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# Who Cares?

Experiences of young people living with a family member who has an alcohol or other drug issue

A report by Debbie Noble-Carr, Tim Moore and Morag McArthur of the Institute of Child Protection Studies, ACU National



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## Project team

This research project was conducted by the Institute of Child Protection Studies (ICPS), ACU National, with funding from the ACT Department of Disability, Housing and Community Services.

The ICPS was established in 2005 to promote and enhance the safety of children, young people and families through quality research, training and community education. Driven by a child-centred philosophy, the Institute is committed to ensuring that children remain at the centre of social policy and practice and work with governments and services to promote their interests and well-being.

The Institute's project team consisted of Debbie Noble-Carr, Tim Moore and Morag McArthur with assistance from Fiona Dempster and Kate Butler.

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## Executive Summary

Over the past twenty years increased attention in Australia has focused on the needs and experiences of children and young people living in families affected by alcohol or other drug (AOD) use. At the same time there has been a growing interest in the experiences of young people who assume care responsibilities for a family member who needs assistance due to an illness, disability or chronic condition. Although the gaze of both these groups has rested, at some stage, upon those young people who assume caring responsibilities for a parent with an AOD issue, there has been no specific research and limited dialogue about how these young people might best be considered and how their needs and those of their families might best be responded to within the current policy and practice environment.

In fact, a divergence of views has developed. The alcohol and other drug literature has primarily focused on the negative impacts of living in a family affected by parental use and has emphasised issues of abuse and neglect. This camp has generally conceptualised these young people as passive victims and has asserted the need to protect children, often calling for assertive intervention. The young carer literature, on the other hand, has seen young people as active players and has generally understated the risks associated within the family context. Instead, they have focused primarily on the nature and impact of the child's caring role and have therefore called for supports that acknowledge and affirm the child's ability to care, whilst reducing any negative impacts that may arise.

It would appear that neither camp has been able, then, to fully capture the lived experience of these young people or to provide responsive strategies to overcome the myriad of challenges that they face. Instead, young people have remained somewhere in the middle – often unwilling to be conceptualised in either way and concerned about the ramifications that identifying as being in need might have on them and their families.

This research project, funded by the ACT Government through its Carers Recognition Grants project and conducted by the Institute of Child Protection Studies with support from Anglicare Canberra-Goulburn aimed to redress this situation by exploring the question:

*What are the specific needs of children who have a parent with an alcohol or other drug issue and how are these similar or different to other children with care responsibilities?*

In exploring this question, the project aimed to grasp the implications for the range of services that might come into contact with these families (including young carer, AOD, family support and care and protection programs) and the way that supports might be provided.

### ***Nature of the study***

This project, conducted in 2008, engaged children and young people directly in the research process. Adopting an ethical and child-centred approach, the research team provided young people an opportunity to talk about their experiences in one-on-one interviews that were developed in consultation with a young people's reference group. The group also helped the research team understand emerging themes and draw out policy and practice implications.

The project drew on the existing young carer and alcohol and other drug literature which highlighted the vulnerability of these children and young people and the ways that their family and caring situation affected their health, wellbeing, education, social inclusion and future life opportunities.



### *The nature of the sample*

15 young people aged between 11 and 17 years of age participated in the study, 13 of whom currently or previously cared for a parent with an AOD issue with the remaining two caring for an older sibling. Parents used a range of drugs including marijuana, heroin, ice and other illicit and prescription drugs and alcohol.

### *Nature and experiences of care*

Young people lived in families which were marked by complexity and chaos. Although significant, young people's caring responsibilities were but one of a number of intersecting and compounding factors such as poverty, social isolation, violence and family conflict which affected their health and wellbeing, their participation in education, social activities and community life and the relationships they had with parents, siblings and other family members.

Although most young people did not identify with the term 'young carer', each assumed significant care responsibilities for their family members. Young people had cared for a significant amount of time over a significant number of years, with most being responsible for providing financial support, taking on household tasks, ensuring the safety of their parent, supervising and supporting their siblings, providing emotional support and personal care. The nature and extent of their caring responsibilities were not dissimilar to those of young carers in other studies, although they were more likely to emphasise their monitoring and emotional care responsibilities and their caring role for siblings, ensuring that all members of their family were safe.

Contrary to popular belief, young people's caring was not episodic although the support needs of their parent did change depending on their wellness and level of AOD use. During periods of wellness, young people reported an increased need for supervision and remained hyper vigilant.

### *The impacts of living in a family affected by parental AOD issues*

Unlike young carers in previous studies, young people focused primarily on the negative impacts and affects of caring for their family member, primarily in regards to access to and achievement in education; to their own health and wellbeing (including their own depression, stress and anxiety), their safety, their opportunities to participate in the community and in their transitions into adulthood. Young people often felt hopeless about their situation and their futures.

### *The key need of young people*

Young people felt that they needed a trusted adult with whom they could talk, linkages to professional workers and services who could adequately identify and respond to the raft of issues and challenges that they faced, opportunities to meet and connect with others in a similar situation to themselves, respite from their home situations, practical and housing assistance, and support for their family unit (including family mediation and counselling and assistance to help their parent deal with their AOD issue).

These needs are similar to those of young carers more generally but are compounded by their family's social isolation, poverty and disconnection. As a result they may be in need of more urgent and intensive support compared with their other caring peers.

### *Barriers to support*

Although in similar levels of need to other young carers, these young people seemed to face significant challenges in accessing mainstream, alcohol and other drug *and* young carer programs and support. This was because: the system failed to adequately assess their problems and needs because: young people did not want to or felt unable to seek support; services were not accessible; and past negative experiences made them less likely to seek further assistance. Not identifying with the

label 'young carer' or being identified by services as such was also a considerable issue.

The targeting of services to either parents or young people, and their focus on either AOD or youth issues kept young people and their families from receiving broad, holistic family focused assistance.

Young people often believed that only statutory intervention might meet their myriad of needs which points to the fact that other parts of the service system have not promoted or provided alternative supports that could meet their needs in a less dramatic way earlier in the life of the problem.

### *Implications for services*

Young people need to be able to talk about their issues and be supported, either directly or through referral, regardless of where in the service system they seek assistance. Mainstream youth, carer and alcohol and other drug services must therefore provide young people with opportunities to engage meaningfully with competent and trustworthy staff who can help them. Although they were ambivalent about the need for a specialised service to be developed to respond to their needs, young people did believe that services across the system needed to be more aware of their issues and more responsive to their needs.

Whilst services fail to recognise the complexity of issues facing these young people and their families, appropriate and responsive services cannot be adequately provided. Better recognition of and responses to the major challenges, including but not limited to a young person's caring responsibilities, is therefore required. This will require better integration of services and coordination of supports.

Young people and families need for services to adopt a family focused approach which responds to the young person within their family context. This does not necessitate services working directly with the family, but does require them to

understand the key challenges and issues that the young person may face within their family context. Where ever possible, services should attempt to alleviate the challenges that young people face by providing holistic supports particularly, where possible, to the family as a unit.

## Introduction

It has been suggested that up to 60 000 Australian children live in families where a parent has an alcohol or other drug (AOD) issue (Odyssey Institute of Studies, 2004). Research, both in Australia and elsewhere, has shown that these children are at a greater risk of poor physical, emotional, education and social outcomes; that they may experience significant poverty and disadvantage; and, due to the trauma and stigma attached to alcohol and other drug use, experience significant social isolation and disconnection.

Although there has been increasing interest in the lives of these children, how children and young people view the experience of living in a family affected by alcohol and other drug use and how this experience has affected their lives is missing. Studies too have primarily focused on children as passive victims within AOD affected families, failing to recognise that some assume a variety of active roles: as carer for their parents; protector of the family; and supporter of other siblings. These roles may either mitigate against or (alongside the family's poverty, social isolation and internal challenges) compound the negative affects for children and families. This study attempts to develop a greater understanding of these young people's experiences and to add to the growing debate on how they might best be considered and supported.

This project was developed as a partnership between the Institute of Child Protection Studies (ACU National) and CYCLOPS ACT (Anglicare Canberra-Goulburn) and aims to be both academic and practice-oriented in nature. The Institute of Child Protection Studies (ICPS) took responsibility for interviewing young people caring for a family member with an alcohol and/or other drug issue, with an aim of providing a voice to their experiences. This report provides the findings, key themes and issues that emerged from these interviews.

As an active partner in the research project, Anglicare was charged with recruiting young people for the study and conducting stakeholder interviews with workers from the ACT service sector who may come in contact with these young people.

### Purpose of research

The fundamental research question of the project was:

*What are the specific needs of children who have a parent with an alcohol or other drug issue and how are these similar or different to other children with care responsibilities?*

To answer this question a number of secondary questions were asked. These included:

- *What would be the implications for young carer programs, children and young people and their families if they were to be/not be considered 'young carers'?*
- *How do existing child, youth, family, alcohol or other drug and/or statutory programs currently meet the children and young people's needs?*
- *Would additional programs/services be necessary to accommodate the needs of these children and young people?*

Some of these questions were addressed by the complementary report completed by Anglicare Canberra-Goulburn, the main findings of which can be found in Appendix 1.

### Scope of research

The project was conducted from January to November 2008 within the ACT, thus including young people residing within the ACT. However, many of the young people had spent time living with their families in other areas outside the ACT and reflected on their experiences during these times also.

The project attempted to talk with young people who were currently caring for a parent with an AOD issue. However due to the sometimes episodic nature of drug use and the implications of this on the level of their caring role, some of the young people did not currently classify themselves as carers. Others had moved out of their family home and this had resulted in a reduction of caring responsibilities. Young people in these circumstances reflected on their past experiences and how their past caring role for a family member who had an AOD issue continues to impact on their lives today.

## Background

### *What we know about children who care for a parent with an AOD issue*

Over the past 15 years Australian researchers, service providers and policy makers have begun to investigate the particular experiences of children and young people who assume care responsibilities for a relative or friend in need of assistance due to an illness, disability or chronic condition (Becker, 2005). These 'young carers' have been increasingly supported by organisations funded and developed to meet their specific needs; and a growing body of research has attempted to better understand their experiences, needs and wishes. However, young people with caring responsibilities for a parent with an AOD issue have generally been excluded from such studies and have had low levels of engagement with both young carer and alcohol and other drug services (Becker, 2005; Earley, Cushway and Cassidy, 2007; Carers Australia, 2002).

### *Extent of the issue*

It is not known how many children and young people in Australia have caring responsibilities for a parent with an AOD issue. Some studies completed in Australia have estimated that 10% of young people are 'young carers' (Gays, 2000; Carers Australia, 2002). However, these figures are likely to be an underestimate, and not

indicative of the numbers caring for a parent with an AOD issue, as those caring for a parent with an AOD issue are often excluded from the definitions of carers (see Carers Australia, 2002).

There is also no data available on the number of children who have parents with an alcohol or drug issue. A recent Australian National Council on Drugs Research Paper (Dawe et al, 2007:17) attempted to identify how many children lived in households where alcohol or drugs were a problem. They found that nationally, based on Australian Bureau of Statistics population estimates in 2004:

- 13.2 percent, or 231,705, children aged 12 years or less are at risk of exposure to binge drinking in the household by at least one adult;
- 2.3 percent, or 40,372, live in a household containing at least one daily cannabis user; and
- 0.8 per cent, or 14,042, live in a household with an adult who uses methamphetamine at least monthly and reports doing so in their home.

This builds on earlier work by the Odyssey Institute of Studies (2004) who estimated 60,000 children in Australia have a parent attending drug treatment (1.5 per cent of children under the age of 15 years); and tens of thousands more children were also likely to be affected by the problematic drug use of parents who don't access treatment for their drug or alcohol problems.

### *The nature and experience of caring for a parent with an AOD issue*

The lack of any reliable data on this issue is indicative of the 'hidden' or 'invisible' nature of this issue in our community. 'Children of parents who have an alcohol or other drug issue' and 'young carers' have been treated separately within the literature available on this group of children. However, both streams of literature emphasise the overwhelming stigma and social isolation experienced by these children and the limited supports which they receive from the formal service sector



(see Dawe et al, 2007; Patton,; Odyssey Institute of Studies, 2004; Hegarty, 2005; Carers Australia, 2002; Morrow, 2005).

Recent literature on 'children of parents who have an alcohol or other drug issue' emphasises that contributing to, and perhaps compounding, these issues of social isolation are the 'highly chaotic and stressful environments' in which these children live (see Tunnard, 2002; Davis and Owen, 1999 cited in Odyssey Institute of Studies, 2004). Children of parents with an AOD issue are often quoted as being at increased risk of experiencing trauma, abuse, violence (from both within and outside of the family), family breakdown and separation, poor housing and homelessness, exposure to criminal activities and poverty and financial stress (see Hegarty, 2005; Tunnard, 2002; Kroll, 2004; Bancroft et al, 2004; Patton, 2003a; Davis and Owen, 1999 cited in Odyssey Institute of Studies, 2004; Dawe et al, 2007; Parliament of the Commonwealth of Australia, 2007).

The literature on 'young carers', while acknowledging the many negative impacts of their role, tends to focus more on the strengths of these children and their caring role. The 'young carers' literature is more likely to describe children as being 'active' and 'doing' and consequently in need of 'acknowledgement and support' within their role. While 'children of parents who have an AOD issue' are often characterised as being 'done to' and 'at risk', and consequently in need of 'protection and care'.

### *The needs of these children and young people*

However, even given the differences in methodological approaches and emphases, there was a striking similarity between the identified needs of these two 'separate' groups of children and young people. Available research has highlighted that both groups of children need:

- Raised community awareness of their existence;
- A reduction in stigma related to their family circumstances;

- Recognition and inclusion by current service providers;
- Access to age appropriate information resources about their parents' illness/issue and the supports that are available to them;
- Access to age and developmentally appropriate counselling;
- Peer support;
- Adult mentoring or be-friending programs;
- Opportunities to participate socially within their wider community;
- A break away from their family situation;
- Education supports and assistance; and
- Direct provision of practical and financial support.

The only apparent difference between the needs of 'young carers' and 'children with parents who have an AOD issue' was the emphasis given to the need to *protect* children who are affected by parental alcohol and other drug use, with much of the literature highlighting these children's risk of neglect and abuse from within their family unit.

Therefore, in terms of implications for policy and practice, the emphasis placed in the alcohol and other drugs literature is on the need for intervention into family functioning to assess risks, challenge the caring roles that have been adopted by children within the family and provide them with safety and stability.

In sharp contrast to this, the 'young carer' literature highlights the need to affirm young carers' roles within their families and to provide informal and formal supports which alleviate some of the negative impacts of their role, whilst still supporting them to maintain their caring role within their current family dynamic.

### *Responding to these children and young people*

An obvious shift, however, has taken place over the last few years within both streams of literature to acknowledge the importance of the family environment for these children.

Previously supports and service intervention focused on either 'children' within the young carers literature (with an emphasis on children's rights) and 'parents' within the alcohol and other drugs literature (often with an emphasis on the issue of parenting capacity with the assumed flow-on effects to children).

However, the policy and service response agenda is changing, with researchers and others asserting the importance of acknowledging and responding to the needs of all family members in a family-focused or family-centred practice model (Tunnard, 2002; Dawe et al, 2007; Odyssey Institute of Studies, 2004; Warren and O'Brien, 2007; Moore, 2005b; Newman, 2002; Moore and McArthur, 2007).

Early intervention, collaboration and inter-agency responses that stretch across and beyond traditional service boundaries and a siloed service provision response has also been emphasised by the new wave of literature looking at children of parents with an AOD issue (Dawe et al, 2003 and Campbell, 1998 cited in Odyssey Institute of Studies, 2004; Ainsworth, 2004; Hegarty, 2004).

Despite these universal calls for change within the policy and practice environment that affects these children, the current literature does not address one of the key questions of this study: *the usefulness of these children being defined as young carers*. In the past these children and young people have been largely excluded from young carer research and services, and to a large degree they are still on the sidelines, with different jurisdictions in Australia defining young carers in different ways, and only a few actively including these children in their definitions.

Throughout the 'young carers' literature there was consistent acknowledgement that labelling any young people as 'young carers' has proven to be problematic. It seems that many young people, regardless of the health condition of the person they provide care for, are reluctant to adopt the term. This has led to many commentators acknowledging that the term's only usefulness may be in promoting an awareness of the needs of young people living in these circumstances and providing an avenue for the provision of services that meets their needs (Gaffney, 2007; Morrow; 2005; Social Care Institute for Excellence, 2005).

Therefore, as debate continues about the usefulness of the term 'young carer', what the needs of the 'invisible' young people who care for a family member with an AOD issue are and how best to meet these needs are questions that require further research and debate within the social policy and service sector environment.

**KEY FINDINGS: Background**

- There is currently no reliable data on the numbers of young people who are caring for a family member with an AOD issue.
- There are no known studies that have specifically looked at the caring responsibilities of children and young people who have a parent with an AOD issue and there has been very little debate on whether it is useful to label these young people as 'young carers'.
- These children and young people are often described as being 'invisible'.
- Research on 'children and young people who have parents with an AOD issue' tends to paint a picture of a group of children and young people who are extremely vulnerable and consequently in need of 'protection and care'. Whilst 'young carers' are more likely to be described as 'active' and 'doing' and consequently in need of 'acknowledgement and support' with their role.
- Despite differences in methodological approaches and emphases, there was a striking similarity between the identified needs of 'young carers' and 'children and young people of parents who have an AOD issue'.
- The need for early intervention, collaboration and family-centred practice models have been identified as crucial in improving policy and service responses to these children and young people.

## Methodology

Over the past 20 years, researchers have consistently argued that to best understand the unique views and experiences of children and young people, time must be spent actively involving them and engaging them in research about issues that affect their lives. Rather than eliciting their needs and views through adult conduits charged with gathering, translating and then promoting children's voices, such commentators argue that researchers must develop methodologies that enable children to participate directly in a sensitive, ethical and effective way (Bessell, 2006; Noble-Carr, 2007).

To date there have been no research projects that have specifically focused on the caring responsibilities of children who care for a parent with an AOD issue. Over the last decade 'young carers' have been cemented within the research, policy and service provision agenda in Australia, but very few studies conducted on 'young carers' (in Australia or overseas) have discussed children who care for a parent with an alcohol and other drug issue. Similarly, research exploring the issues faced by children of parents who have an AOD issue has rarely looked at the caring responsibilities of these children. Studies undertaken into parental drug and alcohol use don't tend to seek the direct views and perspectives of young people themselves.

The project design attempted to reflect both our philosophical position, that children and young people should be at the centre of all processes that affect their lives, and the growing body of evidence that suggests that participatory research can elicit richer data for analysis.

Therefore, to develop an understanding of the caring responsibilities of children who care for a parent with an AOD issue and what the impacts may be of perceiving them as 'young carers', the research team took a qualitative and participatory approach to the research project.

Broadly, qualitative research focuses on how individuals and groups view and understand the world and construct meaning out of their experiences. It has an emphasis on understanding complex, interrelated and/or changing phenomena and therefore seeks to gain a deeper knowledge of lived experiences.

We embarked on interviews with young people that allowed us to elicit an in-depth narrative of their life experiences, particularly in so far as to how their lives had been affected and/or defined by their caring role for a parent with an AOD issue.

The report highlights some of the key themes and issues that emerged throughout the course of this project. The stories of the young people were given paramount importance throughout the research process and as such they are woven throughout the report's findings. The robustness and integrity of these findings was further enhanced by consultation with these young people during the latter stages of the research to review with them the key themes and issues that emerged.

This small qualitative research project does not claim to describe the experiences of all young people who care for parents with an AOD issue. However research such as this is highly valuable in exploring under-researched issues and for providing a more personal understanding of the phenomenon under review.

This project therefore should be viewed as exploratory research that has tried to unpick some of the more important themes and issues for this group of young people. .This project is an important first step that we hope will lead to a larger study and further debate within the social policy and practice arena about this group of young people.

### **Ethical research with children and young people**

Ethics approval is required for all research carried out under the auspice of the Australian Catholic University (ACU National) to ensure that 'the conduct of research protects the welfare and rights of all human participants in research and ensures the

principles of integrity, respect for persons, beneficence and justice are upheld'. Ethics approval for this study was both sought and granted from the University. Encapsulated in, and additional to the ethics process, the research team also attempted to respond to a range of ethical issues relating to engaging children and young people in research.

Each young person was given a consent form to complete that explained their rights as participants in the research study. These rights had been previously formulated for an earlier project and were informed by the ideas and opinions of children participating in that study (see Moore, Noble-Carr and McArthur, 2007). The rights of the young people included:

- The right to be informed about the project and their involvement in it.
- The right to choose whether to get involved and how to get involved in the project and whether they wanted to continue their involvement.
- The right to be treated with respect and to not be harmed or negatively affected because of their involvement.
- The right not to be discriminated against because of who you are or what your background is.
- The right to benefit from the project.
- The right to stop at any time.
- The right to complain if you are not happy about how you are treated.

As one of the fundamental considerations of our research was the protection of the participants' physical, social and psychological well-being, young people were also advised that a counsellor was available to talk with them if they felt they needed this support after the interview. This was organised by the research team prior to the interviews being conducted and the counsellor was independent of the Institute of Child Protection Studies. To our knowledge none of the young people accepted this offer.



Due to the sensitive nature of the discussions, the way young people were recruited for the study and the small sample there were possible constraints to confidentiality. Young people were assured that everything they shared with researchers remained confidential and that they would not be identified as having participated in the project. In some instances, quotes and stories were de-identified while others were not used so that young people could remain anonymous.

However, if any instances of abuse were disclosed during the research process the researchers explained to participants that these concerns would need to be addressed, possibly by notifying Care and Protection Agencies, or by making referrals to appropriate services to provide support. Each young person was informed about this protocol at the start of the interview and signed a consent form to this effect. They were advised that this process would only be undertaken once the researcher had discussed their concerns with them. .

Ethical research also must attempt to address the power imbalances that exist within adult – child relationships in an attempt to ensure that children and young people feel that they can respond honestly to inquiries rather than answering questions in a way that they believe adults want them to (NSW Commission for Children and Young People 2005, p31). In this project, researchers gave young people control over the recorders used to tape the interviews, and used a variety of methods and tools that aimed to make the young people feel more comfortable and engaged with the process.

In recognition of their time and contribution to the project, each young person was remunerated for their participation in the project. In most cases this was a voucher to the local shopping centre to the value of \$20.

### Review of the literature

Prior to embarking on interviews with young people a comprehensive literature review which aimed to identify current knowledge about young people who have caring responsibilities for a parent who has an AOD issue was performed. Key themes explored within this literature review included:

- available research on ‘young carers’ and ‘children of parents who have an alcohol or other drug issue’;
- the prevalence of these issues;
- the needs of these young people;
- historical and current responses to these needs;
- the key questions raised for policy and service responses to these young people; and
- the appropriateness of labelling these young people as ‘young carers’.

This review assisted in the refinement of the research questions. Copies of this literature review are available from the Institute of Child Protection Studies.

### Young People’s Reference Group

Historically, children and young people have often been excluded from research processes that explore their lives. To minimise this exclusion, the research team invited young people to participate in a reference group for the life of the project. The aim was to provide us with a greater idea of how young people, themselves, wanted to be asked about their experiences of caring for a parent with an AOD issue, to provide feedback on the interview format and to assist the researchers in understanding young people’s views. A total of eight young people recruited by members of the Project Advisory Group participated in the reference group.

The research team met with these young people on three occasions. At the first meeting, young people were introduced to the research topic and were asked to identify some of the key issues that they believed should be explored in the research project. They were also asked to highlight areas that may be sensitive to the

participants and how the team might need to consider these issues before designing research tools.

Young people noted some of the risks associated with the study and the reasons why they thought others may not want to participate. For example they raised the issue of how others in their situation may be afraid of statutory intervention and/or painting their families in a negative light. They encouraged the team to be clear with participants about the intention of the study and our position in relation to confidentiality and its limitations. Young people in the reference group offered to endorse the research project and to make themselves available if any potential participant wanted more information from a young person involved in the planning stage of the project.

These young people then tested out the process by being interviewed by a researcher. They were then contacted by another member of the team and asked to provide feedback on the experience: how the interview was conducted and whether they were able to effectively explore what life was like for them whilst caring for their parent with an AOD issue. The interview schedule was then adapted in response to the young people's feedback before being used in subsequent interviews with other participants.

At the final meeting the research team presented the research findings to five young people. They assisted researchers to refine the findings and provided ideas for how they wanted them to be presented in the report. Young people also focused on the language that would be used to describe their experiences and what the findings should be used for both now and into the future.

### **Project Advisory Group**

As well as working with the Young People's Reference Group, the research team were aided by an advisory group made up of key stakeholders including staff from

government and non-government services including ACT Health, CYCLOPS and Litmus programs, Anglicare Canberra-Goulburn, Directions ACT, Ted Noffs, Karralika, ADFACT, Alcohol and other drug program, and the Youth Coalition of the ACT.

The project advisory group worked with the research team to clarify research aims and aided in the recruitment of young people for the project.

### **Re-analysis of primary data**

Young people with parents with an AOD issue had made up a significant proportion of participants in at least one other study into ‘young carers’ conducted within the ACT. This project was conducted in 2005 by Tim Moore at the Youth Coalition of the ACT and permission was sought and granted to review and re-analyse primary data from this study. Fifteen out of the 45 participants in this study were young people caring for a parent with a drug or alcohol issue.

The main aim of this re-analysis was to identify and where possible, compare and contrast the experience and impacts of caring for a parent with an AOD issue against those who are caring for a parent with a disability or other health issue. These issues had not been highlighted in the original findings and discussion of the study.

Our main findings from this re-analysis are found in Appendix 2 and helped shape the design of this project scope.

### **Interviews with young people**

The literature on children’s engagement in research emphasises the importance of providing children and young people with a range of ways through which they might engage with researchers and research projects (see Noble-Carr, 2007). Realising this and recognising the diversity of ages, circumstances, capabilities, interests and experiences of the young people being interviewed, a range of tools was developed through which young people might engage within the interview process.

Interviews conducted with young people usually lasted for an hour and were held at a location and time most suitable to the young person. In some cases interviews were conducted in the young person's home (some with their parents or other family members present), whilst others were conducted at Youth Centres (in one case a young woman was accompanied by her friend) or in other mutually agreed locations.

The interview schedule contained open-ended questions and prompts that focused around a number of key themes developed from the literature. This approach was used to enable young people to tell their own narrative or story in their own words. The young people chose what they wanted to talk about and the issues or themes that were of particular interest or relevance to them were discussed and explored at more length.

A range of task-based activities and other tools or methods were available during the interview. This proved to be extremely useful, especially to gain rapport, in creating an informal atmosphere and assisting those young people who did not feel comfortable in telling their story in a traditional interview format. The tools that were developed or modified for use in the interviews included:

- *'Interview Guide' – or 'So What's This All About' information sheet* – provided to the young person at the commencement of the interview, so that they were fully informed of the key themes and issues that may potentially be covered during the interview. This enabled the young people to make a more informed choice about what areas they might want to talk about or focus on.
- *'Family tree'* – Young people were asked to draw their own Family Tree, including whatever family members they chose. This not only served as an easy way for young people to communicate about their family relationships, but also provided a springboard to discuss some of the strengths and challenges underpinning these relationships. In some cases the interviewer would draw an outline of their own Family Tree if the young person was

unsure of how to go about it and this enabled for building of rapport with the interviewer making some appropriate self-disclosure about their own circumstances.

- *'Support star'* – A piece of paper with a large star was provided to the young people, and they were asked to write the five key people or organisations that provide them with support on the points of the star. The needs that these people/organisations met were then written against these names and other unmet needs were listed in the middle of the star.
- *'Strength cards'* – developed by St. Luke's Child and Family Services, these cards contain pictures and words related to particular strengths. The young people could choose from a variety of these cards which strengths they thought were specific to them and their family, thus enabling ease of identification and discussion around personal and family strengths.
- *'Case studies or Vignettes'* – Two case studies were available to use in the interviews with young people. The first described the experience of a 13 year old female caring for her Mother who has Multiple Sclerosis. The second case study described the experiences of a 14 year old boy caring for his Mother who misused alcohol and prescription drugs. Questions were asked after each story was read which allowed the young people to reflect on the similarities or differences between their own circumstances and the one in the story, what issues they thought the young people were facing and also what supports they thought would have been useful for the young person in the story.
- *'Pamphlets from Young Carer Support Programs'* – these were used as a visual aid to gauge young people's level of connectedness to the term 'young carer' and also as a prompt for discussion on the caring tasks that they perform and the sort of supports that they received or would have liked to receive from the service sector.

Interviews usually finished with a discussion about '*if you were Chief Minister in the ACT and had a bucket of money to spend to help young people in your situation how and where is it best spent?*' and young people were also given space at the end of interviews to talk about their *plans or dreams for the future*. It was hoped that this would end the interviews in a space of 'hopefulness' for the young people. Young people's resiliency was explicitly acknowledged by the interviewers and the interview tried to focus on individual and family strengths.

Above all, the interview process endeavoured to elicit an in-depth narrative from the young person, with particular reference to how they saw their caring role for a family member with an AOD issue had affected or defined their life experiences.

### Data analysis

In qualitative research, data analysis happens throughout all stages of the project, with new analytic steps continually informing the process of additional data collection and new data continually informing the analytic processes. The ongoing input from the young people's reference group throughout the life of the project provided important evidence of this approach, as did the staggered nature of interviews conducted over a number of months. The research team's commitment to reflexivity, which allowed for the critical reflection and team discussion on how the research was being conducted, and how researchers contribute to the construction of meanings in the research process, was central to this project and its aim of remaining true to the voices of young people. Some of the reflective process undertaken by the researchers included regular informal and formal peer debriefing, feedback interviews with participants and follow-up discussions with participants and other stakeholders involved in the project.

This inclusive process allowed for knowledge from a number of sources, including the two reference groups and the literature review, to influence the direction of our data

analysis. It was also instrumental in allowing for triangulation in the data analysis process, allowing us to contrast and compare data obtained by consultants employed to undertake interviews with stakeholders within the ACT service sector and the re-analysis of data obtained from the 2005 Youth Coalition of the ACT young carer study. This all contributed to making sure the findings were rigorous and systematic.

The main focus however was the data the research team had gathered, particularly the interview and workshop transcripts involving the young people. With permission from the young people involved, interviews were digitally recorded and then partially transcribed, so that each young person's story was recorded. This data was then content analysed to identify coherent and important examples, themes, and patterns (Strauss and Corbin, 1998).

Drawing on a theoretical base of grounded theory, key concepts, themes and categories were able to emerge from the data rather than either being imposed or overlooked in the analysis (Strauss and Corbin, 1998; Darlington and Scott, 2002; Minichiello et al, 2000).

A general approach of constant 'comparison' was also a key factor in analysis of the young people's transcripts. This involved taking one piece of data, such as one interview, one statement or one theme, and comparing it with others that may be similar or different. In doing so the research team could propose and explore possible relations between various pieces of data. For example, by comparing the accounts of two different young people who had similar caring or family experiences, the team used analytical questions such as: Why is this different from that? How are these two related? What other variables might explain the differences?

Finally, young people themselves were consulted on the key findings from this data analysis, ensuring that their views remained central to the conclusions of the research.





## Interview participants

### Recruitment of participants

Recruitment of participants was largely the responsibility of the partner organisation in this study (Anglicare). However, due to initial difficulties in recruiting participants the research team also spent significant time pursuing agencies and services that would have links with these young people and/or their parents and also advised local community organisations of the project through newsletter articles and electronic bulletins (e.g. ACTCOSS Newsletter, Youth Coalition e-bulletin).

Recruitment of young people proved extremely difficult. Limited numbers of young people were identified by services, and only some of these young people were willing to talk to researchers about their experiences. Other young people stated they were willing to talk to researchers, but when other events occurred in their lives they decided that they were not able to participate. Further young people participated only after a number of unsuccessful efforts were initially made to attend interview sessions.

It is thought that these difficulties most probably reflect the 'hidden' or 'invisible' nature of these young people and the 'chaotic' nature of their lives (as is often described within the literature). It also reflects the level of secrecy and suspicion that surrounded the young people's family lives and their reluctance to share their stories for fear of unwanted intervention, scrutiny or judgment.

The reliance of the service system to identify, recruit and support young people's involvement with the research process meant that those young people who were not currently supported by organisations did not participate in the project. The research team recognise this as a further limitation of the study.

### Profile of participants in the study

In total 15 young people participated in this study, either in an interview or through attendance at workshops. Twelve young people participated in an in-depth interview for the project, and it is these young people's details that are recorded below. These young people were referred by a number of youth and family support services who had been contacted by the researchers directly or by staff from Anglicare Canberra-Goulburn. One young person heard about the project from a peer and asked to participate.

By way of an introduction to the 12 young people and the issues that they discussed, a brief summary of each of their stories is presented below. All names and other identifying information have been replaced or omitted to protect the young people's privacy and anonymity.

#### **Bobbi**

Bobbi is 16 years old and she has one younger brother and sister. They were living with her mother, who consumed alcohol and smoked 'pot' on a daily basis, until she died in September of last year. After her mum's death her dad came to look after all the kids, but with his 'pot' and alcohol addictions, it meant that Bobbi was left looking after him and her siblings. After a few months Bobbi was experiencing some worrying health issues and major stress from her caring role at home and is now living independently with her boyfriend. However, Bobbi still worries about her family and checks up on them every day and provides them with emotional and financial support, she says she never stops thinking or worrying about them.

#### **Mary Jane**

Mary Jane is 17 years of age and has been living independently for almost two years. Mary Jane describes her mother as being 'a very bad alcoholic' who drank for as long as her four kids could remember and also smoked a lot of cigarettes as well. Mary

Jane has had some serious drug and alcohol issues of her own, starting to use pot in about Year 5 and then developing addictions to heroin and ice. Mary Jane still smokes pot, but has recovered from her other addictions and is now getting support to complete her Year 10 Certificate. Throughout her childhood Mary Jane lived at home with her Mum and her two older siblings. Her mum got drunk every night and relied on Mary Jane for emotional and other practical support. Her earliest memory is of her dad physically abusing her mum, and she has since ceased any contact with him. Mary Jane says that her mum has stopped drinking now, but she still smokes and now preaches to Mary Jane every time they talk. Mary Jane loves her mum, but struggles to maintain a good relationship with her.

### **John**

John is 17 years old and lives with his mum. John has siblings who live elsewhere but he has never lived with them and doesn't really know them very well. Eight years ago, John's father died in an accident that was related to his alcoholism. This had a huge impact on John and his mum who already struggled with a serious mental illness and heroin addiction that stretched back through John's childhood. For much of his childhood, John cared for his mum with little recognition or assistance, although he has received a lot of support from 'young carer' programs in the past few years. He originally got involved with these programs because he was also caring for his mum's friend who had a physical disability which meant he used a wheelchair for mobility. John is a strong and generous young man who has spent a lot of time and energy in recent years helping other young people in the same situation as himself.

### **Michael**

Michael is 17 and now lives with his younger brother and his grandmother. Michael had been the primary carer to his mother, who has addictions to prescription and illicit drugs, for most of his childhood and spent much of his early years caring for his

two younger siblings. He told us that he was too scared of his mother to seek help and often worried for his and his siblings' safety, health and wellbeing. Michael's main source of support throughout his childhood was his grandmother who gave him a great deal of love, care and support. She also allowed him and his brother to move in when Michael decided, last year, to apply for a Domestic Violence Order and to leave home after many attempts to get assistance from his mother's doctor and care and protection services. Michael tells us that his decision to leave home was a difficult one, particularly as he is concerned for his younger sister who is still at home and may not be having her needs met.

### **Luke**

Luke is 15 years old. He lives at home with his mum and has an ongoing relationship with his father and his sister. Both his parents use drugs regularly and Luke believes that this is partly because it helps them deal with pain. Luke's mother was in an accident and his father is living with cancer. These broad health issues have meant that Luke has helped care for both of his parents at different times. He tells us that although it has been difficult, he has appreciated being able to spend time helping his parents and thinks he has a strong relationship with both. Unfortunately he has a tense relationship with his sister who is about to move home. He has decided to move out with a friend of his and her father who also has a drug problem. He plans on continuing to support his mother but from afar.

### **Mark**

Mark is a very resilient 16 year old, who is completing his Year 10 at school. Mark's home life has always involved some level of caring, as his mother has had a serious mental health issue for most of his life that has often required hospitalisation. Although this had been hard for Mark at times, he now feels that he is really struggling to cope with also having caring responsibilities for his two older brothers who are back at home. One of his brothers has a neurological condition and

medicates himself with 'pot' and other illicit drugs, while his other brother has an alcohol addiction and also takes other illicit drugs. Mark has found the caring responsibilities for his brothers to be really tough at times and very demanding. He has spoken about his own mental health issues. The stress at home has also taken its toll on the rest of the family, to the extent that Mark feels as if one of his key care responsibilities is keeping everything and everyone together.

### **Lily**

Lily is 16 years old and lives at home with her mum, her younger brother and older brother who has bi-polar disorder and drug issues. Lily says he mostly smokes dope. Lily's dad also had a drug and alcohol problem and that is one of the main reasons why they don't talk to him anymore. Her older brother's moods and behaviour can be unpredictable and he uses 'pot' to help him to calm down. Many of Lily's extended family members have ceased contact with her family because of her brother's behaviour and she also finds it difficult to maintain contact with her friends. Lily is incredibly determined and is very generous to her friends and family. She is optimistic about the future but worries for her brother and her family.

### **Josh**

Josh is 14 years old. He has not lived with his mum since he was 6 months old, because of his mum's serious drug issues and related incarceration. His dad, who Josh says got his mum into drugs in the first place, has had serious drug issues all of Josh's life. This made life at home very difficult for Josh. There was sometimes violence at home between Josh's dad and his new partner, and Josh was largely left to look after himself and his dad. Josh has now moved out of home and is living with extended family members. He appreciates the support that they have given him and knows that he can rely on them, at least financially, for assistance. Josh found it difficult to identify any hopes and dreams he has for the future but has left school and is looking for some work.

**Stephanie**

Stephanie is 14 years old and lives with her mum and her brother in public housing. Her family moved to Canberra a year or so ago when her mum was admitted into a residential drug rehabilitation program after getting out of prison. Stephanie has spent much of her recent childhood living with her grandparents, because her mum had some serious addictions to illicit drugs and was unable to care for her. She observes that although her mother has given up drugs she continues to binge drink and continues to need her and her brother to assist. She appreciates all of her family, observing that 'they love me, no matter what'. Stephanie knows a lot of other young people in the same situation and feels strongly that young people shouldn't have to care without support.

**Sally**

Sally is 13 years old and, since her parents separated a few years ago, has lived with her dad. Sally and her dad were homeless for a while after they left the family home, but have now settled into public housing in Canberra. Sally's dad has a drinking problem and he also suffers from depression, for which he has been seeking professional help. Sally says that they help look after each other and things are generally pretty good, unless her dad gets really depressed and then he acts all different and can be a bit difficult to live with.

**Sarah**

Sarah is 16 years old and lives at home with her mum. Sarah says that she has taken on care responsibilities in the past for her mum who is an alcoholic. However, she has never had any support or help throughout her childhood which was extremely isolating and she has found it difficult to cope at times. Sarah has recently made the choice to look after herself and to stop using alcohol as a way to cope with her own problems. She also now believes that her mum has to take responsibility for that and help herself. This change in attitude has been important for Sarah who is now

working hard to get her life back on track and to build on her many strengths. Although she has little confidence in herself she knows that her friends see her as being incredibly special and important. She is determined to make the best of what she has around her.

### **Dean**

Dean is 11 years old and lives at home with his mum and dad and younger sibling. Dean is in Year 6 at school and is a high achiever at school and in his chosen sporting endeavours. Dean's mum suffers from bi-polar disorder and both his mum and dad used to be addicted to heroin. Dean's mum is now on prescription drugs and his dad uses 'pot' regularly. The catalyst to Dean's parents stopping their heroin use came when Dean discovered a used syringe in his school bag, which had been placed there by someone who was 'using' with his parents. Dean is proud of his parents and their decision to stop using drugs and talked with some excitement about how his life has significantly improved as a result. He realises that his mother's mental health issue continues to be challenging for his family but believes that their care for each other and their determination will help them through.



## The profile of participants

### *Age and Gender:*

Participants were aged between 11 and 17 years of age. However ten of the twelve participants were aged 14-17 years. Six participants were female and six were male.

### *Cared for relative/s:*

Five of the young people cared for their mother who had an AOD issue while three cared for their father who had an AOD issue.

Two young people cared for both their mother and father.

Although the study primarily focused on young people with a parent with an AOD issue, two young people cared for an older sibling who had an AOD issue. One of these young people actually cared for two older brothers and his mother who has a mental illness.

Three were also caring for another person in their family who had an issue other than AODs.

### *Caring status:*

Some of the young people (9) were currently caring, whilst others (3) had cared in the past. Young people who did not identify as carers were also interviewed when it was determined that they were assuming care responsibilities. The research team believed that it was important to interview both of these groups as previous studies have shown that many of young people who feel that they are not currently caring, do in fact still have some caring responsibilities. Whilst for others who had cared in the past, it was likely that their caring role could re-emerge due to changes in their family circumstances over time.

The level and type of caring tasks undertaken by the participants are discussed in the next section of the report.

***Cultural background:***

None of the young people interviewed for the project identified as coming from an Aboriginal or Torres Strait Islander background and only one identified as being from a Culturally or Linguistically Diverse background. This is not surprising as these young people were not directly targeted by the project. However, as some studies have found that Aboriginal children are more likely to be living in households in which the use of alcohol causes problems (Zubrick and colleagues, 2005 cited in Dawe et al, 2007), it was somewhat surprising that no referrals were received from this group.

This should be noted as a limitation of the project findings, and the findings cannot necessarily be translated to Aboriginal and Torres Strait Islander and/or Culturally and Linguistically Diverse communities.

***Family make-up:***

Ten of the young people interviewed came from a sole-parent household. Seven of these were from sole-mother households and three were from sole-father households. Four of the young people had left the family home. Two of these were living independently with partners or friends. Two were living with extended family members. All but one of the young people had siblings, half-siblings or step-siblings, although for three of the young people none of their siblings resided with them.

***Nature of Alcohol or other Drug Issue:***

Seven of the family members cared for by the young people in this study were currently poly-drug users. An additional three of the family members were currently only experiencing problematic use with one drug, but had previously had addictions to other drugs.

Six of the participants cared for a family member who had an alcohol issue. Of these, two of the family members who had an alcohol issue had also previously been addicted to illicit drugs including heroin and marijuana. Two of them, young people also currently had a problem with illicit drugs, one with marijuana, the other was not specified.

Six of the participants currently cared for a parent with an illicit drug issue. Of these, three family members were using marijuana, one was using 'ice'. Three other family members were using illicit drugs that were not specifically specified.

Three participants also cared for a parent with an addiction to prescription drugs. One of these family members was also currently using illicit drugs and another had used illicit drugs in the past.

## **Experiences of caring for a family member with an alcohol or other drug issue**

Previous studies on caring and specifically young carers have concentrated on examining the level of care provided, the type of care provided and the impacts of care on young people. To remain consistent with this approach and to facilitate an ease of comparison with previous studies, the discussion in this report opens in a similar way by exploring the level and type of care provided by young people.

This report will, however, defer discussion on the impacts of caring for a family member with an AOD issue until some of the key themes and issues related to the complexity of these young people's experiences and family relationships have been outlined. This is because the research team believe that although a young person's caring may well lead to a range of negative outcomes, this relationship must be understood alongside a myriad of other inter-related and complex factors including parental mental health issues, family conflict and separations, neglect, isolation and poverty.

To examine a young person's caring relationship with their family member outside of these issues would overstate the relationship and imply a level of causation that may not be justified.

For example, at the final workshop session, participants stated that their issues and their family's problems would not go away if AOD issues no longer affected them. The impacts of their family's alcohol and other drug use and the many other issues that they had encountered meant that the problems that they face continue to resonate throughout their lives. One of the participants described this as being like an etcher-sketcher... 'It's like you draw a picture and leave it for a while and when you erase it it's still there, you know you can still faintly see it' (BOBBI).

It is therefore not surprising that along with their caring role, the common key issues and themes that the research team identified as impacting heavily on these young people's lived experiences and needs included the complexity of their family relationships and the awkward place they find themselves situated in within their own families and communities; a place that can be characterised by secrecy, fear, stigma, isolation and a distinct disconnection from mainstream society and its safety net of opportunities and supports.

### Level of care

Although previous studies have generally not explored the level of care provided to parents with an AOD issue, all indications so far are that those young people who care for a parent with an AOD issue provide similar levels of care to their young caring peers. For example, our re-analysis of the young carers study completed by the Youth Coalition of the ACT in 2005, showed that these young people actually had higher levels of care to their caring peers – both in the time spent caring for their parent and in the types of caring that they provided.

The level of care provided by the young people in this study varied greatly. To some the concept of 'caring' was quite foreign to them, so to think in terms of the level of 'care' that they provided to their parent posed some initial difficulties:

*'Young carer' sounds a bit weird ... it doesn't sound right ... it doesn't seem right for me because I did it for so long ... it was natural and what it was supposed to be ... it just seemed normal. (MARY JANE)*

*I was a bit surprised by being seen as a 'young carer' ... no one has ever talked about my situation like that ... it's just different. (LUKE)*

Some said they currently had a minimal caring role for their family member, whilst others felt that they spent the majority, or all, of their time caring for, or thinking and

worrying about the person to whom they provide care. For example, when asked how much time they spend caring for their parent, Joshua, Bobbi and Luke replied:

*Whenever I'm there and whenever I'm awake. (JOSHUA)*

*More time than I do for myself. (BOBBI)*

*If I'm not with them, I'm usually thinking about one of them. It's always there.  
(LUKE)*

Others found it hard to quantify how many hours of care they provided, as much of their caring time was spent providing emotional support or monitoring the safety and wellbeing of their parent or just simply 'worrying about them all the time':

*Actually I've never really sat down and thought about it, all that I have to do  
... In a day I'd do like between an hour and maybe 5 hours. (LUKE)*

Although the small sample makes it difficult to decipher what factors impacted on the level of care provided to family members, the young people highlighted a number of issues that warrant discussion and further investigation.

Firstly, the level of care provided to family members fluctuated for these young people over time and was often unpredictable, even on a day-to-day basis. For many, care tasks increased at times of more intense parental alcohol or drug use, often coinciding with times when their parent became mentally unwell. This is similar to the Youth Coalition of the ACT data which showed that those caring for a parent with an AOD issue provided 24 hour care more frequently than other young carers; and that this occurred when there were 'breakouts' in drug taking and drinking.

Although it is often assumed that the level of care provided during periods of wellness (or of non-drug use) is significantly reduced, young people argued that their responsibility for monitoring their parent's wellness and safety was always significant and, in fact, peaked during period of apparent respite. As John explains:

*There were the frantic times, when there were weeks when it was worse, or weeks when it seemed completely normal. I would start looking out for stuff during these good times though. (JOHN)*

Young people explained that during periods of heavy drug use they could better assess their parent's needs and predict their behaviours, but that during periods of non or minimal use there was less predictability. This was sometimes difficult for young people who felt that they needed to be present to monitor their relative, to pick up on early signs of difficulty and to minimise the opportunities for their family members to use. As such, caring was not as episodic as otherwise suggested in the literature.

Young people who had recently moved out of the family home said that the level of care that they provided to family members had subsequently decreased. However, they still appeared to maintain a strong carer role even though they no longer saw themselves as having care responsibilities:

*I check in every day, I can't not leave them, if I can't get in I'll call them ... always every single day I talk to them. I have to; it's just in my conscious that I need to check on them ... I never not think about them every day. (BOBBI)*

Other factors that seemed to contribute to the level of care provided by the young people included how many siblings they had living with them; whether or not these siblings, particularly younger ones, also required care; and whether there were others around to assist with the caring.

Ten of the young people in this study were from sole-parent families and a number of the participants had younger siblings who they tried to shield from their parent's alcohol or drug use and from having to take on caring responsibility for them. Each of these young people in the sample felt they were the only ones available to provide all of the care that was required by their family member. Many of them had assumed

a caring role from a very young age and subsequently felt like they had little choice in the role that they took on:

*I've been doing it from when I started going to school. I always had little chores to do when I was littler but it was then that I started doing more stuff. And like by myself. Being like responsible for it, not just helping mum or dad do stuff. (LUKE)*

In two cases, it appeared that parents made a particular child responsible for helping them although there were other children in the family. These young people reported feeling as though they were 'forced' to do a number of tasks around the family home, many of which might be considered care responsibilities. When one of these two left home, the responsibility for looking after the mother was then assumed by the next oldest sibling.

Interestingly, it appeared that the frequency and quantity of substance use, or for that matter substance type, was not necessarily related to the level of care provided by children. This confirms the view that children are not always adversely affected by parental substance use and subsequently they do not always assume a caring role (see Johnson and Leff, 1999 cited in Hegarty, 2005:21; Hogan and Higgins, 2001 cited in Dawe et al, 2007:79; Odyssey Institute of Studies, 2004). Bobbi's story reflects this variable experience. She lived for many years with her mum and two younger siblings. During this time, Bobbi's mum drank and smoked pot every day. However, Bobbi reflected that:

*Mum, she was good, she kept her drinking habit hers ... and still had food in the cupboards for us kids. When she died she still had two and a half grand in the bank ... [her marijuana use and drinking] didn't affect any of us in no way, no [way] whatsoever, she was really good like that, if she only had fifty bucks left she would rather not smoke bongs, she rather feed us kids.*



However, after her mum's death (when Bobbi was 15yrs), Bobbi and her siblings went to live with her father who also drank and smoked pot on a daily basis:

*You know when mum first died, dad didn't know what to do. I tried to teach him, but I ended up doing everything. I was pretty much a mother at 15, cleaning, cooking, getting the kids off to school, homework and all that.*

Bobbi was able to account many stories of when her father had run out of money and either had borrowed or stolen from her in order to buy alcohol or pot. She says that 'he can't look after himself or any of his children'.

The effect on Bobbi was enormous, after caring intensely for her father and her siblings, she eventually couldn't continue on with her role and moved out of the family home – 'it lasted three months and I couldn't do it any more'.

### Type of care

As with level of care, the type of care provided by young people in this study also varied. Young people described a variety of care tasks that they performed on a regular, sometimes daily basis, including:

- Emotional support – listening to their parent's problems; worrying about their health and wellbeing on a day-to-day basis; 'keeping him calm so then he doesn't have a reason to use it'.
- Financial support – regularly contributing to the household finances, usually by giving of wages or youth allowance; lending money on a regular basis to parents; paying for essential educational or medical needs of siblings; managing household finances and ensuring that bills were paid when they were due; stealing food and obtaining financial aid for food and other household items from support services.

- Household tasks – cooking and cleaning for everyone in the house, including cleaning up after nights of parental drinking; and shopping, or shop-lifting, to obtain food for the household.
- Safety and monitoring – trying to prevent or dissuade family members from drinking or using drugs, physically restraining family members when drunk, organising transport for parents so that they weren't driving intoxicated or under the influence of drugs, removing items that could cause harm when parents were intoxicated, trying to avoid parental self-harm, assisting parents when they had attempted suicide or self-harmed, and managing other crisis situations, particularly when parents became mentally unwell.
- Personal care, including looking after the health and welfare of the person – giving medication, such as *Panadol*, to their parent; and assisting parents to shower or wash whilst intoxicated. Interestingly, some of the young people spoke of how they envisaged that personal care tasks would increase into the future due to the potential health consequences of drug and alcohol abuse.
- Caring for siblings – this was often described as attending to all of the needs of their sibling, especially the need for food, love, comfort and emotional support; and trying to protect them from harm from parents or others, especially when parents or siblings are intoxicated or under the influence of drugs.

Many young people felt a great deal of responsibility for younger siblings. For example, Bobbi stated that she wished she was 16 years old when her mum died, not 15 years, so that she could have been given sole custody of her siblings, instead of all of them having to live with her father who drank and smoked pot everyday and was

‘incapable of looking after them’. Whilst others had this to say about caring for their siblings:

*She [my mother] pretty much is reliant on everyone else, other than herself. When I was still living with her I was pretty much looking after both the kids and doing all the stuff that she was supposed to be doing ... For a while I was doing all that, for a couple of years ... Most of my life’ (MICHAEL)*

*JOSHUA stated that at one stage he was caring for his dad and his half-siblings who were aged 2 years and 6 months at the time. Their mum was around sometimes, but in the bedroom doing drugs with dad and then fighting with dad. (JOSHUA)*

*She [my sister] was the one who took it the hardest ... It freaked the shit out me, but I handled it pretty well ... I feel that she is the one that needs the help most. [Do you feel responsible for her?] ‘Big time ... and I always will. (MARY JANE)*

Where caring for siblings was prominent in the stories of the young people there also appeared to be a lack of parental care and support. This may explain why care for siblings became a major role for young people.

This seemed to parallel with the other main care task identified by the young people; that of emotional care and support. Although young people often talked about an increase in household and other practical tasks and the need to monitor the safety and wellbeing of family members, it was the emotional care provided to parents that the young people spoke about the most poignantly.

The high level of emotional care provided by young people caring for a parent with an AOD issue has also been highlighted in previous research on children of parents with AOD issues (for example see Bancroft and colleagues, 2004; Tunnard, 2002 and Hayes et al 1993, cited in Pattonb2003:8). In addition, research on young carers

carrying for a parent with a mental illness (many of whom are known to also have substance abuse issues) has further found that the high level of emotional support and supervision that these young children provide sets them apart from their caring peers (Becker, 2005:11; Aldridge, 2006:81).

In this study there seemed to be a link between the lack of care and/or emotional support that the young people stated they received from their parents and the increased level of emotional care and support that they stated they had to provide to their parents. Where parents required a high level of emotional care and support, it appeared as though they were not emotionally available to care for their children. Although the sample size is too small to draw strong conclusions this issue was a theme that emerged from the young people's stories and requires further investigation.

This dichotomy of care strained some of the parent/child relationships, and some of the young people were left emotionally spent from providing care to their parent, and in some cases siblings, whilst also missing out on any emotional support and care for themselves. Existing literature on parental substance use has often talked about this in terms of 'parentification' or 'role reversal'.

However, with the young people the research team spoke to, it appeared to be more complicated and complex than a simple case of 'role reversal' as the young people's relationships were more dynamic than any notion of 'one-way care' could encapsulate:

*My youngest memory is of my dad hitting my mum ... she used to sit there and explain to me how many times he used to hit her ... I used to sit there and say to her 'look mum I can't handle this, please don't put this on me, please can you stop, please, and she would say I need you, I need you, I don't have anyone to talk to ... and I was like, 'shit, shit, shit, what am I supposed to do? I had no fuckin' idea ... I was sitting there feeling helpless, just sitting there*

*feeling like you can't do anything while you've got your mum sitting there crying in your arms, it's just one of the worst feelings you can have. (MARY JANE)*

*Checking in with mum on how she is feeling, kind of being a counsellor ... trying not to blow her off ... that would be the primary role I had ... several of the issues that mum had and still does have definitely affected the kind of relationship that we have – especially in the household – its not so much more of a parent and kid kind of relationship– I more see it as a roomie kind of relationship – I see it as more of I definitely have a lot more freedom than any other kids I know of my age. (JOHN)*

*He would tell me the problems he was having with his girlfriend. I didn't want to hear it ... I would act like I was listening, but zone out ... dream about things, don't listen. (JOSHUA)*

One of the other key problems with conceptualising the relationship as role-reversal is that it does not fully appreciate the dynamics inherent in 'normal' parent-child relationships. As adults, parents generally have some control over the relationship and have the capacity to decide how they might engage their children about issues. They will often engage peers, including their own partner, for support and guidance on issues that might arise in the relationship, or the problems identified, and be less reliant on their children to have their own physical, emotional and social needs met. If we are to assert that role reversal occurs in these families we would also need to show that children have similar levels of power, choice and independence which is not the case. Children are reliant on their parents to have their basic needs met, often have limited choice about how they interact with their parents and often feel unable to engage others for support about relationship issues or to talk through difficulties that parents might raise.

Although some of the young people resented the emotional care role, particularly if their relationship with their parent was not good, as in the case of Joshua, for most it was more complicated. The majority of the young people stated that they loved their parents and although finding their emotional care giving took a high toll on their own personal health and wellbeing, most emphasised that they still loved and valued their relationships with their parents, often saying that they had grown closer because of their care giving role. These quotes best sum this up:

*As much as I hate him, I still love him, he's my rock and I'm his rock, it always has been. As much as he's dragged me through the dirt, I really don't care, he's still my father, you know he's been through a lot more shit than I have.*  
(BOBBI)

*I love my mum, she's the only mum I've got.' (SARAH)*

*I loved her to death ... but we fought most of the time. (MARY JANE)*

*We talk a lot more now ... my dad is funny. (SALLY)*

*I love my mum ... because she is my mum ... I still fight with her, but I would never leave her again. (STEPHANIE – she left the family home to live with her grandparents when her mother was using a lot of heroin and other drugs.)*

For other young people in this study, emotional support was just one of a number of care tasks they performed and they did not feel that they were missing out on any parental care and support. Rather, their care giving relationship was characterised by reciprocal care and support, the type of care giving relationship that one could say has been emphasised within the young carers literature:

*He cares for me. ...[But] he thinks that I care emotionally for him. (SALLY)*

Therefore, as well as outlining many of the intricacies and complexities of their caring experience, the findings from this study clearly support similar findings in other

studies which suggest that high levels of emotional care and support may be common within this group of young carers.

#### KEY FINDINGS: Nature of care

- The concept of ‘caring’ was often foreign to the young people interviewed – they rarely saw themselves as ‘young carers’.
- Many of them had assumed a caring role from a very young age and subsequently felt like they had little choice in the role that they took on.
- The type of care provided by the young people in this study varied and included: financial support, household tasks, safety and monitoring; and personal care, with many reporting that care for siblings and emotional support was particularly demanding.
- The types and level of care provided by young people was not dissimilar to that of others with care responsibilities, except that these young people were more likely to monitor their relatives and to ensure safety.
- Parent/child relationships that have often been described in terms of ‘parentification’ or ‘role reversal’ within the literature on children with parents who have AOD issues, were found to be more complex than any one-way notion of care could encapsulate.
- The level of care provided by the young people often fluctuated and was often unpredictable, even on a day-to-day basis. Even at times when the care load appeared to lessen, young people remained vigilant and their emotional and monitoring care tasks could even escalate as they tried to ensure that their care recipient remained well and capable in these times of apparent respite.

### Understanding the family context

As noted above, the family lives of young people in this study were complex and often affected by a range of significant and inter-related stressors that often exacerbated and prolonged some of the negative effects of caring for a parent with an AOD issue. In this section we will explore some of these stressors before describing how they appeared to coalesce around the family, causing significant negative outcomes.

However, before doing so, it must be acknowledged that family often played a positive role in the lives of young people, even when characterised by stress, conflict and disconnection.

#### *The positive role of family*

Seven of the young people in the study were still living at home with their parent and/or siblings to whom they provided care. This was a testament to the importance of family and the determination that families had in staying together even during difficult periods. For these young people, family was seen as a place of belonging and a place where members could both give and receive support.

Even when times had been difficult, a number of young people saw their families as having inherent strengths and resources:

*Family is such a special thing. And I feel special and good about being in a good family anyway ... I've one of the best families: I've got the best parents in the world. My dad puts in so much effort to do stuff with me. Their rules are good, they're not too harsh. They let me go to the mall. They make sure I'm with someone responsible and old and I'm allowed to go play in the dark as long as I'm in someone's house and then they come and pick me up. And I have to call them quite frequently to let them know that I'm safe. See that house there? Three houses away – at 5 o'clock I go there and sometimes I stay late. And I go, 'maybe I need to come home because its not safe [outside]' and*



*they say '[you can stay inside], we'll come and pick you up in half an hour'. So I feel really happy and they don't get mad at me. See my dad, he can get angry but he doesn't believe in smacking. He can yell 'get in your room' because I can do naughty stuff like every kid. (DEAN)*

*Like my dad is always ready to sit down and have a talk with me and help me out with stuff. My mum she usually beats around the bush and that, it takes longer, but she still has things to say. They're not bad parents at all, it's just not true that all parents on drugs are. It's just that they might not always be like able to do everything ... I think their parenting skills could be a little better but they're doing the best they can with what they've got. (LUKE)*

The majority of the young people stressed the need to recognise and acknowledge the strengths and resources that existed within their families and argued that they felt angry and upset when outsiders could only see the weakness and failures inherent in their situation. Although they believed that it was important for others to recognise that things 'weren't good', they said that family was special to them and that they needed people, particularly workers and services, to at least acknowledge their families strengths and respect them.

#### *Family separation*

One of the most common experiences that emerged in this research was that of family breakdown and separation. All, but two of the participants were living in a sole parent household and five of the young people had never known, or had a relationship with, their other parent. In one case (Joshua) a young person had never known his mum, stating that his Ddd had got her addicted to drugs, then left her with drug debts. He reported that his mum had ended up in jail as a result and had never re-established a connection. He has lived with his dad since he was 6 months old and hasn't had contact with his mum since.

Other young people chose not to talk about their 'absent' parent because, clearly put, they 'hated them'. These young people described strained and difficult relationships and spoke about their parents with anger and hostility. Many felt let down after their parents had failed to take up any of the opportunities they had to support their children. They also felt abandoned by the parent who they believed was responsible for providing them with solutions when things got rough at home. In some cases this had led to the young person effectively terminating the relationship they had with this parent.

Only two young people described having a good relationship with an absent parent. In one case a young girl had chosen to live with her father, who suffered from depression and alcoholism when her parents separated. This meant that she had to leave her home and her town and become homeless with her father. She reflected that it was a 'split decision' and that she 'sort of' went to live with dad because otherwise he would have been on his own and he needed someone. She said that she misses her mum but that the two enjoy a good relationship, often spending weekends and school holidays together. She says that she has thought about moving in with her mum but is worried about what might happen to dad if she was to do so.

Another young woman (Sarah) talked about how her parents had separated because of her mother's alcohol use and how she missed her dad terribly:

*I was pretty close to my dad ... not having dad around. I miss having him around ... It's hard when father's day comes around ... and you think I can't get them anything, but you're thinking about them and you're thinking every day.*

Her grief for her father was exacerbated by the death of her grandmother who had also provided her with ongoing support:

*I think about it a lot. That I probably wasn't coping as much. I shouldn't have had so many worries, so much hurt and pain and stuff like that ... Mainly like losing my nan ... You think about having coffee with my nana and all the things I can't do. And that's hard and stuff. (SARAH)*

Losing these two important people in her life was devastating for this young woman who sometimes blamed her mother for how things had turned out.

Extended family members were extremely important to the young people in this study. If available, extended family members were generally the first people called upon by young people for support, especially in times of crisis. Some of the young people that were currently at home with their parents, had spent substantial periods of time living with extended family and/or friends when their parent's alcohol and drug issue and/or mental illness had intensified.

However, extended family members were often not without alcohol and drug issues of their own. It was not uncommon for drug and alcohol use to be a normal part of the extended family life in many of these young people's lives.

*STEPHANIE's story:*

*She [mother] didn't care, she didn't give a flying f\*\*\*, she didn't care ... she just cared about herself and when was her next drug coming in ... When she was on drugs no-one wanted to be near her.*

At the age of 7yrs Stephanie went to live with her grandparents and stayed there for approximately four years whilst her mother was on drugs and then incarcerated. She then moved back to live with mum who successfully completed rehab, but who now has an alcohol issue.

Stephanie went on to talk about what it was like living with her grandfather who was an alcoholic ...

*He sits there and won't come out of his room after 5pm, will only come down for dinner, then goes back up to his room and drinks and he is pretty demanding when he is drunk ... [he is] not rude or violent, but difficult to live with ... but not when he is sober but ... and no matter what, I love him heaps.*  
(STEPHANIE)

It was also not uncommon for extended family to have become estranged from young people and their families. This was primarily because of conflicts that had occurred that were based around the family member's drug and alcohol usage and young people often spoke about this with a sense of regret:

*We as a family have been excluded from family events by some extended family members. My uncles don't want to be part of our family because of what my brother is like and does when he's drunk or stoned ... [this is hard sometimes and hurtful].* (LILY)

*I used to hate my birthday and Christmas so much because there wasn't much money and the [extended] family weren't around, they don't really talk, and you have to come together as a family and pretend that everything was perfect but you know in your head that things aren't perfect. And that used to get me real angry. Now mum doesn't speak to the family. I get angry too because I've got all this family, but family that I don't get to talk to. I've got an uncle in Sydney who I can't see. The only real time we get to see our family is at funerals and weddings or special events, you know, and things like that when they have to see each other, or have to talk to each other. Which I think is so wrong because if something happens to one of us who are we going to turn to because you don't have your family?* (SARAH)

### *Challenges and conflict within families*

As the relationship that young people had with their absent parent was often difficult and complex, so too was the relationship with the parent with whom they resided. Four of the young people had recently moved out from the family home because of

relationship difficulties with their parents. Two of these young people had done so because they had concerns for their own safety and wellbeing. Although both of these young people had had involvement with care and protection services they had not moved as a result of statutory intervention even though they were extremely concerned for their own safety and wellbeing whilst living at home with their parent.

Young people in this study often described regular and ongoing circumstances where they were subjected to anger, mood swings, violence and what they felt were unjust or unfair parenting practices. For example:

*She was never really that violent, but there were a few times when she would discipline me in ways that, like ... in a violent way. She might pull my hair if I'd done something wrong or pull out the jug cord and hit me across the legs. Or the wooden spoon. (SARAH)*

*Him [dad] and his girlfriend have a fight and slam each other into walls, punch holes in the wall and yell ... she tried to hit me once, but I just moved ... all they did was fight. (JOSHUA)*

*She's [mother] not so much physically abusive to us, but she plays with your mind and that's what really causes more damage. (MICHAEL)*

At times this caused long-lasting anger for the young people and it often seemed to escalate into more intense 'fights' and conflict within the home between them and their parents:

*I don't like the idea that she smokes [pot] but I'm not sure why. I'm angry with her. Really, really angry. (LUKE)*

*Sometimes I would try to avoid confrontations, sometimes I would run into them blazing. (JOHN)*

Often the level of conflict or violence that the young people witnessed or were subjected to at home resulted in them and their families having frequent contact with statutory authorities such as the care and protection system and police:

*My dad stabbed my mum with a pair of scissors in front of me ... they've broken each other's arm, in front of the kids, they didn't give a f\*\*\*. My dad's thrown me against walls and shit and bashed the shit out of my little brothers ... my little brother was like 6 or something and my dad punched him in the stomach ... the coppers were always there and my dad was always in f\*\*\*in' jail. (Workshop participant)*

*In my family the coppers came around that much that I knew the coppers, I knew all the unmarked cop cars ... years later I still recognise them, they still recognise me. (BOBBI)*

In most cases the young people saw their parent's behaviour in the context of their parent's drug and alcohol abuse and/or mental health issue. Over half (seven) of the young people had resided with family members who had a mental health issue and at least three of the young people identified as having possible mental health issues of their own. These mental health issues often compounded the already complex and difficult relationships young people were having with their family members.

Young people often described their family member who had an AOD issue, or mental illness, as having two personalities and sets of behaviours. The family member would behave and interact with them one way when they were 'drunk', 'stoned' or under the influence of drugs; often a stark contrast to how they would behave and interact with them when they were 'sober' or not under the influence of a drug. The young people described having to anticipate and be aware of which 'person' they would have to deal with on an ongoing basis, with their parent often 'changing' throughout each day:

*Mum would either be depressed or want to have a fight or a combination of the two ... this would come to a head once a week. (JOHN)*

*If he doesn't have drugs he's in bed asleep, telling me to do everything and not letting me do anything I want to do and then when he is on it, he lets me do anything I want. (JOSHUA)*

*I used to have to look in the rubbish [for empty bottles] to see what mood he was in. (BOBBI)*

*[When he is depressed] ... he acts different, different personality and stuff, like not himself, he is usually bubbly and helpful, but when he's like that he's not, he just tries as hard as he can to not let you do something ... he usually goes to sleep so I have to do things ... It's hard to explain. (SALLY)*

*[When she was pissed] ... that was the only time she had fun ... [when she was not pissed] she was angry, pissed off, upset, in the worst moods. (MARY JANE)*

*He has his good and bad days. Some days he gets aggressive. Some days he is really mellow. (LILY)*

The majority of the young people spoke about these issues very candidly and as stated above, in most cases they were still able to sustain loving relationships with their parents and siblings. After all, as most of the young people pointed out, this was all they had known and they didn't really understand how family relationships could function in a way that was different to their own experience:

*I thought it was normal that people smoked bongos and drank, that's what I got bought up with. (BOBBI)*

*I've had it there my whole life and I don't notice it any more. (SALLY)*

*She never really smoked when I was around ... it was when she was alone ...there was not too much interaction between her and I ... that was family life, so I don't really know much different. (JOHN)*

In fact, as is illustrated by the example below, sometimes when parents do recover from their alcohol or drug issue, relationships break down because those very relationships were based on life-long experiences, roles and interactions that the young person has become used to and often used as a way to survive:

*She [mother] just changed, I have known her as one person and the way that I knew her, she just completely flipped out, and she is just the complete opposite of what she was, and I don't know, like its good because she is not drinking anymore, but at the same time I didn't feel like she was my mum any more, it just completely changed my view on her, I was like well who the f\*\*\* is this, it isn't someone I know, it's true I didn't know her. (MARY JANE)*

#### *Relationships among siblings*

In talking with young people it became clear that it was not just extended family and parent-child relationships that were affected by familial substance abuse: sibling relationships also appear to become more complex and sometimes challenging. As noted in the section on types of care (above), for example, many of the young people talked about taking on a caring or 'protector' role for their younger siblings. However, roles with siblings were not concrete and changed over time, either day to day with their parent's drug and alcohol usage and parenting availability, or as siblings grew older and relationships became more equal, or as young people moved out of home and primary care responsibilities were transferred from one sibling to another. Sometimes these relationships increasingly began to involve conflict or even violence:

*I know that without counselling me and my sister will never speak again. This will put a lot of stress on my family. (LUKE)*

*Justine and my relationship is strained now [since I moved out from home] ... maybe because she is older or the big sister in the house now. (BOBBI)*



*Dad started getting angry at Jesse [brother with drug issue] a lot and then he [Jesse] moved out so he took out everything on me. And not because I was doing stuff, but just as much cos he was stressed out about what was going on with the others ... Now they're all back [both brothers who have drug issues] and he's angry 24/7 ... mum has gone because she is afraid of Shaun [other brother with drug issue ]... so she's moved out 'til he's got help, 'til he's out of the house. So it's hard because we don't have mum so it's just guys in the house. (MARK)*

As this last quote demonstrates, it became evident that many of the young people's caring roles went beyond care tasks for individuals and had emerged into a role of keeping the family functioning as a unit, enabling them to stay together. This not only provides evidence of the meaning and importance of family that these young people placed within their own lives, but also the intra-familial challenges that need to be recognised and responded to when providing support to these young people.

#### **KEY FINDINGS: Experiences of care**

- Young people's care giving roles and relationships were bound by many intricacies and complexities that could only be understood when considered alongside a range of other significant and inter-related stressors affecting these young people and their families, such as poverty, mental health issues, conflict, violence and family separation.
- The importance of family, both immediate and extended family members, was continually stressed by the participants in the study and was evidenced in a number of ways, including the significance of sibling and parent-child relationships.

## **Impacts of living with and caring for a family member with an alcohol and other drug issue**

Unlike most other young carer studies, the young people in this study were not readily able to identify many positive aspects of their caring role. Although some young people spoke about family relationships being strengthened, this was often counterbalanced by the other complications and experiences discussed above in terms of their family dynamics.

Others spoke about one of the positives being that they had an insight into what alcohol and other drugs can do to your life, so they knew that they would never succumb to these temptations, unlike their peers. However, again this was not the case for all of the young people and some had in fact developed their own problematic drug use.

The researchers tried to explicitly acknowledge the strengths and resilience demonstrated by the young people that were so apparent throughout their interviews and some of the young people were able to agree that they indeed had grown as a person and learnt some valuable life lessons and skills from their experiences. During the workshop, several of the young people involved explained that they 'were who they were' because of their experiences and that they had become stronger people because of their experiences.

However, young people overwhelmingly talked of the negative impacts of caring for a parent or family member with an alcohol and other drug issues. A number of young people felt that they had not become stronger or more resilient as a result of their experiences and, in fact, believed that they had little confidence, poor self esteem and limited hope for the future. Again, this is unlike findings of previous studies with young carers caring for a relative with another illness or condition which generally

stress how young carers report that they have grown as a result of the caring experience.

Young people generally did not believe that things were going to get better or that things would only improve if they left their parent. In fact, many felt that things would probably get worse and that as they journeyed towards semi-independence things would become more difficult as they tried to manage intimate relationships, employment and their own futures. Some felt that their parent's AOD use and their care responsibilities would get in the way of them achieving their goals and felt that, at some stage, they would have to choose between the two.

As such, the participants in this study highlighted a number of areas in which they were affected, including financial hardship, their schooling, health and wellbeing, safety and social isolation. These are discussed separately below, along with what young people told us about the impacts that caring for a family member with an AOD issue has on young people's transitions into adulthood.

### Financial hardship

All of the young people who participated in this study were experiencing financial hardship. This financial hardship manifested itself in different ways for different people. Some young people mentioned that their parents would ask to borrow money from them which they would then spend on alcohol or drugs:

*Justine [my sister] and I, when we were little we used to have little piggy banks ... once dad really needed smokes and bongos and petrol ... and he raided it, there you go. (BOBBI)*

Others talked about having a lack of food at home and frequently being hungry. Many said that they ended up having to steal or to ask friends or neighbours for food:

*I stole food or go to other people's houses and they would give me food.*

*(JOSHUA)*

Others mentioned that their families needed financial assistance from community based organisations to buy other essential household items, such as washing machines. Missing out on activities or possessions that were common to their peers was also mentioned by some young people and was just another way that they had become isolated from their peers and wider community:

*Definitely there is less money. Like \$100 a week, a single parent can't bring up kids on that after the drugs have been bought and stuff ... I'm not selfish and shit, I don't need all that stuff. I'm not really one of those people who needs a lot but even so it's kinda hard when you see other kids with all this shit and you're struggling to survive with nothing. (LUKE)*

*We would have stacks of bills, just unopened. That really pissed me off because they cut my internet off and I had no way to communicate with the outside world when they cut the phone line off and then they were going to cut our hot water too. (MICHAEL)*

*If we've planned for it at the start of the week, we've got money for it, but if something comes up we can't do it. (SALLY)*

Other signs of financial hardship included difficulties in obtaining and maintaining suitable and affordable housing. Many of the young people had experienced homelessness, either with their families or by themselves once they had decided to leave home and live independently:

*If my Mum was still on drugs and alcohol this house would not look like this and we wouldn't have this house. (STEPHANIE)*

Young people faced many barriers in breaking away from this financial hardship. Gaining an adequate level of education and/or finding and maintaining employment

was not easy and even when they did get work the money would often be used to help the family:

*When I was living with my dad and I was working I'd give him \$100 a week.*

*(LUKE)*

*It's really hard to keep a job. And like they don't know what's going on at home so if you come to work and you're not handling it they can just fire you.*

*I got fired from my last job. I've got bills stacking up of my own and I'm only 16. (MARK)*

### Schooling

Almost all of the young people we spoke to talked about difficulties they were having with their schooling. Four of the young people had left school early and were no longer engaged with the education system, however, two of these have subsequently found work, one through an apprenticeship. A further three young people had left mainstream schools and were currently completing their Year 10 through supported education programs or through TAFE institutions.

For many of the young people their education had become the most tangible area that they could say was affected by their caring role for a family member with an AOD issue. Some felt that this was because of the chaotic nature of their family life which made it hard keep up with school work, not being able to complete homework and missing a lot of school.

Others talked about conflicts they had with teachers and/or other students, with many of the young people stating that they found it hard to fit in and always felt like the outsider or 'different' in their school community. For many this seemed to translate into frequent experiences of violence and/or bullying within their school environment, either as the victim or perpetrator, or perhaps both.

Other young people stated that their early school leaving had more to do with their disengagement from their wider community and the fact that school just wasn't relevant to them:

*I am pretty terrible when it comes to school, pretty much all your supposed to do at this age is go to school so it's pretty bad .... I missed school because of caring sometimes, [but] most of the time is just because I didn't want to go.*  
(JOHN)

*I would get expelled if I was still in school, so what's the point.* (JOSHUA)

*I could never do my homework and concentrate ... I don't have to do homework now [in Youth Education Program], that's why I can do it ... I couldn't do mainstream school, it's too much.* (BOBBI)

*They don't give you time to do it at school [all your work], so coming home to a family like that, you might not have much money so you might not have a computer, or a computer with internet access and it's not like you could go down to the local library to use it because you've got no time so on top of not doing that well at school because of stuff going on at home you're not going to keep up with assignments and all that stuff so you're failing even more.*  
(MARK)

*When I was in high school I wasn't really going 'cos when [brother] was first diagnosed with bipolar disorder, he was always in the hospital or in the psych ward. I missed a lot of school because of it. And like worrying about him and all that.* (LILY)

*I reckon it's a bit dodge [school]. I'm really good at maths and science but I missed such a big chunk of it so when I went to college I was really confused because I had missed the in-between part. So I stopped going to maths.*  
(MICHAEL)

*I couldn't really do my school work. I had a lot of trouble in my school work. I was in a special class, because I just couldn't concentrate ... when I got home I couldn't get help with homework. But if I didn't get it [understand it] then there was no one to help me. And I tried to explain it to my teacher, but sometimes it was like 'well you could've come to us for help' but they didn't really understand. (SARAH)*

*This kid next door ... he said to all the kids at school like 'oh, don't ' (he was good friends with me) 'oh don't like Dean because his parents have \$20 notes and all they have is all this white powder and stuff and his dad sniffs it up and so does he, and Dean injects himself .... I got really furious because it was such a lie and it spread around a bit. I had to stop it. It hurt me really bad. It was such a lie. My dad would never touch that stuff, never. Me either. I'm fit, I look after myself, I don't inject myself ... You can die from that. And I'm not stupid. (DEAN)*

Young people's disengagement from education appeared to affect them academically but, just as importantly, socially as they disconnected from positive peer groups, from potentially affirming activities and 'normalising' opportunities. This disengagement appeared to compound their sense of isolation and kept them from finding or receiving support.

### **Health and wellbeing**

Issues to do with their own health were also raised by many of the young people. For some this was related to their own mental health, with some young people describing themselves as experiencing ill health related to their emotional state, or experiencing depression, stress, anxiety and even suicidal thoughts:

*I have been not so good emotionally in the last couple of years, especially the last year, the last year or so I have started to have issues that are partly because of my family situation. (JOHN)*

*I lost 25-26 kilos in three weeks, just because I had to do all that shit I had to do ... I've got eczema from stressing. (BOBBI)*

*I feel sad sometimes [and] I have an anger management problem. (STEPHANIE)*

*It's all stressful. (MARK)*

*I felt like shit. [All of the time?] ... pretty much. (JOSHUA)*

*I got really really sick trying to look after them all and then I got mentally ill really badly and tried to do the whole suicide thing. And it was really hard to look after two young children and your parent and then at the same time trying to look after yourself, having a social life and doing all the things you should be doing. (MICHAEL)*

*It's been tough. I often think about suicide, and think, would I be better off if I wasn't here? and then I think, my friends and they always tell me, what are we going to do without you?' and you think there's people out there who love you and need you, and you think OK maybe I should stay around.(SARAH)*

*I was feeling everything: so angry, so sad, you know, all of that.(DEAN)*

Some turned to alcohol and other drugs as coping mechanisms, although only three of the young people interviewed described themselves as having problematic drug use. However, at the time of the interviews two of the young people had already overcome these issues:

*I dunno, all my friends were doing it. And it, you know, makes you feel better. And I wasn't really in a mental place to make a good judgment on my part so I went 'yeah sure' ... I'd drink to get happy, not worry about anything ... there was a lot of pressure on me. It was really hard. (MICHAEL)*

*[When at school I met someone in the same situation as me] I talked to her, but I didn't really talk to her, I tried more distracting myself from my family*



*situation and keeping my mind off family life, and not having to think about shit I have to go home to, my mum being pissed again ... pretty much we just went and got high, that was the easiest thing I could do, it still is now the easiest thing I could do to get away from it, that sucks ... I started smoking pot when I was 8 years, I couldn't be chilled out otherwise, then I used 'ice' and heroin...' (MARY JANE)*

*I got into drink a lot. Because mum was drinking a lot I thought it was the only way to deal with it ... So I thought 'Well if I can go drink, and that takes all the stuff away for a little bit' ... But I've learnt that yeah it takes the pain away for a little bit but then the next day or a couple of hours after its still there and you still have had to deal with it ... I've only just started to think that way, late last year ... I'm not sure [how much I was drinking] to be honest with you ... I was drinking a lot, wiping myself off ... I would see it as a way of dealing with everything. Thinking 'I've got this in my life. I don't have anything else but at least I have this'. (SARAH)*

Other young people stated that they had ongoing health issues throughout their childhood that were not addressed adequately by their parents:

*I was sick all the time and no-one ever took me to the doctor. (JOSHUA)*

*I got really sick from having to run around and to do all that stuff for them and look after myself too. I got glandular fever from it, 'cos I developed chronic fatigue syndrome. (MICHAEL)*

### Safety

Most of the young people spoke about feeling unsafe at certain times throughout their lives and this mostly occurred when they were at home. This was either a regular occurrence due to family violence and the unpredictable nature of their parent's or sibling's drug use, or occasional crises related to their parent's or sibling's alcohol or drug use or mental illness, when they were left alone:

*It was a very strange existence [a couple of weeks before mum's mental breakdown] ... I wasn't sure what was going on until mum just didn't come home one day, she went to the doctor and got hospitalised and the doctor didn't bother telling us ... I was out looking for mum, didn't know what had happened. This was the time when I was the most scared, I was wandering around the city looking for her, this was pretty unsafe. (JOHN)*

*[When I was 11years old] ... I started worrying because he [dad] started not being around when I got home, and he wouldn't tell me where he was going, and 7 o'clock come around and I freak out, and 8 o'clock comes around ... I got scared ... I didn't like being at home by myself. (SALLY)*

*When he [brother] gets aggressive, he doesn't take it out on us, he just goes outside and punches the brick wall, takes it out on the brick wall. Yeah it's not safe, not when he's yelling at you. (LILY)*

*When he comes home drunk he gets real aggressive so it's not just easy stuff, it's more having to do full on stuff like holding him down. Holding his legs so he won't kick the walls, like keeping the family safe because no-one knows what he is going to do. (MARK)*

*[Felt unsafe when] ... him and his girlfriend have a fight and slam each other into walls, punch holes in the wall and yell. (JOSHUA)*

A number of young people talked about being exposed to unsafe people and unsafe things as a result of their parent's 'using' and the fact that parents were unable to monitor their children's safety while intoxicated or under the influence of drugs:

*It was really bad, I knew a lot of words. Like I knew what like 'crack' was and I was only in year 2. I knew really bad words like 'skank' and stuff because I heard them here, cos bad people were always in my house saying things like that. Bad people. I accidentally slipped out one day and I had the absolute worse thing happen to me in Year 5. My parents were out with this really*

*wrong crowd and they met these people only for a week because they got introduced by somebody else and they [a user] came over to my house one day and they put a needle in my bag and ... I got to school and I was going to put my yugio cards in and I saw it, and I threw it down and I ran straight back into class and, yeah. My parents they got so furious. They rang that guy up and they rang up the police but the police didn't do anything because they didn't have any evidence but they knew it was him. That's why, that's one of the things that has scarred me for life and it's driven my parents [to stop using]. I said to them 'never do anything' and that's why they're so good now.*  
(DEAN)

Other young people who had moved out of home, but left siblings behind, worried a lot about the safety and wellbeing of their siblings. There were circumstances described by the young people where their younger siblings were given inappropriate medications and where parents did not take sibling's health issues seriously. Young people also reported that they were worried that their parents neglected to provide their siblings with adequate care and supervision.

This appeared to compound young people's feelings of guilt in leaving the family home and their capacity to 'get over' the challenges associated with living in a family affected by drug and alcohol use. These young people reported feeling conflicted but, in a few cases, reported that they weren't sure whether or not they could actually protect their siblings anymore. In one case, a young man thought that him not being at home would make things safer for his younger sibling: as the conflict that was inherent in his relationship with his mother would desist and that, without him being around to care for his sister, his mother would be motivated to better look after her.

### Social isolation

One of the most stark affects of caring for a family member with an AOD issue experienced by the young people interviewed was the social isolation. The recruitment process of the study proved very difficult. Throughout this process and the subsequent discussions held with members of the Project Advisory Group, it became apparent that young people experiencing these issues are largely hidden from the service sectors that could be assisting them.

For those young people who were able to be identified and eventually participated in the study, many stated that this was the first time they had spoken about their parent's issues in any sort of depth with somebody outside of their family. They stated that they simply had no-one to speak to that they could trust and they ended up leading an insular life, seemingly invisible to outsiders:

*In year 4 to year 6 ... I would always have other people sitting there boasting about how good their families were and what they would do at night ... and I was just like yeh, my mum was sitting at the table last night getting pissed ... I thought that it was more my mum she would rather get pissed than spend time with me ... I would not say anything [at school] I would just sit there.*  
(MARY JANE)

*I had no social life, only going 'round to see a friend' ... who lived one house away.* (LILY)

*I didn't want help, no-one knew what was happening at home ... people at school probably would have known, but no-one ever said anything.* (JOSHUA)

The secrecy surrounding family drug and alcohol misuse and these young people's lives was very apparent. There was evidence of parents trying to shield their use from their children and then children and young people trying to shield their parent's use from others outside of their family. This appeared to be linked with feelings of shame or embarrassment, and a lack of trust and fear associated with what people's

responses would be if knowledge about what was going on 'got out'. Young people were scared about ramifications from their parents, often fearing abuse from the hands of their parents if they told people what was happening at home, or they were scared about what might happen to their family unit from unwanted service interventions:

*I'm thinking that maybe because mum was so quiet, and so isolated that's why she got away with it – people didn't see what was really going on in the house ... Or people saw it but didn't really wanna get involved, to see it. They'd ignore it because they may have been afraid of her. Because I know my mum can stick up for herself when she wants to. She can become a very violent person. I've heard stories from her best friend, how she'd fight men twice of her. I don't want to get on the wrong side of her. (SARAH)*

*With Richard [brother] drinking and when I've got friends over and all that, he starts being a dickhead, drinking and embarrassing me in front of my friends. He gets angry and aggressive and takes it out on everyone else. So when he's like that I don't have friends over. (LILY)*

*We were pretty much too scared to say anything to anyone because we knew there were aggressive consequences if we said pretty much anything to anyone ... We would be told that if we talked to people we wouldn't be allowed out, we wouldn't be allowed to see our friends, see nanna ... She [mum] was very, very intimidating. (MICHAEL)*

*It's scary. You don't want to tell people because you don't know what people are going to do ... There are not many people that I can trust, that I can tell. I just guess our family just has to do what it has to and we've just got to get through it. (MARK)*

The social isolation experienced by these young people was never more apparent than when they were asked the question, 'how is your family different to other

families where there is no-one with an alcohol or drug issue?'. Most of the young people could not answer this question, however they recognised that they were sometimes labelled as 'different' and felt stigmatised as a result of their family background and their families' issues. For example:

*I was seen as the little poor kid in the street. (JOSHUA)*

*A lot of people question all the time why I just live with my dad, they assume something is wrong or something with our situation ... some people are quick to judge other people. [it's] annoying. (SALLY)*

However, many had become so removed from 'mainstream society' that they did not know other families who were not affected by these issues and their experiences had become 'normal' to them, so they were unable to articulate what it would be like to not live with these issues:

*I have friends that have that problem, I can't tell you how is it for someone who doesn't have that problem, because all my friends do! ... I have friends who have been through what I've been through, I have no friends that haven't. (STEPHANIE)*

Therefore, the high level of secrecy, fear, stigma, lack of trust and social isolation all combined to mean that these young people had severely restricted opportunities for participation in their communities. Many of them had left school and with it their only link to mainstream society. Social interactions were limited and often talked about as only being possible with people from similar backgrounds to themselves. In addition, perhaps most alarmingly, most of them expressed that they had felt, or currently still feel, a sense of helplessness and hopelessness about their situation. Other than their family member recovering from their addiction they could not see how their situation and circumstances could really change:

*If they're getting drunk every night you can't really help them if they're drunk.*

*Like what can you do?. (MARK)*

*The only thing that I thought would help is if she stopped drinking. (MARY JANE)*

The literature on children of parents with substance issues often refer to these young people as not hidden, but 'invisible'. This distinction is important and reflects the reality for many young people in this study who stated that even when engaged with mainstream universal services, such as schools, youth centres, health services, the issues of greatest concern to them were often overlooked, ignored and misdiagnosed. As such, many felt that their issues were 'invisible', and reported feeling frustrated and confused when informed that services and supports were available to assist them in navigating the many challenges that they encountered, but had failed to do so.

### **Transitions into adulthood**

Because we spoke to older young people in this study we were also able to highlight a number of common themes and issues that emerged in relation to young people's transitions into adulthood and independence, particularly in relation to moving away from the family home.

Other than decisions to move out of home due to neglect and abuse, as was the case with two of the young people interviewed, the decisions young people made in regard to moving out or staying at home appeared to be largely influenced by the caring role that these young people had.

One young woman felt that she was able to move out of home once her mum had recovered from her alcoholism and another made the difficult decision to leave home because her caring role had got too much for her to handle.

Although staying at home presented many difficulties for these young people, moving out was never an easy option. In a number of cases, young people sought assistance in moving out of unsafe family environments but reported unsatisfactory outcomes. In fact, those young people who asked for intervention from Child Protection Agencies reported that this proved, in all cases, to be not only unhelpful, but harmful to them and their families. In three instances young people told us that they had contacted child protection services and told them that that they felt that they needed to get out of home and were concerned for their own and/or their siblings' safety. They reported feeling frustrated and disappointed, believing that Child Protection workers did not believe their stories and the seriousness of the situation at home and that this was unfair and unresponsive:

*I got Family Services involved, but they don't see there is anything wrong, but I do, I hate Family Services I call them 'Family Fuckers' ... When they came to the house to check up on dad I couldn't tell them what I know, I couldn't say 'come back', because dad was walking in and ... so I went in a couple of days later, they don't see what happens after hours ... she said 'I know how you feel', I said 'no you don't, I am in a shit situation' ... I swore then the worker said she was not going to continue to talk to me because I was abusive.  
(BOBBI)*

*I dunno, Care and Protection did nothing. Nothing that we can say ... I spoke to them once and they told me they went over there for half an hour and that she seemed perfectly fine and I went 'hmm mmm, whatever' ... They were called heaps and heaps. In one week my mother was called on 5 or 6 times but nothing happened ... So Care and Protection is pretty much there to make sure that children are being looked after and whatever. So they would be a lot more helpful if they went like this, 'You've told us what is going on and we'll remove you' even if it's just for a short time but it's still helpful. I mean kids don't like getting separated from their parents but in the long run it's gonna*



*help them ... I tried to get it done [removal], make someone listen to us. Try to get us removed from the situation. (MICHAEL).*

This young man found that in the end his only safe way to move out of the home and the abuse and neglect that he experienced was to 'escape' at an opportune time to his grandmother's house and then seek a domestic violence order against his mother. He stated; *'It was really, really scary ... I'd never felt that scared before'* (MICHAEL).

We cannot ascertain how the young people's situations were assessed by Care and Protection Services nor claim to know what work, if any, was provided for the family without the young person knowing but it would appear that young people in this study felt incredibly disempowered and devalued in their interactions with that service.

For many, reporting their concerns to any adult, let alone a statutory organisation, was a confronting and potentially hazardous act and one which young people felt took great courage and determination. Young people took it incredibly personally when they felt that workers either did not believe their situation or failed to respond to what they believed were critical and compelling situations.

One young person, for example, reported being at a family case conference where a number of community and government agencies were advocating for intervention from care and protection services. He reported that all the services 'were up in arms' when the case worker suggested that they would not intervene but when asked what these services did to help in light of this decision, reported that nothing more was provided. This seemed to be particularly problematic for the young person and the family who had to now deal with the side effects of being engaged in such a process. The young person reported feeling unsafe with his mother after reporting his concerns but did not identify ways in which the system helped him during this

challenging period. If those services who were engaged in the life of this family were concerned about these children, it is concerning that no extra assistance was provided in lieu of the requested care and protection involvement.

Without what they considered to be a helpful response from the broad service system, many young people attempted to move in with extended family and friends to escape their problematic home lives. Although some had these resources available to them some found that the only option available to them was state funded supported accommodation. Acquiring either a place in crisis accommodation or more stable government housing could often take time and resulted in some of the young people experiencing homelessness for extended periods. In fact, most of the young people interviewed had experienced homelessness either with their families or on their own at some stage throughout their life:

*I've been trying to get out of home since I was 13 ... My only option at the moment is a refuge but I've heard all these stories about how you get your stuff taken and how it's dangerous and that, so I don't really have a choice.*

(SARAH)

Young people's transitions into further education and employment were also affected by their experiences of caring for a parent with an AOD issue. As has been outlined above, many of the young people had already become disengaged from the education system and some spoke of how difficult it was to obtain and maintain any sort of employment.

Therefore, it is not surprising to note that when the young people were asked about their future goals and/or dreams many replied that they had not given it a lot of thought and were just living day to day. At their most ambitious, the goals consisted of finishing the school year and one young woman spoke about getting a TAFE qualification so as to get a job and earn money.

**KEY FINDINGS: Impacts**

- The young people tended to focus on the negative impacts of caring for a family member who has an AOD issue and spoke about difficulties they had with their:
  - Schooling: many had already disengaged from the mainstream education system.
  - Financial hardship: families lived in poverty and young people were often reliant on others for assistance and found it hard to break away from the experience of poverty.
  - Health and wellbeing: experiencing ill health related to depression, stress and anxiety.
  - Safety: often experiencing unsafe situations due to the unpredictable and chaotic nature of their family life and the high incidence of conflict and violence within their family environments.
  - Social isolation: high levels of stigma, fear, mistrust and secrecy resulted in many of the young people being totally removed from their mainstream community or the supports it could provide.
  - Transitions into adulthood: leaving home was fraught with difficulties for the young people in this study, as was completing their education or finding employment – this all resulted in feelings of hopelessness.

## **What are the needs of young people caring for a family member with an alcohol or other drugs issue?**

All of the factors that have been discussed in this report, the type and level of care young people provide, the complexity of their lived experiences and their family relationships and the impacts of caring for a parent with an AOD issue, affect the needs of these young people and how they could best be addressed.

As well as describing their experiences, the young people we spoke to were able to articulate many needs that they had and how *they* thought they could best be met. Their thoughts are summarised below.

### **A significant adult to talk to with whom they trust**

Young people argued that the most common and most immediate need that they had was having a significant adult to talk to whom they could trust. This was someone that would listen and who could understand and respond to their feelings and broader needs. When discussing this, young people did not specify that this person had to be a worker, and in many cases the people that young people currently relied on were extended family members. However, it was apparent that even where extended family members were available and supportive, the young person also needed further help from the service sector. Some young people felt they needed to talk to a counsellor, especially if they thought they were experiencing significant stress, depression or had their own alcohol and drug issues.

*Trust* was often identified by the young people as the key factor in determining whether they would seek support. They believed that they needed someone they could trust and that only after finding this person would they explain what it is like for them and for opportunities to be opened up so that things could get better for them and their families. Unfortunately, the number of trusted adults in the lives of these young people proved to be limited:

*Cos just talking to people takes a big load off your chest, like a huge weight is lifted off you. So there does need to be more people. Because its hard to talk to people, you've got to trust them a lot ... there are not many people that I can trust, that I can tell. (MARK)*

Young people also talked about the need to have pre-existing trustworthy relationships with workers, or other significant adults in 'good' times so that when things became difficult they were able to raise their issues and concerns. They said they felt awkward asking for help but thought that when they had workers around them who knew a little of their situation and who believed them and didn't judge their situation solutions could be found:

*And yeah they say you can ring up but what I'm saying is you've got to have that relationship first so it's kinda a vicious circle, you know. (MARK)*

### **Access to, and assistance from, workers and services that are professional and responsive**

Many of the young people were frustrated by the lack of support they had received over the course of their lives. These young people had been linked into the service system, but felt that at times this service system had let them down. To overcome this and address their needs young people stated that they wanted workers to do the job they were employed to do. They wanted workers to listen to and believe them, and respond to what they identified as being their and their family's needs. They wanted workers to follow through on commitments they made to them; and they wanted workers to be available for support when they were supposed to be performing that role.

Young people also stressed that the language workers use is important. They did not want their parents or family members referred to in 'insulting' ways. They did not want workers to make 'derogatory comments', or to make assumptions about them or their family members, or to call their family names, such as referring to their

family as 'dysfunctional'. This only made them feel worse. They also didn't want workers to make value judgements about their relationships or roles within their family or to say that they understood how they felt, when clearly they would have no idea how it felt to be in this situation. They also didn't want to be referred to as 'victims', but they wanted workers and services to respond to them in ways that worked towards acknowledging theirs and their family's strengths and to support them when they need help.

Another common problem identified by young people was the high turnover of staff in some of the services they were in contact with. It took the young people time to develop trust and a productive working relationship with workers and seemingly often once this was done the worker would move on to another job. One of the young people recounted how they found a great worker:

*but he had to leave so he was going to hand me over [to another worker]. But he left and nothing was organised. So everything ... went to a stand still. There was nothing, and everything that was going well was almost wasted.*  
(MICHAEL).

When we asked what sort of skills workers needed, apart from 'just to listen and do the job they are paid for' most of the young people felt workers need to be good at talking to young people, and that they could learn the AOD stuff along the way. They definitely did not want 'pushy' workers, but those who were prepared to listen and believe what they had to say.

Many of the young people had been involved with services for significant periods of time but reported that workers in these services did not know about their family backgrounds. It would appear that was because young people had not yet developed trusting relationships with workers, because workers did not provide young people opportunities to talk about these difficult issues and because young people were not confident that workers would respond appropriately to the information. As such, it

would appear that there had been countless 'missed opportunities' for good conversations which might lead to better assistance.

Some young people also identified how important school teachers could be in providing them with a supportive environment. As has already been outlined in this report, schools were often the only contact these young people had with the mainstream community and could therefore be crucial in decreasing the level of social isolation these young people experienced.

Other young people suggested that care and protection services were of critical importance in supporting them and their family and ensuring that they were safe. There were polarised views about whether children should be removed from their homes when their parents have AOD issues. On one hand, a number felt that all children who were living in a family affected by alcohol or other drugs needed to be removed if their needs weren't being met:

*My parents are not hard core users. The ones who are on heroin or whatever who are wasted from sun up to sun down, where there are 4 year old kids who have to look after themselves, cook their own food. I think that there needs to be, their situation must be assessed to know what's happening. And then maybe the kids should be taken off them but otherwise it's not what should happen. (LUKE)*

Some believed that this removal would force parents to recognise their problems and to seek support:

*If you take away what parents depend on. When your parents are taking drugs or whatever they are reliant on their children. So if you take away the children then nothings going to get done, they're going to have to get up and do stuff. Like with me, I ran away for a month. She pretty much had to do everything herself because no one else did it for her. (MICHAEL).*

Others however argued that splitting up the family was never a good solution and felt that the impacts of doing so were long-lasting and broad. Either way, being listened to and believed was critically important to all the young people, as was finding someone that could provide help to their family.

As noted above, young people's strong focus on statutory responses would suggest to us that young people felt that their needs were pressing and that they needed immediate and significant support. As such we would argue that their concerns were not only about their engagement with care and protection services but also the system's failure to provide adequate and responsive assistance that made what the young people felt was a 'real' difference to their family and their situation.

It also became clear that seeking help was extremely confronting and difficult for young people for a number of reasons. Young people needed to be sure that asking for help was not going to have negative consequences for them or their family. Therefore, instead of simply being told about other services they could access or given contact details of the service, young people said that they needed support to seek help. They wanted someone who they trusted to walk them through at their own pace until they were connected with and being supported by a new service.

As one young woman explained:

*[I] need someone to sit with me to say this is what it is all about; this is how they are going to treat you, what they are going to say etc. If someone sat down and explained the whole thing to me, then I could go 'yep' or 'no.'*  
(MARYJANE)

The challenges that young people encountered when seeking such assistance are outlined in the next section: 'current barriers to obtaining support'.



### Linkages with other people in the same situation

Young people often said they felt extremely isolated and 'different' to their peers. They do not believe that others understand what life was like for them. Therefore, being linked to other young people experiencing similar issues appeared to be important to some of the young people. Those that voiced this idea were those that were involved in young carer programs and who had appreciated the support and assistance they had received from these services:

*[The young carer program] got me out of the house ... Yeah, helped me to understand that I wasn't the only one out there, there were other people. And that helped a lot. (LILY)*

*Like this program is everything for me. It's changed my life. If it wasn't for the young carer camps I don't know what would have happened to me. I say there's so many other kids out there who have it the same as me who don't know about it who need it. (MARK)*

### Support and understanding from the education system

As already stated above in the discussion on impacts, many young people spoke about the difficulties they encountered with their schooling and some had withdrawn from the education system altogether.

Young people said that to be able to continue with their education they felt that tutoring and assistance to access flexible schooling alternatives would be helpful. Those who had been assisted into flexible education programs to complete their secondary education were extremely grateful for this support and stated that they would not be completing their education if it wasn't for these more flexible alternatives.

Other young people spoke about how helpful it was, or would have been, to have supportive and understanding teachers, especially for the times when they hadn't

been able to complete homework or had to miss days of school. One young person recounted how it was helpful that he had a teacher that he could just call and say, 'look I am at the hospital and can't get to school today' and he didn't have to 'go into it', they just understood the situation and made his life at school a lot easier.

### Respite from home situation

*Sometimes it gets a bit hectic so you need to get out of the house. So someone to take you out, to get out of the house. Have some time for yourself. (LILY)*

All of the young people talked about the need to have a break from their family environment. To some respite meant providing 'a place to escape to', whilst others talked about it in terms of just 'having a break' from their family life:

*Respite would've been good. Even just for [my brother], it would've been good. It would've taken him out of the situation ... Having to look after younger kids when you're really just a kid yourself is really hard. (MICHAEL)*

*I think there needs to be more people that like come out and just take kids out so that they can escape even if it's just for a few hours each week. That would make a huge big deal ... would help a heap. (MARK)*

*There needs to be a place where you can go if you need time out ... A place where parents know you're safe and that they're not gonna freak out about or nothing. Like when it gets real bad. Not like a refuge or nothing because those places are full on but somewhere you can go to chill out. Not for a long time but maybe a few days or a week if you need it. Or like if your parent is in hospital or not doing good. Some place you can go, you know, where you can trust the workers and where you can just do the stuff you need to. (MARK)*

The three young people who were involved with a young carer camp program stated that the respite service they received was extremely helpful. They got some 'time-out' from home with other people in similar situations to them and got to access

recreational activities, such as camps, that they would otherwise not have the opportunity to participate in.

### **Practical Assistance**

Many of the young people said that they and their families needed a lot of practical assistance with things such as food and other financial aid. Due to their family's poverty, and their parent's alcohol and drug issue, some of the young people talked about missing out not only on food but other material possessions and essential items that their peers had access to, such as clothes and computers. Some of the participants accessed financial assistance offered by the Young Carer Program which was greatly appreciated. It was mainly used to buy food, pay for school fees and purchase other necessary appliances for their household.

Other young people also talked about needing practical assistance to look after their care recipient, because they were often the only ones at home available to care and perform all of the care tasks that were required. Practical assistance with housework and cooking and looking after their parent were mentioned by some of the young people.

### **Housing support**

Housing stability was seen as important by the young people, as it gave their families an opportunity to deal with their issues, rather than always being in crisis. Many of the young people had experienced homelessness and long waiting periods for public housing whilst living with their families and their families required the support of services to assist them at these times.

For other young people who were struggling with living at home and had decided that they needed to live independently, housing support was also essential. This support was needed to obtain and maintain appropriate and affordable housing to allow them to try and 'start over on their own'.

### Support for their family unit

Young people clearly stated that they wanted help that was aimed at supporting and strengthening their families as well. In fact, when asked to prioritise support that focused on them as an individual and support that had a broader family focus, young people overwhelmingly called for the latter:

*The issues [we experience] are not just all about us and they're not just all about our family, so we need help individually and then as a family.  
(Workshop participant)*

Most of the issues the young people wanted help with were interlinked with issues that other members of their family were experiencing and those that were entwined within the complex roles and relationships within their family. Therefore for any service to support them adequately, their family's issues needed to be included on the table and addressed. Young people thought that this was the only way that they could truly achieve any positive changes in their lives. A number felt that family counselling or mediation was necessary to resolve the significant challenges they and their family were facing.

Other young people felt that their family member would benefit from some support to address their alcohol and other drug issue, while others advocated for additional support for their siblings, reporting that they felt stressed and responsible for their sibling's welfare when assistance wasn't provided to them directly.

### How do these needs compare to other young carers?

One of project's aims was to explore how the needs of young people in families affected by AOD misuse were similar or different to those of other young people with caring responsibilities. To do this we have compared the needs identified by the young people in this study with the research findings on young carers from Australia and overseas.

The literature review conducted for this project found that the needs of young carers and children of parents with a drug or alcohol issue are profoundly similar.

This project further confirms the similarity of needs such as: the need for respite; emotional support; someone to talk to; peer support; financial support; practical assistance; assistance with education and employment. There are only three other needs that are consistently mentioned in the young carer literature that do not appear in the list compiled by the research participants above and these are:

- Decreased stigma related to disability/illness and the need to be recognised, acknowledged and valued;
- Age-appropriate information on their parent's condition and where they can get support;
- Access to social and recreational opportunities.

Although none of these needs were explicitly identified by the young people in this study, upon analysis of the data, we can be certain that they are all needs that were shared by the young people in this study and they have also been recognised as needs of children whose parent has an AOD issue in previous research (see literature review completed for this project).

For example, the level of social isolation and 'invisibility' experienced by this group of young people requires intervention to reduce the stigma attached to living with a parent with problematic alcohol and other drug use. Access to social and recreational opportunities would also minimise their social isolation and promote healthy and 'normalising' experiences with their peers. Whilst age appropriate information on their parent's condition and the supports available may help some young people in their caring role and also to navigate and find supports for them and their families.

The issue of isolation due to stigma of drug and alcohol issues, and mental illness, has been raised by Thomas, Stainton and colleagues (2003:9) who found that young

carers who cared for a parent with a drug or alcohol problem, or a mental illness, were likely to face the most difficulties in their lives compared to their caring peers.

The Youth Coalition of the ACT also concluded in their report that 'young carers caring for a relative with an AOD 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' (Moore 2005a:7).

Therefore these young people may be in need of more urgent and intensive support compared to that of their caring peers.

The re-analysis of the Youth Coalition study also showed that where support was provided to young people caring for a family member with AOD issues it was likely to be in the form of government agencies, the most prevalent being Family Services (now Office for Children Youth and Family Support) and Youth Justice and that help was more in the form of intervention for the safety of the young carer. The help was not of the practical and emotional nature that other young carers received, nor was it the help that these young people said they wanted, with approximately 50% strongly asking for both individual and family counselling and emotional help. This was much higher than their young peers in the same study.

Some of the young people in this study had multiple caring roles, where they also had the responsibility of caring for someone with a physical disability or mental illness either concurrently or prior to their current caring role for a family member with an AOD issue. One of these young people explained the difference between caring for a family member with an AOD issue and caring for a family member with a mental illness:

*The biggest thing I would see myself as a young carer of drugs and alcohol at the moment. Years ago it would've been mental illness because mum was in*

*and out of hospital all the time. But now its alcohol and drugs because [my brother] is drunk all the time. At the moment it's probably the biggest.*

*It's a lot different. When mum was in hospital we went to visit her and when she was out we had to take lots more care of her ... When she was in hospital I had to do more stuff at home like the dishes and cooking dinner and that but with [my brother] it's more a case of like when he gets brought home by the cops and stuff or when he comes home drunk he gets real aggressive so it's not just easy stuff, it's more having to do full on stuff like holding him down. Holding his legs so he won't kick the walls, like keeping the family safe because no one knows what he's going to do.*

*I don't see why young carers who are looking after someone with a drug problem shouldn't get time out too. They're doing the same things, and it's probably even worse. Like I suffer from both so I know it can be worse. (MARK)*

**KEY FINDINGS: Needs**

- Young people articulated that their needs included:
  - A significant adult to talk to whom they could *trust*;
  - Access to, and assistance from, workers and services that are professional and responsive;
  - Linkages with other people in the same situation;
  - Support and understanding from the education system;
  - Respite from their home situation;
  - Practical assistance;
  - Housing assistance;
  - Support for their family unit.
  
- The needs of these young people seem to be profoundly similar to those of their caring peers, but due to their degree of social isolation, the multi-faceted issues that they face and their current lack of support, they may be in need of more urgent and intensive support compared to their caring peers.



### **Barriers to obtaining support (and having their needs met)**

The young people articulated a number of barriers which stopped them from accessing or receiving appropriate and effective support from the service system in their community. Barriers existed at all points along a continuum from a total lack of identification of any 'problem' or 'need'; accessibility to services; and inadequate responses from the current service system to young people and their families.

### **Lack of identification of 'problems' and 'needs'**

It appeared that no one in the community was actively identifying that the young people who participated in this study had any 'problems' or 'needs'. Young people felt that it was up to them to identify that their family member's alcohol or drug usage had become problematic. It was up to the children to alert extended family members, or the other significant adults in their lives that their parent, or they themselves, were not coping and needed help. In some circumstances even when children or young people were able to do this, they were not listened to, believed or responded to in a manner that was helpful to them and their families.

It would also appear that because most of the services that the young people and families accessed focused on the needs of specific individuals in the family, the broader family and interfamilial issues and needs were not identified. Youth services, for example, failed to talk to young people about their family situations and missed opportunities to identify and respond to the stresses and impacts that the young person's home environment had on their broader life experience. Similarly, AOD services appeared to miss opportunities to engage children and young people or to determine their needs when focused primarily on the using parent. As such the complexity of need appears not to have been ascertained or responded to for most of the young people in this study.

Therefore, the 'invisibility' of these young people to their communities and the system's inability to identify or meet real need served as one of the main barriers to them or their families receiving the help that they needed.

### **Not wanting to, or being unable to, ask for help**

Many of the young people said that they did not want to ask for help and that they needed someone else, usually a trusted adult, to do this for them. However, most of the young people did not have someone else who was willing or able to do this for them.

Some said that they did not have the confidence to ask for help, whilst others said that they didn't have anyone they could trust to tell their story to, and others said that they wanted to be independent and sort it out for themselves:

*I need to go and see one [a counsellor], desperately, but I won't. (MARY JANE)*

*There are not many people that I can trust, that I can tell. I just guess our family just has to do what it has to do and we've just got to get through it. (DAVID)*

*I'm a fairly independent person and I don't like having help from other people so I like to do things myself. (MICHAEL)*

Others were also just too afraid to ask for help, as discussed below.

### **Fear**

One of the major issues highlighted by the young people in this study that stopped them and their families from asking for help was the fear of what would happen when their 'secret' was disclosed.

This fear was twofold for the young people. Some of them were fearful of the retribution from their parents if they 'told someone what was going on at home'. Some parents made it abundantly clear to their children that they did not want other

people to find about their drug and alcohol issue and any of the consequent needs of their children. It is also important to note that some of the parents were probably unaware of the level of their children's needs, but as parents were not interviewed, it is not possible to illuminate further on this point:

*We were pretty much too scared to say anything to anyone because we knew there were aggressive consequences if we said pretty much anything to anyone. (MICHAEL)*

Others were fearful of unwanted intervention, such as their removal by child protection authorities. This fear is often cited in other research as a barrier to parents seeking help, even when they are aware that they require assistance and support (Taylor et al, 2006; Gaining Ground Project, 1998, Finnegan and Kendall, 1992 and Hearle et al, 1999 all cited in Hegarty, 2005:22; Tunnard, 2002):

*It's scary. You don't want to tell people because you don't know what people are going to do. (DAVID)*

*I remember being told that [a non-government service] will take you away and don't talk to them. (JOHN)*

There was also another layer to this fear, which was about protecting their family from any unwanted scrutiny and that is associated with drug-taking and alcoholism in the community. The stigma attached to drug-taking and the consequent isolation and marginalisation that people may be subjected to because of their association to it can be very debilitating and is one of the reasons why this issue remains so 'hidden' within our community.

### **Not knowing who can help**

Many of the young people said that they did not know where to go to get help or who to talk to. Most of the young people interviewed who were not currently engaged with a young carer program had not heard of such programs, or even heard

of the term 'young carer' or thought of themselves in this way. Even when they were engaged they were not sure about what supports were available to young people in their particular situation. Young people who were engaged with programs were usually involved because they were caring for another relative with another condition or because their parent had a dual diagnosis.

As noted above, young people often accessed mainstream youth services but were not aware of how these services might support them in regards to their family situation. As such, it is not just about 'not knowing who to contact as a first point of call', but also about not knowing who could help them with issues that arose from their family situation or issues that other family members were living with once in the service system. This left many of the young people in this study experiencing a sense of hopelessness, especially in terms of resolving any of their issues to do with their family:

*When I was younger the only thing that I thought would help is if she stopped drinking. (MARY JANE)*

As the following quote demonstrates, some young people felt they had to make a choice around who deserved help the most, them or their family member, because no-one within the service system seemed to be looking out for the whole family unit and trying to support them to live together and care for each other:

*At the moment I'm trying to help myself before her. And I know that it sounds a bit selfish but sometimes that's all you can do, you can't do anything else ... You've got to look after yourself, that's what people have told me. (SARAH)*

### **Practical issues such as lack of access to transport and finances**

Many of the young people mentioned that services were often located too far away from their homes and therefore they were unable to access them on any sort of regular basis. They were often without transport and could not afford transport to

get to services. Therefore with services being so difficult to access, some of the young people felt that they were unable to access the regular and ongoing support they needed:

*If [the service] is not too far away and is easy to get to, transport's a big issue, you might be able to get there more often and get to talk to them and get to trust them. ... At the moment, it's too hard to get to services. You just can't, they're too far away. And they never come out this way so it's a bit useless.*  
(MARK)

### Poor experiences with services and workers

Many of the young people we spoke to talked of experiences they had had with workers and services that were not able to help them in the way that they had expected. Young people described service encounters with workers who were unresponsive and did not follow through on support that they had promised to offer. They described situations where their stories were not believed, and even worse where they were not listened to at all. Young people were left feeling let down and sceptical of receiving any useful help or support in the future.

For example, one young person told of how she had had quite a lengthy 'pouring out' about her uncle and the troubles he was having because of his drug addiction and the worker responded with 'it sounds like your uncle is a junkie'. This was hurtful and unhelpful to the young person and it meant that she didn't want to speak to that worker again.

Other young people described experiences with Care and Protection workers who they felt had not followed through on the information they provided about their own or another family member's safety.

Young people wanted workers to understand that these responses are not just unhelpful, but are actually hurtful to young people and their families and result in people not wanting to seek help in the future.

Because of poor support experiences in the past, young people often appeared reluctant to seek further assistance, believing that it was not worth the effort.

### **Not identifying with term 'young carer'**

As mentioned above, most of the young carers did not identify with the term 'young carer'. Even those who were currently clients of young carer programs were in two minds about the label that had been attached to them by the service system. It is not that they found the term offensive in any way, it just seemed to have little relevance to them, especially in situations where their level of care had reduced, for example where parental alcohol and drug use had reduced or become more stable or where they had moved out of the family home:

*[There is] a lot of stigma that kids don't want to have this label, I had some friends that I would say give these people a call, but they don't want to.  
(JOHN)*

*Young carer sounds a bit weird ... it doesn't sound right ... it was more taking care of mum, it doesn't seem right for me because I did it for so long it was natural and what it was supposed to be ... it just seems normal, it doesn't seem like it needs a name to it. (MARY JANE)*

*Not many people know what it means. (LILY)*

None of the young people who were not currently engaged in a young carer program had considered contacting one for support and, when this was first suggested to them, found it a little unusual or uncomfortable:

*I was a bit surprised by being seen as a young carer. My mum is still using and that but no-one has ever talked about my situation like that ... It's just different. (LUKE)*

However in the interviews when presented with a case study of a young carer who cared for their mother with MS, all but one of the young people, who was actually engaged in a young carer program, said they related to the story because some elements of the care that they provided to their parent were similar. They also felt that the experiences and impacts of care described in the case study were extremely similar to their own.

Therefore, it appeared to be the actual label or term 'young carer' that these young people did not identify with, rather than the actual experience of being a young carer.

**KEY FINDINGS: Barriers**

- Barriers to appropriate and effective support for young people and their families existed at all points of the support services continuum including:
  - Lack of identification of 'problems' and 'needs';
  - Not wanting to, or being unable to, ask for help;
  - Fear;
  - Not knowing who can help;
  - Practical issues such as lack of access to finances or transport;
  - Poor experiences with workers or services;
  - Not identifying with the term 'young carer'.
- Most of the services that the young people and their families accessed focused on the needs of specific individuals in the family.
- Young people felt they could not talk to youth services about what was going on with their family and thought that care and protection services were the only services available to provide support to their family unit and ensure that they were safe.



## Implications for policy and practice

Although small in scale and exploratory in nature, this project has highlighted some key issues faced by young people who care for a family member with an AOD issue. This is an important first step into the investigation of an issue that has so far received little attention from policy makers and the service system.

### Recognising that caring is just one of a number important aspects of a young person's life

The findings from this project indicate that young people who care for a family member with an AOD issue have similar levels of caring responsibilities to other young people with caring responsibilities and that they perform a wide array of caring tasks. The care provided by young people in these circumstances can be emotionally and physically draining. It strongly impacts on young people's lives in a whole range of ways, affecting their family relationships, financial security, schooling, level of safety, health and wellbeing, social participation and transitions into adulthood.

However, from what the young people told us, it was not the caring role that was uppermost in these young people's lives and it was not the caring role that determined many of the issues they were facing, nor did it necessarily indicate the type of support that they require. The young people faced a myriad of inter-related and complex issues including parental mental health issues, family conflict and separations, neglect, isolation and poverty. These issues, along with the fact that they were caring for a family member who had a drug or alcohol issue combined to make their life, both inside and outside of their family home, extremely complex and challenging.

There is little doubt that the caring role that these young people performed added further dimensions and complexities to their family relationships and the wider

issues that they faced, but it was not possible to identify one single issue as being the most influential in these young people's lives.

The complexity of their lived experience and the secrecy, fear and stigma which seemed to characterise their existence created innumerable service barriers to them and their families and meant that these young people's needs were not being addressed adequately. The young people in this study had low levels of engagement with services and even when they were engaged, most said they were not receiving the level of support that they and their families required.

The young people we spoke to were strong and resilient but also vulnerable people who had survived and were still trying to survive through tough times. They deserved, and indeed they had a right to expect, to be supported and assisted wherever possible to ensure their safety and wellbeing and to reduce some of the negative impacts they suffered as a result of caring for a family member with an alcohol or other issue. However, for this to eventuate, some urgent and comprehensive changes need to be made to the social policy and service system landscape.

We found no evidence to advocate for new services, which would find themselves with the same apparent barriers for access as those that currently exist, but rather that these young people and their families need a refocusing of existing youth, alcohol and other drug and caring services.

Young people need to have open and ready access to, and appropriate responses from, the services that are currently funded to support them, whether this be generalist youth services, young carer services, AOD or other general welfare or family based services.

### The need to reconceptualise young caring

Young people who care for a family member with an AOD issue do not seem to identify with, or neatly fit into existing young carer services. This was due to the traditional exclusion of these young people from carer programs, a lack of identification with the term 'young carer', and other practical program issues.

Our findings indicate that we require a re-conceptualisation of young caring that actively includes these young people, rather than passively or actively excluding them. This would promote identification of these young people throughout the service sector and provide them, their families and services with at least one option of knowing where they can ask for and receive support.

Young carer programs need to be re-orientated to become more relevant to those young carers that are sitting on the fringes of our mainstream community. Access to carer support services, such as the federally funded respite services and carer payments, which are accessed largely on an assessment of the level of care provided by young people, needs to be re-orientated to focus on the impact of the care that is provided.

We are not arguing with the premise that one of the service objectives of carer programs needs to be to 'lessen the load' (the care tasks performed by carers), but we must also pay equal attention to the 'weight of the load' (the impact of the caring experience).

This is important as many of the young people reported that they themselves, their families and the broader service system either underplayed the level of care that they provided in the family or totally disregarded it. It would also seem that when the level of care is the primary focus of assessment, the relative impact of assuming that care, and living in a family affected by parental AOD misuse, is ignored and the real level of need not fully appreciated.

Our observation would be that when focusing solely on the level of care provided, many young people caring for a parent with an AOD issue may wrongly be assessed as having a lower level of need than is the case. However, when we take into consideration the impact that living in a family with an AOD issue has on the life of a young person, the level of need is significantly increased.

We would also argue that appreciating the care experience in this way would provide the service system with ideas on how it might best respond to young people in different situations. For example, those young people with high levels of care but with low impacts of care, for example a 25 year old person caring for a parent who misuses prescription drugs to manage chronic pain and who 'watches out' for their parent, runs the household and supports younger siblings but who has a good support network and is connected to employment, may need a level of in-home support or respite, so that they can go on a business trip or sit an exam, but may not need counselling, educational support or social activities.

Those with low levels of care but high impacts of care, for example a 9 year old caring for a parent with an alcohol issue who does not require much physical assistance but who constantly feels afraid for her parent, misses school and has limited friends, could benefit from having someone to talk to, being given opportunities to meet other children and some help with study.

This conceptualisation also prioritises service to those who are providing significant levels of care with significant impacts. Within the sample of young people in this study, we would argue that most young people were currently in this situation and that their level of need was further complicated by family discord, social isolation and poverty.

We would also argue, however, that if they had been assessed earlier in their lives they may have appeared to have lower levels of care responsibilities but had higher

impacts of care than others, but still be considered to be of lower priority and therefore ineligible for support.

For the young people in this study, we would therefore argue that a service approach that focuses on the impact of their care and to the multi-faceted issues behind these impacts, would be extremely beneficial.

### **Responding to practice-based barriers to access**

As well as these changes this project was able to identify other practical issues on a service level that act as barriers to these young people accessing young carer programs and receiving the support that they need.

Although those involved in young carer support services valued the support they received from these services, young people called for more financial and practical support. They also highlighted the need to make connections with workers they could really trust and talk to. Recognising the significant impacts that living in these stress-filled environments and the emotional impacts that caring can have, the need to assist young people in managing their own emotional health and wellbeing was identified and needs to be focused on as a matter of urgency.

Often participation in some of the aspects of young carer programs, particularly respite support, such as camps and recreational activities, require parental support and/or consent. We found that some parents may have a lack of awareness of the needs of their children, may be fearful of any service intervention into their lives or be otherwise unwilling for their children to participate. Consequently young people often need to seek support for themselves and need services to be able to re-orientate programs and supports so that these issues do not restrict them from accessing and receiving the support that they need.

### Adopting a family focused approach

Perhaps the most obvious area where change was needed to how services respond to these young people, was that services from all sectors need to be re-orientated to adopt a more family focused approach rather than traditional approaches that are aimed at support focused purely on the individual. This need has been acknowledged in recent literature from both the young carer and drug and alcohol sectors (see Warren and O'Brien, 2007; Moore, 2005a & b; Halpenny and Gilligan, 2004; Grant et al, 2008; Dawe, 2007; Odyssey Institute of Studies, 2004; Moore and McArthur, 2007) and was also voiced strongly by the majority of the participants in this study.

Young people wanted services to acknowledge both the strengths and challenges of their families. They needed the issues that they faced to be placed within their environmental and family context, so that they could be better understood and responded to. The importance and influence of family on these young people's lives was obvious and needs to be taken into account as a central premise when working with them. This does not always mean involving all family members in the support that is provided by a service, but rather acknowledging the fact that young people's lives are not led in isolation to their family and the issues that their families face. Aside to this, the place of extended family members and the support that they often provided to these young people also needs to be acknowledged and actively supported.

Young people need all services to provide them with the permission and opportunity to talk about their families. They need to know that all services are prepared to listen to what is going on for them at home and to know that they will take a holistic view of their lives. Therefore, as a matter of course, family issues need to be covered in routine assessment procedures that should be carried out with any young person, regardless of where and how they enter the service system.

### Core service system issues

Young people in this study were of the belief that the only service that provided this family based approach was statutory child welfare services (Care and Protection), so this is where they expected support for them and their family to come from.

There was a loud and emphatic call from some of the young people for child protection authorities to be more responsive to them and to take more of a lead role in locating supports for their family and monitoring the safety and wellbeing of children. In some cases children themselves had contacted agencies and in all cases they were left feeling that the intervention was not only unhelpful, but harmful to them and their families. Feeling not being believed left them with a sense of hopelessness. This does not reflect well on a system that should be a leader in listening and responding to concerns raised by children.

What was absent in these young people's perceptions and interpretations of their experiences was the responsibility and obligation that the whole service system has in these situations. Young people need services from all sectors to reinforce to them, by way of their practice, that it is not just care and protection services that have the sole responsibility for responding to their family's issues and ensuring their safety and wellbeing. The need to support families and protect children from harm is one that needs to be the *modus operandi* of all services, and not seen as the sole responsibility of care and protection services.

Overwhelmingly, although it seems a simple request, young people stated that they wanted them and their families to be treated with respect and they needed workers that they could trust. However, before this occurred they needed key people in their lives who could provide *supportive referrals* to these workers. They wanted workers to be reliable and to follow through on the support that they said they would provide and to help connect them in with other support networks and their wider community.

It seemed to be the case for many of the young people in this study that it was up to them to identify their problems and needs and to navigate a complex service system in order to seek assistance. However, once again this burden needs to be shared by all of those people that come into contact with these children and young people, such as schools, community groups, and services across the whole spectrum of health and welfare services.

Young people need advocates from all of these sectors that are readily available to them and are willing to provide support and assistance for as long as is required until consistent, reliable and appropriate supports are in place for them and their families.

If these changes can occur then we will have gone a long way in addressing the needs of this marginalised and 'invisible' group of young people that have had their needs ignored for way too long.



**KEY FINDINGS: Implications**

- Young people and their families need a refocusing of existing youth, alcohol and other drug and caring services.
- Young caring and the supports offered to 'young carers' needs to be re-conceptualised to focus on the impact of care as much as it currently does on the level of care and services need to be more responsive and flexible in the way that they provide support to those young carers that are the most vulnerable and at risk.
- There is an urgent need for all services in contact with this group of young people to adopt a family-centred approach to their work – young people need permission to speak out about what is going on at home and they should be provided with support around their family's issues no matter where they enter the service system.
- Ensuring that these young people are safe and providing them with appropriate and responsive supports and assistance needs to be a shared responsibility of all of those who come into contact with them including schools, community groups and services across the whole spectrum of health and welfare services.

## References

- Ainsworth, F. (2004). Drug use by parents: the challenges for child protection and drug and alcohol services. *Children Australia*, 29(3), 4-10.
- Aldridge, J. (2006). The experiences of children living with and caring for parents with mental illness. *Child Abuse Review*, 15, 79-88.
- Bancroft, A., Wilson, S., Cunningham-Burley, S., Bachett-Milburn, K., & Masters, H. (2004). *Parental drug and alcohol misuse: resilience and transition among young people*. York: Joseph Rowntree Foundation.
- Becker, S. (2005). *Young carers: evidence and messages from the UK and Australian research*. Paper presented at the Carers: next generation Carers South Australia, Adelaide
- Bessell, S. (2006). Ethical research with children: the time for debate is now. *Communities, Children and Families Australia*, 1(July 2006), 43-49.
- Carers Australia. (2002). *Young carers research project: final report*. Canberra: Commonwealth Department of Family and Community Services.
- Darlington, Y., & Scott, D. (2002). *Qualitative research in practice: stories from the field*. Crows Nest: Allen and Unwin.
- Dawe, S., Frye, S., Best, D., Moss, D., Atkinson, J., Evans, C., et al. (2007). *Drug use in the family: impacts and implications for children (ANCD research paper 13)*. Canberra: Australian National Council on Drugs.
- Earley, L., Cushway, D., & Cassidy, T. (2007). Children's perceptions and experiences of care giving: a focus group study. *Counselling Psychology Quarterly*, 20(1)(March 2007), 69-80.
- Gaffney, M. (2007). *A research study of young carers: the development of a recording tool for agencies to identify young carers*. Wellington: Ministry of Health in association with Carers New Zealand.
- Gays, M. (2000). *Getting it right for young carers in the ACT*. Paper presented at the 7th Australian Institute of Family Studies Conference: family futures - issues in research and policy. Canberra
- Grant, G., Repper, J., & Nolan, M. (2008). Young people supporting parents with mental health problems: experiences of assessment and support. *Health and Social Care in the Community*, 16(3), 271-281.
- Halpenny, A., & Gilligan, R. (2004). *Caring before their time? Research and policy perspectives on young carers*. Dublin: National Children's Resource Centre, Barnardos and Children's Research Centre
- Hegarty, M. (2004). Mind the Gap, The National Illicit Drug Strategy (NIDS) Project to Improve Support for Children from Families where there are Mental Illness and Substance Abuse (MISA) Issues, Literature Review. Retrieved from: <http://www.mhcc.org.au/projects/>
- Hegarty, M. (2005). Supporting children affected by parental dual diagnosis - mental illness and substance use - a collaborative mental health promotion, prevention and early intervention initiative. *Auseinetter*, Issue 25(December no. 3 2005), 21-26.

- Kroll, B. (2004). Living with an elephant: growing up with parental substance misuse. *Child and Family Social Work*, 9, 129-140.
- Minichello, V., Aroni, R., Timewell, E., & Alexander, L. (2000). *In-depth interviewing*. Sydney: Longman.
- Moore, T (2005a). *More than words: supporting young carers and their families*. Lyneham, ACT: Youth Coalition of the ACT.
- Moore, T (2005b). *Reading between the lines: listening to children and young people about their experiences of young caring*. Lyneham, ACT: Youth Coalition of the ACT.
- Moore, T., & McArthur, M. (2007). We're all in it together: supporting young carers and their families in Australia. *Health and Social Care in the Community*, 15(6), 561-568.
- Moore, T., Noble-Carr, D., & McArthur, M. (2007). *Finding their way home: children's experiences of homelessness*. Dickson, A.C.T: Institute of Child Protection Studies, Australian Catholic University.
- Morrow, R. (2005). *A profile of known young carers and identification and snapshot of the ones who are hidden*. Perth: Curtin University of WA and Carers WA.
- Newman, T. (2002). 'Young carers' and disabled parents: time for a change of direction? *Disability and Society*, 17(6), 613-625.
- Noble-Carr, D. (2007). *Literature review: engaging children in research on sensitive issues*. Dickson, A.C.T: Institute of Child Protection Studies, Australian Catholic University.
- NSW Commission for Children and Young People. (2005). *Participation: count me in! Involving children and young people in research*. Sydney: State of NSW and Social Justice and Social Change Research Centre, University of Western Sydney.
- Odyssey Institute of Studies. (2004). *The nobody's clients project: identifying and addressing the needs of children with substance dependent parents*. City? Victoria: Odyssey Institute of Studies, Odyssey House.
- Parliament of the Commonwealth of Australia. House of Representatives. Standing Committee on Family and Human Services. (2007). *The winnable war on drugs: the impact of illicit drug use on families*. Canberra: Commonwealth of Australia.
- Patton, N. (2003a). *The effects of parental drug use - children in kinship care: a review of the literature*. Melbourne: The Mirabel Foundation.
- Patton, N. (2003b). *Parental drug use - the bigger picture a review of the literature*. Melbourne: The Mirabel Foundation.
- Social Care Institute for Excellence (SCIE). (2005). *Research briefing 11: the health and wellbeing of young carers*. London: Social Care Institute for Excellence.
- Stauss, A., & Corbin, J. (1998). *Basics of qualitative research: techniques and procedures for developing grounded theory*. Thousand Oaks: Sage.
- Taylor, A., Toner, P., Templeton, L., & Velleman, R. (2006). Parental alcohol misuse in complex families: the implications for engagement. *British Journal of Social Work*, Advance Access published December 20 2006, 1-22.
- Thomas, N., Stainton, T., Jackson, S., Cheung, WY., Doubtfire, S., & Webb., A (2003). 'Yourfriends don't understand': Invisibility and unmet need in the lives of 'young carers' *Child and Family Social Work*, 8, 35-46.
- Tunnard, J. (2002). *Parental drug misuse - a review of impact and intervention studies*. Devon: Research in Practice.

Warren, J., & O'Brien, N. (2007). *Exploration of the needs of young carers in Peterborough: an analysis of existing services and proposals for future development*. Cambridge: Anglia Ruskin University.

## Appendix 1

### Report on Stakeholder's Interviews: main findings

A full report based on 18 stakeholder interviews conducted for this project can be obtained from Anglicare Canberra-Goulburn.

The following is a brief summation of the main findings of this report:

- The respondents identified that the primary needs of children and young people who are caring in families affected by alcohol and other drug issues were in the areas of:
  - Education
  - Personal support
  - Finances
  - Health and wellbeing
  - Recreation
  - Transport
  - An effective service system; and
  - Housing.
- Stigma and isolation were seen as some of the key social issues affecting these young people.
- While the majority of respondents (13 of 18 services) identified that they do have young carers as part of their client group, a similar majority (10 of 18) also noted that they do not have formal recognition of this group during their intake assessment process.
- Respondents thought that children and young people's needs deserve to be met, regardless of their roles in life and that therefore the definitional issues are less important than issues associated with effectively meeting their needs.
- While recognising barriers to service provision, especially in terms of intake criteria that limit which young people particular agencies can work with, difficulties in identifying potential clients and limitations of advertising or promotion of services, respondents identified 60 different agencies, services or options in 15 different sectors to which they could refer young people.

- The support programs that appear to be most readily available from the respondent agencies are:
  - Referral
  - Support or counselling
  - Respite
  - Camps; and
  - Recreation activities.
  
- Respondents felt that these young people's needs were best met through the existing service system, although some improvements in this service system were needed.
  
- The potential benefits of providing a family-focused approach were acknowledged, as was the need for better networking and joined up service provision. Alongside this though, respondents identified several practice based issues that acted as barriers to making improvements in these areas.

## Appendix 2

### Main findings from re-analysis of Youth Coalition of the ACT Study (Moore, 2005)

Young people with parents with an AOD issue had made up a significant proportion of participants in a study of 'young carers' conducted within the ACT, by the Youth Coalition of the ACT (Moore, 2005a and 2005b). Permission was sought and granted to review and re-analyse primary data from this study. Fifteen out of the 45 participants in this study were young people caring for a parent with a drug or alcohol issue.

Our main findings from this re-analysis included:

- Similar caring roles and responsibilities were described by all young carers, with both groups of young carers caring for similar amounts of time and performing similar care tasks.
- There were some differences between the two groups when describing the impacts of caring on their lives. This included carers of people with alcohol and other drug issues tending to focus on how caring had encouraged them to reflect on getting their own lives in order and avoiding addictions themselves. They were also worried about their exposure to crime and physical violence. Whereas their caring peers focused more on how they had gained a sense of pride from their role and that it has made them more accepting of others and better people.
- All carers mentioned that their schooling had been negatively affected due to their role, but carers of people with alcohol and other drug issues were more likely to have dropped out of school.

- Those young people caring for someone who *did not* have an alcohol or other drug issue were more likely to have access to and use a range of structured networks and social systems and events (such as activities run by Young Carer Groups).
- Young people caring for someone who *did not* have an alcohol or other drug issue were more likely to share their caring role with someone else or to have reasonable levels of other help. The majority of the young people caring for a person with an alcohol or other drug issue had very little support.
- Those who *were not* caring for a person who had an alcohol or other drug issue had more outside help and this was more likely to be help such as emotional support and/or practical assistance. When those young people caring for a person with an alcohol or other drug issue received help it was more likely to be from Family Services or Youth Justice and that help was more likely to be in the form of intervention for safety of the young carer, rather than the emotional support or counselling that they said they needed.