



More than Words:
Supporting Young Carers and their Families

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

by Tim Moore
Youth Coalition of ACT

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Youth Coalition of the ACT
46 Cliathus St, Lyneham
PO Box 5232 Lyneham ACT 2602
(02) 62473540
www.youthcoalition.net

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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 know 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
It 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

Table of Contents

1	INTRODUCING THE PROJECT	6
1.1	READING BETWEEN THE LINES: A SUMMARY OF FINDINGS.....	6
1.2	THE NEED FOR <i>MORE THAN WORDS</i>	7
1.3	POLICY CONTEXT	8
2	WHAT YOUNG CARERS WANT FOR THEIR FAMILIES AND CARED-FOR RELATIVES... 13	
	<i>What young carers want for their cared-for relatives</i>	<i>13</i>
	<i>What young carers wanted for their families.....</i>	<i>15</i>
3	HOW ARE YOUNG CARERS' FAMILIES SUPPORTED?	16
3.1	WHAT SUPPORT ARE FAMILIES RECEIVING FROM OTHER FRIENDS AND FAMILY	16
3.2	WHAT SUPPORT ARE FAMILIES RECEIVING FROM THE SERVICE SYSTEM?.....	17
	<i>For their cared-for relative</i>	<i>17</i>
	<i>Young Carer Story: Terri.....</i>	<i>19</i>
	<i>For their families</i>	<i>19</i>
4	WHAT KEEPS FAMILIES FROM RECEIVING SUPPORT?	20
4.1	WHAT THE LITERATURE IDENTIFIES AS BARRIERS.....	20
4.2	WHAT YOUNG CARERS IDENTIFY AS BARRIERS FOR THEIR FAMILIES	22
	<i>Young Carer Story: MJ.....</i>	<i>23</i>
	<i>Young Carer Story: Mel.....</i>	<i>24</i>
5	RESPONDING TO BARRIERS, ENABLING ACCESS FOR FAMILIES.....	26
5.2	FROM THE LITERATURE	26
5.3	MOVING FORWARD FOR FAMILIES	28
6	WHAT DO YOUNG CARERS WANT AND NEED FOR THEMSELVES?	30
6.1	FROM THE LITERATURE.....	30
6.2	WHAT YOUNG CARERS FELT THEY NEED FOR THEMSELVES.....	31
	<i>When young carers need extra help</i>	<i>34</i>
6.3	WHAT SUPPORTS YOUNG CARERS ARE CURRENTLY RECEIVING	34
	<i>From family, friends and the community</i>	<i>34</i>
	<i>From the service system.....</i>	<i>35</i>
7	WHAT KEEPS YOUNG CARERS FROM RECEIVING SUPPORT?	36
7.1	FROM THE LITERATURE.....	36
	<i>Views and values of families and the community</i>	<i>38</i>
7.2	BARRIERS THAT AROSE FROM THE RESEARCH.....	38
	<i>Reasons Why Young Carers Don't Identify Themselves and therefore Don't Get Support.....</i>	<i>38</i>
	<i>Service Barriers Restricting Young Carers Access</i>	<i>39</i>
8	RESPONDING TO BARRIERS, ENABLING SUPPORTS FOR YOUNG CARERS.....	41

RESPONDING TO GAPS IN SERVICE: 43
ATTACHMENT 2: THE SEVEN CORE PRINCIPLES OF THE ACT CARING FOR CARERS POLICY:..... 45

1 Introducing the Project

In 2004, the Youth Coalition worked with 50 young carers to discover more about the lives, experiences and services needs of children and young people in the ACT who helped care for a family member or friend.

The aim of the research project 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.

1.1 Reading Between the Lines: A Summary of Findings

The findings of the research were presented and analysed in two reports. The first report, *Reading Between the Lines: Listening to Children and Young People about their Experiences of Young Caring in the ACT* attempted to tell the stories of children and young people with care responsibilities in the ACT and to look at the ways in which they felt that caring had impacted on their lives and the lives of their families. A summary of the key findings of *Reading Between the Lines* follows.

Regarding the types of children and young people caring and their levels of responsibility:

- Young carers are often caring for more than one relative at a time, and for relatives with more than one condition;
- Young carers often care for significant periods of time (an average of 6.4 hours per day) for a substantial duration (average of 6 years);
- Young carers caring for a relative with an episodic condition (primarily mental health) do not identify times when they have no care responsibilities;
- Most young carers live in families experiencing financial hardship;
- No young carers in the sample received either a Centrelink Carers Allowance or a Carers Payment; and
- Young carers who are incarcerated often continue their care responsibilities from detention. They may have been sentenced for committing a crime associated with their family's poverty or what they see as their care responsibilities.

Regarding the types of caring tasks they assume:

- A large number of young carers are responsible for tasks around the home (78%), for caring for other relatives (including ensuring their safety)(78%), providing emotional support (74%), helping financially (50%) and protecting the family (68%);
- These caring responsibilities are more intense than their non-caring peers and are most often provided without supervision or support; and
- Young carers often assume similar levels of caring responsibility to adults.

Regarding the impacts of caring on their lives, their health and wellbeing and their participation:

- Young carers may experience positive impacts of caring including feelings of pride and worth, a sense of accomplishment, greater levels of fitness, greater resilience, stronger family relationships, better outcomes in education, more skills and a positive outlook on life;
- Young carers may experience negative impacts of caring including fatigue, injury, greater levels of stress, anxiety and feelings of hopelessness, family conflict and breakdown, financial insecurity, limited social and recreational opportunities and poor outcomes in education; and
- Young carers caring for a relative with an alcohol or other drug issue are likely to experience similar impacts of care to other young carers, though they may experience greater social isolation, be exposed to less safe situations and be less likely to receive support.

1.2 The need for *More than Words*

In developing *Reading Between the Lines* it became increasingly apparent that though they often acknowledged that caring for others was often a positive experience that gained them skills, positive outlook and a sense of self, many young carers in the ACT were also experiencing significant difficulties and hardship.

As will be shown, it was also found that many children and young people caring for a relative were doing so without support for a range of social, systemic and sociological reasons, thus sustaining them and their families in unsatisfactory circumstances.

Rather than just capturing these experiences and difficulties, the Young Carers Research Team was committed to ensuring that the service needs, issues, barriers and enablers be identified so that problems could be identified and resolved and the negative impacts of care reduced.

More than Words aims to place young carers within their local context and to identify the service systems around them. It aims to identify their needs, to explore their experiences of receiving

support (if any) and to propose strategies emerging from the literature, practice and from young carers themselves.

It begins with by placing the report in a policy context before presenting a review of the literature, an investigation of young carers' reported levels of and experiences of support before exploring potential service responses.

1.3 Policy Context

Over the past three years, considerable attention has focused on the existence, needs and rights of carers within the Australian Capital Territory. Carers have been identified as both potential partners in the early identification, planning, design and delivery of services to their relatives or friends with illness, disabilities, mental health concerns or problematic alcohol or other drug use.

Carers have also been recognised as a target group in their own right – with their own service needs and experiences, different and beyond to those of their cared-for relative.

Leading up to and culminating in 2004, the ACT Government has attempted to respond to the needs of carers, generally, in its various policies, plans and strategies including:

The ACT Social Plan (2004) – which expressed the ACT Government's vision for the Territory as a 'place where all people reach their potential, make a contribution and share the benefits of our community'. In it, the Government aimed to 'promote and support the work of carers' by

- supporting carers through advice, information, needs assessment and assistance with support coordination;
- ensure that agencies regard the carer and the person receiving care as a partnership in which each person has rights and responsibilities;
- respecting and supporting the relations between carers and people requiring care through transitions to formal or shared care arrangements;
- ensuring that the health and wellbeing of carers is supported through services and programs that are flexible and responsive to individual needs and circumstances (2004, p39).

This document provides the overarching policy framework for the ACT Government that underpins all subsequent policies, plans and strategies developed across its various Departments. Though it provides strategic direction for the ACT, it relies on subsequent plans to identify specific ways in which they above commitments can be realised.

Caring for Carers Policy (2004) – which outlined how the ACT Government aims to better support carers ‘to reduce the risk that people in the care relationship will have negative experiences’. The policy recognised that carers should have choices, have their own needs met by the service system, and be supported to ensure that they ‘achieve a quality of life that is in accordance with community standards’.

The Caring for Carers Action Plan outlines cross-government commitments to carers and sets policy direction on all issues affecting their social participation, inclusion and support within the ACT. The seven core principles of the policy are attached (Attachment 2) and the commitments.

The objectives specifically targeting or responding to the needs of young carers include:

- objective 2.3: there is equity of access to supports across the diversity of carers, including children and young carers... (p9); and
- objective 6.1: the welfare of both carers and people receiving care is recognised in legislative and policy frameworks that underpin human services, with particular attention to the welfare of young carers.... (p17)

These two commitments are important because they recognise the specific needs of young carers and the traditional reluctance and or inability of services to respond to young carers in their contexts.

The plan continues, by acknowledging that:

Children and young people who are carers can be at particular risk of not being recognised and treated as part of a caring relationship. Sometimes they are simply ignored or excluded. In other cases families with young carers do not seek help from services because they are worried about how services will respond, for example that family relationships or home life will be disrupted or that their circumstances will be labelled or judged by others. We need more sophisticated approaches to support families with young carers in order to protect their welfare and maintain family relationships in positive ways that encourage more young carers to access support (p18).

Future Directions (2004) – outlined the ACT Government’s strategic direction in the area of disability services. *Future Directions 2004-2008* sets out four strategic directions including: influencing policy and culture to promote an inclusive society; strengthening the capacity of people with disabilities, their families and carers to maximise control over their lives; improve planning and use of available funding to meet the needs of people requiring ongoing support; and in partnership with the community sector, strengthen the sustainability and responsiveness of the service delivery sector.

It includes the following principles which are pertinent to young carers and their families (though not specifically mentioning them):

- **Community** All people with disabilities have opportunities for personal relationships and for meaningful involvement in the ACT community in positive and creative ways, building on their individual abilities. This in turn enhances the skills, perspectives and diversity of the ACT community as more people have the opportunity to be involved in the lives of people with disabilities.
- **Self-determination** All people with disabilities and/or their guardians are free to make or influence the decisions and choices that affect the course of their lives. This empowers them to realise their self-worth in every aspect of life.
- **Equality** All people with disabilities enjoy equal rights, responsibilities and opportunities with the rest of society. Equality is promoted by people with disabilities, their advocates and supporters.
- **Family Involvement** The roles of families, guardians, friends, carers and significant others in the lives of people with disabilities are supported, valued and promoted.
- **Equity** Sufficient resources for people with disabilities are distributed strategically to best meet their overall needs, taking a holistic view of the community.

Health Action Plan (2002) – which outlined the Government’s vision for the Territory’s community as one that ‘is inclusive of all Canberrans; is prosperous, progressive, skilled and creative; is cohesive, fair, tolerant and optimistic; is committed to protecting the vulnerable and supporting those in need; and gives its children every chance to achieve their potential’ (p4).

In it, the ACT Government commits to developing a health and community care system that is based on mutual respect between consumers, their carers and services providers’ by:

- ensuring consumers and carers (including those who are unpaid) are actively involved in policy, planning and service delivery and in making decisions about their own health care.

The Health Plan fails to recognise the specific needs of young carers to engage in and be supported as partners within the design and delivery of health care and does not identify ways in which the health system might better support young carers access to information and support in their own right.

ACT Alcohol, Tobacco and Other Drugs Strategy (2004-8) – which identifies how the ACT Government aims to, among others:

- ‘improve the health and social wellbeing of individuals, consumers, families and carers, and the community in the ACT;
- minimise the harm in our community from alcohol, tobacco and other drugs...; [and] develop evidence-based initiatives to ensure that issues associated with harmful alcohol, tobacco and other drug use are addressed in an effective way.’

Though this strategy recognises the impacts that AOD use can have on families, it fails to recognise the specific needs and situations of children and young people of parents who are problematic drug users after their infancy years (there are references to childcare support).

In fact, the document only identifies young people as AOD users or potential AOD users, and ignores the fact that their lives may be vicariously affected. As such, no strategies have been developed to support or service children and young people generally.

Children’s Plan – sets a vision for children living in the ACT as ‘active citizens capable of making exciting and diverse contributions to enhance the vibrancy of Canberra’. It seeks a Canberra that is:

- a community that encourages and supports children to reach their potential – now and in the future;
- a place where children are active citizens; and
- a great and safe place for children.

Among its commitments, the Children’s Plan agrees to build on the strengths of the community (p6) and to respond to the specific support needs of young carers (p12).

This document is a powerful example of how children can be empowered and supported within a community, and comes from a strengths base where their needs and capacity can be successfully married. Though recognition of young carers is limited, the principles underpinning the document recognise the contribution of children to the ACT community, aims to encourage, promote and enhance their involvement and provide them with support when needed.

Young People's Plan - outlines the ACT Government's commitment to young people in the ACT, recognising that 'it has an active role in improving young people's well-being and promoting positive life choices by young people'. It asserts that this can be achieved by:

- increasing young people's abilities to make informed decisions relating to their personal development through enhanced personal resilience;
- more meaningful and active participation in community life;
- increased skills and leaderships abilities; and
- strengthened relationships and personal support works.

The plan recognises that some young people in the ACT community experience disadvantage and that the 'whole community has a shared responsibility to acknowledge this fact and look at ways to reduce the levels of disadvantage and hardship that disadvantaged young people face'.

It follows, by acknowledging young carers as group of 'young people within our community that have specific needs that require consideration' – in particular in accessing services and in making transitions though the various points of their lives.

The plan recognises that young people (including young carers) live within families and that as well as focusing on the needs of the young person, 'that in some circumstances it will be necessary for the family, rather than the young person, to be supported'. Though it sets up a dichotomy, the plan realises the importance of natural communities.

Unlike the Children's Plan, the primary focus of this document is on young people as being 'in need' or 'at risk'. By aiming to 'increase' and 'strengthen' young people's involvement in the community, it assumes that their participation is limited and that without support, young people will not meet their full 'potential'.

Comment

It is positive to see that carers, and young carers in particular, have been recognised within ACT's guiding planning documents as one of the key barriers to appropriate supports for young carers has been a lack of recognition and understanding.

Unfortunately, many of the documents have problematised the young caring experience, painting children and young people with care responsibilities as being 'in need', or 'at risk' and in doing so, have failed to recognise the significant contribution that they make to the community and the fact that when well supported, young caring can be a positive experience.

Even when problematising young caring, the documents fail to take ownership of the issues affecting children and young people with care experience by diverting responsibility to the Caring

for Carers Plan rather than developing key systems and service responses in each relevant portfolio. This in itself is problematic, in that the Caring for Carers Plan has limited funding and must respond to the needs of all carers in the ACT.

2 What young carers want for their families and cared-for relatives

During the interviews, young carers were asked about what kinds of support that they felt would be useful for reducing the negative impacts of care and providing them with opportunities to reconnect to their communities. Unlike previous studies (CA 2002, Dearden and Becker, 2000), the project team also asked young carers about what kinds of supports would be useful for their cared-for relatives and their other family members.

This decision was made for a number of important reasons. Firstly, there is a logical argument within the Disability Rights movement that if the needs of people with illnesses and disabilities were effectively responded to, the negative impacts of care would be reduced significantly for carers (Keith & Morris 1995, p55, CA 2002, p29). As such the locus of support needs to not only be on the young carer but also their cared-for relative.

Secondly, young carers are inextricably linked with their families. Unlike other carers, children and young people receive care, support and nurturance from their families and must be supported within the familial context. Many young carers are reluctant to receive support from outside their families and therefore need to be supported within it.

Thirdly, as we will see, children and young people's access to appropriate services can either be enabled or restricted by the willingness and support of other family members. As such, if family dynamics are not investigated when identifying young carer needs, inappropriate, unresponsive and inaccessible interventions may be adopted.

What young carers want for their cared-for relatives

Most of the young carers interviewed were quick to identify what was needed for their cared for relatives. In responding, many became quite passionate in their responses, calling for more:

Personal and emotional support for their cared-for relatives who often felt distressed, upset and guilty for having to rely on the young carers for support. Young carers felt that this was important because their family members often felt overwhelmed, depressed or guilty about their situations and the level of care they needed from others.

Its so hard for Mum. Its not easy being sick and sometimes it gets too much for her.

Dad wishes he didn't have to rely on me. He gets upset and tries to do things for himself when really just can't. I tell him that its OK but he gets upset.

Mum just needs someone to talk to. To get things off her chest. She needs support.

Respite Care that gave their cared-for relative a break in which they, and the rest of the family could relax, rejuvenate and de-stress.

He loves to go away [on camps and into respite care]. He has fun doing stuff with other kids [with disabilities]. He doesn't stop smiling!

In-home support where workers visited and took on some of the young carers' care tasks, giving them time off to spend relaxing, catching up on school work, socialising with friends and getting a job. They also called on specialised workers who could provide services that the young carers' didn't feel the were adequately providing.

I do my best but I never know if I've done it right and that stresses me and Mum out.

Access to Employment for those cared-for relatives who wanted to enter or re-enter the workforce but didn't have the skills or confidence to do so. Young carers felt that this would help build their relatives self esteem, connect them to networks of support and develop their financial independence.

There needs to be more support for Mum and her mental illness. Help her get back into work – get experience. Help her with her confidence... she feels worthless.

Family-based rehabilitation programs available so that parents with children could receive the supports that they needed while maintaining their parenting.

My parents want to get help but can't because there's nowhere that they can go with the kids. If there was a place where you could go with kids – and where they weren't at risk because there were dodgy people around – then my parents would go.

They need us around to support them, help them through... we don't want to leave them alone either.

What young carers wanted for their families

As well as identifying supports for that would be useful for their cared-for relatives, the children and young people identified supports for other family members. Again, the young carers placed emphasis on the fact that they lived within families that had support and service needs that, if responded to, would have a ripple effect through to them also. The young carers suggested that their families needed:

Financial Support that was available to relieve the financial pressures on the family. This might be provided through rent assistance, money for medication, advocacy to receive benefits (especially those they are already entitled to), food, clothing and electricity vouchers and discounts (like those available to seniors for example).

Advocacy to receive entitlements, but also to get greatly needed modifications to houses, to find more appropriate housing and to gain more services. A number of the young carers felt that this was important because it was always the family who ‘had to fight for everything, if someone else could help out, take charge, then we wouldn’t have to be so tired and disappointed all the time’:

Get the house updated – the hallways are narrow and Dad cant get through.

Help with ACT Housing – I’ve been on the list for ages.

Family Counselling and Mediation to deal with the conflict within the home, to identify better ways of dealing with stress and to help families communicate better with each other.

We need help communicating. Mum won’t talk to anyone... she bottles it up then explodes. We don’t know how she is feeling or what’s going on.

Social opportunities for other caring relatives – who often also experience social isolation and disconnection from the community and support networks. This might be achieved through respite, but also through support programs and social and recreational activities.

Since Dad had his accident, Mum has never gone out.

3 How are young carers' families supported?

Young carers were asked to identify what supports they were currently receiving: be it through informal supports (provided by other friends and family) or formally (through the service system). A large number of the young people were not receiving either formal or informal support, often having to shoulder significant care responsibilities alone.

3.1 What support are families receiving from other friends and family

There was a significant range in levels of support provided to the family through informal support networks including families, friends and communities. Twelve of the young carers identified that they did not receive any support from within their family but had stopped:

My aunty used to come out and help – but she doesn't any more

My grandparents wrote off my Mum and told me to get fucked.

For some, this was because older siblings had previously taken on primary or significant care responsibilities, had 'burnt out' and moved away from the family leaving the next child to assume the carer role.

The rest received support from within their nuclear family as joint carers:

We all care. My younger brother tries to stay out of the way and to be respectful. Dad is a good cook. Mum calms my brother down, deals with his school problems. My younger brother looks after mum and helps around the home.

My Mum does most of the care. Helps him with personal care – getting in and out of bed. My sister does cleaning.

Seven of the young carers also received support from extended family who lived elsewhere:

My Mum did all the caring for my brother – my Gran looked after the rest of us.

My grandparents used to take my brother for a week.

My Dad's mum and dad – grandparents – they can't handle my brother anymore so they help out in other ways by paying bills and stuff.

A number also reported getting support from a neighbour:

Our neighbours are pretty supportive. They know what's going on so I can say "I'm going out" and they'll watch Mum for me.

3.2 What support are families receiving from the service system?

Though thirty-two young carers could identify a formal service or support that was available, or had been available to their family, only five identified a service or support that they could access more than once a month and only seven identified a support that was ongoing (i.e. not once-off) – meaning that very few of them had ongoing, substantial support.

Of those that did receive support, the majority were for their cared-for relative and the broader family as a whole.

Table 1 Formal Supports for cared-for relative

What services provided support	Number of respondents
Respite	7
Occupational Therapy or Rehabilitation	4
Community Nursing	2
Total receiving support	13
No support received	37

For their cared-for relative

Those receiving support for their cared-for relative were receiving:

Respite: Seven of the young carers who cared for a sibling were receiving occasional respite (ranging from fortnightly to quarterly) either in-home, on camps or in residential care.

Had someone from Carers take my brother out for the day and they paid for him to go on school holiday camp. When they found out that he set fire to the house they gave him heaps of attention... and then they realised I cared a lot too and I started to get help too...

Most of them were positive about the support that they received:

Its good as it gives the family a chance to wind down – have their own time

My brother comes back from activities calmer and more relaxed – he’s with people who know and understand.

Mum enjoys the break. She can get things done and sometimes likes to just lie down without having to worry about my brother.

However, others reported times when respite had actually caused more stress and anxiety:

We had a worker once who just sat down all shift and did nothing. My brother was going off and I had to calm him down because the worker wouldn’t. I was supposed to be getting a break – but I was even more stressed because I couldn’t trust them.

I’m always worried about respite – about him being abused. You hear about it all the time.

A number of young carers also did not like it when their relative received in-home respite, feeling as though they were discredited and devalued:

They [the in-home support workers] ignore me. They’re there to look after my brother and they act like I’m not even there.

Those who received respite also felt that their families needed more support and that it needed to be available when they most needed it. As such, the young carers called for more flexible respite packages that could be organised with short-notice.

The remaining 43 young carers, however, reported that they did not receive any respite support for their cared-for relative, though most felt that they needed it.

For a number of families this was because there was no co-ordination of services – that respite services did not take into consideration the needs of the whole family and therefore were inaccessible.



Young Carer Story: Terri

Terri is 11 years old. She cares for her mother who suffers from a liver disease. She is an only child and when her mother is unwell she does all the cooking and cleaning, gives her mother her medication, organises bills and does all the shopping.

Her mother needs to go into hospital for some minor surgery but cannot find anyone to care for Terri while she is away. As a result, Terri’s mother has had to turn down her last three operations – which has impacted on her health dramatically.

Domiciliary Care and Rehabilitation: Four cared-for relatives with a physical illness or disability received occupational therapy and / or support with rehabilitation. The young carers reported that this was useful in that it increased their relative’s level of fitness and mobility.

It helps with his fitness – it has made him a lot better since it started.

Two young carers also reported that their cared-for relative were sometimes visited by community nurses who changed dressings, helped with intimate care and ‘checked up’ on their progress. The young carers said that this help was useful as it meant that their relative didn’t need to go into hospital:

I wouldn’t have liked to have to do it myself or for my Dad to have to go to hospital. They’re not reliable.

For their families

Table 2 Formal supports for the family

What services provided support	Number of respondents
In-home support	1
Emergency Relief	4
Family Services	5
Total receiving support	10
No Support	40

In-home support: Four young carers received in-home support, with a worker from an agency coming in to help with cleaning and cooking preparation. Those who were receiving such support found it useful:

It’s good – I don’t have to do as much because it’s already been done.

However, three of the four young carers reported that they no longer received this support because the agency started to charge for services – making it unaffordable. The other young carer also stopped receiving support because her mother felt that she no longer needed it.

Emergency relief: Four of the young carers received financial assistance or other emergency relief from ACT charities. Though this took the immediate pressure off the family, many continued to experience significant socio-economic disadvantage with government payments barely covering the costs of medications and treatment let alone the ongoing costs of managing a household. As such, ERF was not a sustainable support, especially as many providers have policies that limit the number of times that a family can receive support.

Family Services: Five young carers were receiving or had involvement with Family Services. Some found their involvement positive – receiving respite, emergency relief, help in co-ordinating services, transport and ongoing support:

It takes the stress off Mum.

They told me if I ever needed a hand with money for rent, food, to call.

Others, were not as positive about their interactions:

They helped with practically nothing. Made my life more miserable. I wanted to stay with my Mum. They said they'd help but they didn't do anything.

They make it worse for you. They've got so much money but can't help you out when you need it.

4 What keeps families from receiving support?

As shown, young carers and their families often need support but only a small number receive them. This section will explore some of the barriers that families have experienced, both within the family itself, within individual services and the service system more generally.

4.1 What the literature identifies as barriers

Throughout Australia, various research projects have focused on adult carers and their access to services (CNSW 1998, CASA, 1999; Enduring Solutions, 2000). Though geographically disparate, the findings of these studies proved to be quite similar, with between 18 and 24% of

carers identifying that though they felt that they needed them, they had not accessed appropriate support services. Citing ABS data, Enduring Solutions argues that in the ACT, this equates to around 900 of the 5,200 primary carers never having received the supports that they expressed they had needed.

The reasons identified for this discrepancy between expressed need and received service include:

- a general lack of services available;
- inflexible funding models that stifled innovation in service provision;
- a mal-distribution of existing services;
- a focus on the needs of the consumer rather than the whole family (including the carer);
- a lack of quality in existing services;
- fragmented and uncoordinated service planning;
- a lack of training for workers;
- no respite services available for:
 - o adults with mental health conditions;
 - o culturally sensitive groups;
 - o people with behavioural problems;
 - o people with an undiagnosed mental or physical problem;
 - o people with drug or alcohol issues;
 - o adolescents needing peer support; and
 - o children with challenging behaviours;
- costly fees for service; and
- a lack of services for carers in paid employment.

In addition to the above list, Carers Association of South Australia identified that other factors included: services not being available when needed; carers not being aware of available services; dissatisfaction with existing services; services being unable to provide the level of care required; and that the person cared for not wishing to use particular service (CASA 1999).

As with other aspects of the caring experience, young carers were not mentioned in any of the reports on the provision of services to families. As such, there is little understanding about the service needs of, provision of services to or experiences of young carers and their families within the system. Though Carers Australia (2002), extrapolating data from the ABS census, argues that only 2% of young carers have received respite, we have no way of knowing if this is because it unneeded or, if like other carers, it is because of service-based or systemic barriers.

In their report, Carers NSW highlighted that as well as issues of services and service systems, other factors within the family and their own beliefs and values about caring may restrict their accessing of services (1998, p52). Believing that caring is a family responsibility; an inability to

'let go' or accept help; a sense of independence; pride; a lack of trust of workers; and attitudes of other family members have each been identified as key barriers to the appropriate provision of respite services that must be overcome if effective delivery is to be assured (CNSW, 1998, p53). This discovery is important, as investigators of services must now take into consideration barriers that exist within the family as well as those external to it.

4.2 What young carers identify as barriers for their families

Many of the young carers reported that their families had not received the supports that they needed for reasons of service design, promotion and access and for barriers within their own families.

Service design issues – were identified by 23 young carers, with 5 feeling that they weren't of high enough quality (not of a standard at which families felt comfortable accessing) with another 9 suggesting that they had had bad experiences in the past, and 13 feeling that they were not responsive to the families needs (were not provided when most needed or could not cater to their cared for relatives care needs appropriately).

They [service providers] don't know how to handle my brothers.

Some services won't help because [my brother's] behaviours are too difficult.

Not open when needed – they were booked out when we needed them in January

We got burnt – they treated Mum like shit and we don't want to have anything to do with them anymore. We need help but we just can't trust them – and we don't want Mum have to go through it again.

Young Carer Story: MJ

MJ is 15 and cares for his mother who suffers from chronic back pain. MJ helps his mother around their unit, does most of the cleaning around the house and takes on all household chores when she is particularly bad. When MJ's mother needs to go to the doctor, to the shops or on other errands, MJ has to carry her up and down the steps to their third storey home. This places great strain on his own back, and MJ is worried that if the government doesn't respond to his Mum's request for a transfer to more appropriate accommodation, he will be in a similar position to his mother in the future.

MJ's mother used to get help from the hospital but on her last visit she felt as though the staff disbelieved her and were disrespectful in the way they talked to her about her condition. She says that she will not go back for further help. MJ understands his Mum's decision but is disappointed with her and the hospital because they don't realise that these monthly visits are the only time he has for himself – to relax, to catch up on schoolwork and to meet his friends.

Access Issues - were raised by 17 young carers who felt that having no transport (n=4), being too far away (n=4) and being too expensive (n=9) kept the family from receiving the support they needed:

We can't get help for us anymore because we can't afford it.

They used to come around and help but then they started charging us and we couldn't afford it so we had to stop.

There was no transport available.

We can't get help because we've got too many assets – though you can't really access them.

Service Promotion - was seen as an issue for 23 young carers who either did not know what was available (n=15) or how to access services (n=8). Of the 26 young carers who did not feel that this was an issue, only a few could identify services that existed to support their family members and less believed that they were entitled to any services at all.

I'm sure there's stuff out there – but I don't know how to get it.

There needs to be more information so we know how to get the help. You ring heaps of places and cos you don't know the exact details you can't get help. That's crap.

Reluctance within the family – was also recognised as an issue, with 20 families feeling as though they could cope without outside help, 7 families were unwilling to seek help for privacy reasons, 9 felt guilty for getting help, and 10 had family members (including cared-for relatives and others) who preferred for help to provided within the family.

Wouldn't get someone in to do something I could do – because I'm family

We're too proud to get help. We want an image 'we're ok, we can cope'.

Would rather go without than ask for help

They offered – but I didn't take it. I didn't want to feel like a charity case.

Young Carer Story: Mel

Mel is 13 and she cares for her father who suffers from bipolar. Mel helps her Dad by doing most of the cooking and cleaning, by making sure he's taken his medication and by 'doing her best' at school so that he feels proud of her. When he's sick, Mel stays home and looks after him. Sometimes this is really difficult for Mel who doesn't know how to help her Dad when he's depressed – no one has ever explained what 'bipolar' means or what she needs to do.

Mel knows that there are services around to help her Dad but he's worried that if they find out what Mel does around the house that they would call child protection and she would be removed. Mel's father also feels depressed enough already about the way he thinks Mel is missing out on life, so she tries not to talk about it or make much of a fuss. She just wishes there was someone else she could talk to, and someone who could come in to help out when her Dad was particularly unwell.

Table 3 Barriers to Service Reception

What kept families from accessing services	Number of respondents
Service Design Issues	29
Services do not respond to the family's needs	14
Families had bad experiences in the past	10
Services weren't of high enough quality	5
Access Issues	17
Services are too expensive	9
No transport available	4
Services are too far away	4
Service Promotion Issues	24
Families unaware of what services are available	15
Families don't know how to access	9
Reluctance within the family	48
Families felt they could cope without outside help	21
Families did not access for privacy reasons and fear of scrutiny or inappropriate intervention	11
Other family members prefer help from within the family	10
Family members felt guilty for receiving outside help	10

5 Responding to Barriers, Enabling Access for Families

As has been seen, there are a range of service system and family-based issues that are keeping families affected by illness, disability, alcohol or other drug or mental health issues from receiving the supports that they need. Drawing from the findings of *Reading Between the Lines* it can be argued that as a result of these barriers, children and young people with care responsibilities are experiencing significant hardship, social exclusion and physical and emotional strain because appropriate and responsive services are not reaching their families and, as a result, are forcing families to rely on their children when it is not always favourable for them to do so.

In this section we will explore some of the major themes that have arisen and report the strategies that young carers, service providers and other key stakeholders identified to overcome barriers and to enable families to access appropriate services.

5.2 From the Literature

In his work, Zilber (2002:3) argues that when provided responsively, quality services achieve a 'respite effect' where the whole family is given an opportunity (or a series of opportunities) to experience a 'break' or an 'interval of rest or relief' where they can recover and recuperate rather than just experience 'mere time away'.

Surveying families accessing the disability programs at Marymead Child and Family Centre, Zilber found that carers identified five key domains of quality respite service provision. These included:

- **Trust:** where families felt that they could trust the level and appropriateness of their child's care and their safety and that this was assured through effective policies, worker training and supervision and support and communicated regularly with family members. Families valued services that 'worked with' rather than separate to them.
- **Respectfulness to the client:** where clients were humanised, were valued and their individual needs and wishes were being met responsively.
- **Respite Effect:** where the service provided both clients and their families with opportunities to 'rest' (short-term) and to 'break' (longer-term) away from their child to recover and recuperate; that it was whole-of-family focused and it provided clients with positive and enjoyable time away.

- **Respite Worker Qualities:** where the service is staffed by skilled, capable, dedicated and compassionate workers who are well recruited trained and supervised.
- **Safety:** where the service was provided in a physically safe environment by skilled and responsive workers within a well-designed and facilitated program that accepted risks but ensured client safety.

In addition to Zilber's characteristics, Enduring Solutions argued in a study of services in the ACT that there were five key principles of achieving this "better practice" (2003:67-8) including:

- **the system fosters and encourages independence and sustainable relationships:** where the relationship between carer and cared-for relatives is supported and if each party is given skills and opportunities for greater dependence that the need for respite may be reduced;
- **services and policies are consumer and carer focused:** when service provision is accessible and easily navigated (ie at entry and exit points) so as to be responsive to the needs of the carer as well as the cared-for relative to ensure their access to increased life opportunities, and when services and workers are more aware and responsive to the needs of the carer through training;
- **service delivery are integrated and coordinated:** where care plans are well-managed as 'packages of services' which are consistent, easily accessible, sensitive and flexible;
- **services and policies are flexible enough to meet people's real needs:** where service models accommodate a flux in life experiences and not bind people into set arrangements that may or may not best suit their needs; and
- **the quantity of services available are sufficient** to meet the needs of carers and consumers.

5.3 Moving Forward for Families

In this section we will explore some strategies to overcome key barriers highlighted through the research and from the literature. These recommendations have been developed with young carers, service providers and other key stakeholders.

Barrier identified through the research	Strategies proposed to address the issue:
Families often do not access services because they are not available	<ol style="list-style-type: none"> 1) that the ACT Government increase the level of resourcing made available to community members with an illness, disability, AOD or mental health issue to meet real need; 2) that the ACT Department of Disability, Housing and Community Services and ACT Health develop and fund a flexible brokerage model to be made available to young carers and their families to purchase additional in-home and respite support so that young carers can take time out of their caring, reconnect to mainstream opportunities (such as education and employment) and to life-enhancing activities;
Families often do not access services because they do not respond to the needs of the whole family	<ol style="list-style-type: none"> 3) that guidelines are developed and services resourced so that the needs of the whole family are taken into consideration when assessing the need of clients within disability, health, AOD, and mental health services; 4) that brokerage is made available to address the needs of all family members, and the family as a unit, associated with caring (rather than just those of the cared-for relative). These may include access to respite, family mediation, counselling, social and emotional support;
Families often do not access services because they do not believe that they are of a high enough quality	<ol style="list-style-type: none"> 5) that standards of care in disability and health services be investigated to ensure consumer and carer confidence 6) that carer complaints mechanisms are developed within government funded programs to ensure that quality improvement can be assured 7) that mechanisms for young carers to be involved in quality assurance processes be identified and developed
Families often do not access services because they cannot afford them	<ol style="list-style-type: none"> 8) that the ACT Government urgently review the nature of fee-for-service provision in the ACT 9) that brokerage funds be made available to young carers and their families to secure additional supports and services for their cared-for relatives 10) that mainstream services promote and advocate for young carers to receive the Centrelink Carers Payment and Allowance when appropriate

	11) that a system of discounts be investigated to reduce the costs of health care treatment, medical supplies and medications be investigated
Families often do not access services because transport is not available	12) that transport models that are responsive to the needs of cared-for relatives and their families are explored and developed 13) that brokerage be made available to young carers and their families to ensure their access to services through appropriate transport options
Families often do not access services because they do not know what services are available or how to access them	14) that accessible information resources focusing on available supports, services and user rights (like that developed by the Mental Health Foundation) be developed and broadly distributed; 15) that the CIRSACT database of services be maintained and promoted to the broad community; and 16) that the Making Contact website be maintained and extended to include information about services available to young carers and their families.
Families often do not access services because they are fearful of external scrutiny, blame and fear of child removal	17) that the Commissioner for Children and Young People be resourced to research and design appropriate and responsive supports for families affected by illness, disability, mental health and alcohol and other drug issues that resources and maintains families; 18) that the community sector be resourced to develop appropriate protocols and guidelines and training on how to enact them;
Families often do not access services because they feel guilty in asking for them	19) that families are provided with information and support that legitimises help-seeking; 20) that services working with families support appropriate referrals and ensure family dignity through the project; and 21) that caring be promoted as the responsibility of the whole community so that families do not feel pressured into working alone.

6 What do young carers want and need for themselves?

As we have seen, young carers families and cared-for relatives have significant needs that are not adequately being met by the service system. In addition to these needs, children and young people have service needs and issues themselves and in their own right. This section aims to identify what young carers need to overcome the negative affects of caring and to reconnect to the broader community, its supports and resources. In it the mass of literature is explored before exploring what children and young people themselves identified as their specific needs.

6.1 From the Literature

As has been mentioned elsewhere, young caring can be a positive experience for children and young people if they are adequately supported to ensure that they are not assuming inappropriate care tasks or tasks that will have a negative impact on their health and well-being.

For the purposes of this section we argue that the fundamental principles for meeting young carers needs are ensuring that young carers:

- *are protected from having to take on inappropriate responsibilities that may be harmful to their general health and wellbeing; and*
- *have the opportunity to a full range of choices, independence and participation in society (Becker, Aldridge and Dearden, 1998).*

The literature argues that these basic needs must be addressed as a part of any policy or service response and can be extrapolated to include the need for:

- *recognition*
- *understanding and respect*
- *age appropriate information;*
- *support*
- *access to appropriate, flexible and affordable services;*
- *increased opportunities to re-engage with education and employment; and*
- *the opportunity to enjoy their childhood and youth (CA 2000, p50).*

Recognition, understanding and respect: from government and community members about the role that young carers assume, of the need for increased service support and the need for understanding and flexibility in their access to services (including education) (Dearden, 2000; ACTYCN 2000; Olsen 2000). As partners in the health care treatment of their relatives, young

carers should be also provided opportunities to engage in care plans and be informed of decisions, ensuring the privacy of their cared for relative.

Age appropriate information – that is child and youth-friendly and is about their family members' illness or disability, about how to care safely and what services are available needs to be made accessible to young carers (Cowling 1996, Gays 2001, CA 2002). In particular, information about the hereditary nature of their parent's condition, with many children being afraid of "catching" the condition like a cold or suffering similar symptoms themselves.

Support – is provided to an extent where young carers feel supported by family, friends, school, government and the community as a whole (ACTYCN, 2000, CA 2002). This includes financial support (Fielder 1996, ACTYCN, 2000) and is provided in a way in which young carers feel that it is acceptable to ask for further assistance when needed (Dunn and Hughes, 2000).

Appropriate, flexible and affordable services – are provided to young carers and their families to ensure that young carers do not have to take on tasks that negatively affect their health or wellbeing and are not sustained in a position where they are constantly worried about their relatives condition (Zilber 2002, ACTYCN 2000, Dunn and Hughes, 2000). Young carers also need access to appropriate, flexible and responsive respite that provides them an opportunity to rest, and to re-engage with mainstream life opportunities including education, social and recreational activities and leisure (CA 1997 and 2000; ACTYCN 2000) and personal support including 'someone to talk to' when needed (Cowling 1996).

Increased opportunities to re-engage with education and employment – ensure that children and young people are given opportunities to learn and grow through the provision of flexible and supportive models that encourage continued involvement and re-engagement with education, training and employment (ACTYCN 2000, CA 2000).

The opportunity to enjoy childhood and youth – acknowledges that though caring is a positive experience, developmentally, children and young people need to have opportunities to participate in social and leisure activities, outings with their families, holidays and stress-free respite (Dearden and Becker 2000). They need to feel like they can make age-appropriate choices about their lives and that they will be supported to do so (Dearden and Becker 2000, p46; CA 2000).

6.2 What young carers felt they need for themselves

Unlike when they were asked what supports and services should be made available to their cared-for relatives and families, found it difficult to answer the question 'what supports would be useful

for you?”. In discussing this difficulty with the youth members of the Young Carers Research Team it was realised that many young carers do not feel that they are entitled to any support and that if they do receive them then, potentially, necessary resources were being funnelled away from those they thought needed it more – their cared-for relatives.

When the peer researchers asked children and young people what they thought might be useful for their young carer peers, however, they were much more responsive and suggested the following services and supports:

Personal and Peer Support which included opportunities for young carers to spend more time with their caring peers. This was seen as particularly important as many only spoke about their needs, concerns and fears with others in ‘safe environments’ where they felt understood and supported.

More time to spend with other young carers.

Help people share their stories.

Information about their cared-for relative’s condition was seen as particularly important, with many young carers experiencing significant fear and anxiety because they had been excluded from any discussions about their relatives health, their care plans and how to best support them. In particular, young carers wanted to know about the hereditary nature of their relatives condition, whether they themselves had contributed to their sickness (many young carers felt responsible without reason), and if they were going to die as a result:

*I always thought it was my fault that Dad was sick – because I was naughty or bad.
Noone ever told me that it wasn’t my fault.*

I’m really scared I’m gonna catch it [mental illness]

Greater awareness in the community about illness, disability, alcohol and other drug and mental health to reduce the levels of stigma, and through it bullying, harassment and exclusion felt by families. Young carers also felt that if the community was more accepting and non-discriminatory then their own levels of anxiety and anger would be reduced – with many taking personally comments about people with disabilities, illness and conditions.

Greater awareness in the community about young caring and the important part that young carers play in the care of their family members. In particular, young carers argued that if health professionals acknowledged them for the care they provided, they would be provided with information, support and referred when appropriate.

Training of teachers, counsellors, youth support workers in schools and the broader school community so that young carers were provided with the understanding, support and appropriate responses, thus enabling them to attend and achieve in their schooling.

More flexible and responsive education that recognised the difficulties that young carers faced when trying to attend and achieve in school. This might include a review of homework requirements, assessment processes, the delivery of flexible modules, a mixture of on-campus and off-line programs, the development of Recognition of Prior Learning accreditation for care skills developed at home and greater co-ordination of respite and in-home support services during peak periods of the school year.

Information on services available to young carers and their families. This information should be accessible, child and youth-friendly and available where young people are and be provided through:

- word-of-mouth;
- TV and radio announcements;
- links from websites;
- promotion through schools;
- existing carers and young carers programs;
- the newspaper;
- fliers on the streets;
- agencies that work with people with illnesses, disabilities, and AOD problems; and
- youth centres and other youth services.

Respite for young carers, in particular for those with a single parent needing hospitalisation or other treatment; during key times in the school year when they need to focus on their school work; when they feel ‘burnt-out’ and in need of time out from caring; and when things are particularly stressful at home.

Young carers felt that respite could be provided through a foster care relationship, through a ‘teen house’ where young carers could spend time with others in similar positions, or through joint social activities (such as camps, day activities or support groups) that were staffed by workers who were aware of the issues impacting on young carers, who were supportive and able to provide them with the ‘respite effect’.

There'd be someone to talk to if I needed to.

Somewhere you could go to just chill out.

For them to be able access such a service, or in fact any form of respite care, young carers needed to ensure that their cared-for relative was receiving quality alternate care and that this was available at the same time as their own respite.

When young carers need extra help

Some of the young carers identified times when they particularly would like or felt they needed extra help. These included times when:

- their relative was particularly sick;
- they felt particularly overwhelmed and stressed;
- they had extra work to do for school (i.e. assignments, exams);
- other family members weren't around; and
- they themselves were sick or run-down.

Others identified specific tasks they needed extra help with. These included heavy lifting, intimate care, transport, and help around the home.

6.3 What supports young carers are currently receiving

From family, friends and the community

Young carers placed significant value in the support that they were receiving within their families. As found in *Reading Between the Lines*, young carers often reported feeling supported and close to other caring relatives and could often identify supports within their co-located nuclear family.

However, only one of the young carers identified any external support from family members that focused on them directly. Usually, external support was provided to their cared-for relative or other family members.

Young carers also valued the support of their friends – mainly for companionship but also, in some cases, for help with their caring:

My friend up the street helps cleaning... She's the only one I can talk to. She always comes down and helps me.

This support from other young carers in similar situations was seen as being important by many of the young carers:

There was a guy at school who is really popular and wouldn't usually have anything to do with me. We have nothing in common. But we have this bond because we are both carers and he asks me 'how's your brother' and I ask him about his sister. Its cool just knowing that some else understands. You don't feel alone.

From the service system

Young carers received varying degree of service support themselves. Those that did receive support reported help through personal support, counselling, and holiday camps.

Personal Support

Three of the young carers received personal support from workers who took them out for activities and were available 'for a chat'. One young person also received help in getting her own accommodation.

Its good – I get out of the house and spend time away.

Counselling

One young carer accessed Kids Help Line and two others had received counselling in the past. No young carers accessed a school counsellor, with many concerned that their stories would not remain confidential or that they otherwise felt uncomfortable seeking such support.

Camps

As a large number of the young carers were recruited through the St Nicholas' Young Carers program (St Vincent de Paul), it is not surprising that many of them identified that they received respite through holiday camps and other social activities. Many appreciated opportunities to share time with other young carers, particularly on camps and other social activities where they could share their stories, help each other and be supported by 'caring staff'.

When the carer camps with Vinnies came along we wanted to go to meet people like us. We found out that we had so much in common with other people. We could talk about stuff and not worry about what other people thought because they were all like us.

Camps have made me meet more people who have been through the same as me.

I met more people than I would normally meet through camp.

However, many of the young carers felt that there needed to be more opportunities for them to meet, and for longer periods:

There needs to be more money for Nicks so that we can do more stuff and like have more camps and things. Camps have been the most important thing for me – I couldn't get through without them – and everyone should be given the chance.

More camps – and for longer.

Camps for younger kids, like under 9. And camps for young carers over 16 too. Everyone should be able to go – they're the best!

Table 4 Young Carers Receiving Support

What services provided support	Number of respondents
Personal Support	3
Accommodation	1
Counselling	1
Camps	28
Total receiving support	30
No Support Identified	20

7 What keeps young carers from receiving support?

Though young carers have needs and issues that have been identified within Australian research and have been translated into government policy (such as the Caring for Carers Plan, Children's Plan and Young People's Plan) it seems that many young carers are not receiving adequate levels of support or services. In this section we will explore the barriers to services identified within the literature. Unfortunately, children and young people were unable, for a number of reasons, to articulate reasons why they, themselves, were not receiving specific supports – this section will discuss reasons why this may have been the case.

7.1 From the Literature

Though there is a growing breadth of researching focusing on the needs and issues of young carers internationally, there have only been limited studies in Australia focusing on barriers that keep young carers from accessing appropriate and responsive services. What has been identified, however is that:

There is a general lack of awareness, recognition and understanding of young carers:

- Young people do not identify with the term 'young carer' or 'carer' because it does not always describe their experiences and is often promoted as an activity for older people (Oliver 1996, CA 2000);
- Services are focused on adult clients and do not feel adequately trained to work with children and young people (YCACT 2004; CA 2000);
- Services are not advertised in a way that is accessible or attractive to children or young people (CA 1996, p39);
- Information is not available on young caring or supports available;
- Young carers may not know where to access assistance. Young carers may be more likely to need support in navigating the system and being referred to appropriate services (ACTYCN 2000);
- Workers in disability, welfare, health or education fields do not know how to identify young carers and may be unaware of their needs regardless, limiting their access to appropriate services and supports;
- Young carers may contact youth and education workers who do not know what services are needed or available for them (ACTYCN, 2000, p6);
- Workers in health, disability, mental health and AOD have historically ignored children, focusing on their adult clients (YCACT 2004, CA 1997b);
- The care responsibilities of children and young people are often ignored or undervalued by workers in children's services; and
- Young carers have had negative experiences in seeking support and are reluctant to try again (CA 2000).

There is a lack of flexibility in service delivery for children and young people making them inaccessible to young carers

- Transport is not available;
- Services do not meet the full range of needs of young carers, so children and young people do not feel it is worth making contact (CA 2000, p 65);
- Services have limited hours of operation, often closing when children and young people are able to access (i.e. after school, weekends) (YCACT 2004, CA 2000);
- Without respite, young carers are unable to leave their cared-for relatives alone to access services (CA 2000, Oreb 2000);
- Service costs may be unaffordable;
- Young carers are often not identified as an 'at risk' or 'target' group within mainstream services (ACTYCN, 2000, p5); and
- Young carers may not fit into other 'at risk' or 'target' definitions for mainstream services.

Views and values of families and the community

- Children and young people's roles in the community are often devalued or ignored (CA 2002);
- families may see caring as a private matter (Aldridge and Becker 1994 p30);
- families are afraid of child removal and outside intervention or of been seen as inadequate parents (Keith and Morris, 1995 p43);
- asking for help may be seen as a sign of weakness (Cowling 1996, p3);
- families, children and young people may not want to identify as caring for fear of unwanted stigma and associated bullying and harassment (YCACT 2005);
- families, young people or others may not recognise all the impacts that caring can have on young carers' lives (Carers NSW 1998, p3; CA 2000);
- parents feel more comfortable and prefer their children to provide care rather than a stranger (Frank 1999, CA 1997, CA 2000);
- young people think that they will not be listened to, believed or treated with respect (YCACT 2004, Reid 1996); and
- young people believe that if they share their experiences, information will not be treated confidentially (YCACT 2005).

7.2 Barriers that arose from the research

Young carers were not specifically asked about the reasons why they had not or could not access services and supports in their own rights. However, throughout the interviews, young carers identified some reasons why they did not feel comfortable seeking support and reasons why they were sustained in situations where their health, wellbeing, and participation were being put at risk.

In addition, in developing and conducting the research, the Young Carers Research Team identified a number of other reasons that had been identified by key stakeholders and through their own interactions with service providers.

Reasons Why Young Carers Don't Identify Themselves and therefore Don't Get Support

The young carers identified a range of reasons why they would not let others know that they were caring at home. These included:

Young carers don't identify themselves as young carers and therefore do not realise that there are others in the community with similar experiences, or that there are services to support them.

Fear of unwanted intervention kept many of the young carers from disclosing their experiences to those around them. In particular, families feared child removal and / or unwarranted judgment and ridicule of the whole family unit.

We don't want Family Services sticking their nose in – or taking us.

Fear of bullying and harassment was substantial for many of the young carers, particularly in the schoolyard and classroom. Many of the young carers noted that whilst there were anti-disability, mental health, and alcohol and other drug cultures within their local communities they were afraid to identify.

I don't wanna be bullied plus I don't want my Mum to get greasies or for people to think bad about her.

Lack of Awareness leading to disbelief was raised by young carers who reported times when they had identified as a young carer but because people didn't know that young carers existed were met with disbelief. For some this was quite dramatic:

She said 'all families have problems stop hiding behind your Mum'. She thought I was making it up to get out of homework... That hit me hard.

Bad past experiences were raised by a number of young carers who had experienced the aforementioned issues and were reluctant to repeat their experiences. Others reported times when identifying had not had a positive impact for them, including times when their confidentiality had been broken:

My Mum was sick and I was coping so I told my teacher so he'd get me off homework. But he gave me more cos he thought that would take my mind of things.

My teacher told everyone about what was going on and that sucked cos it made it worse for me.

Service Barriers Restricting Young Carers Access

Services don't acknowledge or know how to deal with young carers which meant that many young carers did not receive any support (including referrals) from disability, mental health, AOD or youth services.

Services don't have a good understanding of the family issues of their clients and therefore do not take into consideration young caring when developing or providing services to children and young people. This became quite obvious for the YCRT when they were recruiting young carers, with a large number of services saying that they were not aware of any children or young people accessing their supports who were in a family affected by illness, disability, mental or alcohol or other drug issues, when, on further investigation they were.

Young carers aren't recognised as target groups or in 'at-risk' definitions which means that many young carers do not receive the services and supports that they need. One worker from a youth service recalled a time when their manager argued that 'young carers don't really have complex issues' and therefore did not require targeted service or priority status.

Services aren't flexible enough to be accessible or to meet young carers needs when they do not provide transport, are not open after hours and on weekends, or when they require an on-going commitment from young carers who often do not know when they will be needed at home.

Services aren't affordable and therefore are inaccessible to the large number of young carers experiencing poverty if they charge, or appear to charge for services.

Services that met their specific needs were not available. This was a particular issue for children under 10, those caring for a relative with an alcohol or other drug issue or an undiagnosed mental health issue. It appeared that young carers in youth detention and on the streets were also not being provided for.

Young carers don't know what services are available or how to access support. This was probably the most commonly raised issue for young carers who wanted and needed support but weren't aware of where to go or how to get the help they needed.

Young carers don't have the time to access external supports because they are often needed at home.

8 Responding to Barriers, Enabling Supports for Young Carers

Barrier identified through the research	Strategies proposed to address the issue:
Young carers don't identify as being young carers	22) that widespread awareness-raising activities be funded including advertising on the television, radio, in the newspaper, and through youth publications (including BMA, and lip mag) and the development of information resources be funded to promote young caring as a natural, positive experience and that it is legitimate and appropriate for young carers to ask for support when needed;
Young carers don't access services for fear of unwarranted interventions	See recommendations 17 and 18
Young carers don't identify as being a young carer for fear of bullying or harassment	23) that a community focused strategy be developed to target the myths, phobias and harassment of people with an illness, disability, mental health or alcohol or other drug issue and their families; 24) that training (similar to those focusing on homophobia) be developed for schools, including students, teachers, welfare staff, counsellors and youth workers, to combat harassment and bullying and to support 'hidden' young carers to identify and access appropriate support
Services do not recognise or know how to best support young carers	25) that children and young people in families affected by illness, disability, AOD and mental health issues be identified as a priority target within children and youth services and that this be written into service contracts and reported against; 26) that practice guidelines for working with young carers and their families (similar to those developed in the UK and those for children of parents with a mental illness) be developed and distributed with training on how to enact them; 27) that, in conjunction with TAE, training sessions be developed with carers (including young carers) and service providers and be provided to the major tertiary and training organisations as core units in their pre-entry and post-entry study for welfare courses and associated university qualifications; and 28) that training sessions be developed and possibly facilitated by young carers for teachers, youth workers, social workers, counsellors and others coming into contact with children and young people; (from the community, youth, AOD, disability, health and mental health sectors), schools and youth services
Services do not have a good understanding	29) that good practice for working with families be explored and promoted to children and

of the family issues of clients (including young caring)	young services in the ACT; 30) that links between family-focused services and supports such as ReConnect be resourced to enhance understanding of family issues and how they impact on children and young people; 31) that family-focussed training be provided to workers within the youth and community sectors to inform practice;
Young carers aren't recognised in 'at risk' or priority targets	32) that young carers and other children and young people in families affected by illness, disability, AOD and mental health issues be identified as a priority target within children and youth services and education;
Services aren't flexible enough for young carers to access	33) that the Office for Children, Youth and Family Support review the provision of out-of-hour services to young people in the ACT and to resource key services to provide extra supports during key periods (including weekends)
Services aren't affordable to young carers experiencing poverty	34) that brokerage funds be made available to young carers to access supports (such as counselling) and to enable them to reconnect to mainstream life opportunities including social and recreational activities, 'time out' and respite, education and employment
There is a lack of services that meet specific needs	35) that the needs of children under the age of 10 be urgently identified with appropriate interventions and supports developed; 36) that the needs of carers aged between 18 and 25 be identified and supported in their transitions to adult carer services; 37) that the linkages between parental alcohol or other drug use and homelessness be researched with appropriate responses developed; 38) that the linkages between the illness, disability or AOD issue in the family and criminality be identified; and 39) that the scope of existing young carer, youth and children's services and their capacity to better
Young carers do not know what services are available	40) that accessible information resources focusing on available supports, services and user rights (like that developed by the Mental Health Foundation) be developed and broadly distributed; 41) that the CIRSACT database of services be maintained and promoted to the broad community; and 42) that the Making Contact website be maintained and extended to include information about

services available to young carers and their families.

RESPONDING TO GAPS IN SERVICE:

<p>Young carers are not provided with age-appropriate information or education about their cared-for relative's condition</p>	<p>43) that specialised disability, health, mental health and AOD services be funded to develop age-appropriate information that is accessible to children and young people and outlines the main effects, symptomology and treatments of the major illnesses, disabilities, AOD and mental health conditions, that these resources be available on-line and that existing generic age-appropriate information (such as that developed by SANE, the Cancer Council, and ARAFMI) be purchased and distributed to schools and youth services and be made available for general access by children and young people</p> <p>44) that health professionals be brokered to provide age-appropriate advice and information (similar to those available through CIT Skills for Carers for adult carers) to young carers either individually, with their families or in group settings;</p> <p>45) that health professionals working with, and with the permission of cared-for relatives engage family members (including young carers), and provide them with information about their relative's condition and treatment plan</p>
<p>Young carers often do not achieve satisfactory outcomes in education because of a lack of flexibility, a lack of time available and lateness to class</p>	<p>46) that training, information and educational resources (similar to those focusing on homophobia) be developed in partnership between carer, disability, mental health, AOD and youth services and be provided in schools to teachers, students, counsellors, youth support workers and welfare staff to combat harassment and bullying and to support 'hidden' young carers to identify and access appropriate support;</p> <p>47) that the ACT Department of Education and Training fund a flexible brokerage model to be provided through regional community services and made available to young carers to cover the costs of education including school fees, uniforms, excursions and extra-curricular activities;</p> <p>48) that ACT DET develops protocols with DDHCS and ACTH to ensure adequate levels of support to young carers' families during key periods in their education to ensure access;</p> <p>49) that schools with support from DET develop flexible guidelines for working with young carers;</p> <p>50) that DET investigate flexible learning models including recognition of prior learning and off-line programs that can complement their involvement in mainstream education and their caring responsibilities;</p> <p>51) that telephones are made available to young carers so that they can be in contact with their relatives throughout the day;</p>

<p>Young carers do not access respite to alleviate the negative impacts of caring and give them an opportunity to relax, rejuvenate and re-engage with community opportunities and resources such as education, employment, and social activities</p>	<p>52) that a host family respite program similar to that currently existing at Barnardos (which focuses on children of parents with a mental illness) be developed to respond to the needs of all young carers; 53) that the viability of a ‘teen house’ for young carers needing temporary respite be investigated; 54) that social, peer-based recreational activities (such as St Nicholas Young Carers Program) be extended so that they can provide more frequent respite and social support to young carers;</p>
<p>Respite is not usually provided to the whole family making it inaccessible or unresponsive to the family’s needs</p>	<p>55) that brokerage be made available to families to go on holidays together and be supported by accompanying workers when needed; 56) that family-based camp programs be explored where carers and cared-for relatives can meet other families in similar situations and be supported by workers who are available when needed;</p>
<p>Respite is not usually available for people with a mental health and / or an alcohol or other drug issue</p>	<p>57) that appropriate and responsive respite models for people affected by a mental health and / or an alcohol or other drug issue be investigated and considered for funding; 58) that the model used at Warren I’Anson house be replicated and be made available to sole parents with a mental illness and their children; 59) that the model used at Karralika be replicated and be made available to mothers and fathers with an AOD issue and their family;</p>

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Attachment 2: The Seven Core Principles of the ACT Caring for Carers Policy:

- 1 Carers have the right to decide whether to take on or continue the role of care and are supported in their choices.
 1. The health and well being of carers is supported through services and programs that are flexible and responsive to individual needs and circumstances.
 2. Resources are available to provide timely and adequate assistance to carers.
 3. Affordable services of a high standard are available to people who need care, complementing the role of the carer.
 4. The critical contribution of carers is recognised, valued and promoted in the community.



5. The carer and the person receiving care are regarded as a partnership, in which each person has rights and responsibilities.
6. Organisations welcome and support carer participation at all levels of decision-making, with respect for the rights and choices of people receiving care