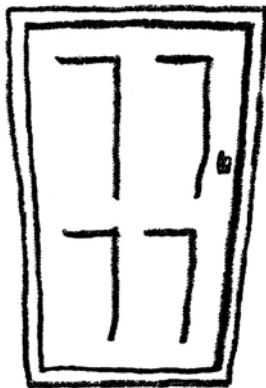




A profile of  
known young carers

and



identification and snapshot  
of the ones who are hidden

*Dr Ros Morrow*

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*This project was undertaken while Dr Morrow was on  
Academic Study Leave.*



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Family and Community Services contributed a seeding grant*



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## ABBREVIATIONS

ABS Australian Bureau of Statistics

DSC Disability Services Commission

PICS Psychological Implications of Caring Scale

EPICC Educational and Psychological Implications of Caring Checklist

FGI's Focus Group Interviews

*sic* Indicates that the wording, spelling, and punctuation is of the original source, even if the source is incorrect

YCIC Young Carers Identification Checklist

WA Western Australia

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## **FOREWORD**

### **Parent Questionnaire**

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

*As a parent I always feel guilty that the disabled child affects every aspect of the other child's life. That they had to mature beyond their age pretty fast, they did not get to be children themselves. They are like a third parent.*

### **Parent of a young carer**

### **Young Carer Questionnaire**

What would help you to carry out your helping role?

*A male carer for xxxxx, it would help a lot.*

### **Young carer age 14**

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

*I am sad and stressed.*

### **Young carer age 16**

### **Young Hidden Carer Identification Survey**

Is there anything else you would like to share or comment on?

*Young carers seem to mature 'too quickly' as a result of their increased responsibilities. It concerns me that they could be missing out on the fun of being a child due to the additional roles they fulfil.*

### **Health carer professional**



## INTRODUCTION

### The Historical Perspective

The available research on young carers within Australia is scarce. Carers WA have identified this specific group of carers who, by virtue of their age, are at significant risk both physically (e.g. being tired and experiencing health issues) and psychologically (e.g., depression and anxiety). The youngest carer identified in WA was aged six years (personal communication, Britta Meyer, Carers WA, April, 2005).

So just who is a young carer?

**“Children and young people up to the age of 26 years who have caring and support responsibilities for a family member or friend who has a disability, is frail aged, or who has a chronic mental or physical disability”<sup>1</sup>**

(Carers WA 2005)

And many of these young carers remain hidden –

**“These children and young people will not be known as carers to any agencies or services and therefore receive no support in their caring role”**

(Carers NSW, 2001)

In the past few years there has been an increased focus on “young carers” which has been evidenced in:

- The Young Carers Research Project 2001;
- The Young Carers Summit 2004;

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<sup>1</sup> The definition of a young carer was amended in late November 2005 to include drug and alcohol. Preliminary discussion with Carers WA had suggested that anecdotal evidence existed that there are young carers caring for parents with addiction issues. As a consequence of this, the present research explored this issue.

- Political Implications: A significant outcome of this summit was to increase awareness of these young peoples' plight to Federal Government Ministers; and
- In the recent past (April, 2005) the media have highlighted not only the issue of young carers but more particularly the impact of caring on a young child and/or adolescent. These are identified as the "Hidden Army" (Four Corners April, 2005).

There are a considerable number of anomalies which face any proposed research on the subject of young carers. Not least of which is the overwhelming need by state carer organisations to *know how many young carers there are in the state*. Such numbers are required not only funding and grant applications, but also:

- To lobby local and state governments to develop and change current policy;
- To increase awareness of the issues these young people face within the education system; and
- To develop intervention programs.

The brief for the present research project was broad:

**"To be able to say how many young carers we have in WA"**

(Personal communication, Britta Meyer, Carers WA, April, 2005)

This specific aim could not be achieved due to the restrictions and the limited funding available for the project. However, the research team accepted the challenge and through the use of a creative methodology endeavoured to maximise all available resources with the specific aim of identifying as many young carers as possible.

***The Story***

Taking this background information into account, a proposal document was prepared which detailed a number of aims, benefits and outcomes for the project. These were as follows:

	<b>Completed</b>
<b>Aim 1</b> To develop a profile of known young carers in WA	☑
<b>Aim 2</b> To identify <i>as many as possible</i> young hidden carers in WA	☑
<b>Aim 3</b> To identify young carers who are informal and/or hidden carers within WA, with a specific focus on the rural and remote areas.	☑
<b>Aim 4</b> To develop a checklist that can be used by medical, educational and other health care professionals as well as case managers within community organisations.	☑
<b>Aim 5</b> Develop a checklist for children aged 10 to 18 years and little people aged 4 to 9 years to assist in the identification of young carers.	☑

The research benefits and outcomes of the project were as follows:

- To use the information sourced to develop a profile of known young carers in WA. This information will include Age, Gender, Town and Shire, Who is being "looked after", Reason for caring, Educational factors (e.g. missing school) and Psychological factors (e.g. worrying and being depressed);
- To increase awareness in the community of the implications of caring on children and young people;
- To increase the knowledge, understanding and awareness of the implications of caring on children and young persons by community organisations and health care professionals;
- To suggest intervention programs and strategies that can be implemented by Carers WA. Essentially, these programs must have the potential to be sustained by the young carers that they endeavour to support and empower.
- To identify significant implications for policy development. As has been demonstrated in the recent Federal Budget, carers have been identified as being under resourced financially. However, there was little discussion about young carers. In collecting and collating the information sourced, the researcher has the responsibility of ensuring that findings are documented and presented to decision makers in an endeavour to effect policy change (Dalton, Elias, & Wandersman, 2001).

Part of this research project was to profile known young carers. The research conducted in the United Kingdom is prolific and addresses issues related to caring as well as policy change and government lobbying. There is significantly less research in Australia and advocacy for young carers, it is imperative that we begin to identify our own cultural norms and political agenda. With this goal as a focal point the literature from Australia is integrated in the chapters, where appropriate comparisons are drawn with the UK.

With regard to the research on young hidden carers studies were located:

1. Was carried out by Carers NSW (Reaching 'Hidden' Carers, 2001) however this project specifically focused on adult hidden carers, although a definition of young hidden carers was given and has been adopted for this project.
2. The second study was conducted by Gays in (2000) the specific purpose was to establish the number of carers within schools in Canberra. The self-report survey was one page, and was complete during school assembly. A number of young carers were identified however the results are presented as percentages and there is no indication of how many students actually participated it is therefore difficult to draw constructive conclusions.
3. A search of the Princess Royal Trust in the United Kingdom revealed one study identifying young hidden carers (Rural Perth and Kinross Children and Young People: How Many Care, 2004). Young carers were identified through school data. Eighty percent were aged between 12 and 15 years, and the youngest little person identified at five years of age. The key findings of the research identified the number of young carers, age range of young carers, relationship to the care recipient and the type of support that would assist them. It did little to enhance our knowledge and understanding of the lives of young carers.

The first chapter details a profile of known young carers in WA which includes two studies – 'The Parent's Perspective' and 'The Young Carer's Perspective'. The second chapter discusses social and service identification of young carers with specific reference to the Australian Bureau of Statistics, Centrelink and

the Disability Services Commission. The third chapter provides an identification and snapshot of hidden carers including a community perspective and a third study – ‘Hide and Seek: Finding Young Carers’. The fourth chapter presents measures which offer a dynamic and innovative approach to identifying young carers not only in WA but throughout Australia. The final chapter integrates the findings from the research conducted, recommendations for future research and the development and implementation of community based programs will be discussed.

## CHAPTER 1: A PROFILE OF KNOWN YOUNG CARERS

### Study 1: The parent's perspective

Carers WA knew of young carers who had been identified through their participation in young carer programs and/or had been referred. The Carers WA database held demographic information and other details which were required by funding bodies. An in depth profile of these young carers was not available. Study 1 was developed with the express purpose of gaining a comprehensive profile of the life of young carers from their parents' perspective, and from young carers aged 18 to 26.

#### *Questionnaire*

The questionnaire was designed and based on previous research (e.g., Dearden and Becker, 1995; Gays 2000) conducted by Carers Australia, and the Australian Bureau of Statistics. Two questionnaires were designed one for the Parent of Young Carers (see Appendix 1) and the other for Young Carers over 18 years of age (see Appendix 2). Both questionnaires required information about the person being cared for, the tasks which the young carer performed, number of hours a week they cared and information about hobbies and other interests. A scale was developed, which was named the Psychosocial Implications of Caring Scale (PICS), and the items related to physical health (e.g., They sometimes feel tired and lack energy<sup>2</sup>) psychological wellbeing (e.g., I think they may sometimes feel depressed) and issues relating to the impact caring had on education or work prospects of young carers (e.g., Sometimes their helping means they cannot attend school, university, college or work and They find it difficult to concentrate at school, university, college or work). The response to these questions was on a 4 point Likert scale ranging from: Definitely true, Probably true, Probably false or Definitely false. The responses ranged from 4 (definitely true) to 1 (definitely false) the higher the score the greater the impact of caring on the young person. The questions were developed based on information gleaned from the Summit Reports produced by Carer organisations throughout Australia and previous research from the UK. The Summit Reports, in part, are accounts by young carers which discuss their caring role and the impact of

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<sup>2</sup>In the case of those over 18 the statements read I as opposed to They

that role on their life and previous research on young carers. Finally two qualitative questions were included which in the case of the Parent Questionnaire asked: "What do you think would help your son or daughter in their helping role?" and "Is there anything else you would like to share with us?" In the case of the Young Carer Questionnaire (>18 years) the questions were "What could help you in your helping role?" and "Is there anything else you would like to share with us"?

### ***Procedure***

For ethical reasons the research team did not have access to Carers WA database which has demographic details which could identify who was a young carer under, or over, 18 years. As a consequence of this both questionnaires and a Participant Information Sheet (see Appendix 3) were mailed to the contact person named on the database. In total 440 questionnaires were mailed, although the database comprised of 220. The participant information sheet explained which questionnaire required to be completed and by whom (e.g., blue questionnaire for parents and yellow for young carers over 18), it outlined the study, and addressed issues of confidentiality and ethics. A tea bag was attached, with the aim of encouraging respondents to take time out and have a cup of tea whilst completing the questionnaire. A raffle ticket was also attached to the questionnaire. When returning the completed questionnaire, half the ticket was to be sent back to go into a draw for a shopping voucher. What had not been anticipated was that the parent would complete one questionnaire and ask the young carer (under 18 years) to complete the other one and then return both. Ethics approval for the project had been obtained from Curtin University of Technology, School of Psychology, but had not included obtaining data from children under 18. Contact was made with the Ethics Officer, Dr Lyndall Steed regarding the ethical issues in reporting the data received from the young carers <18 years of age. Permission was given to report the data as the parents had requested the children (and in a number of instances assisted the child) to complete the questionnaire and returned them on their behalf, this was deemed to be consent (personal communication, Dr Lyndall Steed, 21st October, 2005).

**Parent Questionnaire quantitative results**

The parents returned 57 questionnaires. Three cases were excluded as they did not meet the selection criteria of the study (young carer more than 26 years of age). Information about the care recipient is reported in Table 1.

**TABLE 1: PARENT QUESTIONNAIRE: WHO THE YOUNG CARER LOOKS AFTER**

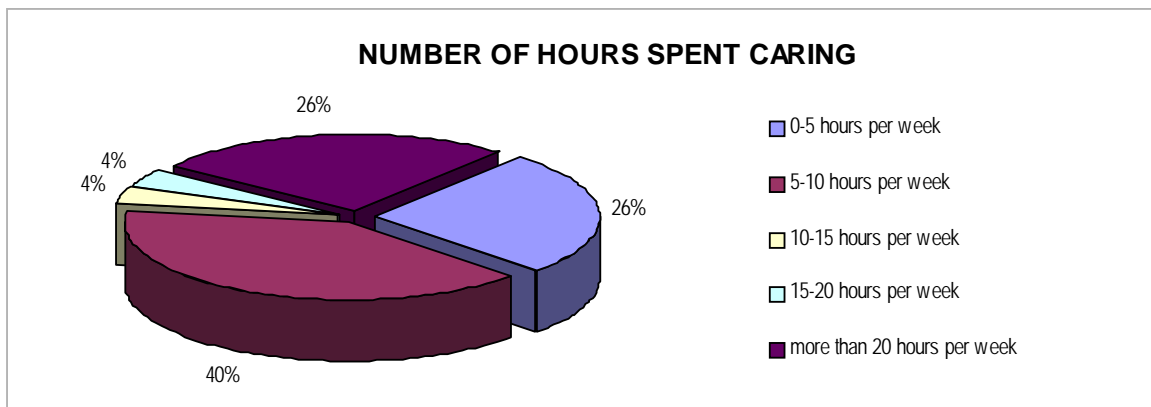
<b>Gender</b>	Males	26
	Females	22
	Missing data	8
<b>Age</b>	4 to 61 years	M=20
<b>Country of Birth</b>	Australia	49
	United Kingdom	1
	New Zealand	4
	Singapore	2
<b>Relationship</b>	Single	39
	Married	9
	Partner/Defacto	4
	Divorced	3
	Widowed	1
<b>Where they live</b>	City	1
	Northern Metropolitan	14
	West Metropolitan	4
	East Metropolitan	7
	South Metropolitan	20
	Rockingham	4
	Rural	6
<b>First Language</b>	English	55
	Non-English	1
Community Organisation Help in the home (tick as many boxes as appropriate)	Silver Chain	7
	HACC	9
	Veteran Affairs	1
	Respite Care (e.g., time out from caring)	32
	School	15
	Family	13
	Friends	18
	Other (cultural or voluntary)	12
<b>Health issue(s) does the person have that your child helps?</b>	Physical	33
	Intellectual	33
	Psychological	11
	Drug/Alcohol	0
	Other	6
<b>Loss of What symptoms do they experience?</b>	Loss of sight	7
	Loss of hearing	7
	Speech difficulties	28
	Chronic or recurring pain	13
	Breathing difficulties	9
	Difficulties	17
	Blackouts, fits or lack of consciousness	13
	Mental illness	28
	Learning understanding difficulties	10
	Incomplete use of arms and fingers	14
	Difficulty gripping	14
	Incomplete use of feet or legs	8
	A nervous or emotional condition	25
	Restrictions in physical activities or physical work	11
	Head injury, stroke or other brain damage	14
	Other	



### The Young Carer

The next section of the questionnaire was on the characteristics of the young carer. There were 31 male and 25 female young carers. All the young carers lived at the same residence as the care recipient. These young carers have cared for periods of between 11 months and 14 years, the average number of years being 6.

**FIGURE 1: GIVES A BREAKDOWN OF THE HOURS PER WEEK THE YOUNG CHILD CARES.**



The ages of the young carers ranged from 6 to 18 years (M=12). The chart below shows the percentage of young carers by age group. The majority of young carers in the study (77%) were aged 9 to 12 years and 13-15 years.

**FIGURE 2: PERCENTAGE OF YOUNG CARERS GROUP BY AGE.**

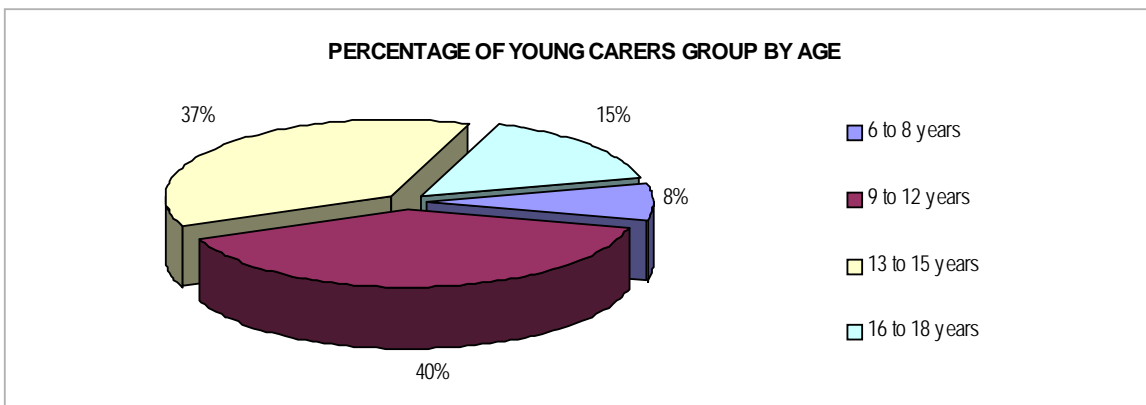


TABLE 2: PARENT QUESTIONNAIRE: THE CARE RECIPIENTS

<b>First Languages</b>	English	52
	Non English	1
	Missing data	1
<b>Country of Birth</b>	Australia	49
	India	1
	New Zealand	1
	Singapore	2
<b>Where they live</b>	City	1
	Northern Metropolitan	14
	West Metropolitan	4
	East Metropolitan	7
	South Metropolitan	20
	Rockingham	4
	Rural	4
<b>Relationship to care recipient</b>	Brother	23
	Father	3
	Mother	13
	Sibling	4
	Sister	7
	Missing data	4
<b>Employment Status</b>	Fulltime	0
	Student	10
	Casual	42
	Unemployed	1
	Voluntary	1
	Other	
<b>Carers or other Allowances</b>	Carers	2
	Allowance/Payment	2
	Unemployment	4
	Study Allowance (Youth Allowance)	3

Parents were also asked what activities the young carer enjoyed participating in, some examples were given which included sport, listening to music, art, hanging out with friends and visiting family. Parents could also indicate other things. To gain insight into the types of activities that a young carer enjoyed the question asked what “types” of activities they participated in. The most frequent response (35) was hanging out with friends, this was closely followed by listening to music and sport which both had 32 responses. Visiting family was also important with the parents indicating that 18 of the 56 children represented participated in this activity<sup>3</sup>.

The parents were also asked to indicate what daily activities the young carer performed in their role. Research conducted in the United Kingdom by

<sup>3</sup> It is important to be aware that the qualitative data indicates a number of children spent time with family when the parent was ill, and this activity may in fact be an outcome of the need for care and supervision of the children.

Aldridge and Becker (1993) comprising of 15 young carers identified commonality of tasks that they categorised as either Domestic or Personal. The domestic tasks performed by young carers included preparing meals, cooking meals and washing clothes. The commonality of personal tasks included feeding assistance, assisting with mobility outdoors and indoors, and a number of personal hygiene tasks (e.g., bathing and lifting onto the toilet). More recent research conducted in the United Kingdom by Dearden and Becker (1998) and in Australia Gays (2001) identified the same areas however they extended the categories to five.

**TABLE 3: COMPARISON OF TASKS PERFORMED BY YOUNG CARERS: AUSTRALIA AND THE UK**  
(SOURCE YOUNG CARERS RESEARCH PROJECT 2001)

Tasks Performed	Australia*	United Kingdom^
Domestic Care (housework)	34%	72%
Personal/Intimate Care	18%	21%
Giving of Medication	17%	57%
Mobility	30%	57%
Emotional Support	58%	43%

\* (GAYS, 2001)

^ (DEARDEN & BECKER, 1998)

The categories above are meaningful, however they do not gives us insight into the 'extent' of the task. For example what is involved in personal/intimate care? Categories of tasks commonly used in Australian research have been drawn from the list defined by the ABS in particular those outlined in the Disability, Ageing and Carers reports. In the present study a list of activities was given as opposed to broad categories these were a composite of those identified by young carers in Australia (e.g., Carers Australia Summit Reports) and the ABS.

The list comprised 31 activities and offered the opportunity to list any others which may have been omitted. For the purpose of reporting these activities they have been allocated to two categories:

- Instrumental Activities (IADLs) (Benson & Marano, 1994) which refers to such things as shopping, cooking and making doctor's appointments
- The more significant tasks related to daily living known as Activities of Daily Living (ADLs) (Benson & Marano). ADLs which involve the carer in more personal, physical and psychologically demanding tasks, such as showering and bathing and bladder and bowel control.

Raphael (2000) states that children and adolescents brought up in a family which is affected by significant health problems are a special group of children who are significantly at risk. This being the case we need to be more diligent in how we categorise the tasks/activities which these young carers undertake. The tasks defined in each of the two activity areas have been classified for this study with the specific purpose of highlighting those tasks which would normally be undertaken as part of the process of growing up and sharing in household activities (Frank, 1995). The second category (ADLs) aims to highlight the tasks which would only be undertaken by a young person in exceptional circumstances. These activities can/do impact on young carers physically (e.g., lifting and physical exertion resulting in exhaustion) and psychologically (e.g., emotional issues such as loss of their childhood due to the intensity of the caring, worry and anxiety linked to the burden of responsibility (e.g., financial paying bills) and emotional (toileting and bathing) all of which can deter the development of interpersonal relationships and social development as a young person. It is not the intention to delineate previous research in relation to how tasks/activities have been categorised. Rather to encourage discussion and debate about the intensity of the caring role for these young people, in order that we may better address their needs when developing community programs. The tasks performed by the young carers are presented in Tables 4 and 5.

**TABLE 4: FREQUENCY OF INSTRUMENTAL ACTIVITIES PERFORMED BY THE YOUNG CARERS** (N=54) (77% OF THE YOUNG CARERS IN THIS STUDY ARE AGED 9 TO 15 YEARS, WITH THE AVERAGE AGE BEING 12).

<b>Instrumental Activities of Daily Living (IADLs)</b>	<b>Frequency</b>
Taking out rubbish	29
Shopping	29
Dusting	11
Cooking food	26
Preparing ingredients	24
Vacuuming	25
Washing	21
Making telephone calls	19
Mowing lawns, watering, pruning shrubs, light weeding, planting	9
Changing light bulbs	4

In reviewing Table 5 which outlines the ADLs, consider the question “Would children who have a family environment which does not include a person with a disability, is frail aged, has a chronic mental illness or physical disability perform these tasks?”

**TABLE 5: FREQUENCY OF ACTIVITIES OF DAILY LIVING PERFORMED BY THE YOUNG CARERS**  
(N=54) (77% OF THE YOUNG CARERS IN THIS STUDY ARE AGED 9 TO 15 YEARS, WITH THE AVERAGE AGE BEING 12).

Activities of Daily Living	Frequency
Dressing	34
Bending and picking up things for them	34
Walking with them	30
Getting them into or out of bed	30
Showering and bathing	30
Eating/Feeding	25
Getting them around a place away from the house	23
Moving them about the house	22
Toileting	19
Attend doctors appointments	19
Walking them up and down stairs without a handrail	9
Helping them to use public transport	8
Transport	6
Writing letters	5
Bladder or bowel control	4
Arrange appointments	2
Paying bills	2
Speak with doctors, pharmacists and other health care professionals	2
Checking bills or bank statements	1

Section 4 of the questionnaire comprised a 10 item scale named the Psychosocial Implications of Caring Scale (PICS). These questions were developed from information given by young carers at previous summits (e.g., Young Carers Summit Report 2004) and previous research. The aim of these items was to give us further insight into how the parents perceived caring as impacting on their child(ren). In order to understand the degree the responses ranged from definitely true (4) to definitely false (1). The PICS was included as a pilot and the internal consistency of the scale was explored and found to be acceptable. The reliability of the scales was examined using Cronbach's alpha and was .77. This report does not allow for further discussion of the psychometric properties of the PICS and this will be addressed in another publication. The mean, standard deviation of the items is presented in Table 6.

**TABLE 6: SCALE ANALYSIS OF PSYCHOSOCIAL IMPACT OF BEING A YOUNG CARER (PICS)**

Item	M	SDev
They sometimes don't sleep well	2.4	1.0
Their life has been affected (e.g., always have to be there to help)	1.4	.57
They sometimes feel tired and lack energy	2.1	.83
They sometimes worry	1.7	.74
They need more support	1.8	.80
Sometimes their helping means that they cannot attend school, university, college or work	3.0	1.0
They have difficulty concentrating at school, university, college or work	2.6	.91
Sometimes their helping means that they miss out on social activities	2.0	.91
Sometimes I have to care and cannot take them to social activities	1.7	.90
I think they may sometimes feel depressed	2.1	.74

As the assumptions of parametric tests were not met Spearman's rho correlations were conducted and are reported in Table 8. In reviewing the correlations it is important to be aware that a relationship between variables does not imply causation, but rather allows us to predict. The direction of a correlation can be positive, as the values of one measure increases so does the other (e.g., a lack of sleep can predict difficulties in concentration at school or work), or negative as the value of one measure increases the value of the other decreases (e.g., the longer a child cares is associated with missing out on social activities) (Shaughnessy, Zechmeister, & Zechmeister, 2000). A correlation matrix is presented in Table 7.

TABLE 7: CORRELATION MATRIX: PARENTS PERCEPTIONS OF THE PSYCHOSOCIAL IMPLICATIONS OF CARING

Item	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1 Age	1.00													
2 Length of time caring	.092	1.00												
3 Hours spent caring per week	-.056	.218	1.00											
4 Gender	.063	-.043	.072	1.00										
5 Sleep difficulties	.021	-.265*	-.216	-.111	1.00									
6 Life always affected	.131	-.216	-.117	.105	.107	1.00								
7 Tired and lacking energy	-.118	-.040	-.491♦	-.243*	.386♦	.046	1.00							
8 Sometimes worry	-.003	-.263*	-.328*	-.048	.410♦	.169	.536♦	1.00						
9 Need more support	.215	-.200	-.309*	.023	.382♦	.185	.381♦	.463♦	1.00					
10 Educational absenteeism	-.006	-.272*	-.068	-.152	.185	.188	.010	.170	.290*	1.00				
11 Concentration difficulties study or work	-.027	-.230	-.079	-.021	.514♦	.051	.251*	.302*	.285*	.573♦	1.00			
12 Miss out on social activities	.064	-.361♦	-.138	.021	.071	.555♦	.064	.146	.224	.337♦	.157	1.00		
13 Parent unavailability	.106	-.235	.018	-.077	.197	.412♦	-.006	.119	.267*	.462♦	.388♦	.654♦	1.00	
14 Sometimes depressed	-.075	-.280	-.221	-.065	.385♦	.062	.382♦	.364♦	.273*	.143	.407♦	.235*	.308*	1.00

NOTE: ♦ CORRELATION IS SIGNIFICANT AT .01; \* CORRELATION IS SIGNIFICANT AT .05 (1 TAILED)

The final section of the questionnaire presented parents with an opportunity to discuss in more detail the role of the young carer.

### ***Parent Questionnaire qualitative results***

Forty-three parents responded to the first qualitative question, which was: "What do you think would help your son or daughter in their helping role?" and 27 responded to the second question "Is there anything else you would like to share with us?" A thematic analysis<sup>4</sup> (for further discussion refer to Flick, 2005; Liamputtong & Ezzy, 2005; Strauss & Corbin, 1998) was conducted and four major categories emerged these were: Time Out/Respite, Psychological, Social Support, and Lifestyle.

#### *Time Out/Respite*

Of the 43 parents who responded to this question 23 highlighted the need for the young carer to have a <sup>5</sup> *"Break away from home – time out"*. What is interesting is that the parents who raised this point used similar words to express the need for the young carer to have their own space *"If she got a break away from the home environment and had time out"* and simply *"Getting away for a break."* Within this theme the activities and camps organised by Carers WA were mentioned and had the most positive impact:

*"Things like the young carer's holiday activities"*

*"...camps and days out have been great"*

*"Being involved in young carer's camps and social activities"*

*"...camps, week-end activities"*

It is clear that these breaks in the young carer's normal routine are important. The parents support the voice of the young carers themselves who have stated at a number of summits the value they place on time away from their normal environment.

The parents not only acknowledged and validated the programs already in place but also identified a desire to have time with the young carer(s). This

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<sup>4</sup> The scope of this report does not allow for a comprehensive discussion of the qualitative methodology.

<sup>5</sup> The use of italics throughout the report indicates a direct quote



was evidenced in statements such as *"Time to reconnect with my other children"*. One mother stated that she wanted her daughter to feel *"...special-spend one on one time with me"*. Another parent wanted to have *"special time just allocated to them when they have your full attention and love"*. This idea was extended further by parents seeking support for the family to have a break and allow time to *"re connect with non-disabled children and so parents can re connect with each other"*.

This is one relationship which has not been identified in previous research. It clearly has implications for the well-being and development of young carer and will be discussed further in the concluding chapter of the report.

### Psychological

The next category to emerge was related to the psychological implications of caring, for the child and also for the parent. Parents talked about the level of guilt which they felt and this was voiced in different ways:

*"I keep promising to take her places and then end up in hospital I wish I could make it up to her. She has missed out on so much" "*  
*As a parent I always feel guilty that the disabled child affects every aspect of the other child's life"*.

*"I wish I could do more for my boys, because they have certainly earned [sic] it"*.

A number of parents took the opportunity to reflect on some of the situations they had found themselves in and how they responded: *"Not blaming her if whilst she is doing that role and something goes wrong"*

The majority of parents talked about how the young carer grows up too quickly. This is not a new finding but it must be acknowledged that it is the first time in which we have had validation from parents about the psychosocial factors which caring has on their children while in the role of carer.

*"My little mum she knows when I really sick and helps every way she can"*

*"I would be lost without him"*

*"...they had to mature beyond their age pretty fast, they did not get to be children themselves".*

*"They are like a third parent".*

Perhaps this remark by a parent sums it up *"She needs to be a kid again".*

Two parents reframed the impact of the responsibility of caring and saw a positive aspect *"They are blessed in so many ways"* and another Mother wrote *"They have more of an adult view of the world and are far less likely to feel disappointed, because they weren't expecting life to be perfect"*

*"Disability has been a blessing to our family"*

The parents highlighted ways in which the psychological implications of caring were manifested in the young carer's behaviour:

*"My second son has a lot to handle for his age and a major chip on his shoulder"* . For some young carers parents also talked about the anger the young carers had and that they perceived their *"life [as not being] fair"*. Another parent shared the fact that her daughter had self-harmed because she was not able to cope and *"didn't want to burden sole parent with added concerns."* This young person is moving forward but the question must be asked about the longer term effects of caring. As one parent said, it is *"Difficult to say how much carer child is affected day to day by the presence of disabled child"*.

The parents also gave insight into the emotional frailty of these young carers when they talked about how they *"often worry about their [parents] health, and about the future"* and another [parent] *voiced concern about "...the little one" [who]...especially gets scared about her mums health often wakes up at night to see if her mum is ok..."*. This father goes on to say this occurs in stages but normally after his wife has been in intensive care. *"I*

*would like to know how to help her anxiety, but it is impossible to get advise [sic], everyone passed the buck”.*

Previous research has also discussed how difficult it can be at school for these children and again for the first time we have a parent describing how her son has *“been teased at school that his brother has “Brain damage” and this he bottled up and reinforced the fact emotionally a young carer is on a rollercoaster ride”.*

A number of parents mentioned the need for someone who could help them to cope and develop the skills to help the young carers, for example where there was fear about the long term health and well-being of the carer. A number of parents specifically mentioned the need for counselling and parents seemed to be unaware that such services are available.

### *Social Support*

- *Formal Support*

*Parents indicated that there was a need for more local activities “more teenager support groups and ‘fun & cool’ activities for youth” and increased support services within their area, such as someone to drive them to doctor’s appointments as taxis were too expensive.*

- *Informal Support*

*Parents indicated that more support could be forthcoming from family “More support from family” and a number of parents indicated a need for “More understanding by community about the isolation felt” and comments such as “Someone acknowledging their role in society”.*

- *Peer Relationships*

*“Being able to invite friends home- spending time with peers” and having “Someone to talk to and more friends”*

*Some parents indicated that having “social activities without his brother” was important.*

A number of parents viewed meeting with other children who live in similar family environment as important and placed significant relevance on the need for young carers to see that other families were experiencing similar difficulties.

### Lifestyle

All of the families who responded to the two opened ended questions indicated in one way or another that their lifestyle was significantly affected by having a family member who required care. These included a parents' inability to hold a driving licence so consequently they could not take their children to sports. The pressure and responsibility of being the Primary Carer (i.e., the parent) made it difficult for the young carer to participate in activities outside the home. *"To take them places but if the parent is caring for a disabled member of the family the young carers do miss out. Especially over the holidays"*

Not being able to just get up and go *"always having to take the sibling into consideration"* and one parent highlighted the difficulty the family faced in participating in activities *"very little to do socially [sic] where you can include a person in a wheelchair"*.

In the majority of cases the parents indicated that financial issues impacted not only on the young carer, but on the lifestyle of the family. For some families only one parent was able to work as the other parent, usually the mother, took on the role of primary carer. This situation led to the father being physically exhausted as he works long hours to support his family *"leaving home anytime between 5am- 7.-30am and getting home anytime from 5-30pm – 11.30pm"*.

One mother said that one of the parents also had to stay home to care and as one income family we *"have had to say no to extra things, which other kids take for granted"*.

The young carers identified in the present study also miss out on sports activities due to financial pressures "*Because money is tight they cant [sic.] join sports groups etc [sic]*"

### ***Findings from Study 1 Parent's Perspective***

One study (Aldridge & Becker, 1994) has been located which is similar to the one reported and titled: "*my child, my carer – the parents' perspective* – this study was a follow on from a study on young carers in 1993 and parents of the children in that study were invited to participate. The study comprised 10 parents and was qualitative in nature. The aim was to ascertain the effects of caring as perceived by the parents (Aldridge & Becker). There are distinct differences in the results reported in the UK study (Aldridge & Becker) and the present research in WA (WA). There are of course fundamental differences as we live in different worlds, culturally, environmentally and in delivery of health care services and provision. Taking these factors into account there are some differences between the two studies which merit discussion.

The UK study identified five areas and discussion on two of these highlights differences which were diametrically opposed to the results obtained in WA.

#### *Coping*

"...the parents seemed convinced of their children's ability to cope with caring" (Aldridge & Becker, 1993, p.10) and mentioned that a recurrent theme was that children took the role of caring 'In their stride'.

Clearly this is not the picture which has been painted by the parents who participated in WA.

#### *Life at School*

The UK study indicated that parents did not keep their children from school and parents were apparently "adamant that their children had never been late or missed school due to their caring responsibilities" (Aldridge & Becker, p. 11). However, they also reported a lack of support from schools. Parents in WA have indicated that children miss school but they also acknowledged that they had support from the school.

There was concurrence that the young children in the Nottingham area of the UK and WA have their social life and friendships severely restricted because of the caring role.

Both studies had the same agenda to understand the perspective of parents in relation to how caring impacts on their children. The study in WA has considerable extended on the UK study in the following areas:

- Significantly more parents participated
- Quantitative and qualitative methodologies have been employed
- It has been all inclusive in considering all the variables which impact on a young carer's life ( Instrumental and Daily Activities)
- How caring can be manifested behaviourally, emotionally and socially (e.g., psychosocial implications of caring)
- The information shared by the parents acknowledges, validates and in a sense normalised the role of their children as young carers.

## **Study 2: The young carer's perspective**

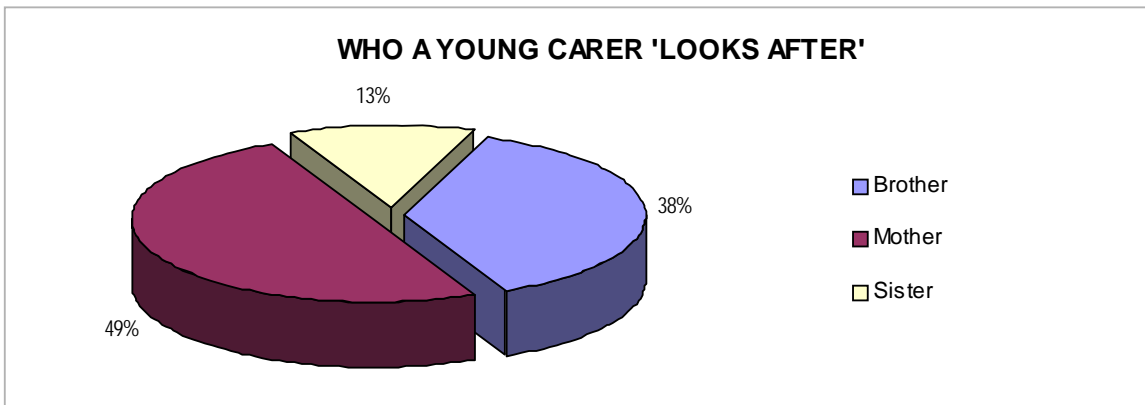
This chapter is reported in two sections. The first section reports the perceptions of caring by young carers aged 6 to 16 years of age, and section two reports how young adult carers age 18-24 perceive their role.

### ***Young Carer Profile***

Seventeen young carers completed the questionnaires. They were all born in Australia. There were 9 males and 8 females, the youngest was 6 and the eldest 16 years of age the mean age was 11.5 years. Four of the young carers were employed on a casual basis and the remaining 13 were students. Two young carers receive the unemployment benefit.

Sixteen of the young carers lived in the same residence as the care recipient, and one lived away from home. The young carers had help from formal (community organisations) and informal (family and friends) support. The most significant perceived source of support for these young carers was from family.

**FIGURE 3: WHO A YOUNG CARER 'LOOKS AFTER' IN THEIR FAMILY**



**TABLE 8: FORMAL AND INFORMAL SUPPORT NETWORKS**

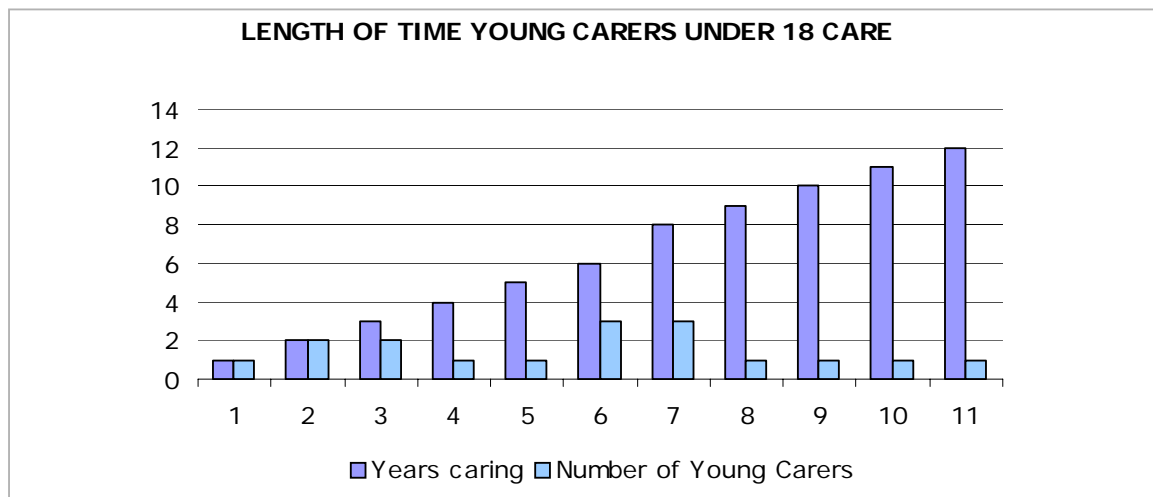
Formal and Informal Help	Number of responses (n=17)
Silver Chain	2
HACC	2
Respite Care (e.g., time out from caring)	6
Meals on Wheels	1
Veteran Affairs	1
School	4
Family	16
Friends	5

**TABLE 9: HEALTH ISSUES OF THE CARE RECIPIENT**

Blackouts, fits or lack of consciousness	9	Incomplete use of arms or fingers	4
Chronic or recurring pain	7	Difficulty gripping	3
Mental illness	1	A nervous or emotional condition	1
Learning/understanding difficulties	8	Loss of sight	5
Breathing difficulties	3	Loss of hearing	5
Incomplete use of feet or legs	3	Speech difficulties	6
Other	2	Restrictions in physical work	9

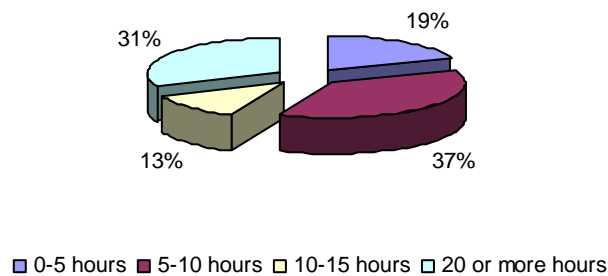
Question 10 asked: When did you start helping? Month\_\_\_\_ Year\_\_\_\_. One of the young carers indicated that they had been caring since they were 2 years of age. To validate the young carers response to length of time caring it was compared to the parent's response to this question, there was concordance. The explanation given is that the young carer was born into a family who had twin brothers with an intellectually disabled and caring began at this early age (e.g., helping with feeding).

**FIGURE 4: LENGTH OF TIME YOUNG CARERS UNDER 18 CARE**



**FIGURE 5: NUMBER OF HOURS PER WEEK YOUNG CARERS UNDER 18 YRS OF AGE CARE**

**NUMBER OF HOURS SPENT CARING**



In the time they spent caring these young children and adolescents helped relatives with physical (n=9) and intellectual (n=9) disabilities and psychological issues (7).

The next section of the questionnaire asked the young carer about the activities that they performed in their caring role

**TABLE 10: FREQUENCY OF INSTRUMENTAL ACTIVITIES PERFORMED BY THE YOUNG CARERS (N=17) (THE AGE RANGE OF THESE YOUNG CARERS IS 6-16, WITH THE AVERAGE BEING 11 YEARS AND 5 MONTHS).**

Instrumental Activities of Daily Living (LADLs)	Frequency
Taking out rubbish	10
Preparing ingredients	10
Washing	9
Cooking food	8
Vacuuming	8
Shopping	6
Dusting	5
Making telephone calls	3
Mowing lawns, watering, pruning shrubs, light weeding, planting	4
Changing light bulbs	1
Making minor home repairs	1



In reviewing Table 11 which outlines the ADLs, consider the question “Would children aged between 6 to 16 years who have a family environment which does not include a person with a disability, is frail aged, has a chronic mental illness or physical disability perform these tasks?”

**TABLE 11: FREQUENCY OF ACTIVITIES OF DAILY LIVING PERFORMED BY THE YOUNG CARERS**  
(N=17) (THE AGE RANGE OF THESE YOUNG CARERS IS 6-16, WITH THE AVERAGE BEING 11 YEARS AND 5 MONTHS).

Activities of Daily Living	Frequency
Getting them into or out of bed	11
Bending and picking up things for them	10
Moving them about the house	9
Walking with them	8
Dressing	7
Other not specified	7
Attend doctors appointments	6
Showering and bathing	5
Getting them around a place away from the house	5
Helping them to use public transport	4
Transport	3
Writing letters	3
Filing in forms	3
Eating/feeding	2
Walking them up and down stairs without a handrail	2
Speaking with doctors, pharmacists and other health care professionals	1
Toileting	1
Bladder and bowel control	1

The final section explored the psychosocial implications of caring, as discussed previously this scale was included as a pilot and it had not been anticipated that children under 18 years of age would complete it. Nonetheless it merits some attention as a number of significant results were found. The total scale had a reliability score (Cronbach’s alpha .66). The mean scores and standard deviation for each item of the PICS is presented in Table 12.

**TABLE 12: MEAN AND SD OF SCORES ON THE PICS**

Item	M	SD
I don’t sleep well	2.7	.99
My life has been affected (e.g., always have to be there to help)	3.1	1.03
I sometimes feel tired and lack energy	2.6	.94
I sometimes worry	3.1	.97
I need more support	2.5	1.1
Sometimes my helping means that I cannot attend school, university, college or work	2.0	1.12
I have difficulty concentrating at school, university, college or work	2.3	1.16
Sometime my helping means that I miss out on social activities	3.0	1.0
I sometimes feel depressed	2.6	.79

A non-parametric Spearman rho correlation was conducted to establish whether or not significant relationships existed between the variables and age, length of time caring, hours spent caring and gender. It is important to remember that a relationship between variables does not imply causation, but allows us to predict. For example there were significant positive correlations between accounts of not sleeping well and feeling tired ( $r = .65 (16) = p < .00$ ), worrying ( $r = .57 (16) = p < .02$ ) and having difficulty concentrating at school ( $r = .55 (16) = p < .02$ ). The correlations are presented in Table 13.

TABLE 13: CORRELATION MATRIX: YOUNG CARERS (UNDER 18) PERCEPTIONS OF THE PSYCHOSOCIAL IMPLICATIONS OF CARING

Item	1	2	3	4	5	6	7	8	9	10	11	12	13
1 Age	1.00												
2 Length of time caring	.384	1.00											
3 Hours spent caring per week	.332	.552*	1.00										
4 Gender	.279	-.194	.238	1.00									
5 Sleep difficulties	.198	-.200	-.123	.314	1.00								
6 Life always affected	-.224	.396	-.007	-.064	-.264	1.00							
7 Tired and lacking energy	-.188	.032	.157	.092	.433*	-.013	1.00						
8 Sometimes worry	.039	.381	.278	-.378	.356	.071	.440*	1.00					
9 Need more support	-.282	.127	-.142	-.459*	-.413*	.384	-.346	.268	1.00				
10 Educational absenteeism	-.504*	-.040	-.502	-.616♦	-.391	.172	-.133	.115	.534*	1.00			
11 Concentration difficulties study or work	-.272	-.022	-.023	-.150	.384	.024	.352	.406	.118	.127	1.00		
12 Miss out on social activities	-.178	.398	.148	-.127	-.024	.723♦	-.001	.489*	.414*	.315	.302	1.00	
13 Sometimes depressed	-.322	.382	.287	-.013	-.057	.479*	.411	.183	-.028	.025	.143	.377	1.00

NOTE: ♦ CORRELATION IS SIGNIFICANT AT .01; \* CORRELATION IS SIGNIFICANT AT .05 (1 TAILED)

Young carers under 18 enjoy participating in a number of recreational activities

**6** enjoyed listening to music



**4** liked to do art



**3** spent time with family



**9** enjoyed hanging out with their friends



**11** of the young carers liked to play sport

### ***Qualitative Results***

Similar to the parent questionnaire the young carers were invited to talk in a little more detail about how caring affects them. As there were a small number of responses a thematic analysis was not undertaken rather a contextual approach has been adopted which allows for understanding the meaning from the young carer's perspective (Dalton, Elias, & Wandersman, 2001).

'What would help you to carry out your helping role?

Support was as important for these young carers as it was for the parents. This was evidenced by comments such as *"more support from community"* and in general they saw a need for *"understanding from community"*.


The role that family has in supporting the young carer comes through strongly particularly when they are from a single parent family and it is the parent who is ill comes through strongly. There is a dynamic interplay where the young carers thought that going to *"Nana xxxxx's when mum needs her rest."* would help them in their caring role. As would the being able to go to family or friends so an *"Aunty (parents sister) can come and take care of her"*

Camps and respite time was also paramount and again the need for more time out was voiced simply by statements such as *"more camps; more time out; and more fun things "*. The notion of respite was not just for the young carer in terms of going on camps and having fun but also they viewed respite for their ill sibling as being helpful *"more respite care for my brother"*. This really links to the fact that young carers didn't want time out just for themselves but rather to be able *"to go camping and do more fun theing [sic] whith [sic] the family."*

In response to the issue of what could help a few young carers stated that they *"manage OK on [their] own"* *"or simply "nothing" or "I don't need help!"*; *"I do not need anymore help I have my dad and my brother"*. Other young carers found it difficult to envisage what could help and said *"I do not know"*.

The focus of the last question was to allow the young carers to share anything else they wanted. Only a few young carers responded to this question.

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Getting to and from places was a problem and for others it was the inability of the parent to hold a driving license due to health problems that made life more difficult *“Mum needs more help when trying to get around. She pays alot{sic.] on taxis because the buses are 2 hrly [sic.] apart. We do walk a lot[sic.] and I know this is not helping mum & [sic] her condition I hate sometimes especially when its hot.”*

The words of one young carer sums up the situation:

*“Yes I am his brother so I am always with him helping him get things talking to him walking home with him. I look after my family when they are sick this does not affect [sic.] my school life.”*

### **Young adult carers**

Six young carers who were born in Australia over the age of 18 completed the questionnaire. There were 5 females, aged 18 to 24 and 1 male, aged 21, they were all single and 2 were in full-time employment and 4 were students. Three received benefits one of which was the Unemployment Benefit and two received Study Allowance. They cared for siblings (4) and parents (2) and have cared for between 5 and 10 years. Five of the 6 young carers lived in the same residence as the person for whom they cared. The things they enjoyed in their recreation time was sporting activities (2), music (6) spending time with friends (5) and being with family (2) and one young carer reported art as a hobby. The Table 14 outlines the help and tasks which these young carers perform.

**TABLE 14: ABOUT THE CARING GIVEN**

<b>Number of hours per week the young Carer helps</b>	5-10	1
	10-15	1
	20 or more	3
	Missing	1
<b>Community Organisation Help in the home (tick as many boxes as appropriate)</b>	Silver Chain	1
	HACC	1
	Respite Care (e.g., time out from caring)	4
	Family	2
	Friends	1
	Other	1

TABLE 14: ABOUT THE CARING GIVEN (CONT)

<b>Health issue(s) does the person have that your child helps?</b>	Intellectual	4
	Psychological	4
	Drug/Alcohol	1
	Physical	1
<b>Loss of What symptoms do they experience?</b>	Speech difficulties	1
	Chronic or recurring pain	2
	Mental illness	3
	Incomplete use of feet or legs	2
	A nervous or emotional condition	1
	Learning, understanding difficulties	2
	Head injury, stroke or other brain damage	2
	Blackouts, fits or lack of consciousness	3
	Incomplete use of arms or fingers	1
	Difficulty gripping	1

TABLE 15: FREQUENCY OF INSTRUMENTAL ACTIVITIES PERFORMED BY THE YOUNG CARERS

<b>Instrumental Activities of Daily Living (IADLs)</b>	<b>Frequency</b>
Taking out rubbish	3
Shopping	5
Dusting	1
Cooking food	4
Preparing ingredients	3
Vacuuming	1
Washing	4
Making telephone calls	2
Mowing lawns, watering, pruning shrubs, light weeding, planting	1
Making minor home repairs	1

TABLE 16: FREQUENCY OF ACTIVITIES OF DAILY LIVING PERFORMED BY THE YOUNG CARERS > 18 YEARS.

<b>Activities of Daily Living (ADLs)</b>	<b>Frequency</b>
Bending and picking up things for them	5
Bladder or bowel control	4
Dressing	4
Showering and bathing	4
Toileting	3
Getting them into or out of bed	4
Eating/Feeding	4
Getting them around a place away from the house	5
Walking with them	3
Transport	4
Attend doctors appointments	1
Walking them up and down stairs without a handrail	1
Helping them to use public transport	2
Writing letters	1
Filling in forms	1
Arrange appointments	2

Although the number of young carers over 18 who responded to the questionnaire was only 6 it is important to acknowledge that the tasks these young people performed in the main related to personal care.

The mean and standard deviation of the PICS is presented in Table 17 and as the number of participants was small, further analysis could not be included. The mean score for the total scale was 3.3 which indicates that these young carers felt the majority of statements were true for them.

**TABLE 17: SCALE ANALYSIS OF PSYCHOSOCIAL IMPACT OF BEING A YOUNG CARER > 18 YEARS (N=4)**

Item	M	SDev
I don't sleep well	3.2	.75
My life has been affected (e.g., always have to be there to help)	3.3	.52
I sometimes feel tired and lack energy	3.7	.52
I sometimes worry	3.5	.55
I need more support	3.5	.55
Sometimes my helping means that I cannot attend school, university, college or work	2.7	1.0
I have difficulty concentrating at school, university, college or work	3.0	.89
Sometime my helping means that ti miss out on social activities	3.0	.63
I sometimes feel depressed	3.7	.52

### **Qualitative data**

There were two open-ended questions: What would help you to carry out your helping role? and Is there anything else you would like to share with us? Two of the four young carers gave some feedback about their lives.

What would help you to carry out your helping role?

*"More support from community" and "Understanding by the public"*

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

*"I'm happy but there need's [sic.] to be more service for young people over 18" .*

### **Findings from Study 2**

The feedback from young carers under 18 has reflected that of parents with regard to having more support.

There is also concurrence between the young carers under 18 and their parents with regard to having family time without the care recipient sibling around.



Understanding from community is also important and both young children and adult carers clearly need acknowledgement and validation of what they do in their lives.

A number of young carers under 18 are carrying out tasks such as bathing and toileting which would not happen if they were in a "normal" family environment.

The PICS has indicated that both these groups of young carers perceive that their life is significantly impacted by the role they play.

The research conducted in the UK on young carers is prolific and in this regard Australia can be seen as the 'poor relation'. It is hope that the present studies will encourage some discourse, particularly with regard to the PICS and the defining of the tasks in which young carers are involved.



## **CHAPTER 2: SOCIAL SERVICE ORGANISATIONS AND IDENTIFYING OF YOUNG CARERS**

This chapter reports the number of young carers that can be identified via Social or Service Indicators (Prilleltensky & Nelson 2005). Social Indicators: Australian Bureau of Statistics (ABS) and Centrelink and Service Indicators: Disability Services Commission.

Young carers are defined for the purpose of identification in this part of the study as:

*“Children and young people up to the age of 26 years who have caring and support responsibilities for a family member or friend who has a disability, is frail aged, or who has a chronic mental or physical disability”*

### **Australian Bureau of Statistics (ABS)**

The current statistics available from the Australian Bureau of Statistics for WA were for 2003. The data was collected as part of the Disability, Ageing and Carers (Catalogue 4430.0). The figures allowed for information to be given for West Australian young people aged 15 to 18 and 18 to 24. The ABS defined

A primary carer is a person who provides the most informed assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and to be provided for one or more of the core activities (communication, mobility, self care). In this survey, primary carers only include persons aged 15 years and over for whom a personal interview was conducted. Persons aged 15 to 17 years were only interviewed personally if parental permission was granted. (ABS Disability, Ageing and Carers, Australia, 2003 Report 4431.0.55.001 p.201).



The data collected allowed for identification of males and females within the age categories mention who were Not Primary Carers but who have the role of a carer. A carer is defined by the ABS as:

A person of any age who provides any assistance, in terms of help or supervision, to persons with disabilities or long term condition, or older person (i.e., age 60 years and over). This assistance has to be ongoing, or likely to be ongoing for at least six months. Assistance to a person in a different household relates to 'everyday types of activities' without specific information on the activities.

(ABS Disability, Ageing and Carers, Australia, 2003 Report 4431.0.55.001 p.207).

The data obtained through the 2003 Disability, Ageing and Carers report for WA are presented in Tables 1 and 2.

**TABLE 18: MALE CARER STATUS BY AGE – WA 2003**

(SOURCE ABS REPORT 4431.0.55.001)

Type of Carer	Less than 18 years	18-24 years
Primary Carers	zero	zero
Not a primary carer	8,600	9,700
Total population of males in WA	250,500	101,400

**TABLE 19: FEMALE CARER STATUS BY AGE – WA 2003**

(SOURCE ABS REPORT 4431.0.55.001)

Type of Carer	Less than 18 years	18-24 years
Primary Carer	Zero	400
Not a primary carer	12,000	8,600
Total population of females in WA	233,800	101,000

The percent of males under 18 years who are not primary carers is 3.4% and for the age 18 to 24 years the percent is 9.5% of the population of WA for these specific ages.

The percent of females under 18 years who are not primary carers is 5% and for the age 18 to 24 years the percent is 8.5% of the population of WA for these specific ages.

The 2003 figures have therefore identified 20,600 male and female non primary carers less than 18 years of age and 18,300 male and female carers

aged 18 to 24, and 400 female primary carers. The overall number of young carers identified who met the selection criteria is 39,300<sup>6</sup>.

## Centrelink

Carers are entitled to one of two benefits: either a Carer Allowance or a Carer Payment. The distinction between the two is that the Carer Allowance is not income or asset tested and is not taxable. Carer Allowance can be paid alone or in addition to other Centrelink payments (personal communication Leonie Haydon, 14<sup>th</sup> October, 2005). A Carer Payment is an income support payment and is for people who cannot support themselves, or cannot participate in the workforce, due to their caring role. These payments are available to people who care for an adult (16 years or over) or a child (under 16 years) (Centrelink). When we think of a young carer we may assume that they would be eligible for one of the above payments, however this is not the case. Currently there is no legislation which dictates the age a child/young person can apply for the Carer Payment or Allowance. Essentially as there is no minimum age for Carer Payment or Allowance if the person "claiming does not qualify they could test their eligibility for other payments" (personal communication Leonie Haydon, 16<sup>th</sup> October, 2005). Therefore a young carer could be allocated a Youth Allowance (personal communication, Centrelink, 5<sup>th</sup> October, 2005). Anecdotal evidence obtained from government organisations suggests that these carer allowances (allowance and payment) commence at age 16.

The information received from Centrelink and the perspective of government agencies seem at odds as the Centrelink population data reports (Centrelink Pensions 2004 Qtr (10-12-04) Ver-01 for recipients of the Carer Payment or Allowance are grouped from 12-25 years of age. The data is broken down by locations, 24 in total, and these include rural areas (e.g., Albany, Bunbury Karratha) and metropolitan (e.g., Victoria Park, Mirrabooka and Morley. For reasons of confidentiality when there are less than 20 receiving payment in a location the data reports <20, which in essence means that there are

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<sup>6</sup> Primary carers only include persons aged 15 years and over for whom a personal interview was conducted. Persons aged 15 to 17 were only interviewed personally if parental permission was granted. No Primary Carers under 18 years are reported.

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anywhere between 1 and 19 young carers receive the allowance in those locations. In reality we have notion of how many young people receive this type of benefit.

In an effort to obtain more meaningful data as to when the carer allowance and payment commence, and how many young people obtain them, information for this project was obtained from The Performance Information Branch (BI Frontdoor). This is the division responsible for generating reports relating to Centrelink data. Let me remind the reader that organisations such as Carers WA thought that young carers were eligible for the carers benefit from 16, yet the Centrelink data reports from aged 12 and whilst in communication with BI Frontdoor the following information was received:

We can provide the following data

*Age and Gender of Carer Payment recipients (Ages 5-26 yrs - singly)*

*Age and Gender of Carer Allowance recipients. (Ages 5-26 yrs singly)*

*Age and Gender of Carer Allowance Adult Carers. (Ages 16 and above, grouped by 10 yrs)*

(Email Bi Frontdoor 15<sup>th</sup> October, 2005).

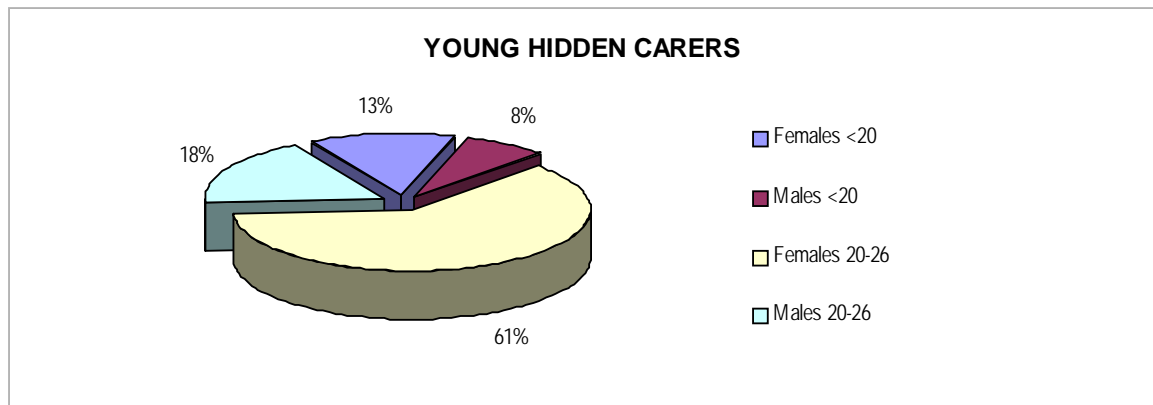
The most important part of the email is the age of the youngest recipient for both payments which is 5 years. Discussion with the BI Frontline has clarified the confusion, the youngest age indicated is the default, that is to say if a 5 year old were to obtain the allowance the system would accept the information, it does not indicate that there are children aged 5, or in the example given earlier (e.g., aged 12) receiving a Carer Payment or Allowance.

**External Publication of Data:** No Centrelink Data supplied is to be used in any External Publication without approval from the relevant areas within Centrelink, FACS, DEST and DEWR. (email communication, 24<sup>th</sup> November 2005).



For the reasons given above the specific number of young carers aged <20 and between 20-26 years of aged who receive the Carer Allowance and/or Carer Payment cannot be reported. However the number will be absorbed in the final analysis of the number of Young Hidden Carers Identified in WA. It is appropriate to note that females are overrepresented in the sample population. A percentage breakdown is given in below.

**FIGURE 6: YOUNG HIDDEN CARERS**



### **Findings**

ABS data is obtained at interview and where there are a significant number of young carer identified whose bio does not appear else where. Gays (2001) stated that the ABS survey “merely provides insight into those in receipt of carer payments” (no page numbers) and supported this by citing Reibelt, 1998). This is not the case and the ABS endeavours to identify, in particular young carers who are unknown (personal communication, ABS, Perth WA 28<sup>th</sup> November, 2005). There is further support for this in that the figures do not even “vaguely” relate to statistical report given by Centrelink.

The data from Centrelink is still unclear but at least we have an understanding that in their reports, the lower age range is only the system default for data entry purposes.

Young people can access a number of different payment options when caring. Young women are vastly overly represented in the caring population

## **Service Indicators: Disability Services Commission.**

DSC, together with other agencies both state and federal government, have witnessed in recent years a growing recognition of the critical role that informal support networks play in 'caring for people who have a disabilities, are frail aged, or have a chronic mental or physical disability within the community' (personal communication, Dana Bensky, October, 2005). In recognition of this DSC have included a question with 5 items, in the Service Users Form to identify informal carers. As this question is asked of the service user, it can be argued that while they are identifying the primary carer and there maybe other young carers within the home environment (e.g., a 14 year old may be identified by a single parent as their informal carer and yet there could be another child/ren). However, the question has been included for two reasons:

1. To establish whether or not there is an informal carer, and
2. To have a snapshot of specific characteristics of the informal carer.

The DSC definition of an informal carer is very similar to that employed by the ABS and perceives


"A carer [to be] someone who provides a significant amount of care and/or assistance to the person on a regular and sustained basis 'regular' and 'sustained' in this instance means that care or assistance has to be on going, or likely to be ongoing for at least six months".

Three items from the question on the Service Users Form were relevant to project:

1. The relationship of the carer to the service user?
2. What is the age group of the carer?
3. If aged under 16 years: Do the service user's parents or guardians receive the Carer Allowance?

The relevance of obtaining this data was to identify young carers other than those known to Carers WA, and secondly to allow for a better interpretation of the Centrelink Carer Allowance and Carer Payment data, and thirdly to increase awareness of what benefits, other than the Carer Payment and Allowance are being allocated to young carers. The Executive Director of the Disability Services Commission granted permission for a customised report

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(non-identifiable) to be generated by the Research Office at DSC. The information extracted from this report is presented in Tables 20 to 28.

### ***Carers under 15 years of age***

The report identified **9** young carers, 6 females and 3 males, **under the age of 15** who were caring for a parent (n= 6) or relative (n=3). They cared for people aged 05-14 (n=3), 25-34 (n=1), 35-44 (3) and 45-54 (n=2). The benefits they received are reported in Table 20.

**TABLE 20: INDICATES THE AGE OF THE CARE RECIPIENT AND BENEFIT ALLOCATED TO YOUNG CARERS 05-14 YEARS**

(SOURCE DISABILITY SERVICES COMMISSION NOVEMBER 2005).

<b>Age of Care Recipient</b>	<b>Centrelink Benefit</b>
05-14	Child < 16 Carer Allowance (n=1) (2 not known if receive Carer Allowance (Child)
25-34	Adult: Compensation Income (n=1)
35-44	Adult: Disability Support Pension (n=2) Other income (n=1)
45-54	Adult: Disability Support Pension (n=1) Adult: Other pension/benefit (n=1)

Excluding the 9 young carers identified as being under the age of 15 there were a further 149 young carers aged between 15 and 24, 17 were males and 132 were female carers.

**TABLE 21: CHARACTERISTICS OF YOUNG CARERS AGED 15 TO 24 YEARS WHO CARE FOR A CHILD 0-4 YEARS**

(SOURCE DISABILITY SERVICES COMMISSION WA NOVEMBER 2005)

**There were 41 female young carers**

Of this number there were 40 mothers and 1 female relative caring for a child  
 23 young carers receive the Child < 16 Carer Allowance  
 1 young carer does not receive any benefit  
 14 of the young carers did not report whether they do or do not receive the Carer Allowance and were recorded as Child <16: Not known if receive Carer Allowance  
 3 cases missing data

**TABLE 22: CHARACTERISTICS OF YOUNG CARERS AGED 15 TO 24 YEARS WHO CARE FOR A CHILD 5-14 YEARS**

(SOURCE DISABILITY SERVICES COMMISSION WA NOVEMBER 2005)

**There were 48 female and 3 male young carers**

Of this number there were 44 mothers, 4 female relative and 3 male relatives caring for a child  
 19 young carers receive the Child < 16 Carer Allowance  
 32 of the young carers did not report whether they do or do not receive the Carer Allowance and were recorded as Child <16: Not known if receive Carer Allowance



**TABLE 23: CHARACTERISTICS OF YOUNG CARERS AGED 15 TO 24 YEARS WHO CARE FOR A YOUNG PERSON 15-24 YEARS<sup>7</sup>**

(SOURCE DISABILITY SERVICES COMMISSION WA NOVEMBER 2005)

**There were 18 young carers.**

Of this number there were 12 relatives, 3 partners, 1 male relative and 2 males

1 young carer receives the Child < 16 Carer Allowance

1 of the young carers did not report whether they do or do not receive the Carer Allowance and were recorded as Child <16: Not known if receive Carer Allowance

**TABLE 24: CHARACTERISTICS OF YOUNG CARERS AGED 15 TO 24 YEARS WHO CARE FOR AN ADULT 25-34 YEARS**

(SOURCE DISABILITY SERVICES COMMISSION WA NOVEMBER 2005)

**There were 8 young carers, 6 were female and 2 were male**

Of this number 5 were wife/partners, 2 were husband/partners and 1 was a female neighbour

**TABLE 25: CHARACTERISTICS OF YOUNG CARERS AGED 15 TO 24 YEARS WHO CARE FOR AN ADULT 35-44 YEARS**

(SOURCE DISABILITY SERVICES COMMISSION WA NOVEMBER 2005)

**There were 8 young carers, 6 were female and 2 were male**

Of this number 5 were daughters, 1 was a son, 1 was a female relative and 1 was a male neighbour

**TABLE 26: CHARACTERISTICS OF YOUNG CARERS AGED 15 TO 24 YEARS WHO CARE FOR AN ADULT 45-54 YEARS**

(SOURCE DISABILITY SERVICES COMMISSION WA NOVEMBER 2005)

**There were 17 young carers, 11 were female and 6 were male**

Of this number 9 were daughters, 6 were sons, 2 were female relatives

**TABLE 27: CHARACTERISTICS OF YOUNG CARERS AGED 15 TO 24 YEARS WHO CARE FOR AN ADULT 55-64 YEARS**

(SOURCE DISABILITY SERVICES COMMISSION WA NOVEMBER 2005)

**There were 7 young carers, 3 were female and 3 were male and 1 not specified**

Of this number 3 were daughters, 2 were sons, 1 male relative and 1 relative

**TABLE 28: CHARACTERISTICS OF YOUNG CARERS AGED 15 TO 24 YEARS WHO CARE FOR AN ADULT 65-74 YEARS**

(SOURCE DISABILITY SERVICES COMMISSION WA NOVEMBER 2005)

**There was 1 male young carer**

1 male relative

## Findings

### Gender

Females (132) are over represented in the population of those who care for someone with a disability compared to their male (17) counterparts. This finding diametrically opposes the assertion in the 2001 Young Carers Research Project which found that females were “only slightly more likely to become young carers than males” (p. 11).

<sup>7</sup> When the carer recipient was aged between 15 and 74 only information about the source of income of the service user was recorded.

However the argument can be presented that a large number of these young carers, are young parents caring for a child with a disability (e.g., autism, developmental delay or cerebral palsy) or a partner who suffers from an intellectual disability or multiple sclerosis as opposed to the normal scenario in which a young carer cares for a parent or sibling. It is important to note that of the 134 female carers 84 were young mothers caring for a child aged between 0 and 14 years.

#### *Age of Care Recipient and Role of the Mother*

Whilst subjective, the argument must be presented that if these young carers are aged between 15 and 24 then the average age of the children will at the low end of the spectrum and be between 4 and 6 ages. In the case of young children the severity of the disability may not be manifested.

There would also be a strong case to support the idea that these young mothers perceive themselves as “young mothers” and not “young carers”. DSC consider a person a carer, and a parent, if they provide more care to their child with a disability than they would to another child of the same age.

#### *Carer Allowance*

All carers identified in the age range of 15-24 who care for a child under 14 years who receive a benefit (n=43) have been allocated the Child <16: Carer Allowance (Child). This number could of course be significantly higher but a number of young carers have not given the information and have been recorded as not known. One parent who cares for a child in the 15-24 age range also received this payment.

Although there are 54 young carers who care for people between the ages of 15 and 74, no information was collected in relation to the Allowance they may receive (e.g., Carer Allowance or Payment >16).



*Young Carers 05-14*

A number of the young carers in this age range are receiving benefits such as Adult Compensation Income rather than the Carer/Payment Allowance, this contradicts what was indicated previously that the alternative allowance for these young people would most probably be the Study Allowance.



## **CHAPTER 3: IDENTIFICATION AND SNAPSHOT OF YOUNG HIDDEN CARERS**

### **Community perspective of young carers**

The initial brief given by Carers WA was to find identify how many young carers there are in WA, that were not previously known to the organisation.

*"We need this for funding. We are always being asked how many young carers are there? We have no idea"* (personal communication, Britta Meyer, September, 2005).

### ***Methodology***

A considerable number of research methodologies were employed in an attempt to answer the question of how many hidden young carers there are in WA.

The methods included

- One-on-one interviews
- Discussion Groups
- Telephone interviews
- Media Releases
- Community and Government organizational newsletters and staff websites
- Young Hidden Carer Identification Survey


This section of the report will be discussed under three headings:

1. Interviews
2. Media: Carers Week October, 2005
3. Young Hidden Carer Survey

### ***Participants***

Six face-to-face interviews were conducted with members of community agencies (e.g., Red Cross) and staff in government departments (e.g., High Schools). Discussion groups were conducted with counsellors, social workers

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and others who have an understanding and specific interest in the issues pertaining to young carers and 4 telephone interviews (e.g., Tim Moore, Carers Australia and counsellors in rural and remote WA). Nine people made contact by telephone and 3 by email in response to the media articles.

### ***Interviews***

The interviews were semi-structured and were used to guide the interview process as opposed to leading the interviewee. The interviews had two purposes, firstly to allow for a more comprehensive understanding of the key issues (e.g., political, funding, advocacy and processes current in place to identify young carers) and secondly to establish whether or not young hidden carers could be identified within a number of settings (e.g., school environment). The articles in the media attracted attention to the project some parents identified their children as young carers and people who had previously cared as children made contact by telephone or email.

### ***Results***

Information was shared which helped develop the project. Tim Moore from Carers Australia gave valuable insight into the role of carer organisations and the services provided. The interviews allowed for a better understanding of some of the services which organisations such as the Red Cross are funded to provide.

In the course of the interviews a number of people mentioned the impact which drug and alcohol abuse had on young children. An example given was of a child who had to help siblings get ready for school as the parent was in an alcohol induced sleep. Young carers also found it difficult to concentrate at school as they were constantly worrying about the situation at home. It was reported that during school these children would approach counsellors to phone home (e.g., mobile phone use was not permitted on the school campus). Another significant issue was that the young carers do not want to be identified as different and this notion was presented often – the silent young carer.

The complexity of who is and who is not eligible for services was frustrating for a number of participants in the study. For example a young carer aged 17

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who cares for a brother was identified within the school environment as being at risk of not completing their studies “dropping out of school” due to their caring role. Contact was made with an agency and the counsellor was advised that the young person did not meet the criteria for assistance. It is apparent that funding can only be used for the specific target group for which it is defined. It must be stated that the frustration felt by this counsellor, and lack of ability of organisations to be flexible, is also experienced by these community organisations.

During the course of the interview process, the interviews the interviewees identified a number of young hidden carers. This information is presented in Table 29.

**TABLE 29: YOUNG CARERS IDENTIFIED THROUGH INTERVIEWS**

Age	Location	Number
12-18	Inner Northern suburb	12
15	Southern Suburbs	1
Not known	Remote and Rural	3
Total	Young Hidden Carers	16

While conducting the interviews it became apparent that counsellors and social workers can and do recognise that their client has a young child at home who is caring. Where appropriate they would try to have the young person become involved (e.g., family session or involvement for the young carer in community activities) or contact with an appropriate organisation or service provider.

The discussion groups raised some new issues about why young carers do and do not attend activities, groups, or counselling sessions. One reason which was put forward was that parents do not believe that their child/children required help. Also parents’ perceptions that a young carers misbehaviour could be due in part to their inability to cope with the caring role was often not acknowledged. There was also an indication that parents used the idea of counselling as some form of punishment “*if you don’t behave you’ll go to counselling*”.

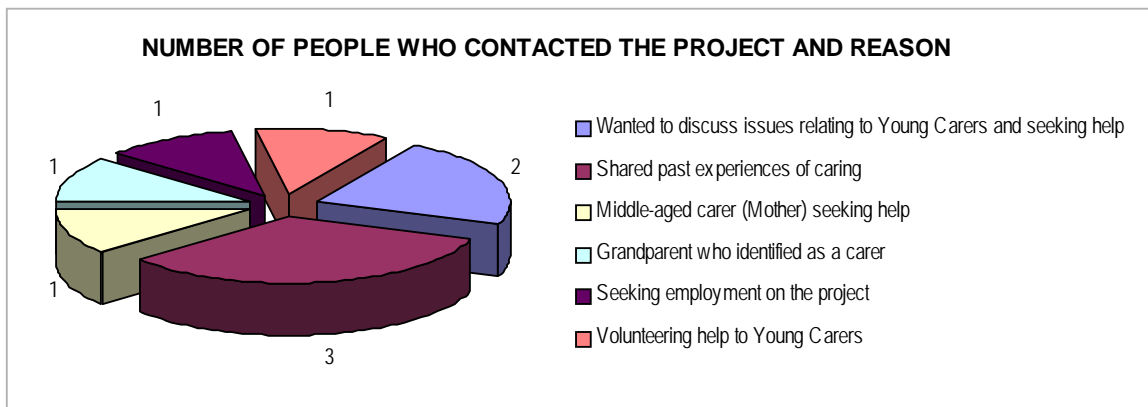
Another issue which was flagged was the inability of the young carers to access services due to the distance from home. The suggestion was made in one group discussion that the development of a comprehensive outreach program would be useful.

**Media**

Carers week was in October 2005 and the project was given media coverage in The West Australian and the Community Newspapers (see Appendix 4).

The people who telephoned and emailed did so for a number of reasons, these are reported in graphic form in Figure 7.

**FIGURE 7: NUMBER OF PEOPLE WHO CONTACTED THE PROJECT AND REASON**



Return calls were made to the 6 people who telephoned, and emails responses were sent to the other 3. It is inappropriate to outline the interview process, however the three people shared their experience of being young carers and talked about how it had, and does still impact on their lives. The first words spoken by one was *“What are you going to do with this research?”* They all indicated relief that these young carers were being identified and that something would be done to help. The contact details of Carers WA were given and information about the services provided by Carers was sent by mail where permission was given.

## ***Findings***

Counsellors and health care professionals can and do identify young carers but find it difficult to engage parents with regard to having interaction with the child or the child having contact with other young carers.

In some instances parents lack understanding of the implications of caring on their child/ren. This is a complex issue and conclusions cannot be drawn from this research project about why parents encouraged their children to participate, or why not.

One finding particularly important finding was that adults who cared as children have *“put up their hand”* and said that caring as a child has and still does affect them. I would refer you to Chapter 1 where parents made statements such as how will caring impact long term.


## **Study 3: Hide and Seek: Finding young carers**

This section of the report presents the results of Study 3 which was the study designed specifically to find out how many young hidden carers there are in WA. Initially it was difficult to envisage how this brief could be undertaken. In conducting the preliminary research it was found that young hidden carers could be identified by many of the service providers and health care professionals interviewed. This information and discussions with Carers WA staff helped in the process of developing the methodology for this final phase of the project.

## ***Methodology***

There were a significant number of factors which impacted on the development of the methodology for this study. The first was the logistics involved (WA is a large state) in addressing the research brief, secondly we required to reach as many service providers and health care professionals as possible and thirdly the timeframe for conducting and reporting the project was 3 months. We also acknowledged that help and support was required from people who are caught up in the day-to-day pressures related to their

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work and a survey may well wait until a “quiet time”, a consequence of which is that it is never returned!

In an endeavour to overcome these challenges a survey was designed which was disseminated electronically (e.g., email). The logic behind this idea was that everyone checks their emails and normally respond immediately, the same response surely would be achieved with the survey. We encouraged those who received the survey to forward it to another colleague, essentially using a snowballing technique (Landridge 2004) to increase participation.

### ***Procedure***

A letter (see Appendix 5) outlining the study was sent to the members of the Carers WA Young Carers Interagency Steering Committee. Letters (see Appendix 6) were also sent to other organisations that could help with identifying young carers. Following from this, the Participant Information Sheet and Young Hidden Carer Identification Survey (see Appendix 7) were sent electronically to the 19 representatives of the various organisations who are members of the steering committee. Three of these members advised that they had forwarded the survey to field managers, counsellors and other network contacts.

A number of organisations (e.g., DSC and the Youth Affairs Council of WA) requested a media release (see Appendix 8) which they could include on their web site or for their newsletter to encourage staff participation in the study.

Young Hidden Carer Surveys were sent electronically to 32 individuals and 39 organisations. Follow up emails were sent 10 days after distribution of the questionnaire.

### ***Participants***

Twenty-four surveys were returned the respondents were representatives of organisations such as Anglicare, Commonwealth Carelink and Respite Centres and High Schools. The role of these representatives was varied and included Chaplains, Counsellors (e.g., psychologists and social workers), Program Co-ordinators and Community Nurses.



### ***Non-participation***

The lack of support and response from government departments, particularly those who are represented on the Carers WA Interagency Steering Committee (e.g., Education Department; DCD) was abysmal.... "the silence was deafening". The support of DSC is acknowledged as is the support from organisations such as YACWA and ARAFMI and individuals who represented those at the coalface.

### ***Young Hidden Carer Identification Survey***

The survey (see Appendix 7) was developed specifically for this study. The task activities checklist was the same as that on the Parent and Young Carer Questionnaire.

It became apparent during the project that there was disparity regarding the appropriateness of the term 'young carer'. Two questions were included in an effort to clarify this issue. The questions were

1. Do they/would they think of themselves as carers?
2. Is there another word which they use other than carer that describes what they do?

If the answer to the second question was yes we asked for an example(s)

The first part of the survey asked for information about the person responding (e.g., location by post code and their organisation and role). Following this was the definition of a young carer and then a statement which encouraged reflection before commencing the actual survey:

*Please take a few minutes to think about the children or young people whose lives are affected that you know of.*

*Now before you begin the survey could you write down a few of the words that describe the children and young people you mentally identified? (e.g., sad, coping, happy, positive, wonderful)*

The next question asked for identification of the number of young carers by 4 age groups (5 to 10, 11-15, 16-18 and 19-26 years of age). The final item

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asked for the respondents perceptions of how caring impacted on the children they had identified. Some items were similar to those on the PICS (tired and lack energy, seem to be depressed) to items which have been reflected in the first study (e.g., report being bullied, homework doesn't get completed) this checklist was named the Education and Psychological Implications of Caring Checklist (EPICCC). In conclusion there was an invitation to add further comments.

***Profile of the Young Hidden Carers***

**Three hundred and eleven young hidden carers** were identified in this study. The number of young hidden carers by age group is presented in Figure 8. The young carers are located throughout WA and a visual snapshot is presented in Figure 9. The care recipients were parents and siblings and the most common health issues were Mental Health, Physical Disability and Behavioural Difficulties. These were closely followed by Learning Difficulties, Drug and Alcohol use and Sensory Impairment respectively. Care recipients who suffered from Head injuries or Frail Age were the least common.

**FIGURE 8: NUMBER OF YOUNG HIDDEN CARERS BY AGE GROUP**

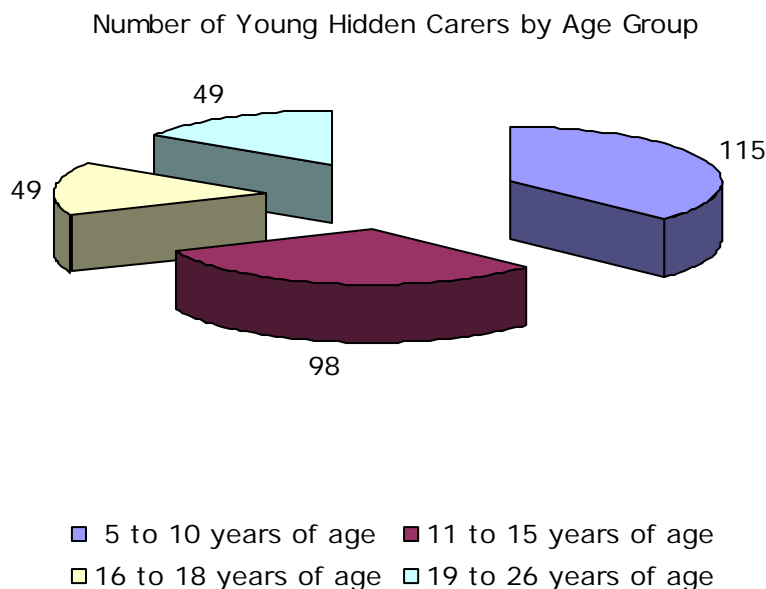
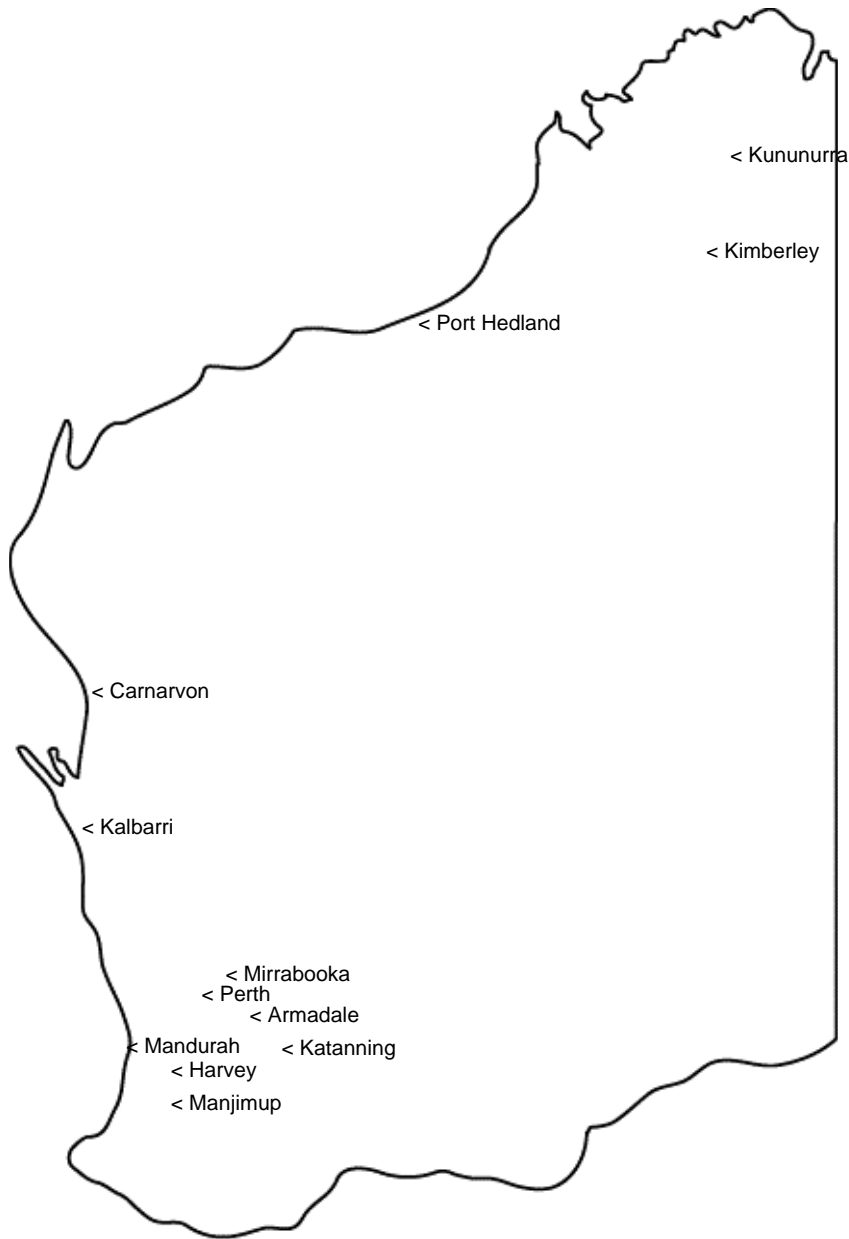


FIGURE 9: WHERE THE YOUNG HIDDEN CARERS LIVE



The occurrence of tasks related to IADL and ADLs are reported in Tables 30 and 31 respondents were asked to indicate the various tasks which the young hidden carer performed.

**TABLE 30: FREQUENCY OF INSTRUMENTAL ACTIVITIES PERFORMED BY YOUNG HIDDEN CARERS**

(N=311) (68% OF THE YOUNG CARERS IN THIS STUDY ARE AGED 5 TO 15 YEARS)

<b>Instrumental Activities of Daily Living (IADLS)</b>	<b>Frequency</b>
Taking out rubbish	12
Shopping	14
Dusting	9
Cooking food	14
Preparing ingredients	11
Vacuuming	9
Washing	12
Making telephone calls	15
Mowing lawns, watering, pruning shrubs, light weeding, planting	6
Changing light bulbs	3
Minor home repairs	3

**TABLE 31: FREQUENCY OF ACTIVITIES OF DAILY LIVING PERFORMED BY YOUNG HIDDEN CARERS**

(N=311) (68% OF THE YOUNG CARERS IN THIS STUDY ARE AGED 5 TO 15 YEARS)

<b>Activities of Daily Living ADLS</b>	<b>Number</b>
Helping with a sibling	22
Getting them into or out of bed	11
Bending and picking up things for them	12
Moving them about the house	10
Walking with them	7
Dressing	11
Other not specified	5
Attend doctors appointments	7
Showering and bathing	8
Getting them around a place away from the house	8
Helping them to use public Transport	2
Transport	3
Writing letters	2
Filling in forms	10
Eating/feeding	6
Walking them up and down stairs without a handrail	7
Speaking with doctors, pharmacists and other health care professionals	7
Toileting	9
Bladder and bowel control	3
Arranging appointments	10
Checking bills or bank statements	3
Other	5

The next section of the survey was the EPICC and the focus was profiling the educational and psychosocial implications of caring. Ten items in the scale considered how caring impacted on the education of these young children. For example, did the young carer miss school and/or did not complete homework. Eight items allowed for identification of psychological issues which could impact on young carers. These included the health care professional witnessing young carers demonstrating anger and/or frustration as well as symptoms of depression. The perceptions of the respondents to these issues are presented in Figures 10 and 11.

FIGURE 10: YOUNG HIDDEN CARERS: EDUCATIONAL IMPLICATIONS OF CARING

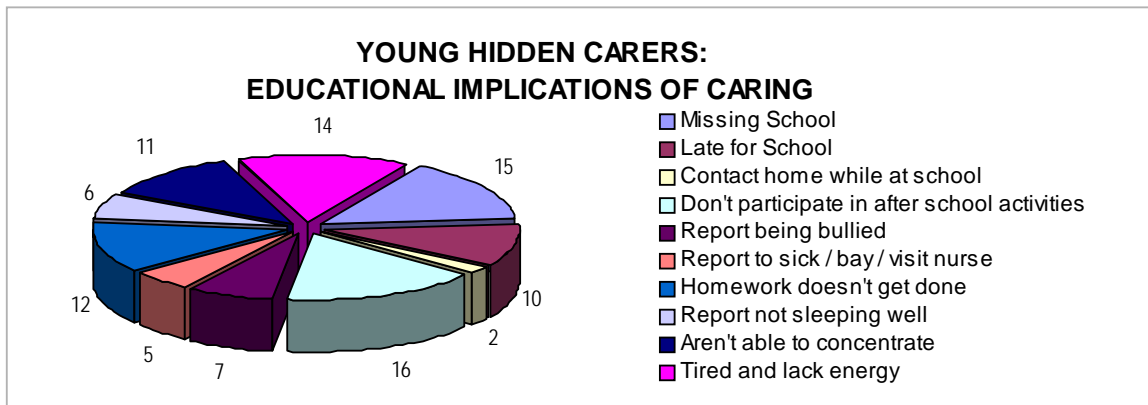
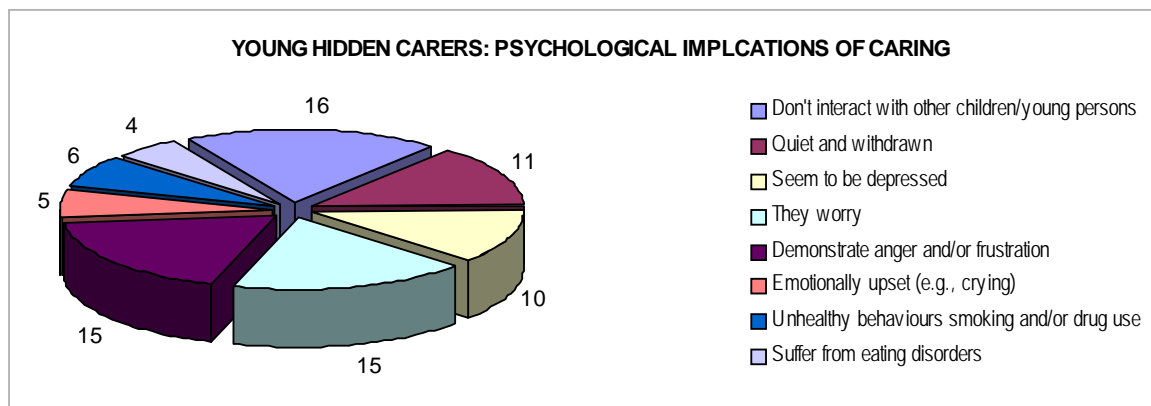


FIGURE 11: YOUNG HIDDEN CARERS: PSYCHOLOGICAL IMPLICATIONS OF CARING



The final two questions on the Young Hidden Carer Identification Survey were included for the express purpose of finding out if the young people who care identify with this role and term and if they do not, then how do they articulate (express in words) what their role is. Twenty-two of the 24 respondents answered the question “Do they/would they think of themselves as carers”, 17 held the view that these young children do not think of themselves as carers. When asked if there was another word which they used to describe what they did, only 7 people responded, the following are examples of the responses given:

*Mothers [sic.] hands*

*Looking out for someone*

*This is just what I do*

*Helping Mum and Dad*

*Little fella*

*Look after*

### **Qualitative Data**

There were opportunities for respondents to share their understanding of how the life of these young hidden carers was affected. We asked *before you begin the survey could you write down a few of the words that describe the children and young people you mentally identified? (e.g., sad, coping, happy, positive, wonderful)*. The responses overall mirrored those of the parents of known young carers in Study 1 with the most pertinent issue relating to how these children grow up too fast. And comments such as *"they display older behaviours"; "they are mature"; "are adult like"; "eager but scared"*. A number of people described these young people as being overwhelmed and embracing the parental role in a surprisingly skilful way.

Other issues revolved around the lack of self-esteem and poor social skills of some young carers. As well as the fact that the *"children often miss out on their childhood"* and that they *"could be missing out on the fun of being a child due to the additional roles they fulfil parental duties are thrust on them at an early age"*.

Comments were made with regard to Indigenous Australians who often care for more than one person, *"they care for siblings as well as parents on dialysis"*.

Concerns were identified by the respondents about the unhealthy behaviours of young carers particularly in the use of drugs (e.g., smoking) and substance abuse. Some health care professionals indicated that the responsibility of caring can be exacerbated by the worry and fear of developing the same degenerative condition as their parents.

*"Often these young people – don't see themselves as anything special. This is just what life is for them if they can be rewarded/acknowledged in some way this would be great!"*

### **How many young carers are there in WA?**

A number of methodologies were used to answer this question. These included sourcing statistics from government instrumentalities, interviews and

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an electronic survey. A letter introducing the project and the Hidden Carer Survey was sent to a considerable number of organisations and agencies (e.g., Holyoake) and societies (e.g., Parkinson's and the Arthritis Foundation of WA) as well as service providers (e.g., Silver Chain). The survey was sent to those who were in a position to identify young carers or could give numbers of young people who presented for counselling or completed programs as a consequence of their caring role. As was stated previously there was a disappointing lack of response from government departments who are represented on Carers WA Interagency Steering Committee.

At the commencement of the project the number of young carers known to Carers WA was 220, this figure was based on the young carers who engage in activities with the young carer network. The number of young carers identified from various sources during the project is 40,922<sup>8</sup>.

### **Breakdown by age of young carers identified**

- 21,131 young carers under 18 years of age,
- 41 at 18 years of age,
- 52 at 19 years of age,
- 149 aged between 15 - 24
- 19,549 aged between 18- 26.

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<sup>8</sup> Cross tabulations have allowed for duplication. The ABS figures are for 2003 and new figures will be available in 2006.

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### **Findings**

Three hundred and eleven young carers were identified from 27 responses. This only confirms that there are many young children caring that are still unidentified.

Respondents were not what could be termed white collar workers but rather those at the coalface.

Comments such as *"Hope this helps. It has opened my eyes. I guess we are all so busy dealing with the issue/crisis which presents, we don't take enough time to analyse the implications on the children/young people. Thanks"* epitomises why, and how, these young carers go unidentified.

The issue of growing up too fast was well documented.

Bullying came through strongly, much more so than in the responses to the Parent and Young Carer Questionnaires.

Lack of participation in after school activities was highlighted and supports the findings from Studies 1 and 2.

Lack of sleep and worry were high on the agenda, as was lack of concentration, not completing homework and missing school.



## **CHAPTER 4: MEASURE DEVELOPMENTS**


The final aim of the research project was to develop a number of tools/measures. The first of these was to assist in the identification of young carers by health care professionals, GPs and staff within the education department. Secondly a measure was developed that could be used within the education system for children to self-identify as young carers. Finally a more comprehensive young carer telephone intake questionnaire was prepared for use by Carers WA.

### **Young Carer Identification Checklist (YCIC)**

Previous research (e.g., Dearden & Becker, 1995) has identified specific tasks which young carers undertake on behalf of their care recipient. We need to define what differentiates a young carer from a child who “helps mummy” as part of the growing up process (e.g., making their bed). By defining the tasks which a young carer does as an Instrumental (IADLs) or a Daily Activity (ADLs) allows for some distinction between what can and cannot be perceived as normal. This is not to say that young carers proportionately do the same or less Instrumental activities than their non-carer counterparts, what it does say is that non-carers will not bath, shower and toilet a sibling or parent. The results from the three studies have shown commonality in the activities and it these activities which form the first section of the checklist.

The research which has been conducted as part of this project has clearly shown that young carers, their parents and the health care professionals who have contact with them have identified educational issues (e.g. , missing school) and psychological factors (e.g., feeling depressed, being angry and frustrated) which impact on the young carer’s life. These items have been included as section 2 of the checklist. The checklist (see Appendix 9) has no psychometric properties. It is only a checklist and as such it is recommended that identification of a young carer would require a threshold score of 50% of the ADLs and the EPICC. Further research will be conducted using this checklist but the author invites feedback and comment and encourages use of the checklist.

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## **Young Carer Self Identification Checklist: Year 7 to 12**

Gays (2001) conducted research in high schools in Canberra 2001. The survey was extremely short and was completed during a school assembly. Whilst it gave numbers it did little to enhance our understanding of how caring impacted on the lives of these young people. A more comprehensive measure was required which could highlight where there could be a need for intervention and to guide program development. The checklist for self identification, is titled *me and my story* is the YCIC with some modifications (see Appendix 10) this will be piloted in high schools (year 8-12) and primary schools (Year 7) in WA in 2006, subject to permission and ethics approval.<sup>9</sup>

## **Little People Checklist: Age 4-10**

For primary school children (Years 1-6) the self identification process is required to be visual. A card sort system has been developed where there are pictures which represent the IADLs and the ADLs list. Scoring on the IADLs is representative of what can be classified as normal healthy helping. Identification of tasks being undertaken on the ADLs list indicates that the young child could be a carer and there should be further follow-up. Information about the children's school attendance by class year should be obtained through the school administration. The cartoons depicted on the next three pages are visual representation of the items on the YCIC for High School students and are for use in identifying young carers aged 4 to 10 years. Similar caricatures are being developed and will be produced as cards, similar to playing cards. This measure will be piloted in 2006 as part of another project.

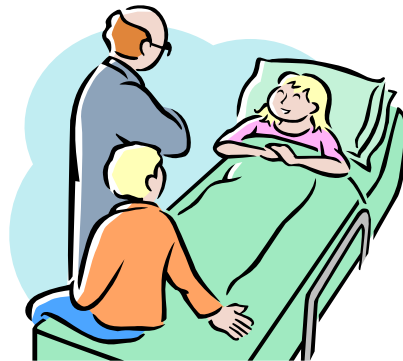
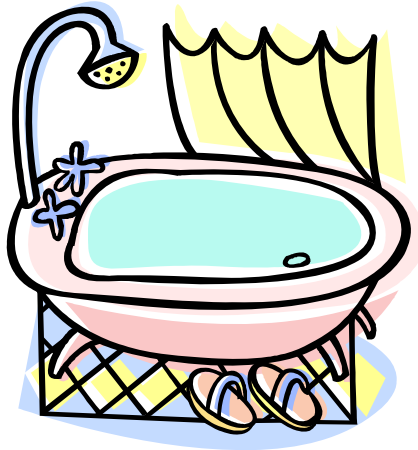
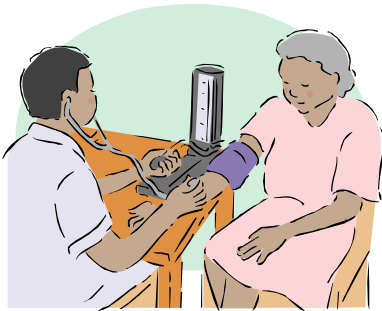
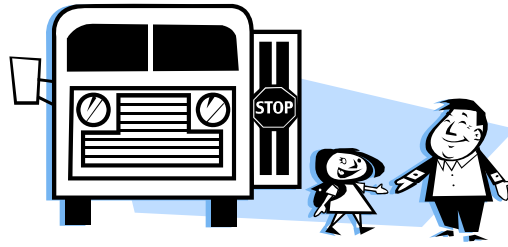
In conclusion none of the checklists discussed above have been piloted and this will be the focus of further research during 2006. They are reported here as an aim of this project was to develop measures, based on the current research, to facilitate identification of young carers and also to develop a tool which would allow for self-identification. They are also presented to encourage debate on the appropriateness and results which are obtained.

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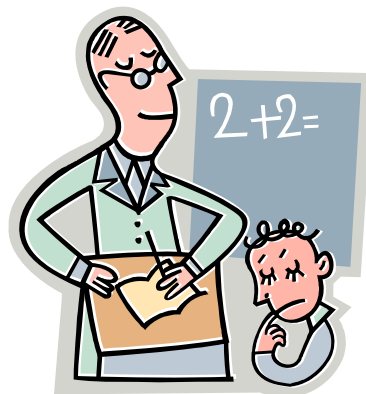
<sup>9</sup>Should you wish to pilot *me and my story* and/or the little people checklist please contact Dr Morrow for scoring and interpretation guidelines



These are examples of instrumental activities which as discussed previously may be performed by children ages 4 to 10 living in a normal family environment.



These are examples of daily activities which as discussed previously would not normally be performed by children aged 4 to 10.



These represent items on the EPICC which specifically identify the educational and psychological impact of caring.

## **Carers WA: Young Carer Telephone Questionnaire**

This questionnaire (see Appendix 11) was designed at the request of Carers WA. There was an existing intake questionnaire with specific questions which were required for funding (e.g., current support services, reason for call). The new questionnaire allows the inclusion of tasks and activities carried out by the young carer.



## **CHAPTER 5: CONCLUSIONS**

The final chapter discusses the key findings of the project, makes recommendations for future research and suggestions for the development of community programs.

The findings from each study were presented at the conclusion of the results. It is not the intention to be repetitious but rather to draw attention to the key findings and raise some points for discussion.

### **Profile of Known Carers**

#### ***Age and Gender***

The mean age of the young carers was 12 (Parent Questionnaire - PC) and 11.5 years (the Young Carer Questionnaire-YCQ). The average age of these young carers is slightly less than the average age which was stated as being 12 to 13 years in 2001 (Carers Australia).

#### ***Number of Years and Time spent Caring***

The majority of young carers spent between 0-10 hours caring, what is alarming is the next highest percentage cared for more than 20 hours per week. There was commonality between the two groups with regard to length of time caring. The range was from 11 months (PQ) and 1 year (YCQ) to and 14 years (PQ) and 11 years (YCQ). The duration of caring is significantly longer than that found for young carers in the ACT in 2005 (Moore).

The youngest that a child was identified as commencing caring was 2 years of age. Anecdotal evidence in WA suggested the youngest carer was 6 years of age when they commenced caring.

Contrary to previous research, studies 1 and 2 identified that there slightly more (3) young male than female carers. This result cannot be generalised rather it should be regarded a 'snapshot' at a specific time.






### ***How the young carer helps***

The young carers in the studies reported assisted parents and siblings. Previous research (Gays, 2001; Moore, 2005) has absorbed the more explicit tasks within broad categories such as personal care. Studies 1, 2, and 3 adopted a new approach to defining the tasks young people carry out for their care recipient. Tasks were categorised as Instrumental Activities of Daily Living (IADLs) and Activities of Daily Living (ADLs) (Benson & Marano, 1994; Martire & Schultz, 2001). It was argued that defining the tasks in this way would allow for identifying the tasks which would not be undertaken in a normal home environment (Franks 1995). It was further argued that undertaking ADL tasks would impact more significantly physically and psychologically on a young carer. Furthermore, while it is acknowledged that young carers do significantly more IADLs (Moore, April, 2005) than their non-caring counterparts it does provide some guidelines for differentiation between carers and non carers. Anecdotal evidence suggests that some health care professionals have difficulty in distinguishing between a young carer and a child who “just does things around the house”. The establishment of two categories will eradicate this problem. The results have increased our understanding of the tasks these young people undertake in so far as the frequency of tasks of a personal nature (refer to see Tables 5, 11,16). The results provide a profile of the age at which these young carers commence these personal tasks (77% of the young carers identified were aged 5 to 15 years).

### ***Educational and Psychological Implications of Caring (PICS)***

To the best of my knowledge, research conducted in Australia has not engaged the use of quantitative and qualitative methodology to explore the impact of caring on the educational and psychological well-being of young carers. The studies contained in this report used this methodology. The quantitative data allows presentation of information regarding the association between factors which are significant and a picture emerges statistically which allows for the assessment of predictors. The means (range 1 to 4 with higher scores

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indicative of educational and psychological difficulties) of the PICS for the two groups indicate that the young carers rated the educational and psychological issues as more extreme than their parents. For example, if we consider the item 'My life has been affected (e.g., always have to be there to help)' the mean score of the parents was 1.4 whereas for the young carers under 18 it was 3.1 and for those over 18 it was 3.3. Similar differences were found on the items relating to worry, feeling depressed, needing support, not sleeping well, feeling tired and lacking energy as well as missing out on social activities. The results of the quantitative analysis indicate that the parents underestimate the impact of caring on their child. Further research is required to explore this issue further.

### ***Social Activities***

The most consistent feedback, from parents the young carers and health carer professionals, is the lack participation in after school activities. A number of reasons were given including financial, time restraints and having to be home to fulfil responsibilities related to the role of caring.

### **Qualitative Analysis**

The parent's perceptions, acknowledgement and validation of the role of their children as carers is documented in Chapter 1. Much of the information gleaned from the categories identified in the thematic analysis reflects what young carers themselves have said in this and previous reports (Carers Australia Summit reports). The value of this for these young carers is that their parents by acknowledging their experience also validate and somehow normalise their family life. The purpose here is not to focus on issues which have previously been addressed in the literature, but to highlight some new and meaningful information.

1. It was not the intention of the project to have young carers under 18 complete the questionnaire, however they did. An extremely positive aspect of this is that parents stated they had asked their children what they thought and then helped them complete the questionnaire. Other



parents indicated they had taken time out to talk to the young carers before they completed the questionnaire themselves.

2. A strong message from the parents and young carers is **that they want to spent time together**. The parents talked about a need to re-connect with their children without the disabled child present. The young carers want respite not for themselves but for their brother or sister so that they could have time with their parent(s) or even a family holiday.
3. Specific to WA is the response of the families to the programs run by Carers WA. This sends a strong message to funding organisations that support for these programs must continue.
4. So many of the parents and health care professionals (Study 3) raised the issue of these young people growing up too fast. They spoke about *"the third parent"* and *"my little mum"*. These findings support what those associated with young carers have been saying for a number of years. The question to be answered is what can be done and how can we make a difference to the lives of the young carers? It is a complex issue and no answered is offered. During the study it became apparent that a number of agencies and organisations (other than Carers WA) are running programs for young people who are in a caring role. It is suggested that:
  - i. A forum should be convened where information is shared about who is doing what, when, where and how.
  - ii. The participants in the forum should consider how effective the current programs are in helping young people. This would allow for identification of duplication in services.
  - iii. The agenda of the forum should include discussion on the development of a more collaborative approach to service delivery programs to young carers.
  - iv. A service directory should be developed which would include information about the programs offered with a specific focus on what services they can provide in relation to funding guidelines.
  - v. A consortium should be established which could take as part of their mission statement to accept the role of advocates for change at the political level.



In conclusion, it is relevant to consider that the number of young carers over 18 who responded was minimal. This may be due to the fact that some of these young carers are mothers and consider themselves parents rather than carers. The argument is also put forward that from 18 years of age these young people are empowered to make decisions for themselves and they can choose to be carers or not. This needs to be taken into account, as the majority of young carers identified are aged 5 to 15 and are not empowered they have no choice and no control over whether or not they care...

### **Social and Service Organisations identifying young carers.**

There has been considerable discussion about the ABS and Centrelink. Whilst the clarification about the source of the ABS data has been given and seems clear, the issues of who is and is not eligible for the Carers Payment and Allowance is as *clear as mud*. It is acknowledged that with young people the allowance is assessed on an individual basis but why is the age discrepancy so large? We know from the statistics that some children aged under 15 are receiving this payment and yet others are receiving Compensation Income and Disability Support. The research and discussion on in Chapter 2 is impartial but clearly it suggests that guidelines need to be structured to ensure consistency and equity. There needs to be political advocacy to effect change, this is an agenda which a Community Organisation Consortium could address. The eligibility of young carers who can receive this allowance is vital as it is argued the allowance could provide financial support for the young carer to participate in sporting or other after school activities.

### ***Identification and Snapshot of young carers***

This survey allowed for further exploration and development of the PICS. Information gleaned in Study 1 and 2 was included. The results indicate that inclusion of these additional factors was warranted and as such lends support to the assertions of the parents and young carers. An item on the Hidden Carers Survey sought clarification about the term carer. Interestingly the response was that young people did not perceive themselves as carers. However when asked for an alternative not many were offered. Future



research requires to work towards going a new term with which young people will relate.

### ***Measures***

Two questionnaires and one survey were developed to collect the data for studies 1, 2 and 3. The results from these studies were used to develop three measures, the Young Carer Identification Checklist (YICC) for use those who are in a position to identify young carers; the Young Carer Identification Checklist for years 7 to 12 and the Little People Checklist for children 4 to 10 years of age. These checklists allow for consideration of the tasks which young carers perform and they also allow for consideration of how caring affects their educational and psychological well-being. Pilot studies of these measure will be conducted in 2006 throughout WA<sup>10</sup> The scales are comprehensive and present a dynamic and innovative approach to identification of young carers within the community and the education system. Discussion relevant to the checklists is encouraged.

### ***Program Development***

An outcome of this project was that any suggestion for the development of a community program would have as its goal the sustainability by community. Time for the young carers to participate in after school activities was identified in all the studies. The following is a brief outline of a program which will be developed, implemented and evaluated in 2006.

- Families living within close proximity of each other who have a young carer will be invited to participate in the program.
- The aim of the program will be to have families assist other families with caring while a young carer in that family participates in after school activities (e.g., similar to what was known as the Babysitting Clubs of the 80's).
- A program of this type can be established and then continued by the families involved. It will also increase communication between families

A second important issue raised was the need for increased social interaction and one program which could be commenced would be a mentoring /buddy

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<sup>10</sup> Should you wish to pilot any of the checklists please contact Dr Morrow for scoring keys and discussion on inclusion in an Australia wide study.

approach. Consideration should also be given to developing communication/interpersonal skills programs for young carers. These programs could be developed by the counsellors at Carers WA and could be implemented in primary and high schools as part of a collaborative project with the education department.


Parents and children indicated that they wanted to spend more time together. Although additional funding would be required, movie days could involve parents and young carers rather than just the carers. It is also suggested that organisations who offer respite (e.g., Red Cross) could be approached to assist with caring to allow time for parent/child bonding.

This project had five aims all of which have been completed. There were a number of benefits and outcomes with one of the most important being the increased awareness of the life of a young carer. A major outcome of this project is that the Health Reform Implementation Taskforce workgroup have agreed to incorporate the issue of young carers on the database (personal communication, Kate Bethell, 25<sup>th</sup> October 2005). The media coverage has also promoted awareness in the community and many of those who participated in the studies have acknowledged that they have become more aware themselves as a consequence of their participation.

There is disappointment at the lack of support this project obtained, particularly from organisations who were requested to just provide the project with the number of young people who undertook programs with their organisations. The task was not difficult as indicated by the support given by the Executive Director of DSC. The influence of policy makers (e.g., government ministers) is required to ensure collaboration from government departments and agencies.

This project was three months in duration and included writing a research proposal and ethics application, developing questionnaires, conducting the research, data analysis and preparing and writing the final report. The duration and the scheduling did not permit for the inclusion of an extensive review of previous literature, as such a list of references and bibliography are given. It has been stated that the UK is much more advanced, not only in

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research but also in the application of the research findings, both in program development and also in political advocacy. In the main this report has integrated previous research findings within the report and had as its focus Australian research. This structure and scope (snapshot of parents, young carers and health care professionals and the development of measures) of this project is a first not only for WA but for Australia. It is acknowledged that there are similarities between young West Australian and young carers throughout Australia but there are also differences. A major finding of this report is that young carers are emotionally distressed and that their education is suffering as a consequence of their caring role. The key findings of this report suggest that we have a long and arduous road ahead to effect change for young carers at a social, educational and political level.

In conclusion this research project has identified 40,922 young carers in WA. This number may not be anywhere near the actual number of young carers in WA, as for example the ABS figures are two years old and as discussed previously we know there are additional data sources which were not included in this project and require to be explored. This exploration can only be undertaken with the permission, support and instigation of the relevant government agencies.

*In golf as in life it's the follow through that makes the difference  
..... we must make the difference*

*(unknown)*




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## **APPENDICES**

### **Appendix 1: Parent Questionnaire**



## PARENT QUESTIONNAIRE

### SECTION 1

This section asks information about the **person the young carer helps**. Please answer all questions by **filling in or ticking**  the appropriate response where necessary.

1. Gender                      Male                       Female
2. Postcode                      \_\_\_\_\_
3. Age (years)                      \_\_\_\_\_
4. Country of birth                      \_\_\_\_\_
5. Is English their first language?                      Yes                       No
6. Relationship status  
Single    Married    Partner/Defacto    Divorced    Separated    Widowed
7. Employment status  
Full time    Part time    Casual    Student    Unemployed    Voluntary
8. Do they receive any benefits?  
Carers Allowance/Payment    Unemployment    Study Allowance (e.g., Austudy)   
Other \_\_\_\_\_
9. Do they have help from any of the following?  
Silver Chain  Home and Community Care (HACC)    Meals on Wheels   
Community Aged Care Packages    Veteran Affairs   
Respite Care (e.g., time out from caring)    School    Family    Friends   
Other (e.g., Cultural or Voluntary)
10. What health issue (s) does the person have that your child helps?  
Physical    Intellectual    Psychological    Drug / Alcohol

PLEASE TURNOVER THE PAGE

11. What symptoms do they experience?

Loss of sight  Loss of hearing  Speech difficulties  Chronic or recurring pain

Breathing difficulties  Blackouts, fits or lack of consciousness  Mental illness

Learning understanding difficulties  Incomplete use of arms or fingers  Difficulty gripping

Incomplete use of feet or legs  A nervous or emotional condition

Restriction in physical activities or physical work  Head injury, stroke or other brain damage

Other \_\_\_\_\_

12. Does the person live in the same house as your child?

Yes  No

## SECTION 2

This section asks information **about the young carer**. Please answer **all** questions or where appropriate **tick** the box.

13. Gender Male  Female

14. Postcode \_\_\_\_\_

15. Age (years) \_\_\_\_\_

16. Country of birth \_\_\_\_\_

17. Is English your first language? Yes  No

18. Employment status

Full time  Part time  Casual  Student  Unemployed  Voluntary

19. Does your child receive?

Carers Allowance/Payment  Unemployment  Study Allowance (e.g., Youth Allowance)

Other \_\_\_\_\_

20. Who do they help care for? \_\_\_\_\_

21. When did they start helping?

Month \_\_\_\_\_ Year \_\_\_\_\_

22. How many hours per week do you help?

0-5 hours  5-10 hours  10-15 hours  15-20 hours  20 or more hours

23. What types of activities do they participate in?

Sport  Listening to music  Art  Hanging out with friends

Visiting family  Other \_\_\_\_\_

### SECTION 3

This section requests information about the **types of activities your child carries out** in their helping role. Please tick  **all** the relevant **boxes**.

<b>Activity</b>	<input checked="" type="checkbox"/>	<b>Activity</b>	<input checked="" type="checkbox"/>
Make telephone calls	<input type="checkbox"/>	Helping them to use public transport	<input type="checkbox"/>
Arrange appointments	<input type="checkbox"/>	Checking bills or bank statements	<input type="checkbox"/>
Attend doctors appointments	<input type="checkbox"/>	Paying bills	<input type="checkbox"/>
Washing	<input type="checkbox"/>	Filling in forms	<input type="checkbox"/>
Shopping	<input type="checkbox"/>	Writing letters	<input type="checkbox"/>
Vacuuming	<input type="checkbox"/>	Making minor home repairs	<input type="checkbox"/>
Dusting	<input type="checkbox"/>	Toileting	<input type="checkbox"/>
Preparing ingredients	<input type="checkbox"/>	Removing rubbish	<input type="checkbox"/>
Cooking food	<input type="checkbox"/>	Showering and bathing	<input type="checkbox"/>
Getting them into or out of bed	<input type="checkbox"/>	Dressing	<input type="checkbox"/>
Moving them about the house	<input type="checkbox"/>	Eating	<input type="checkbox"/>
Walking with them	<input type="checkbox"/>	Bladder or bowel control	<input type="checkbox"/>
Bending and picking up things for them	<input type="checkbox"/>	Transport	<input type="checkbox"/>
Speak with doctors, pharmacists and other health care professionals	<input type="checkbox"/>	Mowing lawns, watering, pruning shrubs, light weeding, planting	<input type="checkbox"/>
Changing light bulbs, tap washers, car registration stickers	<input type="checkbox"/>	Walking them up and down the stairs without a handrail	<input type="checkbox"/>
Getting them around a place away from the house	<input type="checkbox"/>	Other	<input type="checkbox"/>

### SECTION 4

Following is a list of statements, which may or may not be true about your child. For each statement **tick** the box  which you think applies to your son or daughter.

24. They sometimes don't sleep well

Definitely true       Probably true       Probably false       Definitely false

25. Their life has been affected (e.g., always have to be there to help)

Definitely true       Probably true       Probably false       Definitely false

26. They sometimes feel tired and lack energy

Definitely true       Probably true       Probably false       Definitely false

27. They sometimes worry

Definitely true       Probably true       Probably false       Definitely false

28. They need more support

Definitely true       Probably true       Probably false       Definitely false

PLEASE TURNOVER THE PAGE

29. Sometimes their helping means that they cannot attend school, university, college or work  
Definitely true       Probably true       Probably false       Definitely false
30. They have difficulty concentrating at school, university, college or work  
Definitely true       Probably true       Probably false       Definitely false
31. Sometimes their helping means that they miss out on social activities  
Definitely true       Probably true       Probably false       Definitely false

**OR**

32. Sometimes I have to care and cannot take them to social activities  
Definitely true       Probably true       Probably false       Definitely false
33. I think that they may sometimes feel depressed  
Definitely true       Probably true       Probably false       Definitely false
34. I know of an organisation that I can contact for support  
Definitely true       Probably true       Probably false       Definitely false

**SECTION 5**

What do you think would help your son or daughter in their helping role?

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**SECTION 6**

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

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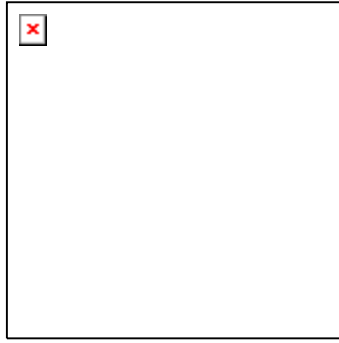
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Thank you for completing our questionnaire

(Remember to keep your half of the raffle ticket! Good luck!)

## Appendix 2: Young carer questionnaire





## YOUNG CARER QUESTIONNAIRE

### SECTION 1

This section asks **information about you**. Please answer **all** questions or where appropriate **tick the box** .

1. Gender                      Male                       Female
  2. Postcode                      \_\_\_\_\_
  3. Age (years)                      \_\_\_\_\_
  4. Country of birth \_\_\_\_\_
  5. Is English your first language?                      Yes                       No
  6. Relationship status  
Single     Married                       Partner/Defacto     Divorced     Separated                       Widowed
  7. Employment status  
Full time     Part time     Casual     Student     Unemployed     Voluntary
  8. Do you receive any benefits?  
Carers Allowance/Payment     Unemployment     Study Allowance (e.g., Austudy)   
Other \_\_\_\_\_
  9. Who do you help care for?                      \_\_\_\_\_
  10. When did you start helping?                      Month \_\_\_\_\_                      Year \_\_\_\_\_
  11. Do you receive any help/support in your caring role?  
Yes     No
- (If you answered Yes please go to question 12, if you answered No go to question 13)
12. Do you have help from any of the following?  
Silver Chain     Home and Community Care (HACC)     Meals on Wheels   
Community Aged Care Packages     Veteran Affairs     Respite Care (e.g., time out from caring)   
School     Family     Friends     Other (e.g., Cultural or Voluntary)

Please turnover the page

13. How many hours per week do you help?

0-5 hours  5-10 hours  10-15 hours  15-20 hours  20 or more hours

14. Does the person you help live in the same house?

Yes  No

15. What types of recreational activities do you participate in?

Sport  Listening to music  Art  Hanging out with friends

Visiting family  Other \_\_\_\_\_

16. What health issue (s) does the person have that you help?

Physical  Intellectual  Psychological  Drug / Alcohol

17. What symptoms do they experience?

Loss of sight  Loss of hearing  Speech difficulties  Chronic or recurring pain

Breathing difficulties  Blackouts, fits or lack of consciousness  Mental illness

Learning understanding difficulties  Incomplete use of arms or fingers  Difficulty gripping

Incomplete use of feet or legs  A nervous or emotional condition

Restriction in physical activities or physical work  Head injury, stroke or other brain damage

Other \_\_\_\_\_

## SECTION 2

Following is a list of statements, which may or may not be true about your life. For each statement **tick** the box  which most applies to you.

18. I sometimes don't sleep well

Definitely true  Probably true  Probably false  Definitely false

19. My life has been affected (e.g., always have to be there to help)

Definitely true  Probably true  Probably false  Definitely false

20. I sometimes feel tired and lack energy

Definitely true  Probably true  Probably false  Definitely false

21. I sometimes worry

Definitely true  Probably true  Probably false  Definitely false

22. I need more support

Definitely true       Probably true       Probably false       Definitely false

23. Sometimes my helping means that I cannot attend school, university, college or work

Definitely true       Probably true       Probably false       Definitely false

24. I have difficulty concentrating at school, university, college or work

Definitely true       Probably true       Probably false       Definitely false

25. Sometimes my helping means that I miss out on social activities

Definitely true       Probably true       Probably false       Definitely false

26. I sometimes feel depressed

Definitely true       Probably true       Probably false       Definitely false

27. I know of an organisation that I can contact for support

Definitely true       Probably true       Probably false       Definitely false

### SECTION 3

This section requests information about the **types of activities you carry out** in your helping role.

Please tick **all** the relevant **boxes**.

#### Activity

- Make telephone calls
- Arrange appointments
- Attend doctors appointments
- Washing
- Shopping
- Vacuuming
- Dusting
- Preparing ingredients
- Cooking food
- Getting them into or out of bed
- Moving them about the house
- Walking with them
- Bending and picking up things for them
- Speak with doctors, pharmacists and other health care professionals
- Changing light bulbs, tap washers, car registration stickers
- Getting them around a place away from the house

#### Activity

- Helping them to use public transport
- Checking bills or bank statements
- Paying bills
- Filling in forms
- Writing letters
- Making minor home repairs
- Toileting
- Removing rubbish
- Showering and bathing
- Dressing
- Eating
- Bladder or bowel control
- Transport
- Mowing lawns, watering, pruning shrubs, light weeding, planting
- Walking them up and down the stairs without a handrail
- Other

Please turnover the page



## **Appendix 3: Parent and Young Carer Introductory Letter**





### ***Participant Information Sheet***

Allow us to introduce ourselves we are Ros and Justine. We are conducting research on behalf of Carers WA. The purpose of the study is finding out how many young people in WA help family and friends and also to find out what they do to help.

If you are the parent/guardian of a child aged between 5 and 18 who gives you an extra helping hand in looking after a family member or friend who is disabled or ill we would appreciate it if you could complete the attached questionnaire on their behalf. If you are aged between 18 and 26 and help someone close to you we would like you to complete the questionnaire. It will only take you 10 minutes and make the task more



***Why not make a cuppa and relax while you complete the questionnaire***



enjoyable we have attached a tea bag for you to make a cuppa.

As you can see we have attached a raffle ticket. When you have completed the questionnaire send it back in the stamped addressed envelop provided (tear off the raffle ticket half which is not stapled) and your ticket will be put in the draw to win one of three shopping vouchers.

Your participation is voluntary and your anonymity is assured. All information will be maintained by the researchers and 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.

Ethics approval has been granted by Carers WA and the Curtin University of Technology (School of Psychology) Should you wish to discuss your participation or the study you may contact either of the researchers:

Dr Ros Morrow  
Project Manager  
School of Psychology  
Curtin University of Technology  
Phone: 08 9266 3036 / 0417 095 725

Justine Spencer  
Research Officer  
School of Psychology  
Curtin University of Technology  
Phone: 08 9266 3036 / 0413 314 578

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

Regards,

***Ros and Justine***

Dr Ros Morrow and Justine Spencer

## **Appendix 4: Media Distribution List and Media Articles**

## Young Hidden Carer Media Release Distribution

The West Australian  
Canning Times  
Comment News  
Cockburn Gazette  
Eastern Reporter  
Fremantle Gazette  
Guardian Express  
Kalamunda Reporter  
Hills Gazette  
Joondalup Times  
Coastal Times  
Melville Times  
Midland Reporter  
North Coast Times  
Southern Gazette  
Stirling Times  
Wanneroo Times  
Week-end Courier  
Western Suburbs Weekly

Disability Service Commission  
CHEERS (Staff Newsletter)  
DSC Staff web page

Youth Sector Update  
Youth Affairs Council of WA



## COVER STORY NEVER TOO YOUNG TO CARE

## YOUNG CARERS

**W**A children caring for sick and disabled relatives are carrying out tasks that occupational, health and safety regulations ban workers more than twice their age from doing, warns Carers WA.

These young carers — often younger than 10 — help to lift parents or siblings and put in long hours, partly because they are shouldering the responsibility of care that has been moved out of institutions and into homes.

Not only do they help with cleaning or cooking, medication, dressing and showering and supervision but also find themselves left with such complex adult tasks as negotiating service delivery systems, pleading for the electricity and telephone services not to be cut off because bills have not been paid,

### 'Young carers have remained a hidden group taking on a burden beyond what could reasonably be expected.'

carrying out intimate personal care and providing emotional support. Even when at school, some are having to leave mobile phones on during class so that they can be called out to respond to problems that suddenly arise at home.

In their own words to Carers WA, they say a lack of effective support and recognition of all they do has robbed them of childhood and innocence, damaged their physical and mental wellbeing, interrupted their education and affected their job prospects, while also making it harder for them to fit in and make friends, leaving them the target of bullying and teasing.

They end up quitting school earlier and achieving less educationally than any other group in the State, says Carers WA. Community relations manager Tina Williams says about 37,300 young West Australians under 26 have already found themselves in the role of carer and numbers are expected to increase dramatically due to recent rises in mental health, alcohol and drug problems among adults and the breakdown of family units.

Others have questioned whether there will be added pressure on the kids

from Health Minister Jim McGinty's plan to invest \$7.6 million in a HealthyHome program, which would pay for doctors, nurses and allied health professionals to visit the homes of chronically ill patients instead of keeping them in hospital.

"Policy changes that have been welcomed in the past, such as deinstitutionalisation and care in the community, have moved responsibility for care directly back into the home," said Carers WA in its report on the needs of young carers. "These policy changes have brought a more humane and respectful acknowledgement of families' needs to be together, however, they have also brought about a range of unintended effects. . . . Young carers have remained a hidden group taking on a burden well beyond what could reasonably be expected."

Carers WA says despite the high estimates of young carers, it is in regular contact with only about 300.

Some youths did not even recognise themselves as carers, just seeing their tasks as something family members did for each other. But also there was an element of young carers and parents concealing themselves because of fears that social welfare intervention may result in the break-up of the family.

There are also stories of others angry at the system because of its inflexibility in the past, with young people acting as the main carer unable to qualify for support because there was an older adult living in the house and those whose allowance was in jeopardy if they took time out from caring to start a university degree. Of WA's 1100 children known to be primary carers, only 560 receive a carer allowance.

Changes that have occurred since Carers WA's young carers' forum was held in 2003 and followed by a national young carer summit in Sydney in 2004 have been small and slow. A bit of extra money has been made available for the establishment of a young carers' network, support packages and social activities, as well as more respite care. Other suggestions not followed up included free follow-up education if their

schooling was interrupted by caring, extra tutoring, home schooling, education credits given for health and care work already done in the home and time-out rooms set up in schools to enable them to get some sleep if needed.

There was also talk of free public transport for young carers and ensuring greater assistance in personal care tasks and home help was provided by those care workers brought in.

"People walked out of that summit vowing that they would make things better for these young people," Carers WA executive director Noreen Fynn said. "It has been an eye-opener to us even working in the caring industry."

Ms Williams said action was happening, but more had to be done. "It is difficult to find young carers and we cannot get help and money to them unless we find them," she said.

"For some, what they are doing is the most normal thing in the world and they do not see it as a chore. But we look in from the outside and see a kid who could do much more to enjoy themselves."

Curtin University psychologist Ros Morrow is trying to determine the exact numbers and needs of young carers in WA, by analysing data from Centrelink, the Australian Bureau of Statistics, the WA Department for Community Development and Disability Services Commission and questioning known carers.

"As yet, we do not have a clue who is out there helping and caring," she said. "I am a psychologist and going through the data we have collected so far. . . . I was in tears and could not work for the rest of the day. I feel sad about what some of these young people are going through and that they are not aware of what they are missing out on."

Young carers, or those who can help to get in contact with one, can contact Dr Morrow on 9266 3036 or 0417 095 725 or on [r.morrow@curtin.edu.au](mailto:r.morrow@curtin.edu.au) and she will email out a survey that takes 10 minutes to fill in.

If you are a young carer (or parent or teacher) and would like information on mentoring programs, time-out days, camps, young carer kits and the young carers network, call 1800 242 636 or see [www.youngcarers.net.au](http://www.youngcarers.net.au).

## Young carers need help

MANY young carers are not identified in their roles and consequently do not get the support they need says psychologist Ros Morrow.

Dr Morrow, a senior psychology lecturer at Curtin University, is studying these "hidden carers" and the problems they face.

"As young carers, they don't get funding from places such as Centrelink," she said.

"A child may become a carer if, for example, they have a single parent with cancer and they take on the role of looking after the family including washing, cooking and sometimes missing days of school.

"We have no idea how many children there are in a situation like that and I want to identify as many as I can."

Dr Morrow said Carers WA asked her to do the research after she had completed research into middle-aged female hidden carers.

She sent questionnaires to young people who were already listed with Carers WA and also to people in the community who have contact with young people, such as chaplains.

She said the questionnaires were anonymous but asked for a postcode to identify the area.

"I'm hoping to find out things such as what the young carers do, what they are missing out on, whether their sleep patterns are disturbed and if they suffer from depression," she said.

"Once we can get numbers and identify specific areas then we can look at intervention programs.



Young carers alone.

"This is going to make a difference to young people's lives."

Dr Morrow is calling for volunteers to help with her research by filling out a questionnaire.

If you know a young carer or you have a child who has this role, email [r.morrow@curtin.edu.au](mailto:r.morrow@curtin.edu.au) or call 0417 095 725.

## **Appendix 5: Introduction of the study to Carers WA Interagency Steering Committee**





September 5<sup>th</sup> 2005

Good morning everyone,

My name is Ros Morrow and I am a Senior Lecturer in the School of Psychology at Curtin University. I am currently on study leave a part of which is conducting a collaborative research project with Carers WA. I met with some of you at the August meeting of the Young Carer Interagency group when I briefly introduced the research project and possible whys in which we could collaborate on the project.

For those whom I did not meet the brief for the project, which is broad, is to *"identify the number of young hidden carers in WA"*. The project has some funding and part of this has been used to employ a Research Officer: Justine Spencer. Justine and I will both be working on the project 2 days a week, for a period of 3 months, not long for the brief we have from Carers WA. The purpose of this letter is to request your help in a number of ways. Firstly let me define for you what we are terming as a young hidden carer:

*" Children and young people between the ages of five and eighteen years whose lives are in some way restricted because of the need to take responsible for the care of a parent, sibling or other family member".*

*(this definition was employed by the Young Carers- Perth and Kinross Project 2002 conducted in rural areas of East Scotland).*

*"These children and young people will not be known as carers to any agencies or services and therefore receive no support in their caring role"*  
*(Carers NSW, 2001).*

How can you help us?

#### Databases

- ✓ Some of you will have a database which can identify young carers through special demographic and social data. We would like to have permission to liaise with the staff member(s) responsible for the database
  1. to obtain information on the type of data collected (e.g., information on your database)
  2. to obtain an activity report based on the checklist for our project (e.g., statistics)

**We do not want to have access to your data bases and we do not require any personal details we would just like you to generate a report for us.**

## Questionnaire/Survey

We are in the process of developing a survey, to be distributed electronically, to all government agencies and community organisations. The purpose of the survey is to source information which will give us an estimate of young people in caring roles (e.g., the hidden carers).

- ✓ To achieve this aim we would like to invite your organisation to participate in the process. The task is really simple:

**We will email you the survey which you can forward to all staff that interact/work with clients (e.g., case managers and counsellors) who may know of children who are helping their clients. It is envisaged that the survey will take 10 minutes to complete and can be returned directly to the research team via email.**

## Flyers and Posters

We would also like you to place flyers and/or posters on your noticeboards and reception areas which give details of the new Young Carers website which is really user friendly.

I understand that you may **not** be the person who can authorise all of the aforementioned. If this is the case could you advise me **who** I should contact. We would like to forward the surveys in the next 3 to 4 weeks.

If you would like to meet with me to discuss the project and share your knowledge of the area I would be very grateful for this opportunity. Perhaps you know of others within your organisation that could help with the project perhaps we could have a focus group discussion. You can contact me by return email or on my mobile 041 7 095 725 if you would like me to visit.

Thank you for taking the time to read this "epistle" and thank you also for the support which I am sure you will give to this important project.

Regards

Dr Ros Morrow

Email: [r.morrow@curtin.edu.au](mailto:r.morrow@curtin.edu.au)  
[rosmorrwo@westnest.com.au](mailto:rosmorrwo@westnest.com.au)  
m 0417 095725

## **Appendix 6: Hidden Carer Project Introduction to Agencies**





September 5<sup>th</sup> 2005

Good morning

My name is Ros Morrow and I am a Senior Lecturer in the School of Psychology at Curtin University. I am currently on study leave a part of which is conducting a collaborative research project with Carers WA. The purpose of this letter is to request your help in a number of ways. Firstly let me define for you what we are terming as a young hidden carer:

*“ Children and young people between the ages of five and eighteen years whose lives are in some way restricted because of the need to take responsibility for the care of a parent, sibling or other family member”.*

*(this definition was employed by the Young Carers- Perth and Kinross Project 2002 conducted in rural areas of East Scotland).*

*“These children and young people will not be known as carers to any agencies or services and therefore receive no support in their caring role” (Carers NSW, 2001).*

I understand that you run a program for children who are living in a family where there is either an alcohol or drug related problem. These young people are quite likely to be helping with household tasks (e.g., cooking, shopping, finances). In terms of the Carer organisations these young people would be classified as young carers. In WA and Australia we have absolutely no idea of the number of young hidden carers. In order to get an “estimate” we are contacting all government and community organisations that who may have databases or other resources which could help us identify these young people. The on going goal is to develop better intervention programs.

### How can you help us?

Young People’s Program

3. to obtain information on the type of data collected (e.g., what demographic data)
4. to obtain an activity report based on the checklist for our project (e.g., statistics)

**We do not want to have access to your data bases and we do not require any personal details we would just like you to generate a report for us.**

## Questionnaire/Survey

We are in the process of developing a survey, to be distributed electronically, to all government agencies and community organisations. The purpose of the survey is to source information which will give us an estimate of young people in caring roles (e.g., the hidden carers).

- ✓ To achieve this aim we would like to invite your organisation to participate in the process. The task is really simple:

**We will email you the survey which your IT support can forward to all staff that interact/work with clients (e.g., case managers and counsellors) who may know of children who are helping their clients. It is envisaged that the survey will take 10 minutes to complete and can be returned directly to the research team via email.**

## Flyers and Posters

We would also like you to place flyers and/or posters on your noticeboards and reception areas which give details of the new Young Carers website which is really user friendly (<http://www.youngcarers.net.au>)

I understand that you are not the person I would meet with or talk to but would be grateful if you could authorise the person who oversees your database to meet with me, or alternatively for me to give them the list of information we are seeking for them to generate a report. May I reiterate we do not require any personal details merely numbers (e.g., how many young people in the last year did the program, type of dependency, age, gender and rural or metropolitan).

I know you are extremely busy and I understand that you must get requests all the time but the only way we can get any idea of numbers of young hidden carers is with the help of agencies such as yours. We know from the young carers who have support that they miss school, are bullied, suffer depression and low self esteem as well as having little time to interact socially.

## **Please take the time to help.**

You can contact me by return email or on my mobile 041 7 095 725 if you would like me to visit.

Thank you for taking the time to read this "epistle" and thank you also for the support which I am sure you will give to this important project.

Regards

*Ros Morrow*

Dr Ros Morrow

Email: [r.morrow@curtin.edu.au](mailto:r.morrow@curtin.edu.au)  
[rosmorrwo@westnest.com.au](mailto:rosmorrwo@westnest.com.au)  
m 0417 095725



## Appendix 7: Hidden Carer Survey





## Participant Information Sheet

Allow me introduce myself I am Dr Ros Morrow from Curtin University of Technology. I am conducting research in collaboration with Carers WA. The purpose of the project is finding out how many young people in WA help family and friends (e.g., a young hidden carer) and also to find out what they do to help.

Firstly let me define for you what we are terming as a young hidden carer:

***“ Children and young people between the ages of five and eighteen years whose lives are in some way restricted because of the need to take responsible for the care of a parent, sibling or other family member”.***

***(This definition was employed by the Young Carers- Perth and Kinross Project 2002 conducted in rural areas of East Scotland).***

***We are also interested in identifying young people between the age of 18 and 26***

***“These children and young people will not be known as carers to any agencies or services and therefore receive no support in their caring role” (Carers NSW, 2001).***

What I would like you to do is complete the attached Survey, which will only take you 10 minutes. The survey asks you to “think about” the number of young people you see, talk to or know that meet the above criteria, we do not want to know who they are (e.g., no names). I know this is only an estimate but at least it gives us a starting point to lobby government, implement awareness and intervention programs as well as develop a checklist suitable for use by health care workers.



*Why not make a cuppa and relax while you complete the survey*

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.

Ethics approval has been granted by Carers WA and Curtin University of Technology (School of Psychology). If you would like to discuss your participation in the study you can contact me:

Email: [rosmorrow@westnet.com.au](mailto:rosmorrow@westnet.com.au)  
[r.morrow@curtin.edu.au](mailto:r.morrow@curtin.edu.au)

Mobile: 0417 095 725

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:

\_\_\_\_\_

# Young Hidden Carer Identification Survey

## INSTRUCTIONS

**PLEASE EMAIL/GIVE the Participant Information Sheet and this Survey to colleagues who you think could answer the questions.**

If you are completing this survey electronically you have two options to indicate your answer:

1. Highlight it, on the toolbar second line down, RHS, next to the **font colour** all you have to do is click on and then click on you answer.
2. Put a capital X on your answer
3. Where appropriate type your response.

## INFORMATION ABOUT YOU

Organisation/Agency (e.g., Education Department, Community Organisation)

**OPTIONAL:** Specific organisational details (e.g., Mt Lawley Senior High School, MS Society)

Location: City    Post Code                      Country                      Post Code

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

## ABOUT THE YOUNG HIDDEN CARERS

### *Definition*

*“Children and young people between the ages of five and eighteen years whose lives are in some way restricted [affected] because of the need to take responsible for the care of a parent, sibling or other family member”.*

*“These children and young people will not be known as carers to any agencies or services and therefore receive no support in their caring role”*

*Please take a few minutes to think about the children or young people whose lives are affected that you know of.*

*Now before you begin the survey could you write down a few of the words that describe the children and young people you mentally identified? (e.g., sad, coping, happy, positive, wonderful)*

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

5 to 10 years of age		11 to 15 years of age	
16 to 18 years of age		19 to 26 years of age	

Who do they care for?      Parent(s)            Sibling(s)        
                                          Grandparent(s)            Other (specify)

This section requests information about the **types of tasks** the children or young people carry out in their role of helping. Please tick **all** the relevant **boxes**.

Activity	X	Activity	X
Make telephone calls		Helping them to use public transport	
Arrange appointments		Checking bills or bank statements	
Attend doctors appointments		Paying bills	
Washing		Filling in forms	
Shopping		Writing letters	
Vacuuming		Making minor home repairs	
Dusting		Toileting	
Preparing ingredients		Removing rubbish	
Cooking food		Showering and bathing	
Getting them into or out of bed		Dressing	
Moving them about the house		Eating	
Walking with them		Bladder or bowel control	
Bending and picking up things for them		Transport	
Speak with doctors, pharmacists and other health care professionals		Mowing lawns, watering, pruning shrubs, light weeding, planting	
Changing light bulbs, tap washers, car registration stickers		Walking them up and down the stairs without a handrail	
Helping with a sibling		Other(specify)	
Getting them around a place away from the house			

What are the most common health issues that the children and/or young persons you have identified have to face? PLEASE RANK ORDER (e.g., **MOST COMMON= 1**)

Mental Health Issue		Sensory Impairment	
Learning Difficulty		Head Injury	
Physical Disability		Behavioural Difficulty	
Drug and Alcohol		Other (specify)	
Frail/Older Adult			

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?			

The next few questions are really important, in thinking about the children and young people you have identified

Do they/would they think of themselves as carers

YES                      NO

Is there another word which they use other than carer that describes what they do?

YES                      NO

If you answered YES could you please give a few examples?

Is there anything else you would like to share or comment on?

*Thank you for taking the time to complete this survey it will make a difference to the young people you have identified lives.*

## **Appendix 8: Media Release to Organisations**





## Media Release

Carers WA and Dr Ros Morrow from Curtin University of Technology are conducting research to identify the number of young carers there are in WA.

Many young people aged between 5 and 26 find themselves helping a parent who is sick or helping a parent look after a brother or sister, or care for a partner. This can in some way restrict a young person's life.

You maybe a parent who has a child who helps you or you maybe a teacher, case manager or counsellor who knows of a child in a family who helps care for someone. Perhaps you are a wife, husband or partner of someone who needs help.

If you know of one or a number of children or young people who fit the above criteria we would really like you to contact us and arrange to complete a survey. The survey is 2 pages and will take 10 minutes and can be completed online or we can post it to you.

This is a really important project and we appreciate your help.

Please contact Dr Ros Morrow on 9266 3036 or 0417 095 725 or by email [rosmorrow@westnet.com.au](mailto:rosmorrow@westnet.com.au)

**For immediate release**  
**11<sup>th</sup> October 2005**



## **Appendix 9: Young Carer Identification Checklist (YCIC)**

**Young Carer Identification Checklist (YCIC)**

Young Carer: \_\_\_\_\_ DOB: \_\_\_\_\_

Assessed by: \_\_\_\_\_ Date: \_\_\_\_\_

Referred: Yes  No  Referred to: \_\_\_\_\_


Age Range of Young Carer: 5 to 10 years  11 to 15 years  16 to 18 years  19 to 26 years

<b>Instrumental Activities of Daily Living (IADLs):</b>	<input checked="" type="checkbox"/>
Taking out rubbish	
Shopping	
Dusting	
Cooking food	
Preparing ingredients	
Vacuuming	
Washing	
Making telephone calls	
Household repairs and gardening	

<b>Activities of Daily Living (ADLs):</b>	<input checked="" type="checkbox"/>
Dressing	
Bending and picking up things for them	
Walking with them	
Getting them into or out of bed	
Showering and bathing	
Eating / Feeding	
Getting them around a place away from the house	
Moving them about the house	
Toileting	
Arranging / Attending doctors appointments	
Helping them to use public transport / Transport	
Writing letters / Completing forms	
Bladder or bowel control	
Speak with doctors, pharmacists and other health care professionals	
Checking bills or bank statements / Paying bills	

<b>Educational Psychological Implications of Caring Checklist (EPICC):</b>	<input checked="" type="checkbox"/>
<b>Educational Subscale</b>	
Missing school	
Contacting home while at school	
Report being bullied	
Homework doesn't get done	
Aren't able to concentrate	
Late for school	
Don't participate in after school activities	
Report to sickbay / Visit nurse	
Report not sleeping well	
Tired and lack energy	
<b>Psychological Subscale</b>	<input checked="" type="checkbox"/>
Don't interact with other children / Young persons	
Seem to be depressed	
Demonstrate anger and / or frustration	
Unhealthy behaviours (smoking and / or drug use)	
Quiet and withdrawn	
They worry	
Emotionally upset (e.g. crying)	
Suffer from eating disorders	

**Identification:**  
 For screening purposes, it is suggested that a **threshold of 50%** of the ADLs and the EPICC is adopted to identify a young carer.  
 If identified, a young carer should be provided the Carers WA – Young Carers Program telephone number - 1800 242 636.



## **Appendix 10: Young Carer Identification List – High Schools: 'Me and My Story'**

## Me and My Story

School: \_\_\_\_\_ Year: \_\_\_\_\_

Gender: \_\_\_\_\_ What age are you? \_\_\_\_\_ Date: \_\_\_\_\_

<b>SECTION 1:</b> <b>Which chores do you do at home?</b>	<input checked="" type="checkbox"/>
Take out the rubbish	
Shopping	
Dusting	
Cooking food	
Preparing ingredients for meals	
Vacuuming	
Washing	
Make telephone calls	
Household repairs and gardening	

<p><b>Do you help anyone at home? Yes <input type="checkbox"/> No <input type="checkbox"/></b>  <b>If you answered YES go to SECTION 2. If you answered NO, go to SECTION 3.</b></p>
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<b>SECTION 2:</b> <b>Which helping roles do you complete?</b>	<input checked="" type="checkbox"/>
Dressing	
Bending and picking up things for them	
Walking with them	
Getting them into or out of bed	
Showering and bathing	
Eating / Feeding	
Getting them around a place away from the house	
Moving them about the house	
Toileting	
Arranging / Attending doctors appointments	
Helping them to use public transport / Transport	
Writing letters / Completing forms	
Bladder or bowel control	
Speaking with doctors, pharmacists and other health care professionals	
Checking bills or bank statements / Paying bills	

<b>SECTION 3:</b> <b>Now we would like to know a little bit about your school life. Do you ever...</b>	<input checked="" type="checkbox"/>
Miss school	
Have to contact home during school	
Get bullied	
Don't finish your homework	
Find it difficult to concentrate	
Get to school late	
Don't participate in after school activities	
Report to sickbay / Visit nurse	
Don't sleep well	
Feel tired and lack energy	

<b>SECTION 4:</b> <b>Now we would like to know a little bit about you...</b>	<input checked="" type="checkbox"/>
I spend lots of time with my friends	
I feel sad and depressed sometimes	
I get angry or frustrated sometimes	
I smoke or take drugs	
I often want time alone	
I often worry	
I get upset (e.g. crying)	
I don't eat meals regularly	

## **Appendix 11: Young Carer Telephone Intake Questionnaire**





## YOUNG CARER TELEPHONE QUESTIONNAIRE

### GENERAL INFORMATION

Date		Time	
Person Contacting		How Contacting	
Received By		History ID#	

1. Client ID# \_\_\_\_\_
2. Title \_\_\_\_\_
3. First name \_\_\_\_\_
4. Last name \_\_\_\_\_
5. Organisation \_\_\_\_\_
6. Position \_\_\_\_\_
7. Street Address \_\_\_\_\_
8. Postal Address \_\_\_\_\_ Suburb \_\_\_\_\_ Postcode \_\_\_\_\_
9. Telephone Home \_\_\_\_\_ Work \_\_\_\_\_  
Mobile \_\_\_\_\_ Fax \_\_\_\_\_
10. Email \_\_\_\_\_
11. Reason for call (#) \_\_\_\_\_

### SECTION 1

This section asks information about the young carer. Complete all questions or where appropriate tick the box .

1. Gender Male  Female
2. Postcode \_\_\_\_\_
3. Date of birth \_\_\_\_\_
4. Country of birth \_\_\_\_\_
5. IATSI? Yes  No
6. Indigenous Australian (Not TSI) Yes  No
7. TSI (Not Indigenous Australian) Yes  No

8. Their primary language? \_\_\_\_\_

9. Their secondary language? \_\_\_\_\_

10. Relationship status

Single  Married  Partner/Defacto  Divorced  Separated  Widowed

11. Employment status

Full time  Part time  Casual  Student  Unemployed  Voluntary

12. Do they receive any benefits?

Carers Allowance/Payment  Unemployment  Study Allowance (e.g., Austudy)

Other \_\_\_\_\_

13. How many people do they help care for? \_\_\_\_\_

14. Their relationship to the care recipient(s)? \_\_\_\_\_

15. When did they start helping? Month \_\_\_\_\_ Year \_\_\_\_\_

16. Do they receive any help/support in their caring role? Yes  No

(If YES, please go to question 17. If NO, go to question 18)

17. Do they have help from any of the following?

Silver Chain  Home and Community Care (HACC)  Meals on Wheels

Community Aged Care Packages  Veteran Affairs  Respite Care (e.g., time out from caring)

School  Family  Friends  Other (e.g., Cultural or Voluntary)

18. How many hours per week do they help?

0-5 hours  5-10 hours  10-15 hours  15-20 hours  20 or more hours

19. Does the person they help live in the same house? Yes  No

20. What types of recreational activities do they participate in?

Sport  Listening to music  Art  Hanging out with friends

Visiting family  Other \_\_\_\_\_

21. What health issue (s) does the person have that they help?

Physical  Intellectual  Psychological  Drug / Alcohol

22. What symptoms does the person they help experience?

Loss of sight  Loss of hearing  Speech difficulties  Chronic or recurring pain

Breathing difficulties  Blackouts, fits or lack of consciousness  Mental illness

Learning understanding difficulties  Incomplete use of arms or fingers  Difficulty gripping

Incomplete use of feet or legs  A nervous or emotional condition

Restriction in physical activities or physical work  Head injury, stroke or other brain damage

Other \_\_\_\_\_

23. Does the person they help suffer from Dementia? Yes  No

24. Can CarersWA contact the young carer? Yes  No

25. Is the young carer a member? Yes  No

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## SECTION 2

This section requests information about the **types of activities the young carer carries out** in their helping role. Please tick **all** the relevant **boxes**.

### Activity

- Make telephone calls
- Arrange appointments
- Attend doctors appointments
- Washing
- Shopping
- Vacuuming
- Dusting
- Preparing ingredients
- Cooking food
- Getting them into or out of bed
- Moving them about the house
- Walking with them
- Bending and picking up things for them
- Speak with doctors, pharmacists and other health care professionals
- Changing light bulbs, tap washers, car registration stickers
- Getting them around a place away from the house

### Activity

- Helping them to use public transport
- Checking bills or bank statements
- Paying bills
- Filling in forms
- Writing letters
- Making minor home repairs
- Toileting
- Removing rubbish
- Showering and bathing
- Dressing
- Eating
- Bladder or bowel control
- Transport
- Mowing lawns, watering, pruning shrubs, light weeding, planting
- Walking them up and down the stairs without a handrail
- Other

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## SECTION 3

This section asks **information about the care recipient**. Complete **all** questions or where appropriate tick the box .

1. Client ID# \_\_\_\_\_

2. Title \_\_\_\_\_

3. First name \_\_\_\_\_

4. Last name \_\_\_\_\_

8. Street Address \_\_\_\_\_ Suburb \_\_\_\_\_ Postcode \_\_\_\_\_



1. Gender Male  Female

3. Date of birth \_\_\_\_\_

4. Country of birth \_\_\_\_\_

5. IATSI? Yes  No

6. Indigenous Australian (Not TSI) Yes  No

7. TSI (Not Indigenous Australian) Yes  No

8. Their primary language? \_\_\_\_\_

9. Their secondary language? \_\_\_\_\_

10. Relationship status

Single  Married  Partner/Defacto  Divorced  Separated  Widowed

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## SECTION 4

Notes:

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<b>Outcomes/Please Send</b>	<b>Issues</b>
<b>CAWA Event</b>	<b>Referral Source</b>

**Referral To:**

<input checked="" type="checkbox"/>		
	Resource Centre	
	Carer Support	
	Counselling	
	Training	
	Mental Health Advocacy	
	Media	
	Other	
	Policy / Young Carers	

**Follow Up Is:**

	Urgent		Non-urgent (5+ days)
	Telephone		Email
	Required on:		