Reading Between the Lines:
Listening to Children and Young People about their Experiences of Young Caring

A report by the Youth Coalition of the ACT - 2005
Reading Between the Lines:
Listening to Children and Young People About Their Experiences of Young Caring in the ACT

A Report to the ACT Department of Disability, Housing and Community Services

by Tim Moore
Youth Coalition of ACT

April 2005
This project was conducted by the Youth Coalition of the ACT with funding from the ACT Department of Disability, Housing and Community Services.

The project was managed by Tim Moore who also compiled this report. It was conducted with the Young Carers Research Team which included peer researchers Jamie Gray, Rebecca Johnstone, Morgan Pettit, Madeleine Nield and Jess Butler with support, training and guidance from Elizabeth Morgan of Morgan Disney and Associates and Helen McPherson from the Youth Coalition.

The project was conducted with assistance from the Australian Catholic University under the supervision of Dr Morag McArthur.

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The front cover was designed by Louise Grant from Ringtail Fine Art.

The project team would like to acknowledge the generosity, courage and insight of all the children and young people who participated in the project and for the outstanding contribution they make to the lives of their families. It is hoped that this report will shed some light on their experiences: their wins, their challenges, their hopes and dreams and that it will lead to greater levels of support from their community.
Drowning Inside

We look fine on the Outside  
We love and care and flirt  
But on the inside we’re drowning  
Under all the pain and hurt  

We try to swim to the surface  
Using good times as our power  
But the bad times all catch up with us  
And we’re deep under within the hour  

We’re wading and wading and wading  
Through the pain and hurtful times  
People think we’re doing quite all right  
But read between the lines  

They don’t know the pain we feel  
I wish they could understand  
Instead I have to keep on walking  
And bury it under the sand  

I hate it when they stare at them  
They didn’t do anything wrong  
And yet because they’re disabled  
It seems they don’t even belong  

They just keep pushing and pulling  
And pushing me more and more  
And sometimes I can’t take it  
And I fall right down to the floor  

I don’t know how I keep on going  
And I don’t how we all do  
We survive another stressful day  
And awake the next all new  

It’s getting harder everyday  
The weights grow more and more  
And slowly I sink down deeper  
To the bottom of the ocean floor  

Options pop up in my life  
Of suicidal release  
Its seems like a good idea  
To let myself rest in peace  

I want to let it all go  
And drop the weights of pain  
I just want it all to stop  
Like the end of stormy rain  

But then I look at my family  
How would they do without me  
They’d be stuck with the pain  
And I would be free  

And so I realise the facts  
I can’t go and die  
I’ve so much to live for  
So I get up and try  

Try to keep it together  
Try to swim to the top  
Try to make it feel all right  
Try to make the pain stop  

But the pain will never stop  
The pain doesn’t go away  
The pain will always be there  
The pain will always stay  

We shout out in pain and tears  
A Voice that cries for support  
A voice that’s never heard out  
A voice that chocks and distorts  

One person may hear this poem  
While a million won’t even bother  
But at least one more person will understand  
What it is to be a young carer  

Michael Peet 2004
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1. Introducing the Project

1.1 Project Rationale

Young carers are a group of young people within our community whose lived experiences, needs, and aspirations have not been fully identified or understood within either popular or academic discourse (Olsen, 1996, Oreb, 2000). In fact, it is only in recent times that they have been identified as a target for research within both the international and Australian contexts (Dearden and Becker, 1998; CA, 2002) and more recently as service recipients (Oreb, 2000).

What has been discovered in the limited research, however, is that as a result of their often-significant care responsibilities, young carers’ lives are impacted upon. For some, this may be positive, with young carers reporting greater levels of connectedness, more positive relationships within the family, more developed skills and feelings of greater purpose (CA, 2002, p11; Olsen 1996, p44). Others however report negative impacts – with many experiencing poor health and well-being (Ell, 1990), social disconnection (Becker, 1999), poverty (CA, 1998), poor outcomes in education and training (ACTYCN, 2000, CA, 2002) and transitions into adulthood (Dearden and Becker, 2000).

Research previously conducted in Australia has primarily focused on the experiences of young people aged 15 to 25 who have been deemed the ‘primary’ carer within families affected by disability or illness. As such, most studies have failed to investigate the needs of children and young people under the age of 15, of those in families affected by alcohol or other drug issues, and of those who assume significant care responsibilities but who are not deemed to be the ‘primary carer’ for their relative or friend. The result of adopting limited targets of focus has meant that often those most in need of support (including those most socially isolated and disconnected) are also forgotten within the research and the ensuing policy and program development.

Recognising these discrepancies, this research project has chosen to focus on the experiences of children and young people under the age of 18 including those with care responsibilities who do not consider themselves to be ‘young carers’ and / or have not previously been identified as such.

1.2 Project Aims

The aims of this research project, developed with young carers, their parents, workers from agencies supporting them, was to identify:

- the lived experiences of young carers in the ACT,
• the reported impacts that caring can have on young carers’ lives (both positive and negative),
• young carers service and support needs, and
• ways that the service system might better respond to their needs and to connect them to increased life opportunities.

This report, *Reading Between the Lines: Listening to Children and Young People about their Experiences of Young Caring in the ACT* attempts to tell the stories of children and young people with care responsibilities in the ACT and to look at the ways in which they see that caring impacts on their lives and the lives of their families.

A second report, *More than Words: Responding to the Needs of Young Carers* aims to identify young carers’ service needs and ways in which the service system and the broader community can best respond.

An Executive Summary, which includes a summary of findings and key recommendations, has also been developed and is available separately.
2 Methodology

2.1 Research Approach

A great proportion of social research focusing on ‘at-risk’ groups within our community has failed to accurately capture and reflect the experiences, stories and wishes of those already marginalised (Oliver, 1992). Through the process of social research where an ‘expert’ controls the paradigm within which the research is conducted and the practices that define it, people can be disempowered, disconnected and disenfranchised.

However, recent work utilising emancipatory research methods show that it is both possible and practicable for research subjects to actively participate within the research process and, by doing so, share in the development of credible and responsive data while developing skills, knowledge and tools to challenge the political and social structures that have acted to disempower them (Oliver, 1992).

As such, the research process acts to enable the target group to empower themselves:

The issue then for the emancipatory research paradigm is not how to empower people but, once people have decided to empower themselves, precisely what research can then do to facilitate this process. This does then mean that the social relations of research production do have to be fundamentally changed; researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose (Oliver, 1992, p 111).

Recognising the benefits of adopting such an approach not only for the young carers involved in the project, but also for the credibility of data gathered, an emancipatory model was adopted which saw workers and young carers working together to capture the experiences, stories and hopes of an often marginalised and discredited group. One of the challenges of this report was to ensure that children and young people’s involvement in the process was ‘real’, empowering and skills-developing and not token:

Participatory approaches to research are not about just including personal quotes in an otherwise unchanged research report or adding ‘subjective’ feelings to the ‘objective’ findings of the researcher. They are about people with direct experience… having more voice in the research process-from defining the issues to working out solutions (Bennett and Roberts 1999).
How the model was used

In 2004, committed to the principles of youth participation and emancipatory research, a set of protocols for researching young people was developed and guided the way in which the research project was conducted. A summary of these can be found in Appendix 2.

Early in the project, a Young Carers Research Team (YCRT) was formed and included 5 young carers aged between 15 and 21 years of age who were involved in the St Nicholas Young Carers Program (St Vincent de Paul). The responsibilities of the young carers were to:

• work with the project staff in setting the project priorities and parameters;
• provide advice and knowledge on how to best identify, engage and illicit information from young carers;
• conduct semi-structured interviews with young carers;
• work with the project staff to analyse the data gathered and to formulate recommendations; and
• provide feedback on drafts of the report.

Social researcher, Elizabeth Morgan from Morgan Disney and Associates trained the Young Carers Research Team on the ethics, practices and principles of best practice youth research and participated in six workshops focusing on the design, development, provision and analysis of the research project and provided mentorship throughout the project.

In recognition of their expertise, members of the Young Carers Research Team were paid for their involvement in the project.

How the interviews were developed

Although the general scope of the study was defined within the project brief, the researchers consulted with a range of stakeholders to set the project’s priorities and parameters and to develop the format of interviews. Consultations included:

• A focus group made up of a representative from a peak body (ACT Council of Social Services), three staff from a young carers program (CYCLOPS ACT), a child protection agency (Family Services, Office of Children, Youth and Family Support), and three Youth Coalition staff including one from its Drugs in the Family Project (AODP);
• A focus group with six staff from a carers organization (Carers ACT)
• A consultation with a project officer working with Children of Parents with a Mental Illness (Child and Adolescent Mental Health Service);  
• A consultation with young carer volunteers (St Vincent de Paul); and  
• Two workshops with the Young Carers Research Team.

Ethical issues
The key informants within this study were children and young people whose life experiences were often challenging and sometimes traumatic. With a large number potentially experiencing poverty, exclusion and isolation, it was imperative that the project be developed in a way that did not further traumatise them. As such, considerable work was invested prior to commencing the project to ensure that children and young people felt safe and comfortable in participating in the interviews and that support was available during and after via the youth worker present.

The Young Carers Research Team also believed that it had an ethical responsibility to ensure that children and young people did not experience any negative impacts individually or as a group by being involved in the research process. As such, young people were not identified individually within the project report and details of their experiences were altered to ensure anonymity. Considerable work was invested to also ensure that the project report was developed in a way that acknowledged the experiences of children and young people with care responsibilities but not actively problematise or sensationalise them. Each draft of the report was reviewed by young carers, key stakeholders, and the project mentor.

When working with any vulnerable group of children, it is also important that issues of child welfare be considered. For this project, the Young Carers Research Team argued that it was necessary, an in line with youth work ethics, to respond to any instances of abuse disclosed through the research project by reporting to the local authorities or by making referrals to appropriate services to provide support. Each participant was informed of this protocol and signed a consent form to this effect.

Ethics approval was sought from the Australian Catholic University and was obtained prior to recruitment.

2.2 Recruitment of children and young people to the sample
Who was recruited?
There is considerable debate both nationally and internationally about how to best define ‘young carers’ (Bursnall, 2003). A summary of this discussion can be found later in this report, but for the purposes of this research, the following definition was adopted in recruiting youth researchers and informants:
Young carers are children and young people under the age of 18 who care for a family member with an illness or disability, or a drug or alcohol or mental health issue.

Recognising that many young carers do not identify with the term ‘young carer’, the project sought to recruit not only those who saw themselves as young carers but also other young people who lived in a family affected by an illness, disability or mental ill health or with a relative who was frail aged or who had an alcohol or other drug issue and did not.

To elicit the insight and experiences of young people who had care responsibilities as children, the project also recruited young people aged 18 to 25 to reflect retrospectively on their experiences.

**How were they recruited?**

To ensure that those interviewed came from a variety of backgrounds and had a variety of experiences, young carers were recruited using a combination of purposeful, convenience and snowball sampling techniques with attention to attracting a good cross-section of the young carer population with respect to age, gender, cultural background and care experience. Young carers were recruited through existing young carer programs including:

- St Nicholas Young Carers Program (St Vincent de Paul);
- Hidden Corners Drama Group (YWCA Youth Services); and
- Young Carers Mentoring Program (Lifeline).

So that ‘hidden young carers’ were also involved, children and young people were also recruited through non-specific youth services and programs:

- Youth in the City (Anglicare Youth and Family Services)
- Quamby Youth Detention Centre (ACT OCYFS)
- Lowanna Young Women’s Service

These non-specific youth services were chosen because the YCRT were aware, from previous research and other interactions, that a large proportion of clients in these services had a parent with an alcohol or other drug and / or mental health issue. Targeting these services was important as the young carer services were open in acknowledging that they had not previously been successful in recruiting or supporting young carers of a relative with an AOD issue or dual diagnosis.

In addition, other young carers were recruited by word-of-mouth via peer researchers and young carer informants. This proved to be invaluable as a number of the young people who were interviewed did not identify themselves as being young carers nor were they identified as being so by services. As such they did not currently access young carer programs or supports.
Young carers involved in existing services were sent a letter inviting them to participate in the project. Another letter accompanied these and was addressed to the children and young people’s parents informing them of the research and seeking their consent for their child’s participation. Those who were interested returned these forms and an interview was organised.

Young people from non-specific youth services and programs were identified by their workers as being potential informants, were given information about the project and were given the choice to be involved or not.

Those who were recruited by word-of-mouth were given a project briefing and were then asked whether they would like to be involved in the project or not.

All young carers completed a consent form. Parental consent was also received from all those who were under 16 years. To ensure the anonymity of all young carer informants, consent forms were stored separately to the completed interview forms, which did not include identifying details.

In recognition of their skills and expertise, each child and young person was remunerated for their involvement.

The nature of the sample.

In planning the research, the YCRT attempted to recruit a sample of the target group that reflected the diversity of the young carer population. The children and young people interviewed in this sample proved to be representative of:

• the Aboriginal and Torres Strait Islander community;
• the cultural and linguistically diverse community (though the study did not recruit any migrants or refugees);
• young carers in each socio-economic category;
• carers of sole parents; and
• gender.

However, comparing data from the ABS (1998), the survey may have over-represented:

• the number of male young carers;
• the number of children and young people caring for a relative with an alcohol or other drug issue.
The sample may also have under-represented the number of children and young people caring for a relative with an intellectual disability or chronic illness.

Realising that their experiences were significantly different to other children and young people with care experiences, the sample did not reflect the experiences of young people with partners or children with an illness, disability, AOD issue or mental illness.

**How interviews were conducted**

Interviews were primarily conducted by peer researchers who had a previous or current carer experience themselves. A youth worker who acted as a scribe accompanied them, and provided support, ensured safety and was available to debrief both the peer researchers and informants when necessary.

A youth worker completed interviews conducted at the Quamby Youth Detention Centre without a peer researcher present as government policy restricted the access of young people into the detention centre. For organisational reasons, three other interviews were also conducted without a youth researcher present. The Young Carers Research Team did not see this as being optimal but necessary within the time constraints of the project.

**Case studies**

To illuminate the experiences, challenges, needs and issues impacting upon young carers’ lives case studies were developed that highlighted key aspects and themes. To protect anonymity, a number of case studies have been built around the experiences of more than one child or young person, while others have been modified with names, genders, family makeup and ages changed slightly. All situations are real.

**Analysis of Findings**

The Young Carers Research Team worked with the researcher to analyse the findings and to draw out the major themes. These were then tested with key stakeholders, young people and their parents. This report firstly examines what was already known about children and young and their caring before presenting the key issues that emerged from the research. This process was adopted to ensure that the true meaning of data was not translated incorrectly through the analysis and that the key priorities of participants (rather than those of the research team) were reported (Bowles and Alston, 2004; Pain et al, 2000).
2.3 From the literature
To inform the project, a literature review was conducted to identify the key findings of previous work and to guide the development of project parameters. A summary of these findings follow.

How many young carers are there in the ACT?
Within Australia it has been estimated that some 388 800 children and young people under 25 take on care responsibilities for a family member or friend (CA, 2002, p6). Of these, approximately 18 800 are recognised as being the main providers of care (primary carer), often taking on the sole responsibility for the intimate care and support of their cared-for relative.

According to the Australian Bureau of Statistics (1998), there are around 7 600 young carers in the ACT with more than half being under the age of 18. It is important to note that only young carers aged between 18 and 25 are identified within these statistics and that, more generally, the figure is a gross underestimation and that, when the true number of young people caring for a relative with an AOD issue and/or undiagnosed mental health issue are accounted for, the figure is closer to 11 500, accounting for 10% of the ACT’s youth population (Gays, 2002). Regardless of which figure is used, a considerable proportion of young people in the ACT community have care responsibilities for a relative.

Who are they?
According to the existing research, young carers come from all socio-economic, cultural and community groups (CA, 2002). Although children as young as three have been identified as having care responsibilities (Dearden and Becker, 2000) most young carers assume their caring role between 12 and 14 years. Of those with primary care responsibilities, over half are caring for a parent, who is most likely their mother and be within a single-parent household (CA, 2002, p17).

What do they do?
Young carers have been shown to provide similar levels of care to their cared-for relative as other older carers (CA, 2002, p15). They are responsible for providing health care treatment ranging from dressings through to catheter bags; emotional support and assistance in the maintenance of a healthy, organised household. Young carers’ responsibilities range from cleaning and cooking through to more major tasks such as bathing, dressing and providing assistance with toileting to incapacitated family members. Some young carers caring for a family member with a mental health condition are also required to provide other types of support sometimes including restraint of suicidal relatives, and emotional and behavioural monitoring. Often providing primary care, young carers take on significant caring responsibilities (ACTYCN, 2000).
Carers Australia (2002, p15) found that unlike other young people, young carers spend most of their time either providing care or thinking about their cared-for relative or friend.

**Why do they exist?**

ABS data indicates that over the past 25 years the number of people within our community who are frail aged and in need of personal assistance has grown dramatically (ABS 1997; Robinson 1997); as has the number of people within the community living with disabilities chronic and mental illness as a result of deinstitutionalisation (CA 2002; 2002b; Dalley 1989; Braithwaite 1989). Concurrently, the breakdown in the family home through the increase of divorce (de Vaus 1995:22), the higher participation rates of women within the workforce (AIHW 2000) has consequently increased the number of and the level of care provided by children and young people within the community (ACTYCN, 2000).

Carers Australia (2002), Keith & Morris (1995) and the ACT Young Carers Network (ACTYCN, 2000) all assert that people with illness, disability, mental health concerns and the aged do not currently receive adequate supports rendering families, including children and young people, responsible for high levels of care.
3 What the research tells us about young carers’ experiences

Profile of the Participants

A total of 50 young carers were interviewed individually, and of these, 26 were male and 24 female. The ages of participants ranged from 9 to 24; 9 participants were Aboriginal or Torres Strait Islander; and whilst there were no migrant or refugee participants, 10 young carers had a parent or parents who were born outside Australia. 12 young carers identified speaking a language other than English at home, including two that communicated using sign language.

Graph 1: Age of Participants

<table>
<thead>
<tr>
<th>Age of Participants</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 - 10yrs</td>
<td>4</td>
</tr>
<tr>
<td>11 - 12yrs</td>
<td>6</td>
</tr>
<tr>
<td>13 - 14yrs</td>
<td>7</td>
</tr>
<tr>
<td>15 - 16yrs</td>
<td>8</td>
</tr>
<tr>
<td>17 - 18yrs</td>
<td>14</td>
</tr>
<tr>
<td>19 - 21yrs</td>
<td>10</td>
</tr>
<tr>
<td>22 - 25yrs</td>
<td>4</td>
</tr>
</tbody>
</table>

**Income** - 10 of the young carers received an income support payment including 6 who received Youth Allowance, 2 who received Austudy, 1 who received a Sole Parent Benefit and a Family Assistance Payment and 1 received a Newstart payment. One young person also received Rent Assistance.

It is important to note that though often eligible, no young carer received either Carers Payment or Carers Allowance.

**Educational Achievement** – though the educational background of the informants was not specifically sought, based on knowledge of the sample, it can be estimated that approximately two-thirds of the young people were currently engaged in education (including primary, secondary, college and vocational training). Those who were not attending had left school prematurely to assume their caring roles or because they had fallen behind in their work and felt that satisfactory outcomes were unachievable.

Profile of Families and Relatives
The young carers surveyed through the project came from a range of family types and cared for a range of different relatives.

**Family Profile** – Most of the young carers lived at home with their caring relative (45 of 50), 23 of these lived with both parents, 9 with their single mother, 6 with a single father, and 6 were living with other siblings or relatives. Those not living at home either lived alone or were currently incarcerated at Quamby Youth Detention Centre.

Those who were in Quamby still felt that they had care tasks, with those who were incarcerated believing that they would reassume some level of care responsibility after being released.

**Young Carer Story: Crystal**
Crystal is 15 years old. Both of her parents use a variety of drugs including heroin, methadone and serepax. With most of the family’s income going towards this drug use, Crystal and her family live in significant poverty.

Fearing for the health of her younger siblings, Crystal began shoplifting at the age of 10. By 12 she had moved on to ‘break and enters’ and was first arrested when she was 13. Over the past 3 years she has been remanded in Quamby Youth Detention Centre 4 times – each time returning to a family home experiencing significant financial hardship, committing crime to provide for her family, getting caught and then returning into custody. Whilst remanded, Crystal organises for her friends to ‘drop in and check on her family’ and to provide them with money when needed. Post release, Crystal ‘makes it up to them’.

Crystal sees this as one of her care responsibilities though she wished that someone involved with her family helped get her parents into rehab and to sustain the family financially. She is always afraid for her siblings whilst she is in custody.

**Number of Cared-for Relatives and relationship to young carer**– The 50 children and young people interviewed cared for 67 relatives and friends. As such, 14 identified as caring for more than one relative or friend with 13 of these caring for a mother and another family member. A breakdown can be found in Table 1 below:

**Table 1: Number of Family Members Receiving Care**

<table>
<thead>
<tr>
<th>Number of family members receiving care</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>One Family Member</td>
<td>35</td>
</tr>
<tr>
<td>Two Family Members</td>
<td>9</td>
</tr>
<tr>
<td>Three Family Members</td>
<td>2</td>
</tr>
<tr>
<td>Four Family Members</td>
<td>3</td>
</tr>
</tbody>
</table>
The young carers were most often caring for a mother (n=25), a brother (n=19) or a father (n=12).

Table 2: Relationship of Cared-For Relative

<table>
<thead>
<tr>
<th>Who they are caring for</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Mother</td>
<td>26</td>
</tr>
<tr>
<td>A Father</td>
<td>12</td>
</tr>
<tr>
<td>A Stepfather</td>
<td>4</td>
</tr>
<tr>
<td>A Brother</td>
<td>19</td>
</tr>
<tr>
<td>A Sister</td>
<td>3</td>
</tr>
<tr>
<td>Grandparent</td>
<td>3</td>
</tr>
<tr>
<td>A Neighbour</td>
<td>1</td>
</tr>
</tbody>
</table>
Young Carer Story: Kenji

Kenji is 14 years old. Six years ago Kenji and his parents were in a car accident that severed his father’s spinal cord and led to his mother’s post traumatic stress disorder. As an affect of the accident, Kenji’s parents rarely leave the home and need significant care throughout the day and night.

Before the accident, Kenji’s parents were the primary carers for Kenji’s older brother who has Aspbergers and can become quite violent. Kenji’s older sister also needs some help as she suffers from a mild intellectual disability.

Kenji sees his care responsibilities as ‘doing everything’ for his relatives and around the home, which includes cooking, cleaning, supervising, co-ordinating mental health and community nurses, banking, shopping and communicating with his siblings’ schools and after school programs. As Kenji’s mother does not speak very much English, Kenji also helps by translating for community workers, her psychiatrist and Centrelink.

Kenji showers, dresses and shaves his older brother and helps his father in the bath. He also ‘looks after the yard’ – after his mother was told that if the family’s large backyard wasn’t kept tidy they would lose their Public Housing property.

Most of Kenji’s extended family live in Japan. He has no informal support networks in Canberra.

Condition of Cared-for relative

The young carers in the sample were caring for relatives with a range of illness, disabilities, mental health conditions and alcohol and other drug issues. A list of these can be found in Appendix 3. For the purposes of this report, all conditions were categorised into illness and disability types:
Table 3: Condition of Cared-For Relative

<table>
<thead>
<tr>
<th>Illness / Disability Type</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol or other Drug Issue</td>
<td>25</td>
</tr>
<tr>
<td>Mental Health Issue / Psychiatric</td>
<td>18</td>
</tr>
<tr>
<td>Physical Disability</td>
<td>13</td>
</tr>
<tr>
<td>Chronic Illness</td>
<td>9</td>
</tr>
<tr>
<td>Acquired Brain Injury</td>
<td>4</td>
</tr>
<tr>
<td>Autism (including Aspergers)</td>
<td>4</td>
</tr>
<tr>
<td>Specific Learning Disability (including ADHD)</td>
<td>4</td>
</tr>
<tr>
<td>Neurological Disability (including epilepsy and Alzheimer’s)</td>
<td>3</td>
</tr>
<tr>
<td>Sensory Disability</td>
<td>3</td>
</tr>
<tr>
<td>Intellectual (including Downs Syndrome)</td>
<td>1</td>
</tr>
</tbody>
</table>

3.1 The Nature of Caring

Young carers in the sample cared for a considerable amount of time over a significant period. Over a third of the young carers reported caring ‘always’ (n=16), while others had taken up caring for their relative after they had acquired their condition or when other relatives had left the family home.

_All my life – since I’ve been able to care._

_For eight years. When my older sister moved out of home it was hard. She used to do everything. Then she left. We never knew that she was caring…_

_When I was little I didn’t do much. But when my brothers were born I helped out _more._
Table 4: Length of Time Caring to date

<table>
<thead>
<tr>
<th>Number of Years Caring to date</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 years</td>
<td>5</td>
</tr>
<tr>
<td>3-4 years</td>
<td>8</td>
</tr>
<tr>
<td>4-6 years</td>
<td>9</td>
</tr>
<tr>
<td>7-10 years</td>
<td>6</td>
</tr>
<tr>
<td>10+ years</td>
<td>4</td>
</tr>
<tr>
<td>Always</td>
<td>16</td>
</tr>
<tr>
<td>Not sure</td>
<td>1</td>
</tr>
</tbody>
</table>

Though these figures may seem low when they are compared with the length of time that adult carers may have cared for their relatives, it is important to note that they account for up to 60% of child or young person’s whole life.

Some of the young people who were interviewed no longer saw themselves as carers, with 4 having lost their cared-for relative who had died, and one who stopped caring because she could no longer cope:

*I chose not to associate with him anymore because it was too stressful.*

**Time spent caring**

Contrary to the belief that young carers have less care responsibilities and care for fewer hours than their adult counterparts, the children and young people surveyed cared for an average of 6.4 hours per day. None of the young carers in the sample cared for less than 2 hours per day.

*I have not uninterrupted time. I just have to available – so I don’t have much time to myself. I know my parents can’t do it for themselves.*

With considerable time allocated to caring, it is not surprising that many of the young carers felt that they never had any time to themselves:

*Really the only time I have to myself is school*

*It depends if I lock myself in my room.*

*I don’t really have any time for myself – when I’m not at home doing stuff. I’ve got to sleep for some hours!*
Young Carer Story: Jason

Jason is 14 and suffers from chronic asthma that makes him often sick and fatigued. He cares for his mother who has renal failure. Two years ago, Jason was told that it would be unlikely for his mother to last the year.

Jason gets up each morning at 6am, wakes his mother and gives her a cup of tea. He then takes her for a bath (except on Wednesdays when a worker comes to wash her hair and do the shopping). He cooks her breakfast, cleans up, has a shower and gets ready for school. He tries to leave home at 8:30am but is often late – especially if Mum is particularly unwell.

At recess and lunch, Jason returns home to help his Mum with dialysis, to fix her a snack and to book any appointments she might need. He returns to school until the bell rings at the end of the day when he ‘races home to make sure that she’s OK’. He then cleans the house, cooks dinner, cleans up, puts a load of washing on and helps his Mum to bed.

He usually tries to get to his homework at 10:00pm but is sometimes too tired to concentrate. On these days he sets his alarm for 5:00am and heads to bed.

Jason sees his time at school, when he’s asleep and the monthly visit from his sister as the only time he has off from his caring.

Caring Tasks

The young carers were asked to describe what responsibilities they had around the home, in providing care to their cared-for relative, in supporting other family members and the family unit as a whole. Types of care tasks included:

- **Caring around the house** included cooking, shopping, cleaning, vacuuming, washing dishes, washing clothes, cleaning windows, mopping floors, and gardening. Unlike their friends who were sometimes also did such tasks, young carers reported that what made their roles different was that they had to do them ‘all the time’ and without help or supervision.

  *My Mum sits in her room. I tidy up what she’s smashed and stuff.*

  *My brother makes more mess than others.*

  *I bought and paid for most of the groceries.*
• **Caring for other relatives** included looking after younger siblings, nieces, nephews and other children in the neighbourhood. Again, young carers saw these tasks as being different to ‘babysitting’ because their responsibilities were more intense:

> I care for my nieces and nephews. They come around because my brother knows that we’ll be at home caring for Mum so he thinks that we might as well care for his kids too.

> I’d be left alone with all the kids or have to look after them when Mum was out of it [under the influence of drugs]

Some young carers also were responsible for protecting their parents and sibling from harm:

> I look after my brother. Dad gets aggressive – I had to calm him down. I have to stand in between him and my brother. I had to punch him once so he’d stop strangling my brother.

> My brother and Dad had a fight. He [brother] got smacked out. I had to get in between… I had to restrain Dad for 1 1/2 hours while we waited for the cops and ambulance… My brother said “you shouldn’t’ve helped – you could’ve got hurt”. I said, “you’re my fucking brother – of course I’m going to step in.”

**Young Carer Story: Summer**

Summer is 18 years old. She has a brother who suffers from schizophrenia and drug-induced psychosis. For some time Summer directly cared for her brother but stopped when he violently assaulted her sending her to hospital. Because of the assault she suffers from post traumatic stress disorder, is agoraphobic and is constantly fearful.

As a result of the attack and the impact it had on her own mental health, Summer decided that she could no longer spend time alone with her brother and could therefore no longer provide personal support to him.

Summer continues, however, to care for her mother who has taken on a more significant care responsibility for her brother. She has also taken on the responsibility of providing emotional support to her youngest brother (a task her mother used to assume) – who also is often fearful and afraid. She takes on the primary role of cleaning the house, debriefing and ‘de-stressing’ her family members and ‘taking up the slack’ when others are unable to do household chores. She
does not live with her brother but her family members still consider an integral part of their ‘care team’.

- **Emotional Support** – included monitoring their relative’s mental health, protecting their relative from stressful situations, and ‘cheering up’.

  *Sometimes I try to cheer him up. Occasionally Dad gets a smile out of him but if he’s in a bad mood he’s in it for a long time.*

  *Read her a book, make cup of tea, take her out to get a coffee, go out on a shopping spree*

  *If he sees me around the house he’s ok. He’s in stitches – until it hurts. I’m always cheering people up… laughing…*

  *Yes, I make him laugh… When he’s sick I cheer him up. Tell him what I’ve done that day. He loves hearing about camp…*

- **Ensuring Safety** – included supervising relatives so they didn’t harm themselves, and when violent or aggressive, ensuring that they didn’t harm others:

  *We had to check Mum in the bath to make sure she was still alive.*

  *When he goes up the back, I make sure he doesn’t get bitten by spiders, make sure he doesn’t fall over going up the hills.*

  *My Mum was violent all the time. I had to protect my brothers*

  *We can’t leave him with hot stuff. When he gets angry he sharpens a knife and threatens people – that’s because of his stroke*

- **Financial Responsibilities** – included paying bills and for contributing to the household budget. Experiencing significant financial disadvantage, for some young carers this meant turning to crime:

  *I have to give Mum 30% of my wage to help out with bills. None of my friends do that.*

  *When she needs money I help her out.*

  *I helped pay for my sisters’ school fees and stuff.*
I’d steal money for food.

- **Mobility** – included helping their relative move around the home, carrying them in and around the home (including into bed, the bath and on the toilet), and pushing wheelchairs.

  *I help him get into bed and the car. I get his wheelchair in the car and help when he gets stuck in the bathroom.*

  *I get him everything he needs. I help him around the house.*

- **Personal Care** – included changing dressings and bandages, bathing and showering, toileting, dressing, application of creams, lotions and topical medications.

  *I help Mum in the bath – help her wash her hair and stuff. And I help her with her bandages and creams when she needs it.*

- **Transport** – included driving relatives to appointments, organising taxis and buses and accompanying siblings on bike rides.

On whole, most young carers were responsible for household tasks, for caring for relatives, for providing emotional support, monitoring and ensuring financial stability as shown in Table 5:

**Table 5: Care Tasks**

<table>
<thead>
<tr>
<th>Care Task</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household</td>
<td>78%</td>
</tr>
<tr>
<td>Caring for other relatives</td>
<td>78%</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>74%</td>
</tr>
<tr>
<td>Ensuring Safety</td>
<td>68%</td>
</tr>
<tr>
<td>Financial</td>
<td>50%</td>
</tr>
<tr>
<td>Mobility</td>
<td>36%</td>
</tr>
<tr>
<td>Personal Care</td>
<td>22%</td>
</tr>
<tr>
<td>Transport</td>
<td>8%</td>
</tr>
</tbody>
</table>
4 The Impacts of Caring

This section explores how caring can impact on a child or young person’s life – both positively and negatively. Firstly it draws from the existing research and then identifies the impacts expressed by the children and young people involved in the research.

4.1 From the Literature

Within the literature, considerable attention has focused on how young caring impacts children and young people’s lives now and into the future. Though earlier work tended to focus on the negatives of caring, more recent studies have shown that when adequately support, caring can be a positive experience. However, when unsupported, research shows that young carers can face financial, physical, emotional, social and educational difficulties:

Positive Impacts: Though much of the literature problematises young caring, a number of researchers have found that the care experience can have positive impacts for children and young people, providing them with practical skills and a sense of responsibility that aid in the journey to independence and assist them throughout life (Dearden & Becker 2000 in CA 2000, p35). Young carers have also reported having stronger relationships with family members, greater sense of achievement, connectedness and feelings of fulfilment (ACTYCN 2000).

Poverty: It has been shown that youth, disability and caring are each identified as precursors to poverty and that, experiencing each of these phenomenon, young carers make up “one of the most vulnerable and financially disadvantaged groups in Australian society” (CA 2002, p39). With escalating costs of care (Braithwaite 1990, p25) and inadequate financial supports (CA 1997), many young carers live in families where sustaining a basic living standard is difficult (ACTYCN 2000, p12, CA 2002, p40).

Physical, emotional, psychological health – writers such as Ell and Northern (1990) and Carers Australia (1999) all assert that children taking on high levels of care responsibility are at serious risk of injury, muscle strain, fatigue, emotional distress, anxiety, depression and compassion fatigue.

Social disconnection – due to significant time commitments and fears about ‘exposing’ their relatives illness or disability, writers such as Matthey (2001), Frank, Tatum and Tucker (1999) argue that many young carers do not have opportunities to participate in social activities, to build connections of support and friendship with their peers or to participate in many mainstream life opportunities. This has led to feelings of social disconnectedness, isolation and a sense that ‘no one is in the same situation as me’.
Education - due to a lack of adequate and appropriate supports, young carers’ attendance at school has shown to be erratic (Dearden & Becker 1998:44) and their opportunities to do homework and assignments significantly limited (ACTYCN, 2000). As such, many have failed to achieve satisfactory outcomes in education – with only 4% completing secondary education.

Pathways into employment have shown to be equally problematic. With poor school achievement, limited extra-curricular experience and limited available hours couple with a lack of carer-friendly workplaces who are able to work flexibly and responsively with the young carers’ care responsibilities, many young carers find it impossible to find or maintain meaningful employment.

Homelessness and criminality – in research conducted by the Youth Coalition of the ACT it was found that over 85% of young homeless people interviewed saw a direct causal link between their parent’s alcohol or other drug use, mental health issue and / or disability and their first experience of homelessness. In the same report, the Youth Coalition also found that 10 of the 17 young people who were incarcerated at Quamby Youth Detention Centre identified as living in a family affected by alcohol or other drug use and / or a mental health issue (2005, p16)

4.2 How Caring Affects the Way Young Carers See Themselves and Their Lives

The young carers were asked about how they felt that caring had:
- impacted on the way that they saw themselves,
- who they were and what they could do; and
- how they saw life generally.

The majority of children and young people (over 80%) felt that their care experience had changed the way that they saw themselves - who they were and what they could achieve:

*I now see how much I can actually do for others instead of just laying around the house.*

*It’s made me wiser*

Many felt proud about the way that they were able to ‘care for’ those they ‘cared about’:

*It makes me feel good. I like making people feel happy.*

*I’m a good helper. I feel good about myself because I can do something for others.*

*I care about people more. Makes me feel special being able to do things.*
Though difficult, many young carers felt that the experience had motivated them and challenged them to work harder:

*I work harder with everything. I’m more responsible. I’m happy all the time even though I’m put through a lot.*

Though the young carers identified many ways that caring had positively impacted on their sense of self, some reflected on the negative affects – including how they felt that they had missed opportunities to be children:

*I grew up quicker. If things had been easier I wouldn’t have grown up as quickly – would have had more time to be a child.*

Some of the young carers felt that caring had negatively impacted on their self-esteem and feelings of self worth:

*As a kid I had low self esteem and when [my brother] got sick it got worse.*

*I’m always screwing up – I can’t seem to do anything right. I wanna help out but I’m useless.*

Others felt somewhat resentful of their caring:

*It gets annoying that I have to continually care for my brothers because they’re sick.*

*I’m sick of doing it.*

*I hate that I’m the only one who does anything.*

Others, however, reflected on how caring had helped them grow and develop:

*I’m stronger mentally. I’m a bit more patient. I listen a lot more. I’m more open-minded.*

*I think it makes you grow.*

**How they saw life**

The young carers were asked to reflect on how caring had impacted on the way that they saw life. Some found answering this question difficult as they’d ‘never known any different’ and because
caring ‘had become their life’ so it was difficult to step outside their lived experience. Others recognised that it had impacted, but couldn’t necessarily articulate how:

*Yes it’s changed because having the responsibility really makes you think.*

Many, however, felt that due to their caring they had greater understanding for people who were ‘struggling’, in particular for those with an illness, disability, mental illness, or drug or alcohol issue, and for their carers:

*I have a lot more acceptance of people, especially people with a mental illness. I look at them with sadness while before I would have been disgusted…. I think differently about people.*

*I’m more tolerant of other people and their injuries when someone has a bad day – you treat it like your brother and you move on. You’re more resilient – you can cope more.*

Many now saw life as a challenge, but one that with persistence, patience and courage you could overcome. There was significant hopefulness within the group.

*I know that I can cope with a lot more that I ever thought I could.*

*I now know that you don’t always have to give up – my Dad didn’t.*

### 4.3 How Caring Affects Young Carers’ Health and Well-being

The outcomes on the health of young people was a significant element of this study. It is one of the most common issues raised in the literature. The study aimed to test how young people themselves perceived and experienced the impacts on their own health and well being including their:

- physical health;
- emotional health; and
- alcohol and other drug use.

#### Physical Health

Many of the young carers felt that their health had been affected by their caring. Significantly and differing to most of the existing research, around 40% of the children and young people who saw caring as having impacted on their health perceived that it had actually made them feel fitter, stronger and healthier:
I can run faster! I always have to run: to my crying brother, to the next job, from this place to the next place.

Because I lift things, strengthening my arms.

Some of the young carers felt that caring had made them more active and motivated:

I’m more active – more used to getting up and doing things

I’m heaps active – I’m always doing something!

However, almost 50% of those who identified physical affects stated that caring could sometimes take it out of them physically with some experiencing significant fatigue:

I feel more tired – its hard work looking after your brothers and sisters.

I’m more tired – staying up late at nights.

I feel tired – [my brother] comes in and wakes people up.

A number expressed a concern about their health more generally:

When Mum was using – I didn’t brush my teeth and stuff. I was practically not eating… I was sick and skinny as.

I’ve put on heaps of weight since leaving home.

While others identified injuries that they had sustained:

Its [caring] been both [positive and negative] – it stuffed my back but I’m stronger from lifting weights.

Sprained ankles, bites – being pushed by my brother.

Emotional Health
39 of the 50 young carers reported experiencing high levels of stress and anxiety – always concerned about their relative and the amount of work that needed to be done to support them and the rest of the family:

*I’m always stressed about mum being unwell. I’m worried about her taking too many pills or doing something stupid.*

*A lot of the time I feel stressed out and anxious. When I’m in the middle of a job and then I have to stop and do something else and then go back and start again.*

For some, this stress was alleviated when they were given support or someone to talk to:

*Sometimes I feel stressed when Mum’s in hospital. My friends listen to me.*

*I know that when Mum is in hospital that she is being taken care of.*

Or when they find strategies to deal with it themselves:

*I use the relaxation CD I got from Big Breakfast*

Grief, loss and other sadness were also consistently experienced and reported by the children and young people in the study. Some talked about how they felt they’d ‘lost’ their family to the illness or disability:

*My brother is no longer like a person. He’s got a body and a mind but he’s like a child… forever…*

*We used to be so close but not now…*

Others realised that their cared-for relative often felt guilty because of their lost opportunities and that had made them feel upset:

*I feel sad because she blames herself and says that we haven’t been able to do the stuff we wanna do.*

This sadness was often great:

*Yes I was stressed out. I was always worried about my brother. If I didn’t have a cigarette I’d cry.*
And often hidden:

   I don’t cry in front of my parents or friends. I cry in my pillow. I cry with my dog and he licks my face.

Some young carers acknowledged that often because they felt they had to mask their feelings, hide them or internalise them, that sometimes they would be expressed destructively:

   At first I was swearing at teachers and chucking psychos when Dad first had a stroke.

One young man involved in the interviews had cut himself because he felt he could not deal with the stress. Another girl had pulled hair from her scalp. Another committed crime to distract himself from the pain he felt:

   It just helps me forget. I started cos we needed food but then with the rush, I don’t think about what’s going on [at home] and I don’t stress about it. It’s the only way I can.

One young woman who had cared as a child felt that the stress, anxiety, and fear she had experienced watching out for brother with a psychotic illness and her family had had long-term impacts on her own mental health:

   Emotionally I’m fucked up. I get panic attacks, social phobia – fear of being outside the house. Whenever I even talk about where I’m at I just lose it.

Though many struggled with stress, sadness and anxiety, many felt that they were more empathetic and more resilient:

   I’m more laid back about people and their needs.

   I can cope with more

And that being able to care for a relative helped them deal with challenges better:

   Feels good because you’re doing something for someone else.

   Makes me feel better – I can get in there and fix it rather than standing on the side not doing anything and being stressed.
Young Carer Story: Alex

Alex is 14. He cares for his mother who suffers from a dissociative disorder. His father, who suffered from schizophrenia, used to also live with the family when Alex was a child but left after he threw Alex out of a moving vehicle believing that he was trying to kill him. Alex’s hip was broken and he still finds it difficult to walk.

Alex cares for his mother by making sure that she is safe. When he was 11, Alex had to restrain his mother when she attempted suicide by cutting her wrists. He is fearful of ever leaving her alone and does not go to school or spend time with other young people his age.

In the past, there have been countless numbers of mental health nurses, doctors, psychiatrists and social workers who have worked with his mother but Alex says that none of them have ever explained to him anything about his Mum’s condition: including whether or not he will contract it when he is older.

Alex suffers from depression, is fearful about his future and has often thought about hurting himself. He feels completely alone.

Alcohol or other drug use

For those young people who had some care experience related to alcohol or other drug use, most felt that after seeing the negative impacts, they were less likely to use the same drugs as their parents:

For ages I watched Mum and didn’t want to drink and be like her.

For others, being exposed to AOD use early in their childhood’s meant that they had experimented earlier than their peers:

I started bonging when I was 9 with my Aunty. I used with my family all the time – it was normal.

Every time he was drinking I drank with him.

New Skills
Many young carers reported that their living skills had been developed positively as a result of their caring – that they now knew how to cook, clean, do washing, ‘look after money’, garden, fix the car, and look after younger siblings:

*It made me gain skills – like cleaning, cooking – things you wouldn’t usually do when you were 7.*

Others had developed specialised caring skills, including first aid, changing dressings, heavy lifting, providing personal care and showering. Some felt that they had developed skills on how to best support someone with a mental illness – including how to monitor, support, medicate and ensure safety whilst others had learnt sign language.

*When we were pretty young our grandfather lived with us. He was disabled and had four strokes… That was amazing! The things we learnt and the stuff we found out just from helping. The nurse we had for him would tell us stuff – like how to change him… It was a good experience… Unless you go into a profession you don’t learn those skills.*

*Others don’t understand what people can have and what they need.*

Others felt that they had developed greater ‘people’ skills. That they had greater empathy and understanding for others

*I know how it feels to have a Mum with a mental illness*

*I’m more aware of people’s feelings…*

*I’m not always thinking about myself*

Some of the young carers felt that because of their care responsibilities they were going to be better parents and carers for their own children:

*I know that I can look after Dad so I can look after my kid.*

*I’ve got better skills, can stay calmer, can be a better mother.*

### 4.4 How Caring Affects the Family
As well as having an impact on how young carers saw themselves, the children and young people reported situations where caring had impacted upon their families - their relationships within the family unit, issues of poverty and safety.

**Conflict**

The young carers spoke about how caring had impacted upon their families and specific relationships within it. For many, the extra pressures and stress within the family had caused conflict:

*When Mum’s sick, people fight more at home.*

*It’s put lots of obstacles in the way… It causes a lot of fights. Strained relationships*

And for some caring had caused distance:

*Our brother was pushing us away. There was heaps of distance. Before he was using we were really close.*

*There was a definite rift within our family.*

With the impacts being considerable:

*I reckon its worse cos my brothers are in foster care. I can’t see them and they were given to their dad because of Mum’s drinking.*

*My mother thinks I am going to turn out like him so she doesn’t talk to me.*

**Stronger Relationships**

Though there seemed to be increased family stress, many of the young carers felt that because their families often worked through their challenges together that they were closer:

*Stronger with all of us – because of the things we went through together.*

*Strengthened – we all realise we love him and we’re always going to care for him… forever.*

In particular, a number of young carers felt close to their cared-for relative:
It makes us stronger – we’re more close because I spend more time with my Mum.

My brother – we’re getting along better now. We were really close when I was looking after him – we were always together.

And for other relatives who they spend time caring with:

I became closer to Nan who was more like a mother.

I’m closer to my baby brother due to caring… We’re always helping each other… spending time together.

As relationships with family members who helped care were stronger, there was some angst towards those who were not caring:

I have a lot of issues with my brothers because they don’t help out as much as they could mentally, financially… They don’t think she’s as sick as she is. They don’t live at home so they don’t see it. They think it’s a lot easier than it is.

My brother is lazy and doesn’t help much. I told him he has to help more so I can go out.

Family Finances

With costs associated with health treatment, medication, modifications of households and transport 75% of young carers in families with a member with an illness or disability felt that they experienced some financial difficulty.

A wheelchair costs $3000 for a good one

Mum has been having operations and seeing doctors. Medicines costs a lot.

In particular, families where parents suffer from an illness or disability or are unable to work because of their own significant care responsibilities are affected:

Ever since we were little she couldn’t get out and get a job. So she had to live off Centrelink which wasn’t that much. I’m not working at the moment and my sister’s not getting much. It hardly covers essentials.
One family where the children were caring for their mother with a mental illness reported that they often did not have enough money because their mother would spend the budget on inappropriate and unnecessary things:

_Sometimes Mum goes out and buys stuff we don’t need. One Christmas she went out and spent $2000 on each kid – which was a bit over the top._

These financial strains mean that often young carers do without basic essentials:

_We have money every Thursday but we often run out. We ran out of milk before we came on camp…_

_Sometimes Mum is broke. Sometimes she is OK. She still doesn’t have the money that she needs and puts groceries back._

_We can’t really afford everything – I tend to miss out._
**Young Carer Story: Mischa**

Mischa is 15. She cares for her Dad who had a stroke 4 years ago after her mother walked out on them. Mischa does all the housework, helps her Dad around the home and cleans him up when he soils himself. Mischa does most of the banking for her Dad and knows that there isn’t much money. She wishes that she could get a job but knows that she can’t leave her Dad alone for too long.

Mischa used to get support from an in-home support program for carers, which meant that she could get out of the house once a week. A few months ago, however, the service reviewed its policies and started to charge for all ‘non-essential’ support and because Mischa’s respite was not seen as being a necessity she could not longer afford it.

Mischa says that she always puts her Dad first and therefore misses out on things for herself – she gets friends to cut her hair, she no longer goes out to the movies and often skips meals when there’s not enough. She was receiving Youth Allowance but when she dropped out of school and couldn’t get a job or be involved in the obligatory training programs she was breached. She had to pay back $2 000 because she had failed to let Centrelink know that her circumstances had changed.

Mischa is looking forward to when she turns sixteen – because hopefully then the Social Worker at Centrelink might finally get her onto Carers Allowance.

Many of the young people interviewed at Quamby Youth Detention Centre stated that poverty in the family led to their criminality and, through it, their prolonged involvement with the juvenile justice system. For some it was cyclical – with no financial support available for their families, they committed crime which, ultimately lead to incarceration after which they returned to their families who continued to face poverty which lead them to reoffend and begin the cycle again.

It was disturbing to find that a number of these young carers saw their criminality as one of their care responsibilities:

*She’d only have like $50 a week for food after pot. I had to help out. I’d go do B and E’s [Break and Enters] so I could buy stuff for everyone.*

*I had to steal stuff for school like textbooks and stuff.*
That’s a big thing. She’d spend all her money on alcohol, so I had to steal money off her to go buy food for my brothers.

Safety

26 of the young carers identified a time when their safety was undermined. 12 of these felt that there were times when their cared-for relative was aggressive or violent:

When he gets aggressive and you don’t know what he’s going to do. When he’s aggressive he doesn’t care about people or who it is he just attacks you and gets violent as well.

When he gets angry, he takes it out on the house and me and my brother are always there.

Others felt unsafe when they were left at home alone – when their parents were at the hospital or otherwise out or when they were put in the care of others they didn’t comfortable with:

We were left by ourselves. There could’ve been a fire.

When Mum was in hospital I had to stay with people I didn’t like.

Some of the young carers caring for a parent or sibling with an alcohol or other drug issue were exposed to people and experiences that were unsafe:

Every time she drank she’d have people over at her house: bad people, violent people, people who’d rip you off and hit her and I’d have to protect her.

There were always junkies [drug users] over – not safe.

I only [felt unsafe] when I had to do break and enters and stuff to get money

Not at home – except there were fits lying around. He’d hide them everywhere.

4.5 How Caring Affects Young Carer’s Participation

Much of the literature describes how young caring negatively impacts on children and young people’s connection to mainstream life opportunities and community engagement. It is important to note that many of the young carers interviewed in the study felt that caring itself was a form of
community participation – an opportunity to assume a valuable community role by supporting their relatives.

However, a large number of the young carers also felt that their access to education, to employment and to social opportunities were also restricted.

Social Life

All but three young carers felt that caring had impacted on their social lives – both positively and negatively. Those who saw it as impeding their opportunities to socialise with their peers commented:

*When I was young I couldn’t go to friends places. Too busy doing chores. Couldn’t ride around with friends. Couldn’t have friends around.*

*Sometimes I feel left out and I get angry when I want to play with my friends.*

*My friends spend more time on their bikes.*

Others reflected on the fact that it was difficult to have people around to their homes:

*Don’t like to have people over. Stopped having birthday parties.*

*When my friends are over I feel embarrassed because my mum’s upset.*

*Its not because my friends didn’t support me its because I couldn’t leave home and they didn’t want to come over because they didn’t want to see Mum sick so they didn’t come. I lost a lot of friends.*

When they were able to socialise, however, they felt that they were able to make stronger relationships with others, especially those with similar stories:

*Some of my friends are carers too – makes you a better friend.*

*I have better friends – at school, out of school and at camp… My friends come over and my Dad is funny and makes them laugh.*

*I’m really close to my friend – we help each other out because we’re the same.*
Having similar stories was seen as being incredibly important for a majority of young carers – with a number sharing stories of previously feeling isolated and alone:

_I always felt alone – felt like the only one in my situation… and you feel alone. Everyone feels sympathetic, but doesn’t really know what it’s like. I didn’t talk about it for 4-5 years. I was like a clam. I was shy. I’d never approach people. I was afraid of what to say. I never really had lots of friends and I was worried about losing them._

Others reported being bullied or isolated from social groups because of their cared-for relatives condition:

_No one wants to talk to you if you have a junkie brother._

**Education**

The young carers were asked about their experiences in education and whether they thought that caring had impacted on their ability to achieve satisfactory outcomes. Questions were phrased around their attendance and their achievement. The young carers also spoke about how school had or hadn’t helped them deal with their caring.

34 out of 50 young carers identified that their caring responsibilities had negatively impacted upon their education, though a large number felt that school was a place where they could get support from friends and teachers.

**Attendance**

With significant care tasks that needed to be completed before going to school, many of the young carers reported missing large periods of time from school, arriving late and having to leave early when their relatives needed them:

_Sometimes I don’t go to school because I’m worried about her_

_before school I have to sort out my brother and get him ready. Usually I’m helping him out. I don’t have time to get lunch and… I’m always late._

For 7 young carers, a lack of support and a heavy care load meant that they had to leave school completely:

_I left after Year 7 to look after Dad… I was the only one who could look after him._
Achievement

Some young carers felt that caring for a relative had had a positive impact on their education:

*It’s helped my English because I am helping my brother how to read – [so] I learn too.*

*I’ve learnt to be more focused and motivated.*

*I know how much it means to Dad that I do well and that it makes him feel good.*

Many, however, felt that caring had an impact on their ability to achieve at school as they were continually distracted from their work and worried about their relative at home:

*My grades and marks were pretty crap because I was worried about getting a phone call – especially if Mum was sick… I went to school but I couldn’t concentrate and I didn’t do well. It was bad. All my reports said I was a good student but that I didn’t attend enough.*

*It had a big impact – if anything happens I get frustrated and can’t do any work or concentrate – like when Mum was in hospital.*

*I get stressed at test time and often just write down any answer so I get marks. I would do better if I could do the tests at another time by myself.*

At home, many of the young carers felt that their education was of secondary importance to their caring and that their time for homework and assignments was limited:

*Usually I’m helping out… I have chores to do before I can do homework.*

A number of the young carers reported being bullied about their relative’s illness or disability and that this had a considerable impact on their education. Others found it difficult to deal with school cultures that allowed, and sometimes even supported, discrimination towards those with an illness, disability, drug or alcohol problem or mental health issue:

*The teachers let the other kids pick on people with disabilities which made it hard to talk about.*

*Some teachers talk about spastics and retards so if they do it how’s things gonna change? I told one teacher and she said that I was being over-sensitive and that I shouldn’t go “schiz… She said that!*
As mentioned elsewhere in this report, many of the young carer’s families experienced significant poverty. This impacts upon young carer’s capacity to achieve satisfactory outcomes in education, with many not affording school resources, textbooks, stationery, uniforms, sports equipment or excursions. Others reported not having enough money for food, which impacted on their ability to concentrate in class.

Sometimes we wouldn’t have lunch. Having no food.

We couldn’t buy Jacaranda [Educational Supplies]. I had to steal my own books and stuff.

I didn’t go to school – couldn’t afford books…

The importance of school for support

As well as getting an education, a large number of the young carers identified that school was a locus for support – from friends and teachers:

When I get sad at school everyone is nice to me. You should try the crying thing – it works!

I didn’t get to do my homework and stuff. I told my teacher I couldn’t really do my homework and she said that was ok.

My friends at school are understanding – more than my teachers.

Others, however, felt that they could have had better support from teachers:

I didn’t do well at school – all the stress at home. The teachers don’t take much notice and don’t really care.

I wrote a story about being a young carer but my teacher said it was a load of crap. That got me cut.

There was this one teacher who made me stand up in front of the class and asked me why I hadn’t done my homework. I told her my Mum was sick and I had to care for her. She said that everyone has to do jobs at home but they still had time to do their homework. She said “I have to look after my husband and clean the house – you don’t see me using it as an excuse”… That made me go off. I said “listen here, you bitch, my Mum is dying and
I have to do everything for her. You don’t know what its like. I’ve seen you sitting around at the shops on your big fat ass drinking coffee – don’t tell me you know what its like because I never have any time to sit around like that. You don’t know nothing”… I got suspended and my Mum had to threaten the principal to let me come back… Nothing ever happened to her [the teacher] – it’s just not fair.

And that bad experiences at school had negative outcomes:

I was quiet at school – I couldn’t talk to people, put my hand up in class. It was hard to be in a big group. I took up drugs to cope with it – and that stuffed me around.
Young Carer Story: Bernie

Bernie is 13. She cares for her mother who has a chronic liver condition and breast cancer. When Bernie was 10, her father left her mother because he felt he could no longer deal with the stress. As such, Bernie and her mother were left alone - with no income and no one to help Bernie with the caring.

As well as feeling exhausted from providing around 6 hours of caring each day, Bernie is incredibly afraid that her mother is going to die and often does not cope well. When she is most stressed and anxious she ‘goes off’ at school – getting into fights and breaking school property. Her teachers have told her that they do not believe that she could be caring for her mother the way that she does and that she needed to take some responsibility and ‘stop hiding behind her Mum’s problems’.

Bernie feels like she is victimised by one teacher in particular who told her that ‘all families have problems so just deal with it’. Bernie is upset because she believes that most families don’t have to deal with the stresses and strains of caring or the ever-present fear that her mother is going to die.

Because of these negative experiences, Bernie is resolved that no-one will ever understand about what’s going on for her and that she will never ask for help from anyone.

Employment

As many of those who answered the survey were under 15, only a small number of young carers reflected on their own experiences of employment: both finding and keeping a job. A number of them felt that they were able to get a job because of the skills that they had developed as carers:

I couldn’t do childcare work if I hadn’t cared for people – my nurturing side came out.

Some of the skills have helped me get a job.

Others who had not yet got a job (including those under 15) agreed, believing they had abilities and personal attributes that would be valued:

I’m more motivated to help out.
I’m going to be a nurse so I’ll be good at it and know what to do.

I’ll get a job when I have more time. I have more skills.

Interestingly, a large number of young carers wanted to be youth workers, nurses, doctors, or teacher or to enter other ‘caring professions’:

I wanna do youth work because I’ve been there. I wanna help people.

I want to be a zookeeper and look after koalas.

For those who had jobs, many found the experience rewarding and gave them ‘time out’ from other care responsibilities:

It’s good to be more independent and not rely on others.

When I’m at work I try to block everything out… I try not to worry. I’m bringing in money to help out.

I’ve been working since I could. It’s had a positive impact.

Keeping a job was sometimes seen as difficult, but a number said that their employers were flexible and supportive:

My sister is often late for work and gets in trouble but her employers are accepting as they know the situation.

I give Mum the work number. If she needs me she can call. If I get a call I have to leave. I say that at the interview and if they can’t give me that leeway I don’t take the job.

Others felt that they just had to work:

I don’t like my job but I’ve got to get money somehow.

At the moment, some saw holding down a job while caring as not possible:

I had a job, I quit when Dad got sick.

Maybe I’ll get a job when I have more time.
Some were not hopeful about their future employment prospects:

Because of my Mum’s depression I have no confidence and I don’t think I’ll get one.

I’ll always be at home.

Many, however, were looking forward to working and felt that because of their caring and also because of the positive impact that having more money in the family would have on their situation that they were more motivated to find work and to help out.

### 4.6 How Caring Affects Young Carers Future Outlook

The majority of young carers spoke with hopefulness about their future lives, but recognised that they would be carers for some time:

It would be hard on Mum if I moved out

I will never be too far away from my Mum and sister to know all the time that they’re ok… that will be forever.

I’m always going to have to look after my Dad.

Some believed that this would have an impact on their future lives:

Her back will never get better. It will be hard to go to university and look after Mum

I want to go to Queensland but I know that will never happen.

A number were concerned about future relationships, particularly when they were caring for someone with a life-long illness:

If I get a boyfriend I’ll have to tell him I’m a young carer but I’m worried that when he finds out he’ll drop me. I don’t want to have to face the impossible choice – if they say it’s either him [my brother] or me… I can’t turn my back on my family.
I’m worried that if we get married we’ll have to look after my brother and that could be hard [on the relationship].

Some of the older young carers reflected on the futures of the cared-for relative – an experience that was difficult for a number of them:

I’m worried about when Mum and Dad can’t handle him anymore and he’ll have to be put away [in an institution].

I still fear the day that she’s going to die. We know its going to be pretty soon. Every year is a bonus. She has low days and you think it could be close. The doctors said like a year ago that she wouldn’t make it… So every year she’s still with us is a bonus. But she’s strong. She doesn’t want to leave us. She wants to meet my sister’s and my kids. She said she doesn’t want us to go out and have kids right away but she wants to meet [them].

Some were also concerned that they themselves may be predisposed to their parent’s illness or disability:

I’m worried about Alzheimers. I’ve already got depression and anxiety… What’s the point in living? I’ve got my son – he’s all I’ve got to live for.

But most of the young carers also felt that their caring had made them stronger and had given them opportunities that they greatly appreciated:

It’ll have a big impact on my life. I’ve gone through a lot of stress and pain which will make me stronger in the end. I will be more aware of the world.

Many of them saw themselves as using these experiences to help others people (including other young carers) into the future:

Maybe I’ll be able to come on camp as an oldie [volunteer].

Maybe I’ll be able to help someone else who cares. Make it better for them.

I will come to camps as a leader because of being a carer. My life’s decision is to help others.

I’m motivated to understand and work with people. I’ve started nursing and doing psychology now… to understand myself too.
It’s strengthened what I want to do in the future – teaching early childhood.

**Young Carer Story: Margi**

Margi is 16 and she helps her parents care for her older brother, Darren, who suffers from autism. At the moment, Darren attends school and receives 20 hours of respite each week, which helps the family rest. At the end of the year, however, Darren will finish his education and will no longer be entitled to the level of support that he is receiving. Due to his inability to communicate (Darren is non-verbal) and because of his violent tendencies, it is unlikely that Margi’s parents will be able to organise an employment program for him. Margi is unsure as to what will happen.

Margi is aware that she will always be a carer for her brother, taking over from her parents when they are no longer able to care for him. She realises that this will restrict the type of work she’ll be able to do and the relationships she will have. She is also afraid that her children might also have autism, and is not sure how she would cope if they did.

Margi recently introduced her new boyfriend to her parents. Her mother asked him how he would feel about looking after Darren if things between them worked out. Margi is not sure if her boyfriend was impressed by these questions, or by being bitten by Darren when he had one of his attacks. In fact, she’s pretty sure it won’t work out.

5 Discussion

In conducting the research it became clearly evident that children and young people in the ACT were assuming significant care responsibilities within their homes and that providing care to a relative had both positive and negative impacts on their lives. In talking with children and young people, however, many felt that their experiences were underplayed, disregarded or disbeliefed and that sometimes they felt unsure about whether they were a young carer, and therefore eligible for support, because traditional definitions did not describe their own experiences.

In addition, many of the participants felt that because young carers are often portrayed as either being victims or heroes they did fell disempowered and misunderstood. In this section we will explore these issues and develop alternate definitions and constructs.

Discussions around young carers service needs and how these definitions and constructs might better lead to practice responses are discussed in the project’s second report *More than Just Words: Responding to Children and Young People with Care Responsibilities.*
5.2 The need for a more responsive young carer definition

A large number of children and young people living in families affected by illness, disability, drug or alcohol use or a mental health condition do not relate to the term ‘young carer’ (Baker, 1996, p8). Throughout the project, children, young people and key stakeholders identified a range of reasons why many young carers did not identify themselves as being carers. They argued it was because some children and young people:

- have never heard the term before;
- do not see that their experiences of caring for a relative as being different to what they considered the ‘normal’ experiences of other family as being;
- feel that the term focuses on care tasks that required you to physically do something (i.e. personal care, mobility etc) rather than emotional care tasks (including monitoring and cheering up);
- feel that the term focuses on care tasks for their cared-for relative rather than other tasks that they performed because their parents were now unable to provide them because of their illness or disability or care responsibilities (i.e. cooking, cleaning, babysitting, providing emotional support to other family members);
- feel that the term did not describe those caring for a relative with a drug or alcohol issue because it wasn’t always seen as an illness or disability;
- feel that because they had parents and other relatives who provided care they would not be considered a ‘young carer’ regardless of what they did or the impact it had; and / or
- feel that the term problematises their experiences and therefore did not want to adopt it.

For these reasons, many children and young people do not identify themselves as young carers nor access the existing services and supports. As such, it is imperative that a more inclusive and responsive definition be developed.

From the literature

Within the international literature there has been considerable debate over how ‘young carers’ should be defined. To date there has been no agreement. Without agreement the young carers sector cannot adequately meet the needs of children and young people with care responsibilities, develop sector responses or ensure the inclusion of all young carers in service delivery (Baker 1996, p9).

Across Australia and the globe, some definitions are objective, where young carers are defined by the level of care they provide (i.e. significant or substantial carers):
Children and young people (under 18) who provide or intend to provide a substantial amount of care on a regular basis. (UK Carers Recognition Act, 1995)

This type of definition is problematic in that the terms ‘substantial’ and ‘regular’ are ambiguous and give professionals the discretion to discount children and young people who are providing ‘episodic’ or variable levels of care to their cared-for relative. This is particularly relevant to mental health carers, and has led to many carers failing to receive the type and level of support that they need (The Network, 2001, 4).

Other definitions focus on the level and type of care that they provide above and beyond what might be expected of other children and young people of their age. Usually this is guided by a notion of ‘adult responsibility’:

Someone under the age of 20 who is providing non-professional care to a person with a long-term illness or disability, or who is undertaking tasks within the household beyond that which would be expected for their age, due to the long term illness or disability of a family member. (CA 1996, p v)

A child or young person (under age 18) who is carrying out significant caring tasks and assuming a level of responsibility for another person, which would usually be taken by an adult (UK Social Services Inspectorate, 1995)

This terminology is also ambiguous and buys into debates about what should be expected of children and young people. It also does not account for the varying levels of care being provided. For example it is not unusual for a young person to help with the cooking or cleaning although it is ‘beyond that which would be expected’ if they are the only one that cooked or cleaned every day with no support (Gays, 2000).

The term also maintains limiting notions of childhood by asserting that children and young people do not, cannot and should not be partners within their households. This can act to discredit their roles and hide their caring from the external world (as outlined above).

More subjective definitions focus on the way that assuming care responsibilities can ‘restrict’, ‘impact on’ or ‘limit’ the lives of children and young people with care responsibilities:

anyone under the age of 18 whose life is in some way restricted because of the need to take responsibility for the care of someone who is ill, has a disability, is experiencing mental distress, or is affected by substance misuse (UK Children’s Society, 2000).
This type of definition implies that caring is a harmful experience for all children and young people and restricts those who, rightly or wrongly, do not identify negative impacts of providing care. Many children and young people involved in this project were quite reluctant to identify any negative impacts of care in case it implied fault, dependence or failure of their cared-for relative, and would therefore be restricted by this definition.

In addition, such framing of young caring discounts the ways in which caring can build relationships, skills, and opportunities and the positive impacts it can have on children and young people’s mental and physical health and wellbeing and can act to disempower and victimise young carers and their families.

**What needs to be encapsulated**

For a definition to be adequate and accessible, it must recognise the variability of the characteristics of those caring, the care responsibilities they assume, the levels of care and the impacts (both positive and negative) that caring can have on a child or young person’s life and be presented in a way that affirms rather than problematises their experience.

As such, it must recognise that young carers may:

- be any age under 18
- care for a parent, sibling, grandparent, other relative or friend or a collection of these;
- care for a relative or friend with a physical, intellectual, or sensory disability, a mental health issue, or a chronic illness, who may be frail aged or have a substance use issue, or a combination of these;
- be the only person who cares for their relative or friend or be one of a number of informal carers;
- spend varying amounts of time caring;
- live with their cared for relative or friend or not;
- be supported by formal services or not;
- take on responsibilities focusing specifically on their cared-for person or on other family members or the broader family unit (i.e. young carers who care for other siblings, or spend time counselling and supporting a parent not coping with the pressures of caring for another relative);
- identify themselves as being a ‘carer’ or not; and
- experience varying degrees of and types of impacts of caring (physically, emotionally, educationally, socially, financially). These may be both positive and negative.

The rhetoric surrounding the definition must acknowledge:

- that caring is natural and can be, when adequately supported, an empowering, nurturing and positive experience;
• that caring is the responsibility of the whole community and that families should not be placed in a situation where children and young people assume inappropriate types or levels of care that may negatively impact on their health, wellbeing or ability to participate in the community; and
• that caring in itself is not exploitative or abusive, but that a lack of appropriate formal supports and services may be.

At what age do young carers stop being defined as young carers?
Whether to include young people aged 18 to 25 within definitions of ‘young carers’ has been the focus of much discussion within the newly forming young carer sector. In Australia, there has been always disagreement with early definitions seeing ‘younger carers’ as being aged 15 to 44 (CA, 1996), and future definitions of ‘young carers’ as being under the age of 18 (ACTYCN, 2000, Gays 2000), and up to the age of 25 (CA, 2000).

Having a clearly defined definition of young caring is important as it sets the parameters of investigation, of the design and delivery of ‘young carer’ services and provides a basis on which to advocate for the needs of those who fall within and outside this description.

Those who argue for the inclusion of this older group in young carer definitions argue that young people aged 18 to 25 (including CA 2000):

• are technically ‘adults’ but may need support transitioning from childhood, and enacting their adult rights;
• are often engaged in education (university, adult training etc), apprenticeships or traineeships and may continue to be reliant on their parents;
• may need support in transitioning from the family to independence, (and from young caring to adult caring or to no longer providing care);
• may not be considered ‘adults’ by mainstream (i.e. non youth) services problematising their access and equity of service.

Those who argue against their inclusion however, suggest that young people aged 18 to 25:
• are quite different developmentally and therefore have substantially different needs to children and young people under 18;
• are formally considered adults and therefore have extended rights to decision-making, self-determination and citizenship, making them more politically and socially powerful than their child peers;
• are eligible for adult services and should therefore be supported to access more responsive help;
• are often caring for a partner or child – making their experiences and needs considerably different to children and other young people who care for parents and siblings.

Responding, on one hand to the evidence that young people aged 18 to 25 may not fully access adult services, but on the other to the reality that they are entitled to full adult rights and services, it is recommended that this group not be considered young carers but be supported in their transition to adulthood, and be provided with age-appropriate and directed service provision.

This may occur within existing young carers programs with targeted programs specifically for this age group. In addition, it is imperative that adult services also respond to the specific needs of this group and that mainstream youth, young carer and adult carer services support the young people through the transitions. Only if this is possible can such a division be made.

A new working definition

It is beyond the scope and capacity of this project to develop a new, encompassing and responsive definition of ‘young caring’. However, in extracting the main themes from the literature and from the interviews conducted with young carers and workshops with the Young Carers Research Team the following working definition is provided. It acknowledges that young carers may be caring for multiple relatives, with multiple conditions; and that young carers may not provide direct care to their ill, disabled, mentally ill, alcohol or drug-dependent relative but may be part of the family’s ‘care team’ by caring for other family members:

Young carers are children and young people who care for or help care within a family affected by the illness, disability, drug or alcohol and / or mental health issue of one or more of its members or friends.

5.3 Young Caring: A Hidden Responsibility

Young caring is a relatively hidden phenomenon. Most young carers in the study reported that though they were proud of the roles that they assumed within the home, experiences or fear of harassment; of attracting unwanted scrutiny and inappropriate outside intervention; and of threatened family privacy kept them from sharing their stories and restricted them from receiving the support they needed.

Others talked about times when they had shared their experiences with their peers and professionals and had been disbelieved, undervalued or disregarded. Many stated that because of these negative experiences they would not share their stories again.
In a workshop, the Young Carers Research Team analysed the data gathered through the interviews and explored some of the other social norms, values and beliefs that collude to hide young carers’ stories from the community at large.

**Experiencing bullying, harassment, stigma and a lack of awareness**

Many young carers reported that they would not tell their friends that they were carers because they were afraid that they would be bullied. For many, this was because they felt that disability, illness, alcohol or other drug use and mental illness were stigmatised within the community and that if they shared their situation that they, and or their family members would be judged, criticised and harassed.

*I wasn’t invited places because they said I had a ‘retarded’ brother and people thought I was retarded myself.*

*I was too scared that I’d get bullied about it… Its not fair that they cant see what its really like.*

This was particularly a problem for young carers at school – many of whom reported times when they had bullied about their home situation. As mentioned elsewhere, the young carers felt that the harassment stemmed from an anti-disability sentiment that was often left unchallenged if not sustained by school cultures and teaching staff.

The impact of this harassment can be significant. In a study of young carers in the UK, the Princess Royal Trust for Carers found that 71% of young carers had been bullied and that this had led to 20% of them not attending school (1999).

Within the broader community, young carers saw this stigma as having similar effects – arguing that these myths and misunderstandings were being perpetuated through media. Greater community awareness around illness, disability, alcohol and other drug use and mental illness was called for with many arguing that until stigma was challenged they felt unable to come forward, identify themselves and seek the support they needed.

**Avoiding Blame and Shame**
Other young carers reported that they did not want for their families, and their parents in particular, to be to be blamed or shamed for their caring, and therefore did not talk about what was going on at home.

Olsen (2000) argues that this reluctance is shaped by a misconception, whereby young carers are seen to have ‘lost’, or are in danger of ‘losing’ their childhood and that their parents are responsible. Parents are thus viewed as being morally corrupt or, as Zelizer (1985, p74) puts it “suspect collaborators in the exploitation of their own children.”

This questioning of parents’ roles has shown to have ‘far-reaching, and potentially devastating consequences for disabled and / or ill parents” (Keith and Morris 1995, 55) for as well as hiding young carers, this misconception has shown to permeate our service system which now views families affected by illness and disability with suspicion, legitimising the over-scrutiny and policing of their lives. McConnell and Llewellyn (1998, p34), show that this has led, among others, to many children being taken into care as a result of the “prejudicial treatment from child protection agencies and courts” against people in families affected by illness or disability.

Though writing on children in the developing world, Steiner and Allston summarises the situation for young carers and their families:

_The imperative of the best interest of the child gives outsiders the legitimacy and powers to intervene. Thus many…through the failure to comply with Western childhoods become permanent objects of outside intervention (Steiner and Allston, 2000, p518)_

In a workshop focusing on how and why children and young people with care responsibilities were hidden, the Young Carers Research Team vehemently denied the assertion that they had their childhoods taken from them, and that their parents had exploited them through their caring:

_It’s like they think that we don’t get a childhood – that we don’t get what we need – and that it’s our family’s fault that someone’s sick._

_They should talk to us young carers – because it’s crap._

They identified how this misconception impacted on their lives, arguing that people saw young carers as victims who:

- should be rescued;
- should be pitied;
- had no choices;
- received nothing from the experience;
- received nothing from their parents;
• were exploited;
• were powerless;
• had nothing to offer; and
• should not offer anything to their families.

And that people saw their parents as exploiters who:
• could not care for their children;
• provided them with nothing;
• use their children willingly;
• chose for their children to care;
• have other options (from the service system) but do not accept them;
• are the only ones who benefit from the relationship;
• should lose their children into care; and
• should be forced into institutional care themselves rather than exploit their children.

They believed that community misconception had significant impacts on their lives, how they saw themselves and their families and their ability to access support by:

• Forcing them to hide their experiences;
• Making them feel devalued and disempowered;
• Having the service system waste resources ‘saving’ rather than helping families to reduce the negative impacts of care;
• Devaluing the skills and positive experiences they had gained;
• Making them more reluctant to ask for help;
• Developing unnecessary tensions, feelings of shame and blame within the family; and
• Making them feel as though they have nothing to take with them into adulthood except a feeling of hopelessness.

Olsen (2000) agrees with many of these points and argues that young caring is not an issue of parental exploitation but more about the ‘dissonance between what is expected of parents regarding the childhood their children can enjoy, and the ability (or otherwise) of families to deliver such a childhood in the context of the economic and social barriers associated with disability’. As a result of structural and socially-sustained inequalities, he claims that families are forced into relying on children and young people to assume heavy care responsibilities with little or no outside help.

As such, while we focus on issues of morality and exploitation we miss the fact that it not the family who places children and young people in difficult situations, but the failure of the service system designed to support them:
… the most critical factor in determining who cares and what they do appears to be the availability of support from outside the family itself… the provision… of services… seems to decrease the level of caring provided by children (Dearden and Becker, 1998, p84).

The impact of limiting notions of parent-child and carer-cared-for relationships

Tied to this conception of childhood, and raised within this context by the Young Carers Research team, was the social construction of parent-child and carer-cared-for relationships.

Popular understandings of parent-child and carer-cared-for relationships have constructed the former as being the provider and the nurturer and the latter as the dependent and consumer. As such, the relationship is unilateral with love, care and guidance flowing downwards but never up again (Olsen, 1996).

In the case of a disabled parent-child relationship, obvious difficulties arise when working within such a dichotomy. On one hand, you have a parent who requires a certain level of care from their child, but on the other provides their child with nurturance, support, love and protection.

Rather than acknowledge the duality of the relationship, much of the literature on young caring, particularly of children with parents with a mental illness, have tended to problematise the relationship by arguing that children are not having their needs met by their disabled parent.

This was spurred on by early work of Rutter and others (1966) who focused their studies on maternal deprivation – finding that there were significant correlations between mental health problems of parents and their children. However, when this research was analysed more carefully, it was discovered that, more that parental mental ill health was less a precursor than other factors and that a child’s own mental health problems stemmed more from:

the complicated interplay between the illness itself, family support, the quality of parental relationships, the degree and causes of stress in the family, socio-economic disadvantaged and the outcome in terms of the child’s psychological well-being.

Though this early work was challenged, there continues to be a considerable focus on the idea of ‘parentification’ within the literature. Parentification refers ‘to children and young people assuming adult roles before they are emotionally or developmentally ready to assume those roles successfully’ (Stein et al 1999, p194) and is usually used to describe the impacts on children with parents with an illness, disability, or alcohol or other drug issue. Inherent in this work is the idea
that children and young people take on the responsibilities of parenting for their parent with no support.

Though it is not within the scope of this paper to challenge the psychological data that underpins such research projects, it is important to challenge some of the underlying assertions that have both premised the report and have been sustained within the community’s own commonsense understanding of parenting.

The young people in the Young Carer’s Research Team felt that adopting such a discourse impacted on their lives and the lives of their families by:

- devaluing the support, guidance and nurturance that they received from their parents or other cared-for relative;
- failing to recognise that caring is a bilateral relationship within which both carer and cared-for relative (and parent and child) can benefit and grow;
- problematising what they ultimately saw as a positive contribution – an ability to care for those they cared about;
- reframing young carers into victims of parental exploitation rather than as co-contributors in the family;
- playing off the needs of their cared-for relative and their own – making it impossible to respond to both;
- making what they saw as a natural and affirming contribution into something ‘un-natural’ and diminishing.

By doing so, the Young Carers Research Team argued that the community:

- would be unable to respond to the holistic needs of the family and to design and deliver responsive supports that met the needs of each members’ needs as well as those of the family as a whole;
- worked within a child protection rather than a child welfare model, adopting interventions such as removal rather than resourcing and enhancing family capacity; and
- forced families to hide their young caring to avoid scrutiny and child removal.

As such, it is imperative that the development of future policy enhances rather than problematises the care experience – resourcing and supporting families and only separating them in cases of abuse and disclosure rather than a structural inability of the family to adequately meet the needs of its members.
Service design and delivery must also encapsulate this principle, working holistically to ensure that all members of the family unit are adequately supported and resourced to meet their needs and to achieve their goals with and within the family unit.
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7 Attachments

7.1 Attachment 1: Researching Young People

Youth Coalition of the ACT

The project will:

- recruit young people from a range of different backgrounds and circumstances as both participants and peer researchers;
- involve young people in the planning, development of research tools, delivery of training, conducting of interviews, and review of the final report;
- provide remuneration for all young people as a recognition of the value of their skills and expertise and do so in a way that does not impact on the young person’s ability to respond openly and honestly;
- ensure that all young people are informed of the scope and purpose of the research, how and why they are being asked to participate and how the information gathered will be used;
ensure that no young person will be harmed throughout the process or as a result of their involvement in the project;

- ensure that participation by young people in the project is purely voluntary and that young people are made aware that they may cease their involvement at any time throughout the process; and

- identify appropriate resources and services for young people who may need additional support after the consultations.

Peer Researchers will:

- be recruited broadly and represent young people from a range of backgrounds;

- be recognised as partners within the research process, be shown due respect and be provided with opportunities to shape, direct and evaluate the research process;

- receive appropriate initial briefings explaining what they will be asked to do, what the expectations of partners are and how they will be supported through the process;

- be provided appropriate and youth-friendly training and will develop their skills through the research project;

- be provided with ongoing support to ensure that they feel comfortable and not limited in their participation;

- be offered supervision and timely feedback about their performance;

- be offered choices throughout their involvement – including the choice to leave the project when necessary;

- be supported to facilitate their involvement (including transport); and

- be remunerated for their involvement.

Information received throughout the project:

- will not be used against young people – either specifically or generally;

- will only be used for the purposes identified within the project and expressed to participants;

- will be considered confidential unless workers are concerned about the safety or wellbeing of participants. Researchers will inform participants of this limitation and will remind them if they believe that the young person is going to provide such information;

- will be presented in a non-identifying way to ensure the anonymity of participants;

- will be checked by the youth researchers to ensure that it is valid and a true account of proceedings before being submitted. Wherever possible this should also occur with respondents; and

- will be owned jointly by participants and partners.
7.2 Attachment 3: Illnesses, Disabilities, Mental Health Issues and AOD Issues

Acquired Brain Injury
ADHD
Alcohol Abuse
Alzheimer’s
Antidepressants
Anxiety
Autism
Aspergers
Chronic Back Pain
Bipolar
Brain Stem Haemorrhage
Broken Back
Cancer
Carpel Tunnel
Damage to Knee
Deaf
Depression
Emphysema
Epilepsy
Hearing
Heroin Abuse
Ligament Damage
Liver Disease
Marijuana Abuse
Paraplegia
Personality Disorder
Psychotic
Renal Failure
Schizophrenia