their role, being able to do things without being told, sticking up for family members (CAA 1997) and developing closer relationships with family members. However, studies have outlined the negative effects of caring on children. Such impacts range from restricted social lives, to low educational achievement as well as physical and emotional impacts which in turn will affect their health (Aldridge & Becker 1993; CAA 1997; Dearden & Becker 1995; Frank 1995; Aldridge & Becker 1996; Liddiard & Tucker 1997; Reibelt 1998).

Due to the physical strain of working with an immobile parent or sibling, young carers who are working with physically disabled relatives also report a variety of physical ailments resulting from the caring role. Muscle strain, fatigue, and exhaustion are common ailments reported. Such injuries are directly caused in the general provision of the caring role. The caring day can place heavy physical and mental demands on young carers (Aldridge & Becker 1993; Liddiard & Tucker 1997), thus physical health may be affected through the inappropriate heavy lifting of someone. Young carers emotional/mental health is affected through isolation and the stress of extra responsibilities (Aldridge & Becker 1993).

Young carers too have reported anxiety, depression and illness as a result of emotional distress. Young carers are also often restricted from access to information about their relative's condition and thus encounter immense confusion and frustration.

Several studies, have also shown an increase in acting out behaviour among adolescents whose parents had cancer and high levels of anxiety among those with a parent with Huntington's disease (Ell & Garden 1990). In one study, mothers' reports indicated that 81 percent of the families had siblings who developed maladaptive behaviour changes following the diagnosis of childhood leukemia (Ell&Garden 1990). Similarly, siblings of children with spina bifida have been found to be more poorly adjusted than siblings of control children. Although objective severity of the illness was not found to be significantly related to the siblings adjustment, siblings of children with visible handicaps had greater emotional and behavioral problems than siblings of children with non-visible handicaps (Moore 1999).

A young person's education and career opportunities may be affected due to not attending school or being unable to concentrate once there. Young carers will often stay at home to care for their relative (Dearden & Becker 1995; Frank 1995). Even where care responsibilities are episodic, school success and attendance can be affected. Consultations with school counsellors held by the Carers Association of Australia (1997) indicated that the most often noted impact of caring was an inability of the child to attain the educational standard that they would otherwise expect. Due to the fact that many young carers are still hidden, schools are often unaware of the impact of disability or illness on student's family life and are then unsympathetic to their needs (Moore 1999). Many young carers have school results with low levels of academic achievement (Reibelt 1998), and a considerable number of absences (approved and unapproved). This in turn could also mean lack of employment opportunities, especially with lower educational outcomes.

The opportunity to have a 'normal' childhood can also be severely impaired, as they may not be able to mix freely with peers. For example, young carers may not feel able to join after school social activities due to their need to go home and start caring. Organising and meeting the demands of home and school, and finding space for leisure can be a difficult balancing act.

As a result of stigma attached to many disabilities and conditions, children who provide care often are reluctant to invite peers into their homes. This compounds feelings of isolation. Such feelings are compounded by negative attitudes towards disability and illness within the community. Young carers in particular feel concerned about the way their relative will be accepted within the wider community – not necessarily because of its impact on their social status but because they feel a great need to protect them from abuse or humiliation.

As a young person takes on the caring role, it can exert a powerful grip, because young people are given, or assume, high levels of responsibility for care and may become worried about making a mistake, or leaving someone in distress. These responsibilities can bind young people into their role. It is also worth mentioning that many young carers may feel devoted to their caring role, while at the same time feel deeply resentful that they are trapped into their role and cannot have a 'normal' childhood like their friends (Parker 1995).

A parents' disability can also affect the child indirectly by leading to family poverty and isolation. The family income may fall as parents may be unable to work due to disability or care responsibilities. Single parent families are among the poorest in Australia and disability or

illness will compound this poverty (Harding 1994). The lack of family funds mean that families are unable to purchase services, and they may be forced to rely more on the child's caring contribution.

As has been demonstrated, children have been impacted in a number of ways through illness and disability. Young carers have adopted responsibilities within the family for care of relatives they have shaped the construction of family, developed networks and assumed unpaid work roles. In these positions, children have been affected physically, emotionally, psychologically and behaviorally.

### *Changes in the family*

The amount of young people who take on a caring role is on the increase. This is due to a variety of reasons: advances in health technology - people are living for longer; community care - patients are discharged from hospital and cared for at home when previously they would have stayed in hospital: changes in families - increase in two parents working, or single parent families. Young carers are also becoming more visible due to interest from the media and research.

Since the end of World War II, a number of demographic, social and economic changes have combined which can place enormous strain on families. As a result of changes in education and employment structures, for example, families are now responsible for maintaining their children for longer. The higher participation of women in the workforce has also had an effect, with mothers working a number of jobs to maintain financial stability (Mitchell & Dowrick 1994). It has been shown that, as a result, many families have broken under such pressure with both parents working harder, for longer, for less, as well as caring for older, ill or disabled family members. With both parents working, it has been shown that children are often the only family members able to provide significant care (CAA 1997).

In the past families may have been able to rely on the extended family when a family member becomes ill or disabled. Due to the highly mobile nature of Australian families, it has also been noted that this support network has broken down (de Vaus 1995). Family size is declining and the family unit has been restructured, as seen in increasing numbers of lone parent families and more reconstituted families (YCRG 1994).

The increasing number of marriage breakdown within Australia has been highly publicised (Moore 1999). What has not been reported, however, is that illness and/or disability is often a factor in such breakdowns (CAA 1997). Single parent families are thus called to provide care with pressure once again being placed on young children to assume such roles. As a result of the breakdown of the family network and the number of children in the family, school-aged children may be the only person available to care.

As a result of technological advances and an improved quality of life, the number of elderly people within the community has gradually risen over previous decades. This rise in the population of our senior citizens has had a substantial impact on the family due to the fact that this age group occupies the greatest portion of care reception. Unable to live independently, many older people are forced to rely on their families for care (Moore 1999).

Coupled with frailty, it has been shown that our elderly population are more susceptible to illness and disability. The ABS, for example, found that 36.4 percent of 60-64 year olds and 66.7 percent of those over seventy-five years have some form of disability or handicap – a population that needs an ever increasing amount of care. As the primary unit and traditional carer of members, the family, including grandchildren, was thus asked to accept the role of carer for a widening population of older, reliant people (Moore 1999).

As the number of our elderly citizens has risen so has our population of people suffering with disabilities and handicaps. In 1993 the ABS confirmed that 18% of Australia's population had a disability and 14.25% had a handicap. Though statistics about the rise in depression, anxiety and other mental health conditions were scant, it has been found that the number of people suffering from such conditions has also risen dramatically in recent years (Robinson 1997).

As with the elderly, there has been a trend within the Australian community to keep people with such ailments out of institutions and within the family home. Now, more than ever, families are expected to provide a whole range of care to relatives with often chronic conditions. It is not uncommon for people with disabilities as extreme as quadriplegia to be maintained outside the hospital (Moore 1999).

### What do young carers do?

Helping can be a healthy part of family life (Frank 1995). For many young carers domestic work is a part of their everyday life, for others it is something that they do only in times of crisis (Dearden & Becker 1995). Olsen (1996) concludes that our knowledge of what young carers do, and how they differ from other children is extremely limited. NSW and ACT Carers Associations have indicated that much of the caring undertaken by young people is hidden – young people do not have access to income support or to formal services (Reibelt 1998).

Professionals from the welfare sector could be accused of imposing their views on 'what is acceptable' for young people to be doing in the home. Their views of 'what is right' may be based on their own childhood and not take account of how society has changed, or take account of the views of the young person themselves, which will add to young carers invisibility.

However it is clear that young carers are involved with caring tasks which their peers are not. For example giving of medication, being involved in therapy, personal care and helping with mobility. The level of responsibility for household labour also differs from their peers. Young carers report more injuries, start housework from a younger age, perform a wider range of jobs around the house and do these tasks more often and on a regular basis. (Gays 1998).

When assessing young carers needs, consideration needs to be given to the level of caring responsibilities that the young person is undertaking. Are their responsibilities of an acceptable or unacceptable level? According to (Frank 1995) there can be 'no set guidelines for making this differentiation'. Each family's circumstances will vary and the impact of caring responsibilities on the child will also depend on their age, physical ability, emotional development, temperament and so on. The CAA (1997) observes that young carers are engaged in household tasks that most young people are expected to do, but that some caring tasks may be inappropriate, and that occasional household labour will help young people develop a sense of responsibility (CAA 1997: Gays 1998).

Walker (1996) described the role of the young carer as 'bridging the gaps'. Either by covering periods when the adult carer was at work, or had other responsibilities, or when outside agencies

left. And Liddiard & Tucker (1997) found that caring responsibilities for some young people continued, even when the person they were supporting was on the 'road to recovery'. If a young carer's relative is chronically sick, the young carer may try to do more and take on more responsibility, in the attempt to keep everything 'normal' and relieve any additional burden from adult carers. (Gays 1997).

When surveying the tasks that young carers perform, Walker (1996) reported that none of the young carers had any days when they were not involved in caring and most had to spend more time caring at the weekends. The majority of young carers were involved in housework tasks, giving physical help with mobility and 'keeping an eye' on the person with a disability. Only two were involved with personal care.

(Dearden & Becker 1995) found that young people most commonly performed domestic tasks. The nature of illness and level of disability (Aldridge & Becker 1993; Parker 1995) also influence this. Aldridge & Becker (1993) also state that a family's disposable income could affect the levels, and effects of caring on children.

Young carers are more likely to provide intimate care where there are physical health problems' (Dearden & Becker 1995), and 'emotional support is far more likely where the care recipient has mental health problems.' Young carers undertake a range of tasks which include practical and physical assistance, as well as coping with the associated emotional stress and responsibility (Frank 1995; Dearden et al 1994).

Not only does a parent's illness have an effect on who is available to do the housework, (Segal & Simkins 1996), but also on the amount to be done. As is the presence of other adults in the household (Parker 1995). This includes children. Parker goes on to state that the sex of a disabled parent, and that of the child, may also determine whether or not a young person is involved in caring. Segal & Simkins (1996) reported that a few fathers who were seriously disabled or ill 'seemed to take to an invalid role' when they could have contributed more to the household tasks. Aldridge & Becker (1993) found that levels of outside help also determined level of caring.

### Numbers of young carers

Several studies have taken place into the number of young carers, and most conclude that we know very little about the numbers of young carers, (Aldridge & Becker 1993; Parker 1995; Frank 1995; Reibelt 1998). It is difficult if not impossible to accurately measure the number of young carers (Reibelt 1998). Lack of knowledge about numbers inhibits the provision of assistance to young people (Reibelt 1998).

CAA (1997) said there has been little research on young carers in Australia. However, the Australian Bureau of Statistics (ABS) estimates that there are 33,800 Australian children under the age of 15 who provide care to a family member who has a long term illness or disability. Of these, 14,500 have been deemed 'primary' carers or the person who provides the majority of care, 86% are aged between 10-14 years 15% aged 9 and less, 13% caring for more than only person, roughly equal in gender. (ABS 1993). This ABS survey is not representative of the whole young carer population, and merely provides an insight into those in receipt of carer payments, (Reibelt 1998). The ABS survey is self-reported by adults with disabilities or medical conditions so underestimates the number of children CAA (1997). The methodology of the ABS survey has not taken into account young people in full-time education, and/or young

people under the age of 15, which the report itself acknowledges. Such statistics are a gross underestimation of young people who have a caring role.

Most of these studies have either relied on case histories, or professionals and/or adults to recognise young carers, which has largely proved to be inadequate. A different approach has been used in Canberra asking young people themselves to self-identify if they 'look after' a relative and the results are quite different.

### Methodology

In order to find out how many young people may have a caring role, a school-based survey is currently underway in high schools and colleges in the ACT. Results from the first two schools are presented below.

This survey asks young people themselves to self-define if they are looking after a relative with an illness and disability. The results show that young people are able to associate themselves with 'looking after', thus avoiding the difficulties using the term 'young carer'. Self-definition aids our understanding about how young people see disability and gives young people freedom of expression. No eligibility criteria has been set by the researcher, thus young people are not fitting into existing definitions, a process which can exclude rather than include.

Having a relative with an illness and/or disability does not necessarily make children or young people carers. Throughout the assemblies a few young people asked me further questions usually along the lines of 'does this count?'. Depending on the circumstances I said yes or no. I know from this that some young people therefore did not include themselves, and likewise I know some therefore did.

I also believe that some young people will not have identified themselves if they are looking after someone with mental ill health, or their parents are misusing alcohol or drugs. Whilst these young people may have a caring role, I believe it is hard for them to come forward, due to family loyalty, and a five minute speech from me in an assembly is not enough to overcome their anxieties about identification.

The survey is very simple, asks few questions, and is designed to be filled in during a school assembly. A short presentation lasting no more than five minutes is given, followed by the handing out of the questionnaire, which is returned on completion to the researcher. Young carers may not have told their friends about their caring role, and loyalty to their family means that they may not wish to reveal their caring role. The survey is therefore quick, can be anonymous, and is designed to take roughly the same amount of time to fill in, whether a carer, or non-carer, thus minimising identification of young carers to their peers.

It is important when carrying out a piece of research to use the right tool to answer a question. Surveys are a tool to gather numbers and are not meant for in-depth personal data. However sometimes students write additional information on their questionnaire, and follow up interviews are available at the request of those surveyed.

Ethical issues, such as parental consent, have been explored and approved by all concerned. Permission has been sought and obtained from the Department of Education. Each school approached has the right to refuse to take part, as schools are often the target for research into

young people. Yet each school must also be interested in following up issues raised as a result of the survey, for example staff training and support for those identified.

The methodology has been designed to minimise the disruption and work for school staff. All students enrolled in each school are surveyed, including absentees, which avoids special attention for anyone, and creates the impression that this is an issue for all to consider. As completed questionnaires are gathered prior to leaving the assembly returns are good. All absent students are then sent a letter and questionnaire as a follow up through class registers. The letter explains the survey and requests they fill in the form and return to the schools front office. The returns for this process are poor.

However the questionnaire has worked well in high school and college settings. Year seven appear to have more difficulty with the questionnaire, and it is therefore not recommended for use in primary schools, due to age appropriate language and literacy skills. See Appendix A for a copy of the questionnaire.

## Results

### *Age*

Age and gender are collected at the top of each questionnaire, allowing for analysis and greater understanding of a young person’s caring role. Table 1 shows the age range by percentage of those young people who self-identified as having a caring role. 135 students self-identified in St Clare’s College, and 45 students self-identified in Ginninderra District High School – 12% and 10% respectively for each school. A graph follows each table allowing the reader to make comparisons at a glance.

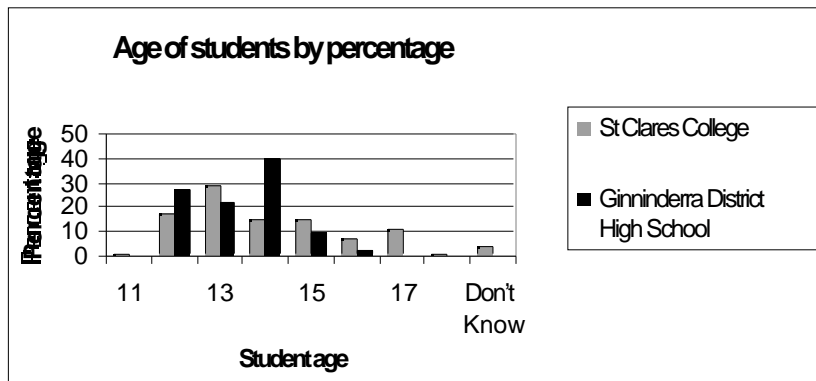
An additional question used in Ginninderra District High School revealed that 36% of those who said they were a carer, used to care, so are in fact no longer caring. Ceasing to care can be because of a number of reasons. For example, temporary illness or disability (a broken leg); the cared-for person may be in remission, or their condition may be stable as a result of medication; they may have moved away, gone into residential care, or died. So despite starting a caring career in childhood, it doesn’t always last through to adulthood.

Table 1 Age of young carers

<b>Age</b>	<b>St Clare’s</b>	<b>Ginninderra</b>
11	1	-
12	17	27
13	29	22
14	15	40
15	15	9
16	7	2
17	11	-
18	1	-
Don’t know	4	-
	<b>100%<i>n</i>=135</b>	<b>100%<i>n</i>=45</b>

Figures have been rounded up to down to whole numbers.

Graph 1 age of students by percentage



We know that caring can affect students' education and the figures above show a decrease of students caring in the older school years, suggesting that there are fewer older young carers attending school. Yet age can be a determinate for taking on a caring role, the eldest child in a family is often the carer.

So what does this mean? Do these figures show that young carers are dropping seemingly wholesale out of school? Previous studies I have conducted (Gays 1998) show that at times of exams, or important school years, older children are given time to study and younger children start to take over chores. What then happens to the only child? Or the youngest child? Or does it mean they are no longer carers? How does gender of the young person, and other family members being available, influence chances of being a carer? Without in-depth further studies these questions may remain unanswered.

### Gender

St Clare's College is an all girls' Catholic school, whereas Ginninderra District High School is mixed. 66% of those who identified in Ginninderra are female and 33% are male. (Statistics gathered on the gender of adult carers are the same.)

### Who young people are looking after

Table 2 details who these young people are looking after. It is clear that young people are more likely to be looking after a female relative. As mentioned earlier disability or illness contributes, or can cause family breakup. It has been well documented in studies looking into disability that if male adult members of a family are ill and/or disabled, their partners are likely to stay and look after them, yet if female adult members of a family are ill and/or disabled, their partners are more likely to leave, thus children are left to care. Young people may be caring for more than one person.

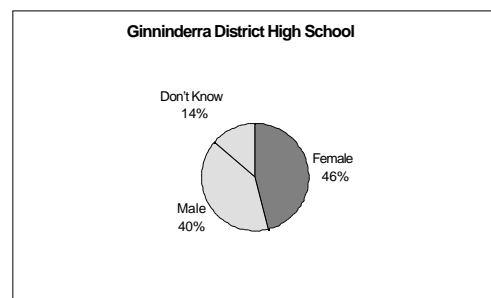
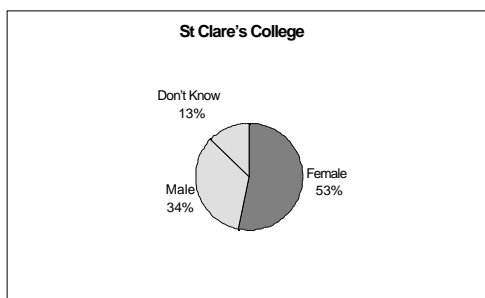
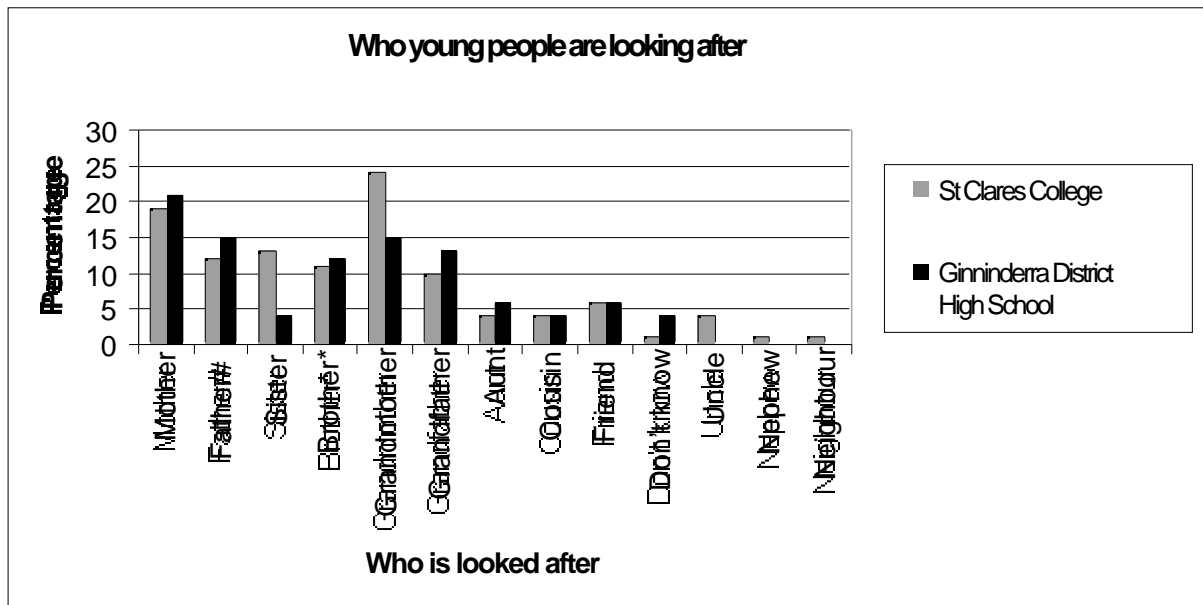
Table 2 who these young people are looking after.

Who	St Clare's	Ginninderra
Mother	16	21
Father#	10	15
Sister	12	4
Brother*	8	12
Grandmother	22	15

Grandfather	10	13
Aunt	4	6
Cousin	4	4
Friend	5	6
Don't know	3	4
Uncle	4	
Nephew	2	
Neighbour	1	
	<b>101%</b>	<b>100%</b>

# includes god father, step father, and mother's boyfriend, \*includes one foster brother

Graph 2 – Who young people are looking after



From the two pie charts above, we can see quite clearly that female relatives are being looked after more predominantly.

If young people identify caring for more than one person, their relationships are detailed in table 3 below.

Table 3 Combinations of who is being cared for.

Combination	St Clare's	Ginninderra
Mum/dad	2	1
Mum/brother	2	-
Mum/grandmother/aunt	-	1
Mum/friends	-	1
Dad/grandmother	1	1
Grandmother/grandfather	3	2
Grandparents/neighbour/cousin	1	-
Sister/brother	1	-
Sister/nephew	1	-
Brother/god father	1	-

*Range of illnesses and disabilities*

Below is the range of illness and disabilities where young people are called upon to care. It appears that no matter what the illness or disability is, young people may be caring. It is hard to categorise conditions mentioned by students into physical, mental or sensory impairment. This is due in part to lack of medical knowledge on behalf of the researcher; some conditions do not neatly fall into one category or another; and sometimes it is guesswork as to what young people mean. However, rough calculations show that half the conditions could be described as physical, a third could be categorised into mental health, the rest split between sensory impairment and not known.

Osteoporosis	ADD	Parkinson's
Dialysis/Renal failure	Leukemia	Polio
Visual impairment	Dementia	Epilepsy
Glaucoma	Intellectual disability	Heart condition
Lupus	Cancer	Mental illness
Brain disorder	Hearing loss	Recent operation
MS	Diabetes	Skin disorder
Backache	Obsessive compulsive disorder	Brain tumour
Downs Syndrome	Depression	Psychiatric condition
Stroke	Schizophrenia	Post Traumatic Stress Disorder
Wheelchair/mobility	Low muscle tone	Spinal injury
Speech impairment	Spina Bifida	Retts Syndrome
Migraines	Schlorosis	Broken limb
Cerebral Palsy	Pinched nerve and tendentitus	Over active thyroid
Arthritis	Osto-genesis imperfecta	Hernia
Autism		
High blood pressure		

Some people may have more than one illness.

*What young carers are doing*

Table 4 shows what young people are doing as part of their caring role. Young people are usually doing more than one activity. If a student only reported doing one thing, it was most likely to be 'make sure they're alright', which is the activity most report to be involved in. Unfortunately these categories do not allow for any measurement of the length of time taken by each task, or the level of responsibility involved.

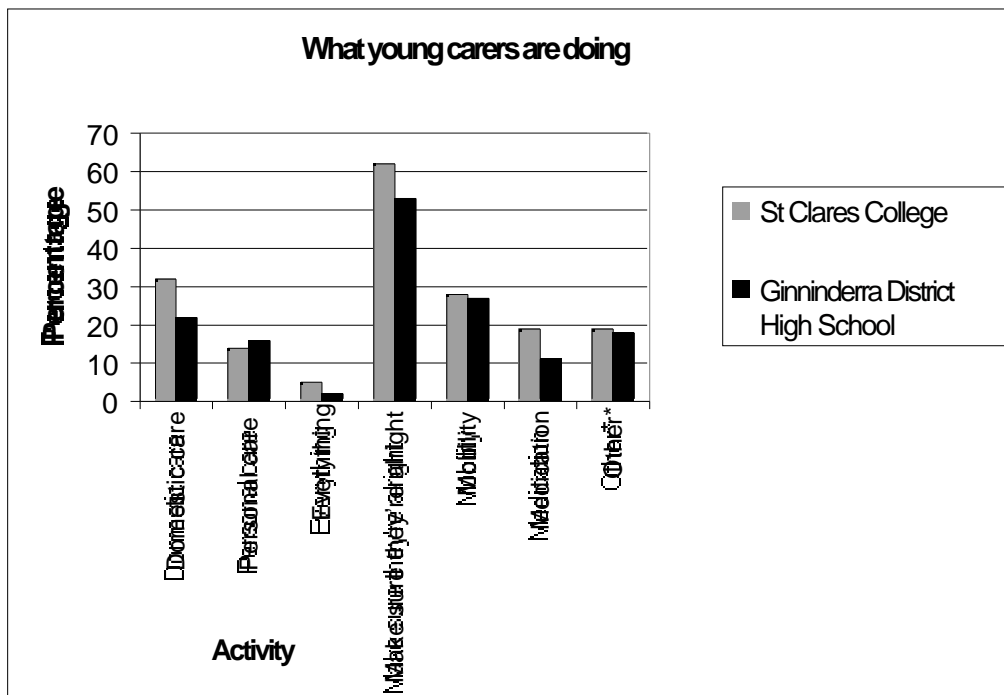
During the short presentation I explain to students exactly what I mean by each category:

- domestic care anything from hoovering, ironing, cooking, washing up, cleaning, dusting, tidying, taking the rubbish out, washing, pegging the washing out
- personal care feeding, bathing, toileting
- everything no-one else around who helps
- make sure they're alright the emotional responsibility for someone, thinking and worrying that they are OK
- mobility helping up stairs, or pushing a wheelchair
- medication administering drugs, or remembering to get repeat prescriptions
- other anything else they're involved with

Table 4 What young carers are doing

<b>Activity</b>	<b>St Clare's</b>	<b>Ginninderra</b>
Domestic care	32	22
Personal care	14	16
Everything	5	2
Make sure they're alright	62	53
Mobility	28	27
Medication	19	11
Other*	19	18

\*babysitting/going to appointments/translation/classwork/therapy/gardening/visiting/signing



Most young people are engaged in more than one activity.

#### *Services young carers would like to see developed*

Table 5 below details the services young carers would like to see developed. During the pilot phase of this research young people were asked the question ‘what would help young people in this position?’ Their suggestions have been summed up in the categories below. Each student is asked to pick the three they think are most important. Sometimes students tick more than three categories, or all categories, their answers have been included below. The top three requests are ‘learn what to do in an emergency’, ‘less homework’, and ‘better services for the person with the disability’.

I believe if you asked any child what they would like ‘less homework’ would figure quite high on a wish list. But I also believe that teachers and education staff may be the only adult in a child’s life who is there for them, and not other members of their family, and are thus uniquely placed to support young carers.

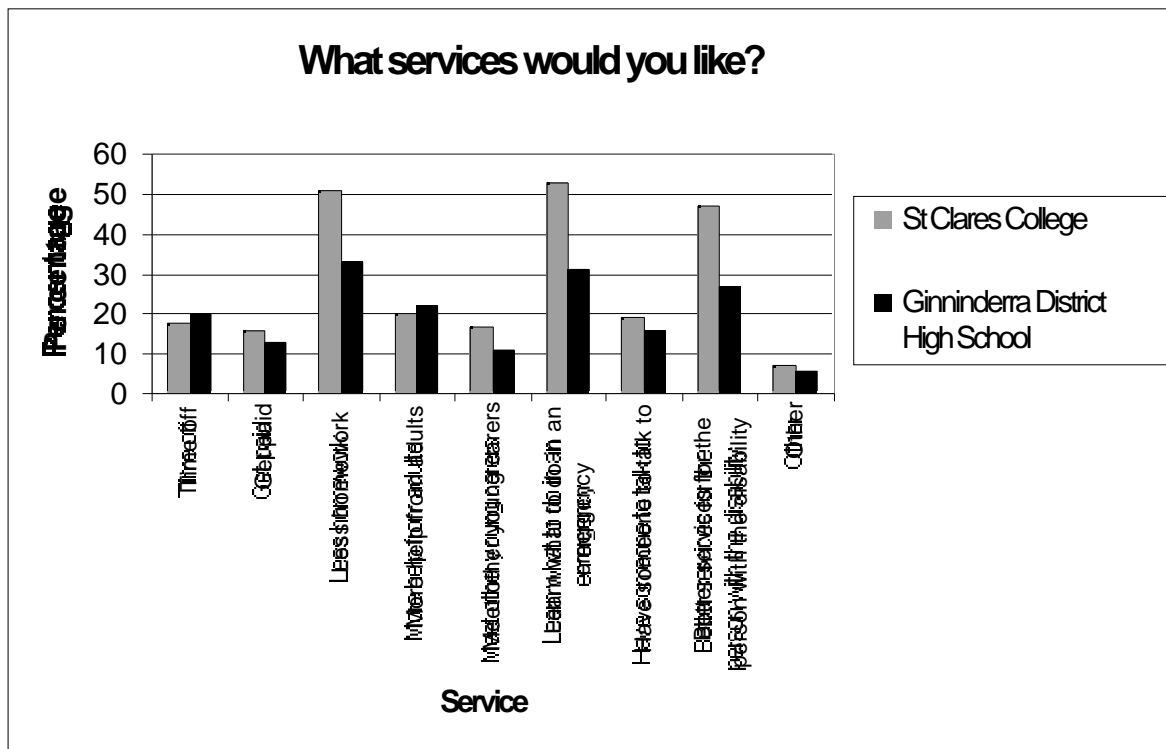
‘Learning what to do in an emergency’ is about wanting to be a better carer, and gives some indication of the anxiety some young carers are under. Upon further questioning emergency situations include how to get someone out of the house in case of a fire, first aid emergencies and household emergencies – how to fix a broken window, turn the water off.

‘Better services for the person with the disability’ is I believe self-explanatory, but what I find really interesting is none of the top three requests are really for themselves.

Table 5 services young carers would like to see developed

Service	St Clare's	Ginninderra
Time off	18	20
Get paid	16	13
Less homework	51	33
More help from adults	20	22
Meet other young carers	17	11
Learn what to do in an emergency	53	31
Have someone to talk to	19	16
Better services for the person with the disability	47	27
Other*	7	6

\*help for family members/help from family members/money to buy equipment/cure for illnesses/camps/better housing/have a friend round more/help from anyone/sign language course



### Conclusion

This paper has begun the exploration of young people's caring role in Australia. More work needs to be done.

We know that young people will be called upon to care for relatives more often in the future, they need to be recognised.

Caring has been shown to affect a young person's health, education and social development, provision of support through services and legislation is long overdue.

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July 2000

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