Researching with young people who provide primary care for a family member with mental or physical health problems: A critical psychology approach

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Abstract

Using a critical psychology approach, this research examines the experiences of young people providing primary care for a family member with mental or physical health problems. A poststructural stance led to the questioning of past research that has been driven by a social justice agenda to act in the interests of young carers, but derives problematically from the construction of children in Western society as innocent, partially competent and vulnerable. In this same culturally specific context, young carer research has been predominantly adult-designed, adult-led and conceived from an adult perspective, and hence reflects adult-centred interpretations and agendas. The socially constructed nature of childhood was examined in terms of a Foucauldian-type genealogy and the roles of developmental psychology and the psy-complex, which were brought together with a children’s rights perspective to advance a new approach to research that could develop a young carer’s standpoint. This encompassed a collaborative approach with a group of young people, between the ages of 12 and 17 years, in the development of the research design and methods and provided the opportunity for them to stipulate their own terms of participation and to be involved in the analysis of the data. This resulted in a prolonged immersion in the home lives of these young people and their families. It also included ethnographic work in young carer networks. Using Foucauldian Discourse Analysis to interrogate the data, there emerged a complex interrelationship of dominant Western discourses about the adult-child binary and ‘normal’ children, adolescents, and family. The various subject positions available under these discourses stemmed largely from the problematic and polarising impact of normalising discourses that positioned young carers as not normal, compromised, and missing out on an idealised and culturally constructed Western childhood and family life. This in turn produced a range of tensions and complexities as the lives of young carers are generally in conflict with these discourses. There was, however, often resistance to these normalising discourses, which included the positioning of young carers and their families in various ways as ‘better off’ and ‘better than’ peers. To a significant extent the outcomes of this research can be seen as a complex narrative about normalisation and resistance. Importantly, by collaborating with young carers, this research has moved the conversation away from the more superficial and negative aspects of caring that dominant the research literature and provided space for the emergence of issues that are more important to these young people, including some positive perspectives on their situation, such as reciprocal family loyalty and support. A significant outcome was the validation of the epistemological and methodological
foundations of this research with young people. The approach allowed the *performativity* of young people to strongly emerge, evidenced not only through highly complex caring roles, but often in their capacity for very sophisticated insight and critical analysis. This level of performativity starkly contradicts the dominant discourses about young people and the adult-child binary that have acted to marginalise young people. By unpacking these culturally constructed discourses and creating space for alternative discursive regimes, this research can provide a basis for reform of the existing social justice failures in respect of young carers.
Dedication

Optimis parentibus

Although my parents passed away more than three decades ago, their influence is present in every day of my life. They imbued in me the belief that all people should be treated with equality, fairness and respect. Their work ethic was inspirational. My parent’s implicit belief in my ability to succeed and achieve goals has been profoundly important to my life.
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Certificate of authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma at Charles Sturt University or any other educational institution, except where due acknowledgment is made in the thesis. Any contribution made to the research by colleagues with whom I have worked at Charles Sturt University or elsewhere during my candidature is fully acknowledged. I agree that this thesis be accessible for the purpose of study and research in accordance with the normal conditions established by the Executive Director, Library Services or nominee, for the care, loan and reproduction of theses.

Signed: [Signature] Date: 29 February 2016
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PART I

INTRODUCTION TO THE RESEARCH

Chapter 1: Introduction to the thesis and standpoint of the research
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1.1 Introduction

1.1.1 The beginning of this research

This section begins by providing an explanation for the origins of this research. My involvement with young people who care for a family member began with a small research project undertaken for an Honours degree (see Watson & Fox, 2014). That study may in some sense be considered a pilot for this research. What became apparent to me during the course of that study was the seemingly bewildering array of complexities and contradictions that were being managed, suppressed and negotiated by young people in a caring role. Not least of the contradictions was the disconnect between the young people being recognised for having the skills and competency to undertake so-called ‘adult’ responsibilities while, at the same time, being treated as children which paradoxically impaired their capacity to undertake the care for their family member. Nowhere was this more apparent than in the research literature, which positions young carers as children who are not able or capable of ‘knowing’, much less articulating, their own experience of what it means to be a carer. Perhaps the most striking outcome of the fieldwork for that research was my own surprise at the young people’s sophisticated understanding and insight into their own lives and their family relationships, as well as their capacity to manage their difficult situations. This reflected the extent to which accepted understandings and assumptions about young people had been implicated in my own expectations.

I emerged from this study with an understanding of the need to re-think young carer research and, by extension, researching the lives of young people more generally. What was most obvious was the need to challenge the accepted knowledge and assumptions about young people, parents, families and, of course, young carers.
1.1.2 Focus of the research

It follows from the preceding discussion that the small Honours study was the major impetus in my decision to make young carers central to this research. An outcome from this earlier research was further opportunities to work with young carers and their families living in rural and remote communities throughout parts of New South Wales (NSW). Although these young people were less accessible and there would be practical and logistical difficulties in conducting fieldwork, it was seen as a valuable opportunity to work with a particular group of carers who have been largely overlooked by researchers.

The particular focus was on young people, aged between 10 and 18 years, who were the primary carer for a family member, or who regularly provided primary care for a family member, with an illness, disability, or other debilitating condition. This particular age range was chosen to correspond to the designation of ‘young carer’ used by many (but not all) young carer bodies. A distinction was made between a ‘primary’ and ‘secondary’ carer. In a situation where a young person is a ‘secondary carer’, she/he typically assists a parent (the primary carer) with the care of a sibling or the other parent. Accordingly, the role of ‘secondary carer’ is usually, but not always, less demanding.

It is important to note that the label ‘young carer’ did not originate from young people with a caring role, but rather the term refers to an identity defined and imposed by academic researchers and government service agencies. It is not necessarily how these young people see themselves (Morris, 1997; Svanberg, Stott, & Spector, 2010) and while some research has noted the rejection of the label by some young people (McDonald, Cumming, & Dew, 2009), the extent to which it is seen as an inappropriate label is disguised by the need for those caring to accept the designation and register as same in order to access funding and services. There are many problematic assumptions embedded
within the term; it is assumed that it is known what is ‘normal’ for young people to do within families and that some particular level of care warrants the label of ‘young carer’. The label tends to have a polarising effect between those young people to whom it is assigned and their ‘normal’ peers, and it assumes that other young people never care for a family member. Notwithstanding its problematic nature, the label has been used in a limited way throughout this thesis in order to consider the knowledge generated by the group young people so designated and to question the term and the impact of the term on the experience of being a child caring for a family member.

1.1.3 Context of the research: The expanding role of young carers

There is a substantial and increasing number of young people under 18 years of age who are providing primary care to a family member. This is most often a parent or sibling that is physically or mentally ill, disabled, or has a substance abuse problem. In some circumstances young people are also caring for infirm grandparents (Department of Family, Housing, Community Services and Indigenous Affairs [FHCSIA], 2009).

*Carers Australia* have estimated that there are more than 18,800 young people providing primary care to family members in Australia, and a further 388,800 providing supporting care (Carers Australia, 2002). They also estimate that one-third to one-half of these young people live in rural and regional Australia. Even these significant numbers are considered to be an underestimation. As has been widely discussed (e.g., Banks et al., 2002; Smyth, Blaxland, & Cass, 2011), many young people who provide care do not identify as carers and others are often ‘hidden’. This has been attributed to factors such as preserving the privacy of the family, cultural issues, the stigma associated with some disabilities and illnesses, or the fear of children being separated from their parent. Smyth, Blaxland, et al. (2011) report that ‘hidden’ carers are likely to substantially outnumber those who are known to service organisations.
The number of young carers is very likely to increase in coming years and decades. Due in large part to increasing life expectancy, Australia’s most notable demographic characteristic is population ageing. The number of Australians over 65 years of age has increased by over 60% in the two decades since 1990 (ABS, 2010). Changing family structures will also have an effect on the part young people play in supporting family members. There is a significant trend towards less traditional family structures, with substantial increases in the number of one parent families (ABS, 2003) and a reduced role for the extended family (ABS, 2004; Lackey & Gates, 2001). Parents in Australia are having children at an older age (Laws, Li, & Sullivan, 2010), which increases the likelihood that some will experience chronic illness while their children are still young. There is also evidence that the onset of some illnesses once associated with older people, such as Parkinson’s disease, are now occurring at an increasingly earlier age (Shifren & Kachorek, 2003).

1.1.4 De-institutionalisation and normalisation of care in the family home

Notwithstanding the factors outlined above, the expanding role of young carers has its genesis in the actions by Australian governments over the past two decades to progressively withdraw from providing care facilities for people with physical and mental health problems. In large part, this care must now be provided in the family home. While this process has been underway, it would also seem that government has been simultaneously normalising the view that ‘caring for its citizens’ now means ‘caring by the family’.

Deinstitutionalisation

In Australia the major impetus, and indeed paradigm changer, was the Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled (Richmond, 1983) which began the process of de-institutionalisation. While commissioned for the
New South Wales Government, the thrust of the report’s recommendation of de-institutionalisation was soon taken up by all Australian States. The notion that people with physical and mental health problems should be able to participate in community and family, instead of being isolated in institutions and psychiatric hospitals, was a sound one. It is also the case that the outcome from the process of deinstitutionalisation has been characterised as being of overall benefit for a majority of people (Fuller Torrey, 1997). However, at the same time there have been severe shortcomings that have impacted very badly on a substantial minority, most particularly those who do not have a family or those who do not have a family that is in a position to provide for their care. Implementation was poorly devised, badly put into practice, with large numbers of the people ‘decanted’ from institutions turning up in prisons or amongst the homeless (Chesters, 2005). The sector continues to be under-resourced, without the services and support necessary for the ill to live successfully in the community. As a result, deinstitutionalisation has been described as a “psychiatric Titanic” for a substantial number of people (Fuller Torrey, 1997, p. 11) and as “an unrealised desire” (Chesters, 2005, p. 280).

Deinstitutionalisation can be positioned as offering freedom, self-determination, autonomy, and dignity to the ill, and these possibilities are strongly advocated in the Richmond Report (1983). It is acknowledged that these were genuine emancipatory goals that underpinned the move to deinstitutionalisation. However, what emerges in the report as an inconsistency with these emancipatory goals is the motivation to reduce welfare expenditure, with the introduction to the report containing a statement that “resources available to government are severely limited and will continue to be” (1983, p. 3). It can be further argued that during the process of deinstitutionalisation the emancipatory ideals were exploited by neoliberal Australian Governments in the pursuit of cost-cutting measures that could evolve in a ‘cheap’ family care network. This raises serious
questions about whether the commitment by governments is to the genuine wellbeing of individuals, or rather reflects their commitment to a normalising construction of care in the home, drawing on language which serves this purpose. The notion that people can be supported in the community by family, friends and neighbours, arguably depends to a large extent on constructing this as normal, and it can be suggested that the report contained the seeds for this subsequent normalisation of care by the community. In arguing for community care, the values on which the report was premised included “promote independence”, the desirability of maximum involvement with the “normal community” (p. 18), and the provision of services on a “human”, domestic scale (p. 20). From this very beginning, there is evidence of a political discourse and the social construction of a moral imperative to care: rhetorical language advocating home care as the best approach for the disabled and mentally ill and, by extension, the ‘right and proper thing’ for family members to take on their care. As noted by Dean and Thompson (1996, p. 154) “informal caring is to be perceived as natural, common sense, and ‘taken for granted’”.

*The advent of family carers: A genealogy*

Heaton (1999) has attempted a Foucauldian-type genealogy\(^1\) of the advent of family carers and, while based on the circumstances in the UK, the experience in that country parallels the emergence of care policy and practice in Australia. Heaton reports on government documents that present an ‘understanding’ that care should come from kinship, friendship and neighbourhood, and she has concluded that “the contemporary policy discourse ... reinforced an ideology of welfare which places a moral imperative on families … to function as carers” (Heaton, 1999, p. 764). Similarly, the normalisation of family care was described by Dean and Thompson (1996, p. 150) as being pursued

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1 The historical work of Foucault, including his concept of genealogy, is discussed in more detail in Chapter 2.2.1
through a discourse that “implied and has promoted an unprecedented notion of what family obligation might constitute”.

This conclusion accords with a recurring theme of Bourdieu, evident in a number of his works (see for example Bourdieu, 1999; Bourdieu & Wacquant, 1999), that language is the tool by which the government changes its responsibility to its people through what he calls “political codewords and mottoes” (Bourdieu & Wacquant, 1999, p. 42). This is evident, for example, in the use of terms such as ‘rationalisation’ to describe reducing government services. Of particular relevance to this research is the argument advanced by Webb, Schirato, and Danaher (2002) (drawing on the work of Bourdieu) that a discourse of ‘independence’ and ‘family values’ has come to mean that the sick and mentally ill are displaced from public institutions to be cared for by their families – regardless of whether they have families or whether their families have the capacity to undertake the role.

**Institutional-legislative**

Australia has enacted legislation to recognise family (informal) carers: The *Carers Recognition Act 2010* (Cth). The Act, which has no purpose other than ‘to recognise’, specifically excludes from the definition of ‘carer’ any person who provides services under contract (i.e., being paid) or works for a voluntary/charitable organisation, which leaves only those providing care through family devotion or obligation. This legislation and the associated statement serve to underline the positioning of informal carers as the ‘natural’ mainstay for the provision of care, while distancing the government from responsibility for directly providing services. The statement refers to [family] carers being a “partner” with other (unspecified) care providers, and is silent on any government role. Heaton’s proposition that under contemporary policy discourse the government is now being positioned as a supporter of the ‘family care network’, with its
role largely limited to providing back-up in times of crisis and respite, applies equally well to the Australian context. While the Government would characterise its relationship with family carers as a partnership, it can be suggested that its function in the partnership is more about ensuring that the ‘cheap’ family care network remains ‘afloat’. The process of normalisation has served well in masking the underlying economic motivation by the government, but it should also be noted that the disabled, the ill, and the young, are the most disempowered members of the community and so there is little political cost to their alienation.

_Hiding disability and mental illness_

A less obvious but more insidious and paradoxical explanation for deinstitutionalisation would be that it ‘hides’ a perceived distasteful problem. Foucault has outlined how in earlier times ‘madness’ was seen as an alternative mode of human existence and sufferers were not socially feared or persecuted (Foucault, 1993). He also noted how the building of institutions in the late 18th century came at a time when the mentally ill were considered socially useless and less than human. They were to be hidden away in institutions where they could be forgotten – a period characterized by Foucault as the “Great Confinement” (Foucault, 1993, p. 38). Institutionalisation made the population of mentally ill invisible to the general community. However, over time, and with the intense scrutiny of an anti-psychiatric movement in part led by Foucault, large scale institutions became very noticeable, and particularly so outside cities. Their notoriety also grew as declining funding led to declining standards and conditions. It can however be argued that deinstitutionalisation has resulted in this population becoming ‘re-hidden’ – now widely dispersed in family homes throughout the community or, in many cases, amongst the homeless (Chesters, 2005) and as part of the prison population (“Victorian Prisoner Health Study," 2003), groups which also go largely unseen by the wider community.
Accordingly, it can be suggested that there is an important political context within which carer research is situated. While not subscribing to the strong language of Bourdieu in asserting “the abdication of the State” (Bourdieu, 1999, p. 181), it can be suggested that while the wealth of the nation increases, the government seeks to minimise its responsibility to the detriment of many of its sick, disabled, and mentally ill citizens and, perhaps at some level, even to hide groups of people who would require more support to meaningfully participate in society.

To summarise the key issues to this point, there has been a substantial increase in current and projected future demand for the provision of care, resulting from changing demographics and family structures, as well as a government process of deinstitutionalisation. Coinciding with the process of deinstitutionalisation, it is suggested that governments have sought to minimise its responsibility for care (and expenditure) and to normalise the view that care is a family responsibility. These factors have been a major driver of young people increasingly taking on a caring role.

However, while caring by families has been ‘normalised’ to form part of Western cultural and familial expectations, at the same time the idea of children being carers is seen to transgress societal ‘norms’ which position children as dependants under the care of adult family members. One of the outcomes stemming from this conflicted situation is the potential for young people with a caring role to come to the attention of child welfare authorities.

1.1.5 Child welfare and legal considerations

The assumption that young carers are often experiencing hardship and are at risk of long term damage, as well as suggestions of inadequate parenting when children care for their parent/s, can place these families under the gaze of child welfare authorities. It will be
useful to briefly outline the legal setting, not least of all because of how it can impact on
the lives of young carers and the conduct of the research.

It was noted earlier that the term ‘young carer’ is one that has been adopted by agencies
providing respite and associated support services (and by researchers). It is applied on the
basis of a young person being assessed as undertaking a particular level of domestic and
caring duties for a family member. The application of the term does not alter the legal
status of the young person or the parent. The need for a child to undertake these tasks for
their parent is not of itself considered to be suggestive of an inability to function as a
competent and responsible parent. In circumstances where the level of incapacitation is
such that a parent can no longer make parental decisions or that the safety, welfare or
well-being of the young person is considered to be in jeopardy, the provisions of the
Children and Young Persons (Care and Protection) Act 1998 (NSW) come into play.
The removal of children from the family home is provided for by the Act if the situation
is considered to be extreme, or it may be that legal guardianship is changed and
additional support is provided for the family. The situation does of course change when a
young carer reaches the age of 18 years and is legally recognised as an adult.

Based on anecdotal information it is understood that the provisions of the Act are not
often used to intervene in families where a child is in a caring role. However, regardless
of how often welfare authorities intervene, this legal backdrop has the potential to impact
in significant ways on how the young people experience caring. In particular, there is the
potential issue of families being deterred from seeking help from support agencies
because of a fear of coming under the scrutiny of child welfare authorities. Exclusion
from accessing services would obviously exacerbate the difficulties of young carers and
their families. Similarly, families who hold concerns about how they might be perceived

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2 Conversations with Australian Government officials and staff of respite centres who have responsibilities
in relation to young carers.
by authorities may be much less likely to volunteer to participate in research. These issues will be further explored in Chapter 8 (Institutional/structural context).

1.2 Standpoint of the research

This section discusses the standpoint from which this research operates. This encompasses ontological and epistemological positions, a commitment to the principles and values of critical psychology, and an explanation of what is considered to be the elements of good research. These considerations form the foundation for the development of this research, as will be progressively outlined in the following chapters.

1.2.1 Ontological and epistemological position

This research draws upon a framework of social constructionism (Willig, 2001). It takes the position that knowledge is constructed, not simply discovered. It is accepted that multiple versions of ‘reality’ are possible and that research seeks to gain insight into the consequences of social reality being constructed in a particular way and the impact this has upon how people can act and how they are treated. The reality to be understood is the reality that is important to young carers. It also follows that since knowledge is constructed through discourse and discursive practices, research papers are discursive constructions produced by the researcher. The researcher can therefore be considered as ‘authoring’ rather than discovering knowledge (Willig, 2001).

The research also subscribes to a critical realism epistemology. As Parker (1992) has advocated, although our knowledge of the world is mediated by, and therefore also constructed through language (i.e., epistemological relativism), discursive constructions are not entirely independent of the material world and there are underlying structures and mechanisms that give rise to conditions that make possible the formation of particular discourses (i.e., ontological realism).
While not wishing to engage with the seemingly intractable realism-relativism debate that surrounds social constructionism (see for example Burr, 1998), taking a critical realism position has implications which I consider to be important for this research. Contextualising the discourse of young carers within the material conditions they have to negotiate, enables consideration of why particular discourses are available to them. There is a context in which some discursive constructions are more easily enabled or disenabled than other constructions. For example, I would argue that a young carer with access to support services, grandparents living close by, and a supportive school environment, may be more likely to remain at school. These factors, which Sims-Schouten, Riley, and Willig (2007, p. 103) describe as having an “extra-discursive ontology”, are important for producing a context in which actions take place and determining the structure of the account they use to explain a decision; that is, it enables and disenables the particular accounts which emerge in conversation with young people. These factors can be important in the analysis: explaining why one account is presented, and not another, and places the discourse of young carers within the material conditions they have to negotiate as carers. Sims-Schouten et al. (2007, pp. 103-104) also argue that there is an ethical component – to ignore material existence may not “do justice” to the lived experience of the participants.

As will be developed more fully in following chapters, this research has a poststructural foundation, predominantly drawing upon the works of Foucault (1970, 1972, 1980a, 1980b, 1988a, 1988b, 1988c, 1988d, 1993, 1995, 1998). Following on from the concepts discussed above, poststructuralism seeks to deconstruct ideas of essentialism to allow for a more accurate discourse and produce alternative understandings (Williams, 2005). Briefly, in terms of this research, the adoption of a poststructural approach provides the mechanism of challenging and disrupting established ‘truths’ and unquestioned assumptions about children, families (Burman, 1994) and young carers, that are both
overt and hidden. A poststructuralism approach provides for the questioning of common oppositions (such as adult/child) that are fundamental to mainstream understandings and the ways things are spoken and thought about, and allows alternative ideas and understandings to emerge (Williams, 2005).

1.2.2 Critical psychology

This project applies a critical psychology perspective to research with young carers, a position which draws in turn from works on poststructuralism. It is however first necessary to distinguish the use of the term ‘critical’ in the context of critical psychology, as it is very different to general usage. The term ‘critical’ is widely used to refer to an objective analysis and evaluation of a work or issue in order to form a judgment. In the discipline of psychology, the term ‘critical’ often refers to positivist issues about whether research is ‘scientific’ and produced from ‘logical’ reasoning.

However, a fuller understanding of ‘critical’ is centred on the examination of the political, social and moral assumptions underlying theories and practices of mainstream psychology. A major criticism made of mainstream psychology is its claims to be an objective science, free of values and politics, often portraying constructed concepts as natural concepts based on empirical support (D. Fox, Prilleltensky, & Austin, 2009). It is further argued by I. Prilleltensky (1994, p. 4) that critical thinking in psychology is limited to the “analysis of empirical positivist research” while failing to critique the “social, political, and moral assumptions implicit in psychological theories and practices”. As Teo (2009, p. 41) has argued, there is no recognition that psychological concepts are “constructed in a specific cultural context for specific purposes”. There is insufficient recognition of how a researcher’s subjective context influences their choice of a theoretical and methodological framework, the selection of research questions, the conduct of research, and the interpretation of data. The basis of these choices are hidden
so to maintain the appearance of objectiveness and neutrality. Mainstream psychology is also criticised for an over-emphasis on Western values of individualism and competitiveness, which disproportionately disadvantage marginalised groups by locating problems within the ‘individual’ while ignoring problematic power arrangements in society. This focuses the need for change on individuals, diverting attention from the need for changes in society. This occurs through the promotion of ‘norms’ based on values, assumptions and interests of dominant groups; largely older, middle class, white men from a Western culture, and dominant institutions (D. Fox et al., 2009).

As has been well canvassed (D. Fox et al., 2009; Hook, 2004a), there is no ‘one’ critical psychology, but multiple perspectives with a common approach. Some of the important central components might be summarised under the banner of promoting human welfare and social justice. As might be surmised from the preceding discussion, this includes challenging mainstream psychology and the acceptance of so-called ‘normal’ and ‘traditional’ values, structures, and arrangements in society that bring oppression, inequality, and disempowerment to many segments of society. Implicit in these components is opposition to the problematic individualism and positivism of mainstream psychology.

In terms of conducting research, critical psychology has a focus on the development of theory and methods to ‘make a difference’: that promote social change rather than facilitating social control. Critical psychology research seeks to detect and uncover the problematic assumptions that underlie the status quo and give rise to inequality and discrimination, and which are most often manifested in a ‘blame the victim’ culture. It seeks to explore issues that have been ignored and misrepresented by mainstream psychology (I. Prilleltensky & Fox, 1997).
It should however not be ignored that critical psychology has been questioned for its capacity to move from the realm of academic theory to research methodologies and practices that can bring social change (Goodley & Parker, 2000). There is the related criticism that: “There is no method, just individual opinion” (Kagan, Burton, Duckett, Lawthom, & Siddiquee, 2011, p. 12). It is also acknowledged that it a difficult ‘balancing act’ to conduct field work in the community with young people while striving to maintain critical theoretical principles. These considerations are recognised and will be described and problematized as they arise throughout the research.

As noted earlier, this research is grounded in the poststructuralist aim of challenging the status quo and ‘accepted’ knowledge and assumptions about young people, families and young carers. I will argue that this process of ‘challenging’ mandates an approach to research that fully involves those whose lives are being researched. The following section elaborates my understanding of what constitutes ‘good research’.

1.2.3 What is good research?

“The philosophers have only interpreted the world in various ways; the point is to change it” (Marx, 1970, p. 123).

In addition to the matters discussed above, there are number of positions that are important to me in developing what I consider to be ‘good research’. They are drawn from, or consistent with, understandings from critical psychology.

This research is grounded in a desire to make a positive difference for young people who care for a family member. This draws upon a personal commitment to social justice issues which was complemented by a reading of Bourdieu who criticises the academic field for “construe [ing] the world as a spectacle [italics in original], as a set of significations to be interpreted rather than as concrete problems to be solved practically” (Bourdieu & Wacquant, 1992, p. 39). It was important to my research that I seek to
produce outcomes that could ultimately bring some benefit and improvement to the lives of the group of young people being researched. This was a particularly salient issue for me given the altruism, enthusiasm and commitment the young people demonstrated through their ongoing involvement in fieldwork conducted over a period of two years. It was a deeply felt privilege to be welcomed into family homes to talk, listen and observe young carers and their families in managing their difficult situations. This privilege warranted an equally profound commitment from me to produce an outcome that was a significant contribution to young carer research and, by extension, young carers. It is however acknowledged that making ‘a significant contribution’ is very difficult to achieve and that notions of what constitutes a meaningful, positive contribution will differ amongst readers.

It is also my position that good research uses methods that strongly engage with those people whose experience is being researched. Implicit in this position is an acknowledgment that the people being researched are the experts with the expert knowledge about their lives: as Parker (2005, p. 8) has argued, researchers should “…treat our ‘subjects’ as experts on their own lives”. A corollary to this position is that research should adopt a methodology that provides for meaningful, genuine participation and collaboration of those to whom the research is directed. The participants should feel part of the research and be able to influence the research process, rather than be positioned as ‘subjects’. Methods should be adopted that allow participants to provide accounts which reflect their interests and concerns. Research should also provide for the careful and respectful involvement of participants in the findings and provide an opportunity for feedback. Research should respect all participants’ accounts as authentic and worthwhile. It should recognise that young carers are not homogenous: while they all share the experience of caring for a family member, there is a need to be mindful that their family situations are all different, as are their capacities and skills. The research
needs to provide the mechanism for the experiences and ‘voices’ of all participants to be heard. It should seek to reflect a young carer’s ‘standpoint’\(^3\), rather than the adult world of service and government organisations and academia.

I see the poststructural aim of challenging the status quo and unmasking ‘accepted’ knowledge and assumptions as being complemented by an adventurous approach that will advance new ideas and insights and stimulate further debate and enquiry. It is hoped that this research will bring forward new approaches to young carer research and create new knowledge.

I also take the position that research should be accessible. While accepting that ‘new’ language is often necessary to go beyond the status quo and construct different ways of knowing and understanding different realities, I am conscious that the aims of critical psychology are often compromised by the tendency of many critical researchers to obscure their perspectives in neologisms and almost unreadable prose. This deficiency has been acknowledged by I. Prilleltensky and Fox (1997) who argue that the message of critical psychology has been obscured by academic writing couched in jargon that does little to raise awareness more widely within society. In this research I seek to immerse myself in the lives of young carers and their families so as to avoid Bourdieu’s criticism that the academic field is too removed from the practical problems of people (Bourdieu & Wacquant, 1992).

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\(^3\) The notion of a young carer’s standpoint used here has its origins in standpoint theory. This theory posits that marginalised people experience a different ‘reality’ as a consequence of their situation. Accordingly, different understandings will emerge when research begins from the standpoint of a particular marginalised group who have experienced the phenomenon being researched (Swigonski, 1994). However, this research does not make the claim that more objective knowledge is produced (as per feminist standpoint theory), but rather seeks to ‘stand’ in the viewpoint of young carers and to bring a social justice focus.
1.3 Summary

This chapter has first sought to provide an understanding of the context in which this research into young carers was developed. This includes consideration of the political context in which the research is situated. Having outlined the ontological and epistemological assumptions, and a consequent standpoint that embraces critical psychology and poststructuralism, the next consideration is the theoretical literature to be drawn upon to underpin the research. This is the subject of the following chapter.
PART II

FOUNDATIONS OF THE RESEARCH

Chapter 2: Theoretical literature

Chapter 3: Research literature review – Young carers

Chapter 4: Western construction of children – Contextualising young carer research

Chapter 5: Epistemology and methodology – Theoretical considerations
Chapter 2: Theoretical literature

2.1 Introduction

This chapter details the theoretical literature that was drawn upon for this research. As was made clear in the previous chapter, there is a poststructural perspective to this research, with the works of Foucault providing the primary theoretical foundation. Foucault’s historical work and his concepts of power, knowledge and discourse provide explanatory power in relation to the dominant discourses surrounding childhood and adolescence\(^4\), family and young carers. This explanatory power extends to the institutional and structural context in which young people experience caring. Foucault’s work has also been an underlying influence on the epistemology and methodology for this research.

An important point to make is that this thesis is not just about theory; it is about the lives of people. Accordingly, rather than being an exegesis of the works of Foucault, this chapter is appropriately targeted at those core theoretical concepts of Foucault that were drawn upon to inform new research that can better explore and understand the experiences of young carers.

There are a number of other poststructural and postcolonial writings that have at times been used throughout the development of the research and in this thesis. These build upon, and are complementary to, the works of Foucault. After explicating my use of the works of Foucault, the chapter will briefly make reference to these additional works that were employed to extend the usefulness of my Foucauldian-based theoretical approach.

\(^4\) Mainstream developmental psychology generally uses the term ‘adolescence’ to refer to a time of emotional and biological disruption between the stages of childhood and adulthood. The term is also often used pejoratively. This thesis takes a critical view of this construction and used the terms young people or teenagers, except when referring to the mainstream psychology understanding of adolescence. These considerations are discussed in Chapter 4.
2.2 Foucault

A critique is not a matter of saying that things are not right as they are. It is a matter of pointing out on what kinds of assumptions, what kinds of familiar, unchallenged, unconsidered modes of thought the practices that we accept rest. (Foucault, 1988c, p. 154)

The works of Foucault have much to offer this research and the above quote encapsulates an important focus for this research. An underlying premise of Foucault’s work is to question assumed, taken for granted, knowledge and social understandings, and to untether thinking from the notion that there are ‘set in stone’ truths. Much of Foucault’s work is focussed on giving a ‘voice’ to those people who are trapped within a particular discourse. This stance is central to my research: challenging the status quo embraces the idea of an adventurous and innovative approach to research. This accords with my discussion in Chapter 1.2.3 (Standpoint of the research) concerning what constitutes good research.

To repeat what has now become an often used quote, Foucault describes his work as a “toolbox that people could rummage through to find a tool they could use however they want in their own domain” (Foucault, 1994, translated by and cited from Gutting, 2005, p. 112). The use of any particular ‘tool’ is determined by the context, but the following are the key components from Foucault’s work that I have drawn upon in this research.

2.2.1 Historical work

…history serves to show how that-which-is has not always been; i.e., that the things which seem most evident to us are always formed in the confluence of encounters and chances …. since these things can be made, they can be unmade, as long as we know how it was that they were made. (Foucault, 1988b, p. 37)

One of Foucault’s most important contributions is his historical work, which is quite different from what might be called ‘standard’ history. He explicitly referred to his earlier works as archaeology (The Order of Things; The Archaeology of Knowledge) and his later works were described as genealogy (Discipline and Punish; The History of
Sexuality) (Foucault, 1970, 1972, 1995, 1998). Firstly, as suggested by the above quote, Foucault’s work challenges what might be considered as the generally accepted view that knowledge progresses in a linear manner, with new ‘discoveries’ building upon the existing body of knowledge, as if each were a building block for the next ‘advancement’. This understanding sees change as the replacement of one theory with a better one, such that science continues to get better and better, moving closer to an ultimate truth as if guided by some fixed, underlying principle (McHoul & Grace, 1992). This notion of continuity and progressivism is not accepted by Foucault. His method of history does not involve teleology; there is no necessary natural linkage or connection between periods.

Foucault’s concept of archaeology relates to the idea that every mode of thinking involves implicit rules that materially restrict the range of thought: some things that are unquestionably accepted at a given point in history may later be unthinkable and vice versa (Foucault, 1972). Instead, his history focuses on the systems of thought and knowledge that epitomise the thinking of a particular period of history: while essentially operating below the consciousness of individuals, enabling and constraining what people are able to think in a particular period. For Foucault what is going on in the minds of people is less important than the underlying structures that form the context of the thinking. By exposing these rules, it can be seen how arbitrary constraints appear to be sensible and logical when considered in the framework laid out by those rules (Foucault, 1972; see also Gutting, 2005).

While Foucault was generally vague and inconsistent in describing the differences with archaeology, genealogy can be seen as focusing more on the causes for the transition from one system of thought to another. Foucault’s genealogy seeks to understand the origins of systems of knowledge and to examine discourses. It seeks to show how there have been other ways of thinking and acting in the past and that the dominant discourses
of today are no truer than those of the past. Most importantly, it seeks to show that dominant ideas of today are not self-evident, but are the result of the workings of power. This functioning of power can be revealed by disturbing and challenging taken for granted, assumed knowledge. Foucault’s writing on punishment (see Chapter 1 of *Discipline and Punish*; Foucault, 1995) is a powerful explication of the above argument.

A relevant example of Foucault’s historical work is *Madness and Civilisation*, wherein he outlines the very different discursive formations that governed how people could talk and think about madness from the 17th through to the 19th centuries (Foucault, 1993). This begins with madness first being considered as a benign alternative mode of human existence, followed by positioning as ‘animals without reason’ which required their conceptual and physical exclusion from the human world. More recently madness became the domain of the medical model: an illness to be cured, and current thinking is that there is no rational alternative to thinking of madness as mental illness. Applying Foucault’s perspective to the present, it can be seen how psychiatrists and psychologists now ‘own’ madness – these disciplines and the associated discourses, theorists, and institutions have the authority to decide the truth of madness (Danaher, Schirato, & Webb, 2000; McHoul & Grace, 1992). Differing viewpoints are either not heard or discredited. Danaher et al. (2000) interestingly note that the same process in assessing madness exists today as in the Renaissance – the former involves looking ‘below the surface’ for signs of deviance from norms; the latter involved looking below the surface for signs of possession by the devil.

This example of Foucault’s work demonstrates the importance of directing analysis at uncovering these rules that control the range of thought. The example also graphically illustrates “that-which-is has not always been” (Foucault, 1988b, p. 37). Foucault has referred to his approach as writing the “history of the present” (Foucault, 1995, p. 31);
that is, to use history as a way of understanding the present. In relation to the research in this thesis, a Foucauldian genealogical approach can provide an understanding of how ‘the child’ came to be a specific object of scientific study (Arribas-Ayllon & Walkerdine, 2008) and how different concepts of childhood, and more recently adolescents, have gained prominence at different times. Such concepts deeply inform assumptions in research, as will be argued in relation to young carer research. These considerations of Foucauldian genealogy, as they apply to the construction of children and the Western family, are explored further in Chapter 4.2. They are also relevant to the discussion of de-institutionalisation and the normalisation of care by the family, which was discussed earlier in Chapter 1.1.4 and is taken up again in Chapters 8 and 9.

2.2.2 Power, knowledge and discourse

“Power is never localised here or there, never in anybody’s hands, never appropriated as a commodity, or piece of wealth. Power is employed and exercised through a net-like organisation” (Foucault, 1980a, p. 98).

Foucault's conception of power, and the relationship between power and knowledge, is central to his work. His trinity of concepts – power, knowledge and discourse provide some important underpinning to my approach to researching young carers. The example of madness in the previous section (2.2.1) illustrates the relationship between power, knowledge and discourse. In that example, knowledge authorises and legitimates the power of the medical and psychiatric professions; in turn this power provides the authority to specify what is considered knowledge and to legitimate practices. The discourses of these professions determine what it is possible to know about madness and speaking outside of these discourses is made difficult and deviant.

“a normalising gaze …. establishes over individuals a visibility through which one differentiates them and judges them” (Foucault, 1995, p. 184).

Some of the key concepts for Foucault in the emergence of power are normalisation, observation and self-regulation. These are, in part, encapsulated in the above quote from
Foucault’s thesis, *Discipline and Punish* (Foucault, 1995), which discusses disciplinary techniques. There is one distinctive aspect of this work on disciplinary control which I found to be particularly useful for my research; that being his concern with normalising judgements, which provides part of his exegesis of power. Foucault argues that normalisation is a principal outcome of power and a very persuasive manner of control – almost all achievements and activities are measured against standards of ‘normal’, positioning selected actions and discourses as ‘abnormal’. Crucially, individuals are required in these normalising processes to compare their selves with others, observing, evaluating and modifying actions in order to comply: the fear of being abnormal becomes a powerful tool of compliance. Foucault referred to this self-management as ‘technologies of the self’; an acting of self upon self (Foucault, 1988d). Drawing on Foucault, this is described by Cannella and Viruru (2004, p. 62) as power being imposed on people by “creating the ‘desire to be normal’” [italics in original], and that normality is created by discourse. This may, for example, have particular relevance on how young carers experience and understand their selves, comparing and judging against what they perceive to be the norms of their peers and the families of their peers.

Linked to Foucault’s concept of normalisation is his understanding of the role of observation and surveillance. This is illustrated by Foucault’s much discussed example and metaphor of the prison panopticon5, where prisoners know they may be under surveillance at any given moment (Foucault, 1995). The outcome is the prisoners become self-regulating on the assumption they are being watched, even when they were not. Foucault argues that this self-regulation is the main way in which control is exercised, with people acting as if they are under constant surveillance. His metaphor of the prison

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5 Panopticon refers to the design of a prison which has a circular structure with an observation tower at its centre from where it is possible to observe all prisoners who are stationed around the perimeter. This allows a single person to observe all prisoners without the prisoners being able to tell whether or not they are being watched at any given moment (Foucault, 1995).
applies to society more generally, in areas such as schools, factories, hospitals, and social service and welfare agencies.

For Foucault power is not concentrated in some central body as is usually supposed, but rather is diffused through society, which he described as a “net-like organisation” (Foucault, 1980a, p. 98). For Foucault, power must be analysed as something which circulates and only functions in the form of a chain. It is never localised in a particular place, never resides in one person’s hands, and is never appropriated as a commodity. Therefore, by way of example, there will be experiences where young carers are positioned as powerless, but not so much overpowered by individuals, as overpowered by certain subject positions, institutions, and systems. Furthermore, given the fluid, circulating nature of power, it will be important to examine ways in which young carers are presented with opportunities to both resist and to exert power.

Foucault’s concept of power as a capacity not a commodity, as being relational, and employed throughout society via a network of micro and macro powers (Foucault, 1980a) is applicable to the network associated with young carers which includes the Australian Government, young carer support providers, schools, and disability and welfare agencies. These considerations are important in terms of the institutional and structural framework in which young people experience being a family carer. These institutions and their practices provide grounding for discourses and analysis which “needs to attend to the conditions which make the meaning of texts possible” (Parker, 1992, p. 28).

Foucault also argues that power does not result “from the choice or decision of an individual subject” (Foucault, 1998, p. 95). Those in the ‘network’ do not control what will be the outcome of their actions, and indeed their intention and the outcome may be quite different, and even be contradictory. In analysis, the intentions of those involved are not relevant; rather, what is important is “where it [power] installs itself and produces its
real effects” (Foucault, 1980a, p. 97). This point is significant for young carer research since, in the main researchers, psychologists, schools, welfare agencies and other relevant players often have good intentions. It would also seem to be an important point to consider in relation to the claims made about what is purported to be ‘participatory’ research with young carers; that is, researchers may set out to involve young people in a participatory manner but the ‘network’ overtly or covertly diverts this aim. This is an issue that needs to be reflected upon throughout the course of research.

Of particular interest is Foucault’s argument that the human sciences are linked to power because of the way in which they are used to regulate and normalise individuals (Foucault, 1970). They are evidenced in structures and practices that comprise systems like the ‘psy-complex’ which is of particular relevance to this research. This is a Foucauldian-related term coined by Nikolas Rose to describe the wide-ranging network of theories and practices within and around psychology and which act to create abnormality, pathologise, and regulate and control thinking and behaviour (N. Rose, 1985). It is a network of both professional and informal forms, with the various concepts, language and procedures of ‘scientific’ psychology becoming infused in popular culture, appearing in the media, talk shows, self-help publications, and everyday conversation. This illustrates Foucault’s concern with how macro and micro forms of power emerge at numerous and different levels. There are top down and bottom up flows of power that join together, including “minute interactions and transactions of seemingly mundane daily life” (Hook, 2004b, p. 249). These considerations are important in understanding the positioning of children, young carers and families that have a member with a disability or illness.

Foucault is a dominant author in the field of discourse and discourse analysis. His fundamental rethink provides a different conception of discourse to those that had
previously been based on sociological or linguistic understandings. His understanding of discourse is considered to be of pivotal importance to this research, which aims for a form of discourse analysis that is consistent with and informed by the works of Foucault. As was discussed in relation to ‘madness’ in Foucault’s *Madness and Civilisation* (Foucault, 1993), in any particular period of history it has been more possible to think, speak or write about an issue in certain ways, and not others. A discourse constrains and enables what can be written, spoken or thought – indeed what we can know and what is true or false in a particular field. The subject positions available (and denied) in discourse have implications for subjectivity. The self that a person ‘can be’ is constrained by power. There is a relationship between discursive constructions and practices and how people experience themselves; their ‘ways of being’. As Willig (2000, p. 557) has noted, “placing the subject within a network of meanings and social relations which facilitate as well as constrain what can be thought, said and done by somebody so positioned”. An example is the positioning of young people as vulnerable and partially competent – a subject position which denies or limits their opportunities, not least of all the limitations this places on their opportunity to be involved in research about their own lives. This is discussed in detail in Chapters 4 and 5.

A Foucauldian approach entails examining how discourses constitute particular objects and subject positions and make them appear as ‘natural’. Analysing a discourse enables problematic assumptions that were previously taken for granted and unquestioned, to be unmasked “to dissect, disrupt and render the familiar strange” (Graham, 2005, p. 4). Foucault’s concepts of power, knowledge and discourse can show how ‘truths’ are produced about children, adolescents, young carers, the Western family, and disabled/ill persons. Importantly, Foucault also argues that the exercise of power is neither simple nor unidirectional, which offers the possibility for resistance (Foucault, 1998).

Deconstructing, ‘taking apart’ and unmasking provides both insight and the opportunity
for transformative action. To repeat part of an earlier quote from Foucault: “since these things can be made, they can be unmade, as long as we know how it was that they were made” (Foucault, 1988b, p. 37).

A Foucauldian approach therefore provides a valuable tool for the examination of dominant discourses in the research literature and the community as a whole about young carers, children, adolescents and the Western family, available subject positions, and resistance to these discourses. A more detailed consideration of Foucault’s approach to discourse and discourse analysis is provided in Chapter 7.

2.3 Other poststructural works

It was mentioned at the beginning of this chapter that a number of poststructural and postcolonial works were drawn upon to support and complement the theories of Foucault. These works include Bourdieu’s (1984) innovative theoretical framework on the relationship between social structures and everyday practices, Burman’s (1994) deconstruction of mainstream developmental psychology, the postcolonial writings of Edward Said (1984, 1991), Judith Butler’s understanding of discourse (J. Butler, 1997), and Ian Parker’s work on discourse, discourse analysis and critical realism (Parker, 1992, 1998, 1999, 2005). It is important to make clear that these additional works do not conflict with Foucault but are considered as belonging under a poststructural umbrella with Foucault which build upon his work in a complementary manner. While these additional poststructural works are elaborated upon at relevant points throughout the thesis, it will be useful to very briefly define the core concepts of Bourdieu’s work here as these are more regularly drawn upon in the following chapters when considering the lives of young carers and their families.

Bourdieu’s core concepts are *habitus, field* and *capital* (Bourdieu, 1993). His concept of *habitus* refers to socialised norms or tendencies that predispose people to think, feel and
behave in ways that are adapted to the structures in which they are constituted (Bourdieu, 1984). Habitus is considered to be created and reproduced “without any deliberate pursuit of coherence … without any conscious concentration” (Bourdieu, 1984, p. 173).

Bourdieu’s concept of *capital* extends beyond material assets to include capital that may be cultural, social or symbolic. This might include prestige, honours, status, and qualifications. Cultural capital is considered to play a central role in power relations in society and provides the mechanism for a non-economic form of domination and hierarchy that mask causes of inequality. As described by Bourdieu (1984, p. 471), the “social order is progressively inscribed in people’s minds” through ‘cultural products’ including systems of education, language, judgements, values, methods of classification and activities of everyday life. These all lead to an acceptance of social differences and hierarchies, to “a sense of one’s place” and to behaviours of self-exclusion (Bourdieu, 1984, p. 471). Bourdieu’s concept of *fields* refers to various social and institutional networks, which include intellectual, religious, educational, political, and cultural structures or sets of relationships (Bourdieu, 1993). These are the arenas in which *capital* is expressed and reproduced.

As Leonard (2005) argues, the concepts of fields and cultural and social *capital* can provide a useful perspective for understanding childhood and the experiences of young people (and hence the lives of young carers). Adults possess *capital* and young people have very little; this has implications for young people in seeking to care for parents. Young carer families often do not have access to the *capital* that is necessary to obtain resources and support and to navigate the associated bureaucratic networks. The concept of fields can be drawn upon in considering how young carers are positioned as children.

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6 It is important to note that Bourdieu’s version of *capital* differs from, and dramatically extends, the versions by theorists such as Putman and Coleman. Notions of social capital derived from Coleman and Putman are considered to be highly problematic, simplistic theories, which are blaming, individualising and ignore power. They are sharply at odds with the position of this thesis. For a critique of the work of Putman and Coleman in relation to capital and children, see Leonard (2005).
performing adult roles and responsibilities. These issues will be explored in following chapters.

2.4 Summary

In the chapter I have outlined the theoretical underpinnings for this research which predominantly concern the works of Foucault, with supporting material from other poststructural writers. Poststructural theory will provide the perspective for my examination of the research literature and the theoretical context for the epistemological and methodological assumptions made in the development and conduct of the research (Chapters 3 to 7). Foucault’s genealogical approach can be used to gain insight into the origins of assumed and taken for granted knowledge that pertain to discourses surrounding young carers. His views on normalisation and ‘technologies of the self’ also potentially offer insights into how young people understand their experience as carers. Foucault’s concept of a network of powers offers a perspective for the institutional and structural context in which young carers are placed (Chapter 8). As will be discussed in detail in Chapter 7, Foucault’s concepts of power, knowledge and discourse will provide the theoretical basis for decisions to be made about my approach to analysis and the construction of knowledge. As such, Foucault provides the foundation for the analysis to be presented in Chapters 9 to 12. My use of poststructural theory and, in particular the work of Foucault, is a very deliberate strategy to inform and guide new and exploratory research into the experiences of young carers.
Chapter 3: Research literature review - Young carers

3.1 Introduction

This chapter examines and critiques the existing research literature on young people who care for a family member and discusses its influence on the development of this research. The chapter first looks at the origins of existing research and, in particular, factors underlying the development of a research paradigm that is dominated by negative aspects of caring. This is followed by consideration of a number of issues with the research that are considered to be problematic – these include definitional and representation issues with young people, the pathologising and stigmatising of young people and their families, and the methodology and methods that have been mostly used for the research. It should be noted that the label ‘young carer’ is used almost exclusively in the research literature and is therefore also used in this critique.

3.2 The origins and development of a negative paradigm of young carer research

Perhaps as a result of the steady growth in their numbers, young people who cared for a family member were ‘discovered’ by researchers in the United Kingdom (UK) in the 1990’s. They were identified and labelled as members of a new social welfare group called ‘young carers’. The most prominent and prolific of these early UK researchers were Aldridge and Becker, who described being explicitly motivated by an agenda to generate assistance for young carers (see Aldridge & Becker, 1996). The research was largely focussed on probing the negative effects of caring by young people and, not surprisingly, caring was “portrayed in almost wholly negative terms” (Olsen, 1996, p. 44) and the young people positioned as “tragic victim[s] of circumstance” (O'Dell, Crafter, de Abreu, & Cline, 2010, p. 650). Caring was referred to as “punishing children” (Aldridge & Becker, 1993) and as a “curse on children” (Sidall, 1994, p. 15). Underlying the findings of this research were concerns about young people taking on responsibilities
and duties considered to be ‘adult’, which were argued to contradict the accepted notion that they require, and are subject to, the protection of adults. The findings were also predicated on positioning these young people in comparison to an idealised and socially constructed ‘normal childhood’ that is free from family disability and illness (e.g., Aldridge & Becker, 1993, 1994). While the negative focus and findings of this research may have been grounded in a social justice objective for young people with a caring role, it did mean that their situation was portrayed very negatively.

This perspective on young carers was established as the dominant research paradigm, driven in particular by Aldridge and Becker, whose work dominated the field and was extensively cited in almost all subsequent research (e.g., Aldridge, 2006, 2008; Aldridge & Becker, 1993, 1994; 1996, 1999). In pursuing this perspective and the aim of generating both awareness and assistance for these young people, other researchers sought confirmation of all possible negative impacts, which included restricted opportunities for social activities, sport and leisure (Thomas et al., 2003), poor educational outcomes (e.g., Cree, 2003; Warren, 2007), mental health problems such as depression, anger, anxiety, and emotional exhaustion (e.g., Thomas et al., 2003). Moreover, as has been argued more recently in Meyer (2007), there is an underlying assumption that all bad childhood experiences are harmful to the future adult. It is important to note here that this discussion is not included to diminish the significant difficulties faced by young carers, but rather to question this research for problematic assumptions, and the consequent effects on young people’s experiences.

The construction of young carers as tragic, exploited, and possibly damaged, with their education and careers compromised, then became the accepted portrayal of ‘what a young carer is’. O’Dell et al. (2010, p. 649) describe the “dominant construct of young carers [as] a profoundly negative view”. It can be argued that this view has become so
ensconced into the foundation and rationale for young carer research that the premise has familiarity and the status of accepted wisdom that goes largely unchallenged. Underlying this research approach are unstated assumptions that: (1) what constitutes a ‘normal’ childhood and adolescence is an empirically verified and certain truth, and (2) it is problematic for those young people who differ when compared to this ‘taken for granted’ notion of a ‘normal’ and supposed universal childhood. Stemming from these assumptions is an unquestioned belief that children need and deserve a ‘normal’ (Western) childhood and hence a further assumption that research is best directed at finding out how the childhood of young carers is disrupted and differs from the ‘norm’, and how to ‘fix it’ or at least ameliorate the consequences of this difference.

The extent of these assumptions is well illustrated by the frequent references in the literature to nebulous concepts such as “mature before their time”, “forced to grow up too fast” (Charles, Stainton, & Marshall, 2009, pp. 39-40); “delay in social development”, or the more emotive “robbed of childhood” (Charles, Stainton, & Marshall, 2010, pp. 85-87). References to “caring responsibilities greater than their age” and that “some degree of caring is valued and encouraged as part of healthy child development” [italics added] (Harstone, Bergen, & Sweetgrass, 2010, pp. 40-41) carry an implicit assumption that there is a known and normal level of age appropriate domestic chores and caring.

Discussion of “the transition between childhood and adolescence and adolescence and adulthood” (Harstone et al., 2010, p. 41), which draws upon an understanding that there is a need to progress through a particular series of milestones or ‘markers’ (Blatterer, 2007), implies there is one normal way of growing up. There are implications if these dominant discourses, which position young carers as missing out and compromised by not having a normal childhood, are the only language available with which to describe a position of young carer – for researchers, service providers and young people alike. This circumstance highlights the discussion of the concepts of Foucault in Chapter 2 regarding
the relationship between discursive constructions and how people experience themselves and their ways of being; how the available (and denied) subject positions have implications for subjectivity. Also relevant is the discussion of Foucault’s ‘technologies of the self’, which theorises how people self-manage themselves against standards of ‘normal’. The study by O’Dell et al. (2010) was the only one found which both recognised and sought to redress the problematic negative construction of young carers. They have argued for a new view of child development and for the coexistence of different constructions of children (and hence young carers), an important pointer for how new research might be approached.

The continuation of the approach from the 1990’s is maintained by a UK ‘industry’ of young carer research and associated funding. Much of the impetus appears to be derived from the Young Carer Research Group (YCRG), cofounded and directed by Aldridge, which has been a foundation for research both there and in other countries, including Australia. UK organisations that receive significant government funding to provide young carer support services have also played a prominent role in research. In particular, the Princess Royal Trust and Barnardo’s are active in commissioning and publishing research on young carers (e.g., Grant, Repper, & Nolan, 2008) that indirectly and, in some cases, directly support their activities. The widely cited work of Cree (2003) is stated by the author as having been specifically commissioned by the Trust to support its case for funding. The research reflects a young carer ‘industry’ as a group of researchers, services, community organisations, and government agencies competing for resources and hence claims to authority, validity and authentic knowledge.

The outcome from having a research field with dominant researchers and organisations pursuing a dominant research paradigm is that the same findings and same messages are continually repeated, reinforced and extended. There are an increasing number of
overview or summary articles which draw together the ‘well-documented’ status of young carer research (for example Charles et al., 2009; Harstone et al., 2010; Moore, 2005; Simon & Slatcher, 2011). This circle of confirmatory views can serve to inculcate existing beliefs and inhibit new thinking, as well as benefiting those who hold existing claims to authority and authentic knowledge (and funding), as referred to above. It is significant that O’Dell et al. (2010) surmised from their study that young carers were constrained from discussing positive outcomes from caring because they could not reconcile this aspect of their experience with the dominant (negative) representation.

To conclude this section, it is argued that there is a largely negative paradigm entrenched in young carer research. This stems in part from the initial social action agenda of researchers but, more significantly, is based on comparisons to an idealised understanding of childhood and family. This is an issue explored in more detail in Chapter 4 (Western construction of children – Contextualising young carer research).

3.3 Definitional and representation issues

In critiquing the body of young carer research, there are a number of definitional and representational issues that need to be considered. Firstly, there was discussion in Chapter 1.1.2 about the problematic nature of the term ‘young carer’ and how it was developed and imposed by researchers and service providers and is not necessarily how the young people understand their situation. To extend that earlier discussion, it can be argued that the manner in which the term ‘young carer’ is defined and used for research is problematic on a number of levels. While definitions vary, generally the term refers to a person under the age of 18 years who provides significant care and support to another family member assuming a level of responsibility which would usually be taken by an adult (e.g., Newman, 2002; Walker, 1996). This definition is based on assumptions about age appropriate levels of responsibility which are not directly described. It was earlier
discussed how the literature is punctuated with references to “caring responsibilities greater than their age” and that “some [italics added] degree of caring is valued and encouraged as part of healthy child development” (Harstone et al., 2010, pp. 40-41): this viewpoint assumes that there is a known and normal level of caring and chores for children. The difficulty with this assumption is well illustrated in a retrospective study by Charles et al. (2010) of young carers from migrant families in Canada wherein it was thought necessary to add to the definition: “beyond what would be culturally expected” (pp. 83-84). This addition highlights how fragile is the concept of ‘normal’ levels of caring and domestic tasks on which young carer research is founded. It also serves as a pointer to studies showing that in many non-Western societies children from the age of five years take on so-called ‘adult’ responsibilities within the family, including childcare of younger siblings, where this is considered normal and an important preparation for adult life (East, 2010; Whiting & Edwards, 1988). East (2010) also notes that children in migrant families often perform a liaison and brokering role on behalf of the family in dealing with health care, social services, schools, and the community generally. This culturally based diversity shows that the notion of ‘normal’ and age appropriate tasks and responsibilities for children is a ‘slippery’ concept and one which is based on Western assumptions. Furthermore, there is considerable variation in the tasks and responsibilities that young people are expected to undertake in the home amongst Western families, irrespective of whether a caring role is involved.

A further consideration is the groups of participants that have been the main focus of past research. While acknowledging the difficulty of recruiting young carers to participate in research, arguably this body of research is largely founded on an unrepresentative population of young people. As has been noted by Vromen and Collin (2010), engagement with young people tends to be pursued through formal, adult-led processes that limit the ‘kinds’ of people who will participate. Most often it will be those who are
‘better placed’ and who are comfortable with the ‘system’, rather than those who are angry, disenchanted or marginalised. This theme is touched upon in the German study of Metzing-Blau and Schneppe (2008) who judged that parental agreement for young carers to participate was more forthcoming from families who were ‘doing well’, rather than those in more distressed situations. It is also the case that much of the UK research was conducted with clients of Young Carer Projects (e.g., A. Butler & Astbury, 2005; Cree, 2003; Thomas et al., 2003) and participants in social welfare programs (e.g., Banks et al., 2002; Grant et al., 2008). The experience of these young people is likely to be substantially different for those who are caring, but not in either a project or program and who have not been identified and labelled a ‘young carer’. In addition, it is apparent that in many studies no distinction is made between primary and secondary carers (e.g., Cree, 2003; Thomas et al., 2003), when their experiences will usually be significantly different, not only in terms of tasks, but profoundly different in terms of responsibility (the distinction between primary and secondary carers was outlined in Chapter 1.1.2). The use of the term ‘young carer’ occasionally also extends to the inclusion in studies of young people who live with a disabled/ill person, but are not performing a caring role (e.g., Earley, Cushway, & Cassidy, 2007).

Issues concerning definition and representation are inherently difficult for young carer research. However, the point to be made is not the existence of these difficulties, but the presentation of ‘scientific’ research findings that choose to ignore them. This research will seek to be transparent about these difficulties and to recount them as part of the context which mediated the research process. One of these issues is the problematic nature of the term ‘young carer’ that is used throughout the research literature (and by service providers and agencies). However, as has been discussed in this chapter and Chapter 1.1.2, being categorised by this label is in itself an important aspect of a young
person’s experience of caring for a family member and is appropriately incorporated into
and examined by this research project.

3.4 Pathologising and stigmatising of young carers and their families

There is an argument that young carer research, although well intentioned, may be
impacting problematically on both young carers and the persons for whom they care.
Because of the understanding that the lives of young carers deviate markedly from the
accepted notion of childhood, researchers and the media seem to be fascinated with the
idea of children caring for parents (Keith & Morris, 1995). This perspective is reflected
in the use of emotive titles such as “Punishing children for caring” (Aldridge & Becker,
1993) to accentuate the view of young carers as exploited victims, notwithstanding that
such a standpoint would seem to over-simplify complex family structures, ignore the
agency of young people, and pathologise.

There is a body of research that focuses on the phenomenon of ‘parentification’ of young
carers and the nebulous idea of a damaged transition to adulthood (see for example the
discussion in Aldridge & Becker, 1999; Earley & Cushway, 2002). Parentification
generally refers to an emotional or functional reversal between parent and child wherein
the parent surrenders their role as a parent and transfers that responsibility to their child.
It operates through culturally constructed notions of what are ‘normal’ activities and
roles for children and adults. Parentification is characterised by Chase (1999) as having a
destructive and life-long effect on the child. However, the notion of parentification
implicitly places major emphasis on the physical tasks that are involved in providing a
home and being a parent (e.g., cooking, cleaning, shopping), and less emphasis on the
concern and responsibility that parents feel for their children. It does not necessarily
follow that a child undertaking domestic and caring tasks means that there is a
relinquishing of parental responsibility or that there is a diminishing of an ability to
provide affection and a nurturing home environment. The concept of parentification and
indeed the focus on negative outcomes of caring generally, is also argued to engender
guilt and disempowerment and to stigmatise and diminish disabled and ill parents (Keith
& Morris, 1995; Newman, 2002). This outcome has the potential to compound the
existing prejudice and scepticism already faced by many disabled parents concerning
their ability to function as parents. Furthermore, it can be argued that the notion of
parentification divides the roles of parents and children in a very polarising manner,
ignoring the varied and blended arrangements that occur in all families. It is also
suggested that children generally provide some level of care for their parents and that
parents generally find emotional support and benefits from their children; a point that
goes unrecognised by the polarising literature on parentification.

The focus on negative aspects has been extended in more recent quantitative and quasi-
qualitative studies to include the mental health of young people. This can also be argued
to be problematic. It is not surprising that young carers should often find their situations
difficult and stressful but research focused on their resilience and perceived coping
problems (e.g., Mayberry, Reupert, Goodyear, Ritchie, & Brann, 2009; Shifren &
Kachorek, 2003; Svanberg et al., 2010) locates the problem within the young person’s
mental health and away from context. This context includes the stressful environment
and how families with disabilities and illness should be treated and supported by welfare
services and government agencies. It rationalises systemic failings and inequalities and
psychologises young people on the basis of what are deemed ‘age-inappropriate’ tasks.
This is well illustrated by the discussion of Byng-Hall (2008, p. 147) proposing therapy
for children’s loss of self-esteem, depression and other mental health problems that
purport to result from the (very tenuous) notion of “crossing adult/child boundaries”; that
is, the focus is on the individual rather than context.
The dominant ‘negative’ research paradigm can further be challenged from a disability rights perspective (Keith & Morris, 1995; Olsen, 1996; Olsen & Parker, 1997). These authors have criticised the research for portraying young carers as exploited victims and by implication, parents as selfish and inadequate. The negative positioning of young carers as compromised and burdened can only exist with a corresponding positioning of their parents as failing to provide a proper childhood environment for their children; that is, as bad parents. Those authors presenting a disability rights perspective also suggest that the focus on young carers serves to obscure fundamental problems of lack of support and poverty, which forces young people into caring roles. Most significantly, drawing on a Foucauldian perspective, it is also argued that young carer research has helped normalise the role of young people as carers which in turn has led to a channelling of (albeit limited) government resources towards supporting the young carer network. This paradoxically diverts focus and resources away from supporting disabled and ill people, which would lessen or remove the need for young carers. While this disability rights perspective has raised important issues, it too can be critiqued for a polarising understanding of parents and children; implicit in the perspective are the same underlying assumptions as the dominant research paradigm about the vulnerabilities of young people that require being protected from taking on ‘adult’ responsibilities.

To briefly summarise this section, the intense focus by researchers on negative aspects of caring is argued to have problematic outcomes on young carers and their families. This includes pathologising notions of parentification and the stigmatising of parents with a disability or illness. It is also argued that this focus on young carers obscures issues of poverty and lack of support for families struggling with disability and illness.
3.5 Research methodology and methods

It can be argued that the approaches adopted in much of the research to date have not been ideal for exploring the experiences and lives of young carers. In particular, it is suggested that the research has not engaged appropriately with young carers. Quantitative research drawing data from structured telephone and email interviews, questionnaires or surveys (e.g., Cree, 2003; Shifren & Kachorek, 2003; Warren, 2007), does not allow input beyond the parameters set by the researchers and hence cannot adequately construct a young person’s perspective. Similarly, much of the research that is presented as qualitative, has a positivist flavour and, while purporting to engage with young carers, is often characterised by superficial participative practices pursuing ‘established’ topics and producing survey-like data with no theoretical underpinning or interpretative component (e.g., Moore, McArthur, & Morrow, 2009; Shifren & Kachorek, 2003; Svanberg et al., 2010). As such, this approach can also only provide limited insight into the lived experiences of young carers.

Of major significance throughout much of the research literature is an underlying assumption that young people are partially competent and fragile. This view acts as a barrier to young carers being recognised as competent individuals who are able to provide significant input into how research into their lives could be designed and conducted. The outcome is research that will necessarily be biased towards adult perspectives and agendas. At its most extreme is the considerable body of research on young carers that does not involve young carers at all, but rather seeks the views of adults. This includes parents’ accounts of their children caring (Aldridge & Becker, 1994), recollections of adults of earlier times as a young carer (Charles et al., 2010; Lackey & Gates, 2001; Shifren & Kachorek, 2003), and the views of professionals from the health and social welfare sectors (Gray, Robinson, & Seddon, 2008; McClure, 2001). While these ‘adult’ studies offer an important perspective, they also serve to highlight the
extent to which the research is ‘removed’ from a young carer’s standpoint. Young carers have reported being “excluded from discussions and decision making processes, as they were considered too young to be involved” (Underdown, 2002, p. 59).

More recently there has been an emerging recognition that researchers need to seek deeper insights by engaging more directly with young carers (Aldridge, 2006; Doran, Drever, & Whitehead, 2003; Gray et al., 2008). However, it is telling that almost two decades after Aldridge and Becker embarked on their campaign of research to promote a social welfare program for young carers, the attempt by H. Rose and Cohen (2010) to conduct a meta-analysis of qualitative research on young carers using “first person accounts” (p. 475) was hamstrung by a lack of studies.

While the qualitative studies that were included in the analysis by H. Rose and Cohen (2010) provide some access to first person accounts, it is notable that most sought to explore specific negative aspects that had been identified by the dominant research paradigm, such as educational difficulties, mental health, and access to services. It is also evident that the methodology for these studies provided limited opportunity for the genuine participation of young people. It is instructive to consider the study of Earley et al. (2007) which is presented as obtaining a young people’s understanding of their caring situation. The study involved interviews (questions set by adult researchers) and standardised survey questionnaires about stress and coping strategies and is hence is very clearly and overwhelmingly adult designed and led. Bolgas, Van Wersch, and Flynn (2007) and Gates and Lackey (1998) have come some way in adopting an approach that allowed young carers some opportunity to raise and pursue matters that were important to them. However, with both these studies the design and parameters of the research were determined by the researchers in advance of meeting with the young people. It seems clear that those studies which have been identified by H. Rose and Cohen (2010) as
providing first person accounts were still largely managed by researchers and can be characterised as “adult-led, adult-designed and conceived from an adult perspective” (Kellett, 2004, p. 329). The young people did not have the opportunity to influence the structure, substance and outcomes of their participation.

*Australian research involving young people with a family caring role*

Although based only on anecdotal information, it is understood that the first written reference to young carers in an Australia context was a media release referring to ‘Children used as carers’ [italics added]. This is instructive, since the term “used” suggests young carers as being exploited. It is similarly instructive to note that the first program which included support for young people with a caring role had the title *Young people at risk*. The negativity attached to this label is stigmatising for parents and acts as a deterrent to seeking help, given the implication they had placed their own children at risk. Both of these ‘firsts’ are indicative of the mindset in which researchers and the community first engaged with the notion of young people having a caring role for a family member.

In finding very few qualitative studies that involve first-person accounts, the experience of H. Rose and Cohen (2010) also highlights the limited nature of Australian research. The one Australian-based study they included was focused specifically on barriers to accessing services (Moore & McArthur, 2007). This study, although limited to a pre-determined and narrow focus, does nonetheless provide a useful pointer for more innovative research, with young people being enlisted to assist with the conducting of the research. Other Australian research has consisted predominantly of government or government-sponsored reports with a policy-driven agenda. As a consequence, this

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7 This information was provided during a conversation with an Australian Government official who has responsibility for funding young carer programs.

8 This advice was provided by both a Respite Manager and the Australian Government official referred to in the footnote above.
research is generally focused on such issues as carer characteristics and circumstances and support services for young carers (e.g., respite, schooling assistance). This includes the report by Carers Australia (2002) and a 2009 report by the Department of Family, Housing, Community Services and Indigenous Affairs (FHCSIA). The FHCSIA study, on which a number of articles have been based (Smyth, Blaxland, et al., 2011; Smyth, Cass, & Hill, 2011; Smyth & Michail, 2010), is extensive in nature and involves quantitative and qualitative methods. It can though be suggested that this study is an example of the limitations of the current approach to young carer research. The qualitative component, while purporting to be ‘participatory’, involves the use of structured focus groups, which necessarily constrains the study to the parameters set by adult researchers.

It was noted in Chapter 1 that this research project has provided the opportunity to work with young carers in rural and remote areas of New South Wales. It is noteworthy that there could not be found any published Australian research on rural carers, given that an estimated one-third to one-half of young carers are located in rural and regional areas. As Smyth, Cass, et al. (2011) have noted, these young people are usually precluded from participating in research because of their comparative remoteness. In the very limited UK research that discusses rural young people, there is the suggestion that their experience is different. When evaluating a carer project, A. Butler and Astbury (2005) noted that rural young carers perceived greater isolation and social and physical exclusion, presumed to relate to restricted access to services and support groups and reduced ‘on-site’ facilities. However, in one other study which touched on rural carers, the opposite conclusion was drawn by Lackey and Gates (2001) who suggested that rural young carers in the UK may not perceive that their social and leisure pursuits have been restricted to the same extent as their urban counterparts, since opportunities for these activities in rural areas are
already relatively limited. Accordingly, a rural focus for this research has the potential to generate new insights.

3.6 Summary

The research in large part continues to reflect the motivation of the initial UK researchers to promote a social action agenda for protecting and assisting young carers. It also reflects the ongoing acceptance of the established research paradigm and the associated ‘taken for granted’ assumptions about childhood, children and young carers on which it is based. Most particularly, the research has been devised without the involvement of young carers. From this critical review of the research literature there emerges a need to consider the theoretical literature that encompasses assumptions about children and childhood. The review also provides an imperative to employ methodologies which engage in more meaningful ways with young people who are a family carer.

Accordingly, these two considerations are explored respectively in Chapters 4 and 5 which follow.
Chapter 4: Western construction of children – Contextualising young carer research

4.1 Introduction

The previous chapter examined and critiqued the research literature on young carers, applying a poststructural perspective that is consistent with the epistemological position of this research. This chapter details the important next step in developing my research approach; that is, to construct a contextual account of why young carer research might have developed in this particular way. As foreshadowed in Chapter 2, this will be done by drawing upon a range of poststructural and postcolonial works, most particularly the writings of Foucault. This is brought together with some specific works that include Bourdieu (as earlier discussed), Burman’s deconstruction of mainstream developmental psychology, the postcolonial writings of Edward Said, and the writings by Lansdown, Meyer and Boyle that relate to children’s rights.

Research and literature such as the body of work described in Chapter 3 does not emerge in a vacuum: they reflect cultural understandings (as well as influencing them). The concept of childhood, as it is generally understood in the Australian community, presents an important context to young carer research. There are two important aspects to the contemporary and widely accepted manner in which childhood is perceived in Western society which, I would argue, underlies how the young carer research paradigm developed and became entrenched. Firstly, childhood is a period characterised by innocence, dependence, and vulnerability (see for example the discussion in Lansdown, 1995). Childhood is seen as a time for play and no responsibility (Cannella & Viruru, 2004). Secondly, children are considered to develop according to a natural, universal, timeless, and biologically driven progression through to adolescence and adulthood (Turner & Helms, 1995).
This understanding of childhood is so strong in the community that it is very difficult to problematise. As Crafter, O'Dell, de Abreu, and Cline (2009, p. 178) have argued, it “pervades and mediates our understanding of childhood and, therefore, the treatment of children and the development of policy governing this group”. This position is significant in relation to young carer research. These two pertinent concepts are examined below in order to subsequently consider their implications for a different approach to young carer research.

4.2 The concept of childhood: Foucauldian genealogical and postcolonial perspectives

It is instructive to examine (and question) the accepted concept of childhood from a Foucauldian genealogical perspective. The seminal work of Philippe Aries, *Centuries of Childhood* (Aries, 1962), an historical analysis of the development of the concept of childhood, has been likened to the genealogies of Foucault (Hook, 2010). Aries’ historical research into the lives of children from the Middle Ages and onwards describes the socially constructed nature of many constructs of childhood which are assumed to be ‘natural’ and unchangeable.

Significantly, Aries concluded that the notion of “childhood did not exist” in medieval society (Aries, 1962, p. 125). He argues that in the Middle Ages, children were not afforded a special or distinctive social status and, from an early age, participated in society according to their physical abilities. There was not, Aries argues, any awareness that children might require a different and specific kind of social experience. This awareness, Aries suggests, only gradually emerged over time. A fundamental change in the construction of childhood arose from the introduction of anti-child labour laws in the 19th century and related concerns about delinquent children (Hendrick, 1997). With young people not able to work, there were concerns about their idleness, anti-social behaviour, and delinquency. The concern to keep young people ‘off the streets’ led to
compulsory education, which was to become a cornerstone of what constitutes a ‘normal’
modern childhood. Compulsory education had the effect of reinforcing the notion of
childhood as a special stage. The extension over time of the length of compulsory
education also effectively extended the period of childhood as a stage of life (Burman,
1994; Clarke, 2004).

While Aries’ research has been criticised for methodological flaws, in particular his
reliance on 15th and 16th century iconography for an accurate depiction of children’s lives
(e.g., Pollock, 1983; Wilson, 1980), his contribution is nonetheless profoundly significant
in that it recognises childhood as a modern invention: a social construction rather than a
presumed ‘natural’ given. In a similar vein, Burrows (1999, p. 28) has discussed the more
recent ‘invention’ of adolescence, suggesting that the concept arose “in response to some
very special sets of social conditions linked to the extension of the length of compulsory
education” and a desire to control a part of the population. Adolescence is now widely
regarded as a natural development stage, during which young people need to meet
milestones necessary for them to progress through to adulthood (Lesko, 1996). As will be
further discussed, the advent of developmental theories, such as that conceived by
Erikson (Turner & Helms, 1995), lends scientific credibility to the idea that there actually
exists a phase in the lifespan between childhood and adulthood. The significance of these
understandings is that the current concept of a ‘normal childhood’ which underlies young
carer research is neither universal across cultures nor permanent across time. Childhood
and adolescence are now presented as simple descriptors of a natural and biological
stage: as objects that have no history.

This genealogical examination can also be instructively extended to include a
postcolonial perspective on childhood which provides further understanding of what
underlies the conduct of young carer research. Stephens (1995, p. 18) has argued that the
The evolution of our modern concept of childhood has been “profoundly influenced by European colonialis experiences”. In a similar vein, Cannella and Viruru (2004), drawing on the postcolonial works of Said (1984, 1991), have likened the construction of children to that of the ‘primitive’ people of the colonies – exotic in their innocence, weakness, immaturity, and lack of responsibility. Children, like ‘natives’, shared an otherness as defined by white middle class men (Lesko, 1996).

While not yet rational, children (like the ‘natives’) have the potential to become citizens but must be monitored and controlled and taught (Western) adult knowledge and forms of thought to ensure they pass the divide into responsible adulthood. Children and adolescents are positioned as “citizens in waiting” who have the potential of “becoming” adult citizens with the “capacity for having authority over oneself” (Arneil, 2002, pp. 70-71). The works of Said, can be usefully drawn upon in considering this adult-child binary. Using poststructural analysis and the work of Foucault, Said developed an understanding on binaries in relation to cultural concepts of the Western world (us) and an ‘inferior’ homogenous entity of the Eastern world (them) (Said, 1991). He discusses this ‘us-them’ binary relation as social constructs which mutually constitute each other; that is, they each exist by virtue of the other. By further drawing on the work of Foucault, Said describes how power and knowledge are inseparable when such a binary relationship exists, as is evident when considering Western children and adults.

A Western understanding of childhood is presented as being appropriate and necessary for children throughout the world. The constructed and idealised view of childhood in Western society is held to be the standard to which all ‘respectable’ nations should aspire. The treatment of its ‘vulnerable’ children is considered to be a measure of a nation’s social order and morality; its civilisation and development. This provides part of the explanation for the reaction to children in a caring role who are perceived as being
deprived by having to sacrifice the childhood they need and deserve. It is seen as an affront to a (Western) nation’s status to be producing a ‘deviant’ childhood that is a feature of backward and uncivilised Third World countries (Gadda, 2008). The need to protect and ensure a ‘normal’ Western childhood underlies much of the young carer research and similarly provides the rationale for young carer programs and services.

4.3 Children, developmental psychology, and the psy-complex

“Metaphors of progress and gradualism have been amongst the most pervasive in Western thought” (Gould, 1981, p. 24).

The above comment by Gould can very aptly be applied to (Western) discourses about child development. The late 20th century saw an explosion of micro-powers engaged in childhood, with children and their development becoming a ‘proper’ subject for scientific study which formed the foundation of policies and practices about education, parenting, and the treatment of children. The growth of psychology as a discipline, and developmental psychology in particular, is in part related to the role it played in the increased surveillance and regulation of childhood (Burman, 1994; Clarke, 2004).

Developmental psychology, founded on biologically driven stage-related phases and a belief in a natural, knowable and observable process, reflects mainstream psychology’s underlying concept of linear progress towards a better and more advanced state. This viewpoint is exemplified in developmental theories, such as those of Piaget, Erikson, Kohlberg (Turner & Helms, 1995). The corollary is the testing, measuring, ranking, and categorising of children – deciding what is normal and abnormal, based on age-related or stage-related ‘norms’ (Foley, 2001; Prout & James, 1990). Also included in the ‘science’ are middle-class notions of play which have been constructed as necessary for children’s normal, natural and happy development. Psychology has developed purported scientific ‘truths’ about play, which includes Piaget’s designation of age appropriate lower and higher levels of play (Cannella & Viruru, 2004) against which normal development is
judged. Chronological age is the all-important shorthand for all kinds of information that is automatically inferred about a young person when told her/his age. A particular behaviour, seen as appropriate for a 13-year-old, may be perceived quite differently for a 15-year-old, and vice versa.

There are a number of additional considerations from developmental psychology that apply to adolescents, and which stem in part from the origins of the construct of adolescence. There is a discourse on adolescence that revolves around vulnerability to peer pressure and peer cultures, risk taking, and the understanding that these young people are erratically under the control of hormones. There is the understanding that the physical maturity of adolescents has raced ahead of their psychological maturity; that is, their judgment, reasoning and stability (Lesko, 2001; Wilbraham, 2004). This conversation about adolescents is characterised by Lesko (2001, p. 1) as “the trouble with teenagers”.

While there are often different schools of thought on specific developmental issues, the acceptance of this knowledge as scientific truth is assumed and taken-for-granted. The principles of developmental psychology have been recycled and massified through medical and welfare agencies, schools, and the popular media such that its origins are not always visible. This situation can be considered a demonstration of the *psy-complex*, the Foucauldian-related term that was discussed in Chapter 2 and used to describe ‘the wide-ranging network of theories and practices within and around psychology and which act to create abnormality, pathologise, and regulate and control thinking and behaviour’. Bourdieu also views positivism to be a mechanism for regulating people through scientific or quasi-scientific disciplines which judge normality across many aspects of society (Bourdieu & Wacquant, 1992).
It is also suggested that there is a compounding factor that further entrenches this dominant discourse on childhood. In Western society there is a middle-class ideology that promotes the notion that having and raising children is a primary purpose of adult life. This results in a powerful emotional rhetoric surrounding children, a situation which Meyer (2007, p. 96) has characterised as “sacralisation”. The associated discourse, positioning this special and sanctified status of childhood as ‘natural’, renders it difficult to challenge. Opinions, policies and practices relating to children are justified simply by invoking vague notions of ‘the best interests of the child’, with no further explanation considered necessary.

4.3.1 Compulsory education and schools

As noted earlier, compulsory education is a cornerstone of childhood and thus plays a significant role in these technologies. It can, as Robb (2001) has noted, be considered as the ‘work’ of children. There are two aspects of the education system that are particularly pertinent to the construction of childhood. Firstly, teachers are positioned as experts in childhood development and schools are the forum for testing, comparing and ranking – that is, they are a significant component of the psy-complex. Secondly, as has been argued by Freire (1970) and Bourdieu (Bourdieu & Passeron, 1990), the education system is involved in the representation and reproduction of dominant social relations and structures. Using Bourdieu’s terminology, the education system is a primary mechanism in conferring cultural capital and reproducing existing social relations, structures, and inequalities. This includes the existing construction of childhood and children and the powerful understanding in Western society about the roles, responsibilities and competencies of young people; an understanding that is reinforced and perpetuated by the education system.
The problematic outcome of this construction of childhood and the role of the psy-complex is the pathologising of children and adolescents whose progression through these ‘natural’ stages does not conform to the ‘norm’. As noted earlier, disruption to a ‘normal’ educational path is deemed to be one of the most detrimental outcomes for young people from caring for family members and is a major focus of young carer research (e.g., Moore, 2005; Moore et al., 2009). Moreover, young people who lead different lives may be labelled as incompetent, abnormal and inferior and, in the case of young carers, “viewed as non-normative and deficient” (O'Dell et al., 2010, p. 643). This discursive regime limits possibilities for considering children differently and, by extension, young carers.

4.4 Power, control and children’s rights

Children lack power in our society. They are amongst its most vulnerable members, and have traditionally been denied basic civil rights – the right to freedom of expression, to freedom of conscience, to freedom of association, to privacy or confidentiality and, perhaps most fundamentally the right to participate in decisions that affect them. (Lansdown, 1995, p. 19)

4.4.1 A Foucauldian perspective

The preceding discussion of developmental psychology, the psy-complex and education can instructively be considered with reference to Foucault’s theorisations about power, which were described in Chapter 2. As was discussed, Foucault has explicated how discourse creates people as normal or abnormal. Human science disciplines such as education and psychology have ‘discovered’ and established ‘truths’ about children and childhood with both the normal and the abnormal believed to be known and understood. Childhood is labelled normal or abnormal, as if there was a “particular way of passing through these early years of life” (Cannella & Viruru, 2004, p. 78). Regulation of the lives of children is legitimised in the name of normality.
Under the ‘scientific’ discourse of childhood, power and authority resides with ‘experts’ such as teachers, psychologists and child welfare workers. Those who dispute the experts or challenge these disciplines are to be discredited and labelled as unscientific. Although usually well-intentioned, the psychological expert is, in Foucauldian terms, the human embodiment of a controlling corporate body (Cannella & Viruru, 2004), creating discourses and being an authority for observing, judging and intervening into the lives of children. This has a problematic impact on the rights of children.

This control extends beyond the child. Experts on the family have also been created who promote the understanding that there is a particular type of family that is best for the development of children. This serves to devalue the diversity of family situations, such as young carer families who have a member with a major disability or illness and are usually single parent families with very limited financial resources. Children and parents are not heard if their views are not compatible with accepted expert knowledge about raising children. As a corollary, the welfare of children has increasingly become a government responsibility and children have become “one of the most intensely governed groups” in society (Gallagher, 2008, p. 401). It was noted in Chapter 1.1.5 how young carer families are often mindful of being under the scrutiny of child welfare authorities.

More generally, children and parents are under the gaze of experts in education, law, welfare, and mental and physical health. This repressive paternalism, pursued on the basis of the ‘best interest of children’, places very obvious constraints on the diversity of childhood. The network is designed to feel very comfortable for those children and families who ‘fit in’ and do not resist.

These notions of control are developed by considering Foucault’s concept of ‘technologies of the self’ that discipline and regulate by creating the desire to be ‘normal’ – a normality that is defined by the relevant discourse (as was discussed in Chapter 2).
People accept being judged and tested against standards of ‘normality’ constructed by discourses, such as the desire to be a good parent, a good daughter/son, or a ‘normal’ teenager. They constrain their behaviour to what is considered ‘appropriate’. In doing so they reproduce and strengthen these dominant discourses.

To extend the reference to the work of Edward Said from the previous section, any discussion of power in relation to children also needs to recognise the importance of their positioning as part of an adult/child binary. The definition of children is relational: it exists in relation to adults. Adulthood is the point of reference for discussing childhood and adolescence (and also the elderly). It is the accepted, taken-for-granted benchmark which comprises various markers and attainments (largely based on white, middle-class males), which purport to constitute the status of adulthood. Cannella and Viruru (2004) also link the adult/child binary to a work/play binary, with the work of adults corresponding to the play of (Western) children.

The existence of this adult/child binary becomes a method of both denying complexity and stifling alternate viewpoints. The acceptance of such a binary places a boundary around what may be said and indeed voices from the non-dominant side of the boundary may be silenced completely. The ‘scientific’ construction of the adult/child binary has legitimised the need and the right for adults to control the lives of children.

Consideration of the adult/child binary raises the seemingly paradoxical situation of children who are carers being recognised as performing adult tasks and responsibilities on the one hand, but otherwise being marginalised and required to occupy the subject position of traditional child in all other aspects of their lives. Bourdieu’s concept of *fields* provides an explanation of why people often experience power differently in different aspects of their lives. Moncrieffe (2006) provides the example of a woman Member of Parliament (MP) in Uganda who has authority and standing in the public arena, but in the
home is dominated by her husband. This situation has application to the dichotomy in the manner in which young carers are often positioned. The notion of a binary has significant explanatory power in relation to the experiences of young carers, and the issue is taken up in detail in Chapter 10.

As foreshadowed in Chapter 2, Bourdieu’s work also provides a perspective for considering the marginalisation of children (and young carers). Children are positioned to have very little social or cultural *capital* that enable them to participate in an ‘adult’ world and are excluded from any input or decision making on matters affecting their lives. As described by Bourdieu, *capital*, whatever the form it assumes, exerts a symbolic (non-physical) violence when arbitrary power and social relations and divisions are seen (misrecognised) as natural and necessary, disguising their arbitrary nature. These categories of thought are imposed on dominated people who then take the status quo to be just and legitimate and their own position to be ‘right’. There are a related set of core discourses and values which are considered to be inherently true and necessary. This is described by Webb et al. (2002, p. 25), as people being treated as “inferior, denied resources” and have their aspirations limited, but this is not perceived by them because the situation is thought to be the “natural order of things”. This well describes children and by extension, young carers. These considerations provide a perspective for considering the level of participation of young people in young carer research and are also suggestive of significant obstacles for young people in trying to negotiate the adult world as young carers. This discussion of the marginalisation of young people provides an appropriate segue to the next section on children’s rights.

### 4.4.2 Children’s rights

The preceding discussion on the construction of children and that relating to power and control, explicitly and implicitly highlight issues about children’s rights. Careful
reflection on these issues was important for formulating my approach to young carer research.

The corollary to the positioning of children as dependent, incapable, vulnerable and without *capital* is a denial of their agency and rights as independent, intelligent people. As mentioned above, this includes legitimising the right to observe, test, judge, create discourse and intervene in the lives of children and their families. This position renders it unnecessary and perhaps even inappropriate to seek the participation and collaboration of young people in research (as reflected in the research literature). As noted by R. Fox (2007, p. 11): “Their [young people] voices are rarely heard in a meaningful way that is not tokenistic, and they have little control or opportunities to make decisions, even over matters that directly affect them”.

Lansdown (1995) has challenged these concepts of children from a human rights perspective. She argues that the notion of being incapable and innocent is contradicted by the level of responsibility taken by children in many other countries (which also highlights our Western-centric, culturally specific notion of childhood). As was noted in the previous chapter, this includes very young children caring for baby siblings and doing ‘adult’ domestic and agricultural chores (Whiting & Edwards, 1988). Lansdown (1995, p. 23) also notes, for example, that children in difficult medical situations have shown they can “develop a capacity for understanding and decision making which far exceeds commonly held perceptions about children’s capabilities”.

It is instructive to examine the related notion of childhood vulnerability. Meyer (2007) persuasively argues that vulnerability has come to be used as a generic term that includes and conflates the physical state of children (i.e., being physically smaller and weaker) with social vulnerability. This ignores what Meyer (2007) refers to as ‘structural’ vulnerability of children that results from discourses about children and social practices.
Lansdown (1995) also persuasively argues against the idea of inherent vulnerability, turning this commonly held viewpoint ‘on its head’. She argues that a “self-confirming cycle is established” wherein children are construed as vulnerable and in need of protection, and hence adults are given power to act on their behalf – because children are denied the opportunity to participate in decision-making and gain experience of independence, they are in turn more vulnerable to adults (Lansdown, 1995, pp. 22-23).

A similar argument is presented by Boyle (2003) in her consideration of the manner in which the term ‘vulnerability’ is used to pathologise. Boyle asserts that designating particular groups as vulnerable leads to “a set of behaviours associated with passivity, and possibly gratitude” (Boyle, 2003, p. 28). She also notes that a discourse of vulnerability tends to be applied to groups who are “already socially and economically subordinate” (Boyle, 2003, p. 27), and this obviously applies to children. The way the adult world behaves and acts toward children necessarily shapes their experience of being a child. The application of the label child, and all that is associated with the construct, limits expectations of the capacity and competency of those who have been labelled. This is well captured by Cannella and Viruru (2004, p. 2): “What is controlled, lost, disqualified, and even erased through our expectations [of children]?”

‘Official’ discourse on children’s rights

This depiction of children’s rights as being compromised may be seen as being contradicted by the very public commitment by Western Governments in recent decades to the rights of children. An official discourse on children’s rights became ‘part of the conversation’ in the late 20th century, a period punctuated by the passage of the United Nations Convention on the Rights of the Child. This ‘official’ discourse on children’s rights can however also be seen in the context of the Western construction of childhood as a time of play, freedom, innocence and dependence. Children’s rights are argued from
a position of a child having what they need in order to have a Western childhood. By
focussing on preserving and reinforcing this ideal, the status quo is necessarily
maintained. While presenting as liberating, the official children’s rights discourse can
instead be seen to be a way of maintaining control over children. It can be argued that
this seemingly paradoxical situation has parallels with Boyle’s argument that the
discourse surrounding the vulnerability of children and the need to protect and make
them safe, does instead make them more vulnerable. As Gadda (2008, p. 12) has noted,
albeit in a different context, children’s rights discourse needs to move from “salvation to
true participation”. This understanding mandates a different standpoint on children’s
rights, and by extension the need to take a new approach in researching the lives of
children and young people.

4.5 Summary

This chapter has provided important context for understanding the body of research
literature that was examined in Chapter 3. It also provides a powerful basis for
challenging the assumptions and taken-for-granted knowledge about children and
childhood and the conduct of research into their lives. Reflecting on the issues arising
from these two chapters was an important part of the process in the development of this
research that would better serve the interests of young carers. In particular, this reflection
led to consideration of how to develop a methodology that could best incorporate this
understanding of children and childhood. These considerations are the subject of the
following chapter.
Chapter 5: Epistemology and methodology – Theoretical considerations

“…the people best equipped to research, understand, explain and address any issue are those who experience it every day” (McAlpine, 2006, p. 10).

5.1 Introduction

This chapter outlines the core theoretical and methodological assumptions that contributed to the methods employed in constructing an account of young carers’ experiences. As well as offering some concluding possibilities about the lives of young carers, the poststructuralist reading and critique of the literature and research (outlined in the previous chapters) also presents imperatives for research methodology itself. This review has informed a set of assumptions for a research methodology which places young carers at the centre of the process, acknowledging they are “best equipped to research, explain and understand” their own experiences (McAlpine, 2006, p. 10).

5.2 Components of a more collaborative methodology

It was discussed under Standpoint of the research (Chapter 1.2) how this project is grounded in a fundamental belief that research must fully involve those whose lives are being researched. It also aims for a poststructuralist objective of challenging the status quo. Consequently, the critique of the research literature was influenced by whether a particular study provided a participative and meaningful engagement with young carers, and hence whether it could provide a genuine insight into their experiences. It was also driven by a questioning of accepted knowledge and assumptions about young people and young carers that characterises much of the previous research. Naturally, these same ontological and epistemological considerations also underlie the rationale for development of the research methodology.
It has previously been argued that much of the past research has been dominated by adult-centred perspectives, interpretations and agendas, which carries with it the implication that young people are not capable of knowing or describing their experiences. This research has as its starting point the understanding that young carers have the capability to reflect on and articulate their own experiences. Moreover, this standpoint acknowledges that they are the experts of their subjective experiences and hence assumes that young people can uniquely describe these experiences and their needs, and offer insights not otherwise available. It assumes that authentic research must empower and give a voice to young carers.

A research approach was therefore required that would provide a platform for young carers to directly tell their stories, that would generate insights into their experiences, and be respectful of, and take seriously, their views. It required a way of conducting this research that would complement, rather than hinder, an understanding of how young people experience caring. The project sought to create spaces for young people to express their lives and their selves on what matters to them and the ways in which it matters. The project also sought to move toward spaces where the young people are able to define and choose the terms of their participation in the research.

Epistemologically, this project assumes that the young people’s accounts are socially constructed and influenced by the subjectivity of both the researcher and those being researched, and the located context of the research and the lives of the young people (Banister, Burman, Parker, Taylor, & Tindall, 1994; Willig, 2001). This assumption was fundamental to the development of the research methodology.

These underlying assumptions, as well as the nature of the research question, led to the deployment of qualitative approaches. As outlined by Willig (2001), a qualitative approach is concerned with how people make sense of their world and experience events
in their lives; in this case, what it means for young people and how they feel about caring for family members with an illness or disability.

This research was exploratory which was in keeping with an epistemological standpoint of challenging what is ‘assumed’, and ‘taken for granted’ in relation to young people and more specifically young carers. Exploratory methodology supported the participatory and collaborative desires of the research, providing flexibility that sought to allow for new and unexpected issues and complexities to emerge, and to lessen the control and power of the (adult) researcher.

5.3 Participative-collaborative methodologies

An initial point of reference for consideration of participatory methodology was the writings of Hart (1992, 1997). It is acknowledged that Hart’s understanding of power does not accord with Foucault’s ‘network of relations’ (see discussion in Gallagher, 2008), but his ladder of participation, as detailed in the diagram below, can be described as a valuable tool in setting down a framework for considering the participation of young people in research (Hart, 1992). While this framework has provoked criticism, and alternate frameworks have since been proposed (see discussion in Thomas, 2007), Hart’s ladder was an important advance that enabled the discussion to move beyond the simplistic binary notion of participation versus non-participation. As was noted in the literature review, young carer research that is described (or implied) as being participative, is often done so simply on the basis of young people being invited to respond to questions or complete surveys and questionnaires or, in some cases, take part in a facilitated discussion. However, this level of engagement ranks at the bottom end of Hart’s ladder. Importantly, Hart’s ladder provides a reference point for considering more genuine levels of participation, including encouraging young people to have an impact on the research design, process and analysis. Their involvement in the development of the
Accordingly, a major strategy for this project was to disrupt the status quo and the power relations inherent in traditional research by seeking the input and participation of young people in developing the format of the research and how it should be conducted. This approach has not appeared in young carer research to date, but does have some precedence in participatory studies with (non-caring) young people in other disciplines, such as education (e.g., Kellett, 2004; Oldfather, 1995), sociology (e.g., Bagnoli & Clark, 2010) and, perhaps of more relevance, young people in social welfare situations (e.g., Holland, Renold, Ross, & Hillman, 2010). These studies employ a wide range of approaches, illustrating that there is a continuum of possible levels of collaboration and participation between young people and adult researchers. This has included, for
example, young people making decisions about aspects of the research design and methods (e.g., Bagnoli & Clark, 2010; Dona, 2006), formulating topics and developing interview guides, advising on definitions and questions, peer interviews (e.g., Dentith, Measor, & O'Malley, 2009), and involving young people in interpreting data (e.g., Dona, 2006).

In seeking the involvement of young people in the research, it was important not to decide in advance how they were to be employed in the process. That would presuppose a particular view as to how young people want to be involved and suggests ‘directed’ collaboration. As noted by Birch and Miller (2002), there is also a need to be ethically mindful of pursuing a particular notion of participation that may inadvertently impose an unwanted research relationship on participants.

While this project has at its core a desire to move beyond the binary notion that children are dependent and fragile while adults are wise, powerful and independent, this does not mean that there are no differences in researching children. As earlier discussed, young people are marginalised in an adult-centred world (Lansdown, 1995) and there is an ingrained and largely taken for granted notion that adult knowledge is superior to that of young people. The way in which young people (and adults) are constructed in our society means that age equates with authority which, combined with the perception of a researcher as an expert, exacerbates the risk that young people will conform to what they think is wanted or expected by the adult ‘expert’. The perceived divide between adult researcher and research participants who are young people can therefore be particularly problematic. In a related vein, Smith (1997) also notes that people being researched have often internalised assumptions about conventional research and their expectations lead them to make conventional decisions, rather than to seek participation.
It is acknowledged that even in carefully planned and conducted collaborative research the young people will be ‘guided’ to some extent by the researcher. This would seem to be impossible to fully eradicate. Some level of ‘guiding support’ may even be appropriate at times to challenge and encourage the engagement of the young people in the process. More problematic ‘intervention’ can however stem from the researcher’s investment in the project. It is accepted that no matter how enthusiastic the young people are about the research, the researcher is more invested, particularly in striving to achieve academic outcomes. Hence there is the potential for the researcher to unintentionally engage in subtle forms of control or ‘suggestions’ to guide the young people so that they formulate their issues in terms of the perspectives of the (adult) researcher. This would obviously erode the collaborative intent and potentially reproduce conventional outcomes (Freeman & Mathison, 2008). This is a consideration that requires careful and ongoing reflexivity through the research project.

It is also acknowledged that there can be resistance from adults who feel ‘uncomfortable’ with the notion of ‘children’ having some control of research (as experienced by Dentith et al., 2009), which may be problematic where adult gatekeepers have some involvement in the research process. Accordingly, as noted above, reflexivity needs to be a major part of the process. It is necessary to critically reflect on these issues, including my role in directing the research and my interactions with young people during the research. It is also important to reflect on structural barriers that might impede meaningful participation so, where possible, these barriers can be addressed, or otherwise recounted as part of the reflexive process.

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9 Reflexivity has been described as being, at its simplest, “disciplined self-reflection” (Wilkinson, 1988, p. 493). There are ‘personal’ aspects of reflexivity which involves reflecting upon the ways in which our own values, experiences, interests and beliefs have shaped the research. Reflexivity includes reflecting on the implications for the research findings of the epistemological assumptions that have been made in course of the research. Reflexive analysis also engages with the reciprocal relationship between how the researcher’s life experience influences research and how the research feeds back into the researcher’s own life experiences (i.e., the researcher is changed by the research) which, in-turn, again influences the research (Wilkinson, 1988).
context which mediated the research process. Too often researchers do not acknowledge (or seek to ignore) the limitations of their approaches, claiming that adopting a particular method will overcome difficulties.

In seeking advice from young carers on the conduct of the research and how they would wish to be involved, it is necessary to be flexible to encourage and enable participation based more on young people’s own desires and preferences. Bagnoli and Clark (2010, p. 116) conclude that basing their “research methods on the expectations and ideas of its potential participants ... produced research that was better suited and more relevant to young people ... [and] produce[s] data that is a little closer to the everyday realities of young people’s lives”. Similarly, Hart (1997), in writing of the various barriers that often make it very difficult for research to be participatory, emphasises the need for engaging and creative approaches using methods preferred by young people. Punch (2002) also argues that making young people central to the process, and enabling them to stipulate their own terms of participation, is empowering and helps diffuse some of the power imbalances found in research with young people and adult researchers.

The decision to involve young carers more meaningfully throughout the research was an adult-led decision, and the initial ideas about what that involvement or collaboration might look like did not itself involve young people. Ideas were grounded in the epistemology that this chapter has elaborated upon and in the critical review of literature, and formulated in an adult university environment. Methodologically then, this included the notion that participation itself needed to be aligned with concerns of young people and in particular of young carers. It was felt that participation needed to be fluid, flexible and different for different young people. Unlike traditional research which usually supposes uniformity in how people participate, even in participatory work, this project assumed different young carers would want to be involved in different ways, at different
times, and might join or leave the research at different stages. This was therefore integrated into the research rather than being ‘ironed out’, akin to the ‘informal mechanisms of participation’ advocated by Vromen and Collin (2010).

As well as methodology that sought to be participatory, prior to meeting with the young people, different methods and techniques were reflected upon that might create better spaces for collaboration than would more formal, traditional methods. Quantitative methods were outright rejected for their fundamental distancing from participants, but formal methods of qualitative researching like interviewing were also felt to be too informal and reproducing of problematic relations of power between adults and young people, and researchers and those being researched.

Having young people nominate their own method/s of participation was an exciting prospect that would allow for a multi-method approach to be adopted. While care would be taken not to pre-empt what ideas and forms of participation might be forthcoming, based on participatory research with young people in other fields (as discussed earlier), it was expected that some traditional methods, such as semi-structured interviewing, would be combined with more innovative techniques that might be favoured by young people (e.g., video diaries, internet-based methods, informal discussions, and perhaps drawing or art for younger children).

The use of multiple methods was presented as having value in recognising a diversity of social competencies, skills, interests and life experiences. It was thought for example that different methods might be nominated and adopted for older and younger carers. As Freeman and Mathison (2008, p. 59) have argued, multiple approaches give young people a range of opportunities “to express their thoughts and share their experiences in ways that build on individual differences and styles of interaction”.
Notwithstanding that some traditional methods would likely be advocated by young carers, it is not necessarily the kinds of methods used that make research participatory, but rather it is the level of involvement that the young people have in the overall research process (Kindon, Pain, & Kesby, 2010). Again, ongoing reflexivity was to be engaged in relation to the use of particular methods and their advantages and disadvantages and the implications for the analysis of the data.

Careful consideration was given to how to initially engage with young people in seeking their input about the conduct of the research. Firstly, it was important that the process of engagement be informal, flexible and open, and that I had no pre-determined ideas of what would emerge, other than to further my understanding of how to best work with the young people in conducting the research. It was also necessary to provide a ‘participatory environment’ that was conducive to young people feeling comfortable in openly sharing their ideas and opinions on methods, topics, and general ideas on the appropriate way to proceed. The young people would be offered the opportunity to meet informally, either one on one or in small groups at a location of their choosing. This is similar to the process followed by Bagnoli and Clark (2010). While this was considered a suitable way to commence the participative process, it was recognised that there were some practical limitations. The capacity to bring together groups of young carers in rural areas is constrained by them being located over a wide geographic area which has few transport options. Some young carers would also be unable or unwilling to leave their homes and caring responsibilities. In situations where young carers are located in very remote areas, it would only be possible to meet them individually. Significantly, it eventuated that these discussions were held in the family home, providing a familiar environment where the young people would feel most in control. The details of this process are fully outlined in the next chapter (Working with young carers).
5.4 Summary

Building upon the epistemological foundations and critique of the research literature that was developed in the previous chapters, this chapter has provided the methodological framework for the development of a very specific approach to researching the experiences of young people. The primary focus of this approach was to work collaboratively with young carers in providing for participation on their terms and which explores the issues that are of significance and interest to them.

It is recognised that the initial phase of this project – reviewing the literature and developing the parameters of the research plan – commenced in advance of consulting with the young people. Accordingly, even though the plan was very preliminary and fluid, at this stage it was nonetheless adult-led and theoretical. The point, however, was that this preliminary planning was done with the desire and expectation that it would be subsequently challenged and undone by the young people. Relatedly, the fluidity and non-uniformity that characterises the plan and enables each young person to drive the level and manner of their own involvement, was seen as providing a strong foundation for participatory research with young people. Details of the research method and processes that emerged from my collaboration with young carers are presented in the following chapter.
PART III

THE RESEARCH PROCESS

Chapter 6: Working with young carers
Chapter 6: Working with young carers

6.1  Method

6.1.1  Introduction

This chapter details the method and processes that were followed in conducting the participatory/collaborative fieldwork. At this point it might be useful to very briefly bring together some of the main considerations in how I arrived at this juncture. It was discussed in Chapter 1.1.1 how the impetus for this participatory research came from a small study of young carers conducted by Watson and Fox (2014). This research recorded, alia, that young carers possessed a sophisticated understanding and insight into their own lives and their family relationships. This made for a jarring disconnect with their marginalisation from adult designed and led research on young carers that assumes young people are not capable of ‘knowing’ or understanding their experiences as a carer (as is reflected in most of the research literature – Chapter 3). These considerations provided a strong argument (and motivation) for conducting participatory/collaborative research with young carers. The methodological considerations for such an approach to the research were developed in Chapter 5, which have led to the participatory methods that will now be outlined.

The fieldwork took place over two years and progressed from initial immersion, through to engagement with young carers in a number of ways. There were four components of the fieldwork: firstly, there was ongoing ethnographic work as a volunteer at young carer events and activities, engagement with the young carer bureaucracy (described below in section 6.1.2), while the other three components involved working directly with young carers. The three components (stages) which directly engaged with the young people emerged as the fieldwork progressed and were dependent on the outcomes of preceding work with them:
• Stage 1: Consultation discussions with young carers on how the research might be conducted. This included seeking their input into topics and issues that might be explored and their preferred methods for participation in the research.

• Stage 2: Implementing the research plan based on the outcome of the consultation interviews of Stage 1; in this case a series of one-on-one discussions in the family home.

• Stage 3: Working collaboratively with young carers on the analysis of the data that was derived from the discussions that formed Stages 1 and 2 and my ethnographic work as a volunteer at young carer events and related activities.

It is important to stress that in keeping with the participatory intent of the research, these three stages were not pre-planned. It was of course necessary to conduct initial consultations with young carers (Stage 1) – as foreshadowed in Chapter 5 – as part of the participatory methodology, but even this was intended to be as open and fluid as possible in order to provide the space for the young people to ‘drive’ the process. This intent was constrained to some extent by the need to provide some structure to this process in order to prepare an Ethics Application and have it approved by the University’s Human Research Ethics Committee. The young people were provided with the opportunity in Stage 1 to make their own decisions about method and to stipulate how they wished to participate in the research and the terms of their participation. Accordingly, Stage 2 emerged from the participatory process of consulting with young people in Stage 1. Similarly, Stage 3 was not specifically planned, but as the fieldwork with the young carers unfolded it emerged as an important possibility in working collaboratively: the opportunity for the young people to consider and provide feedback on preliminary analysis. This included the opportunity to also provide feedback on the research methodology itself, which can be suggested as ‘completing the circle’ of a collaborative research proposal.
6.1.2 Ethnographic work

An important component of the research over the two years of the fieldwork was to incorporate an ethnographic approach in which I sought, as far as possible, to immerse myself in the ‘worlds’ that mediate the lives of young carers. This was considered to be an important component in constructing an informed account of the context of their experiences and an understanding of subject positions and discourses. During the first 18 months of the research project I worked periodically as a volunteer with a Commonwealth Respite and Carelink Centre in a rural region of New South Wales (NSW). The Centre is one of 58 such facilities across Australia that provide respite and related support services to both adult and young carers. One of their main support programs for young carers is multi-day trips or camps. These are intended to be both a holiday and a respite from caring, as well as providing the opportunity to debrief with other young carers.

As a volunteer I attended four-day young carer camps as well as smaller functions and activities. This intensive contact provided the opportunity to develop relationships with the young people, to engage with them in a variety of situations and, if they wished, to discuss matters of interest to them. Again, as previously touched upon, at the forefront of my thinking at these events was informal, flexible and open engagement without any pre-determined notion of what might emerge, other than to further my understanding of ‘what it means to be a young carer’ and of conducting participatory research.

The purpose for my attendance was made very transparent to the young people (and their parents) and of course other staff of the Respite Centre with whom I was working at these events. My volunteer work with the Centre was approved by the University’s Human Research Ethics Committee and conducted in accordance with that approval. The
Information Sheet provided to the Respite Centre in seeking their consent for me to work as a volunteer as part of my research, is at Appendix A.

I decided not to provide this Information Sheet to the young people as it would almost certainly have been perceived to be a very formal and authoritative document. Instead, on the first morning of each camp I spoke informally to the young people, mostly individually but sometimes to a small group of two or three, and briefly described my presence as a university researcher and the general subject of my research. Even at this very early stage of the project I was very conscious of my aim of conducting open and informal participatory research. I noted at the time that the young people seemed to be completely unfazed by my presence and the reason for my presence.

My involvement as a volunteer at these events allowed, to some extent, for general experiences with young carers to be informing the decisions I made in the early stages in the research. I maintained a fieldwork diary of this ‘immersion’ which was later used as part of the analysis and which aided in constructing narrative accounts of the research process as detailed in this chapter. In accordance with the Ethics Approval for attending these functions, my notes did not include the names or personal details of any individuals, and were my subjective accounts. The notes were considered as a subjective interpretation rather than a ‘recording’.

These periods of interaction with young carers at camps and activities informed my reflective processes when reading literature and designing the research. The development of a set of assumptions and values for the research was informed by and challenged by these interactions. This can be illustrated by one seemingly minor incident. On arriving at the airport on the first day of my first camp, I met and chatted to the young carers. A 12-year-old carer quietly took me aside from the group and gently explained that he preferred to be addressed by an abbreviation of his name, rather than his full name which
I had used. On reflecting on my surprise at this child’s sophisticated social skills and self-confidence in dealing with adults, it was evident that I had underestimated the competence and capacities of young people. This realisation contributed to an expanding of my understanding of the possibilities for participatory research with young people.

My attendance at camps and activities enabled me to develop a good relationship with Respite Centre staff as well as with young carers and parents. This proved to be most valuable. Firstly, it assisted relationship building and likely gave some young people the confidence to volunteer to work with the research project. Secondly, for those young carers who did subsequently volunteer and whom I visited in their home for discussions, this previous contact seemingly contributed to a more relaxed and less formal atmosphere and perhaps went some way towards diminishing the adult researcher-child participant divide.

I also considered it important to gain some insight into the experiences of young people (and their families) in dealing with the young carer ‘bureaucracy’ and the service providers who developed and conducted support programs. I therefore wanted to understand the thoughts and assumptions of service providers about young carers and how they should be supported. I wanted to understand the decision-making processes for young carer programs and those that impacted more generally on young carers.

In order to pursue these aims I established contacts with and met officers of the Australian Government responsible for young carers (the then Department of Families, Housing, Community Services, and Indigenous Affairs). I attended a number of carer respite centres throughout rural NSW, spoke with staff, and attended some of the functions they held with young carers. I also attended and spoke at a meeting of the managers of all the respite centres throughout NSW. This involvement provided some understanding of the institutional framework within which the respite centres and young
carer bodies operated, the processes they followed, and the assumptions they held about young carers and how they should be supported. In the course of my volunteer work I had extensive involvement with Respite Centre staff and my discussions with them provided important background information. A variation to the initial Ethics Application was submitted and approved by the Committee which provided for these discussions to be incorporated in the thesis. Copies of the Information Sheet and Consent Form in respect of this application are at Appendices F-1 and F-2. The outcomes of discussions with respite centre staff are included in Chapter 8 (Institutional/structural context).

6.1.3 Recruitment of young carers
The recruitment of young carers was facilitated through the Commonwealth Respite and Carelink Centre that was described in section 6.1.2 above. The large physical size of this rural NSW area provided a sizeable and diverse pool of young carers and young carer experiences. As also discussed above, a relationship had been developed with this Centre which was providing me with the opportunity to undertake volunteer work with young carers and to attend relevant meetings and activities. It had approximately 30 young carers as clients and another 60 young people who were intermittently in contact with the Centre, of which approximately one-third to one-half are primary carers in the age range of 10 to 18 years, the focus of the project.

The definition of ‘young carer’ used by the Centre was generally similar to that used in the research literature, that being a person under the age of 18 years who provides substantial care and support to another family member, assuming a level of responsibility usually associated with an adult (Banks et al., 2002; Newman, 2002).

The Centre searched their database of carers to identify those between 10 and 18 years of age, those who were primary carers, and those who had, when registering with the Centre, given their permission to be sent material considered by the Centre to be of
relevance or interest to young carers (in accordance with an undertaking given in the Ethics Approval Application). A leaflet prepared by me seeking expressions of interest from young carers in working with the project was circulated by the Centre to its young carer clients. The Centre provided a covering note to the leaflet that included a statement to the effect that the project was being conducted independently of the Centre, and neither participation nor non-participation would in any way affect their dealings with the Centre. A copy of the leaflet and covering note is provided at Appendices C-1 and C-2.

Those young carers expressing an interest in participating were asked to contact me by email, text message, or telephone.

Telephone discussions were conducted in the first instance with the young person or their parent/guardian to outline the research project and the initial interview process. For those carers under the age of sixteen years these discussions where most often with the parent. These discussions allowed for a verbal communication of the ethical considerations of the project in addition to the written information. Consequent to these telephone conversations, the Information Sheet was provided to the young people to enable them to give further consideration to participating and be in a greater position to give informed consent.

This recruitment process was one of the constraints that mitigated against the participatory intent of the research. The letters from the Respite Centre to young carers were usually first read by parents/guardians and, as such, the final decision on whether their child would participate would likely come from them. This ‘gatekeeper’ role means the possible exclusion of those who were keen to participate, while young people who were less engaged may have been influenced by their parent to participate. Similarly, my ongoing telephone communication with some young carers over the course of the project was often conducted through the parent, particularly for those who were young children.
This constraint did however often seem to diminish as my relationship with the family developed over time.

It is important to acknowledge the existence of these constraints and barriers to conducting participative/collaborative research with young people, and to describe attempts to overcome or mitigate these constraints. This research aims to be deliberately transparent about these limitations, contrasting with much of the research which fails to concede the existence of difficulties. The issue of ‘parents as gatekeepers’, and other constraints on collaborative research with young people, is further discussed at the end of the thesis at Chapter 13.2.2.

All young people who wished to be involved with the project were accepted, with twelve joining the project for the initial consultation stage. They were in the age range of 12 to 17 years and comprised six girls and six boys. They were from a diverse range of caring and family situations and geographically spread over 300 kilometres throughout a rural region of NSW. Some of the young carers lived in the remote countryside, some in villages, some in small rural towns, and one in a medium sized town. Further details of the young people who worked on the project are provided below at section 6.1.4.

As has been noted, the project focussed on rural young carers. Given that the term ‘rural’ has been defined in different ways by different government agencies, it may be useful to detail the parameters of ‘rural’ that was adopted for this research. This is done with reference to the classification system developed by the then Commonwealth Departments of Primary Industries and Energy and Human Services and Health which provides for seven zones ranging from major metropolitan through to remote (Australian Institute of Health and Welfare, 2012). Without going into the details of this classification system, the young people were recruited from areas classified as ‘small rural’, ‘other rural’ and ‘remote’: this meant areas had populations with less than 24,999 people). All but one
young carer was from a locality with less than 5,000 people and in some cases they were small and remote communities of less than 100 people.

The reasoning for adopting this designation of ‘rural’ is because larger centres can be expected to have services, amenities and infrastructure (and perhaps lifestyle characteristics) closer to those of metropolitan areas, and hence further removed from the experiences of those young people in small country communities, the intended primary focus of the research. It was recognised that this parameter may have needed to be varied as the recruitment process proceeded if there was difficulty in recruiting sufficient young carers from small rural areas, but this situation did not eventuate.

6.1.4 Young carers who worked on the research

Brief profiles of the twelve young people who directly worked on this research, including details of their caring situations, are provided below:

- Allison is 16 years old and lives in a small village. She cares for her 18-year-old brother who is profoundly affected by autism, having no speech and has incessant erratic body movements and seizures. Allison is involved in all aspects of her brother’s care including personal care, dressing, and feeding and, in particular, close supervision, as he is prone to ‘run’ from their home at any opportunity. The demanding caring role is shared with Allison’s mother but she is regularly absent on extended respite breaks, during which time Allison is the sole carer. As Allison is two years younger than her brother she has essentially always been a carer, with her responsibilities increasing as she got older.

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10 In accordance with the undertaking given in the ethics applications (and to the young people), the names used throughout this thesis are pseudonyms.

11 The ages of the young carers listed are their ages at the commencement of the 13-month period over which the interviews were conducted.
• Mitchell is 17 years old and has been in the primary caring role for his mother since she first became ill six years ago. There are no other members of the family. They live in a tiny, remote community. The mother has a potentially life threatening disorder and is mostly confined to bed, although she has some periods of relative well-being. During the period of the fieldwork she was hospitalised for a lengthy period. Towards the end of the period of fieldwork, Mitchell’s relationship with his mother had broken down and he had moved out of home.

• Jonathon is 15 years old and is the sole carer for his mother who has cerebral palsy and his father who had a brain aneurism which has left him with some physical disabilities and aphasia. His father has also been diagnosed with Bipolar Affective Disorder and his mother with depression and anxiety disorders. He has been involved in providing care to his parents since before he was 10 years old, with his responsibilities increasing as he got older, which apparently coincided with the decline in the capabilities of his parents. In addition to household chores, his caring role includes managing medication for his parents and, at times, assisting with dressing and toileting. The family live in the countryside about 20 kilometres from the nearest town.

• Stephen is 17 years old and is the sole carer for his elderly and frail grandmother who is in ill health with a number of chronic health concerns. Stephen was raised by his grandparents from birth and considers them to be his parents. His grandfather died when he was 12 years old at which time Stephen began his sole caring responsibilities. Stephen and his grandmother live in a poor area of a small coastal town.

• Liam is 12 years old and is a co-carer with his mother (one parent family) for his younger brother, aged 8 years, who has autism. There is a limited custody arrangement with the boys’ father, but which Liam emphasises results in him being a
full-time carer for his brother since both his parents have respite when they (the children) are with the other parent. They live in a small village near the coast.

- Emma is 17 years old and lives in a small coastal town. Her caring situation is complex. Her 10-year-old half-sister has severe autism and is low functioning with no speech and no possibility to be toilet trained. Her mother has ongoing mental health issues which at times are severe and render her incapacitated and requiring hospitalisation. Emma has been a carer to some degree from a very young age. Emma has her own physical health concerns.

- Jack is the 12-year-old half-brother of Emma with whom he shares some of the caring responsibilities as outlined above. Like Emma, Jack has performed some family caring roles from a very young age. At the end of the period of fieldwork, Emma had left home to commence university, and Jack now has sole responsibility as the carer for his mother and sister. Jack also has his own physical health concerns.

- Melissa is 17 years of age and is involved in a very complex caring situation. Her caring role has involved to varying degrees her father, mother, and two brothers. Her caring duties reached a pinnacle between the age of 13 and 17 years. When she was 13 years old, almost simultaneously her father was diagnosed with cancer, her mother suffered an injury, and her baby sibling was born. With the recent death of her father from cancer, her mother’s improving health, and her youngest sibling no longer being a toddler, her caring responsibilities have lessened. There are however still significant health issues in the family, most particularly her mother and older brother, who is completing secondary schooling through distance education because of physical and mental health issues. Melissa also has physical health concerns and, at least in the past, mental health difficulties. During the course of the research the family moved from a small country town to the outskirts of a large regional centre.
• Mia is 13 years of age and lives in a very small village. She is a carer for her 18-year-old half-brother with cerebral palsy-spastic quadriplegia, who has no speech and almost no physical capabilities. During the course of the fieldwork Mia also played a role in caring for her mother who underwent brain surgery.

• Rebecca is 15 years of age and lives in a poor and dilapidated area of a small regional town with her father, mother and four younger siblings. She has a difficult role in relation to her father who has a very severe mental health issue, diagnosed as paranoid schizophrenia with hallucinations. He is understood to have episodes every few days and a major aspect of her responsibilities is to act as a buffer between her father and her four, much younger, siblings.

• Kate is 16 years of age and lives in an extremely remote and very small rural community and cares for her 8-year-old sister who is profoundly affected by Down’s syndrome. Her sister requires constant monitoring and attention. During the course of the fieldwork her mother underwent treatment for cancer. There is another sibling of primary school age whom it was advised had developmental problems.

• Sam, who is 13 years of age, is Kate’s sister and they work as a close team in managing the caring situation described above.

While it is stressed that young carers do not consider household and caring chores to be the important part of being a carer, it may be useful to provide a brief overview of what is most commonly involved. Household tasks such as cooking and cleaning was the common role undertaken by all the young carers. In some cases, dressing, toileting and showering were involved, as was the administration of medication. For those young people with siblings with disabilities there was also usually major disruptions to sleep and a requirement for close and constant monitoring of their sibling. In addition to these physical caring tasks, in situations where the parents had mental health issues, the young
people were required to perform a more complex role in ‘counselling’ and providing emotional support. This occurred to a varying extent with Jonathon, Rebecca and Emma.

A description of the general characteristics of the group of young carers will provide further context for understanding their lives and experiences. In almost all cases the young people are in single parent families. Firstly, it would seem that in two parent families (i.e., two adults present), the imperative for a child to become a carer does not usually exist, or at least not in the terms of being labelled and registered with service providers as a ‘young carer’ so as to come into focus for this project. It was also evident that in families with profoundly disabled children the parents had very often separated, which in one case was attributed by the young carer (Liam) to the stresses that can be inherent in such a situation. Young carer families are also, in general, quite poor. There are usually no adult income earners in the family, with the parent being on a disability pension or a carer allowance, and in many cases there was a heavy financial burden from the cost of medication and medical care. With one or two exceptions, the low socio-economic status of young carer families was very evident from my presence in the family home for extended periods and was also commented upon by many parents and young carers. It was a concern for a number of parents that they were not able to provide their children with ‘normal’ teenager accoutrements. This accords with the research literature which has reported that young carers are predominantly situated in families of low socio-economic status, most particularly single parent families without a member of the household in the workforce (e.g., Keith & Morris, 1995). It is important to record that these families have not always ‘inherited’ this low socioeconomic status. Mitchell’s mother, for example, possesses post-graduate qualifications and prior to her illness had worked as a manager for a very prominent company. While families of a certain affluence can no doubt afford to pay for private care, the context of disability and illness,
as well as an apparent lack of social support and services, should be understood to be the root cause of this poverty.

Brief mention should be made of the much larger number of young carers with whom I was involved when working as a volunteer for the Respite Centre and attending young carer camps and activities. From my interaction and discussions at these events, as a generalisation, it can be suggested that the young people attending these functions appear to be similar to the twelve carers who were working directly with the research; that is single parent/guardian families of low socio-economic status. There was however one notable difference: those young people attending camps usually seemed to be in less difficult caring situations than those who directly worked in this research. For example, the constraints of the caring situations would at most times make it extremely difficult, if not impossible, for carers like Jonathon or Mitchell to be away from home for four days to attend a camp. It can therefore be argued that young carer camps are largely not supporting those young people who most need support, an issue that is discussed in Chapter 8. Conversely however, it was the case that Melissa, Emma and Allison, who all seemed to have very difficult caring situations, had at one time attended a young carer conference and are exceptions to the generalisation.

In discussing the profiles of the young people, it is appropriate at this point to again reiterate that the research did not seek to pursue notions of representativeness of participants as found in quantitative research. However, while this research does not seek to present a representative account of young people caring in some way for a family member, it is suggested that the characteristics of this group of young people would be common amongst young carers who are accessible to researchers. Families of low socio-economic status are most likely to be in contact with a respite centre (or welfare and support agencies more generally) and, not surprisingly, were overwhelmingly represented
in the recruitment process. While it was conversely noted in the literature review that some researchers have found that families that are ‘doing well’ are more willing to be research participants (Chapter 3), this did not appear to be the case for this research. It was also argued in the literature review that an unstated assumption underlying young carer research is the primacy of a ‘normal, Western childhood’. This raises the issue of participants from culturally diverse backgrounds and from the Indigenous community. It has been suggested that young carers in families from a non-Western background are more often ‘hidden’ because of cultural factors (Smyth, Blaxland, et al., 2011) and hence will be less accessible through respite centres. In my involvement as a volunteer at young carer camps and activities and during the recruitment process no Indigenous young people or those from a non-Western background were knowingly encountered. It is understood that during the two years over which the fieldwork was conducted, the Respite Centre had no ‘active’ young carers registered who were Indigenous or from a non-Western background. This outcome, suggesting that some groups of young people are not being identified as carers, accords with the discussion in Chapter 1.1.3 about ‘hidden’ young carers. This important issue is, however, a subject for another research project. For this project a focus on representativeness would misunderstand the nature of the research. Those volunteering represented a sample of young people who are carers for whom the research sought to develop a deep and extensive account of their experiences.

6.1.5 Conduct of meetings

Before discussing the specifics of each of my interviews with young carers, it would be useful to provide some general comments on the conduct of our meetings. Firstly, all stages of the research, including meetings, were the subject of ethics applications approved by the Human Research Ethics Committee of Charles Sturt University. This ethics approval process was a constraint in terms of conducting exploratory and emergent
research. With each stage of the research emerging from preceding work, it was not possible to anticipate or pre-plan what ethical considerations would need to be addressed. As a result, it was necessary to prepare, and have approved, multiple new ethics applications as the project progressed. While ultimately this was not overly problematic, it did impact on the timeline of the fieldwork and, more significantly, it impacted on the flexibility of young carers and their families in terms of their participation and arranging times for our meetings.

For all meetings, each young person was asked to nominate their preferred location, date and time for the interview so as to minimise inconvenience for them, as well as to provide an environment for the interview where they feel most comfortable. All except one young person chose their own home.

Prior to the commencement of each meeting, the relevant Information Sheet and Consent Form were read by the young people (and their parent/guardian where necessary) and the opportunity provided for questions to be asked. Once the young carers had confirmed their agreement to participate, they were asked to sign the Consent Form. Six of the young people were under 16 years of age and in these instances the Consent Form was co-signed by their parent/guardian.

6.1.6 Stage 1: Consultation discussions

The initial stage of working with young carers involved consultation discussions to obtain their input into how to conduct the research: to elicit ideas on research design and methods, topics they considered most significant and important that might be pursued in the research, how they would wish to participate and the terms of their participation in the research, and general thoughts on the appropriate way to proceed. This is similar to the process followed by Bagnoli and Clark (2010). As was touched upon in the previous

12 This number declined to four over the course of the fieldwork as two carers turned 16 years of age.
chapter, it was thought that some consultation discussions might take place in small
groups in order to lessen the voice of the researcher, but this turned out to be logistically
impractical as most were from a diverse geographic area. In any event, almost all the
young people specifically chose individual meetings in their homes, presumably so that
their caring responsibilities and other activities were less disrupted.

These initial discussions were not audio-recorded. As this was the first acquaintance with
most of the young people it was felt that the absence of recording equipment would make
the discussions less formal and better facilitate open discussion and relationship building.
Although it was specifically stated in the Information Sheet and Consent Form
(Appendices B-1 & B-2) that they would not be required to discuss their own family and
caring situation at this initial stage, most chose to talk about their own caring role, and
some were clearly very anxious to discuss their experiences in detail. This openness by a
number of young people was indicative of their mostly high level of engagement
throughout subsequent stages of the research.

These initial rounds of consultation discussions were used to inform the research plan for
the following stages. Based on the preferences expressed by the young people about how
they wished to participate in the research, a further Ethics Application was submitted and
approved for the next stage of the fieldwork, as outlined in section 6.1.7 below.

6.1.7 Stage 2: Working with young carers
This stage was the primary data collection process for the research, building on the
outcomes of the initial consultation interviews. All twelve young people expressed the
firm preference to be involved in the research through a series of one-on-one interviews.
In order to provide the space for the young people to pursue issues of interest and
concern to them as carers, the interviews were largely unstructured. The young people
were invited to ‘drive’ the interviews and I tried to limit my questioning to enhancing my
understanding of the issues they were raising. For some of the very young and more introverted carers it was however necessary at times to be more intrusive in order to encourage fuller discussion. These discussions were audio-recorded for transcription. The Information Sheet and Consent Form, as approved by the University’s Ethics Committee, are at Appendices D-1 and D-2.

6.1.8 Stage 3: Analysis work with young carers

After the Stage 2 discussions it was necessary to then consider how to involve the young people in the analysis, which was an important aspect of the collaborative nature of this project. It was evident at this point that it would need to be done individually because of their diverse physical locations. It was also considered impractical and inappropriate to ask the young people to analyse voluminous raw data because of the imposition on their already limited time. After reflection, it was decided that the best approach would be to prepare for their consideration a preliminary analysis of the data that emerged from the first two interview rounds and my volunteer work with the Respite Centre and related activities.

This preliminary analysis was presented to the young people as being a very tentative overview (which it was) so as to allow space for them to feel unconstrained in providing feedback. As an aid to this collaborative process, a list of questions was compiled from the preliminary analysis to form a basis for the discussion, a copy of which is at Appendix G. This also included some questions which sought their views on the previous research literature, as well as the methodology used in this research. It was thought useful to provide the young people with the questions prior to our discussions, enabling them the opportunity to more fully contemplate their viewpoint and responses. Interestingly, almost all declined to receive the questions in advance, offering various explanations. By way of example, Stephen and Jack both stated they did not wish to “overthink” the issues
and Liam similarly said it was “better if I’m unprepared”, which was perhaps another way of saying they considered their spontaneous thoughts would be of more value. While the offer was made, it was not ‘pressed’: even aside from the collaborative nature of the research, I was conscious of the value of our previous informal and relaxed discussions and that it may have been counterproductive to engage in what may have appeared to have been a more formal process with a ‘homework’ component. Those young people who did not receive the questions beforehand were given a lengthy opportunity prior to the commencement of discussions to consider them. It eventuated that the young people preferred a number of approaches, ranging from me ‘walking’ them through the questions (Mitchell) to others studying the questions in detail and repeating the process to ensure that they had exhausted their views on each of the issues (Emma). This outcome is viewed as a positive in allowing each young person to engage in the discussions in a manner that was most comfortable for them and most suitable for their age and associated verbal and comprehensive skills.

6.1.9 Discussions with ‘cared for’ parent/guardian

In the consultation interviews (Stage 1), seven young carers suggested that it would be valuable to interview their parent/guardian so as to gain additional insights into the experiences of young carers. These interviews were held subsequent to the interviews with young carers in order to enable their views to inform the preparation of an interview guide that were the basis of discussions with the parent or guardian.

The recruitment of the ‘cared for’ family member was approached through my existing involvement with the young carers in the family. In the two rounds of interviews with the young carers and during my volunteer work I had met and established relationships with most family members (which was of course mandatory where the young carer was under 16 years of age and the consent of the parent/guardian was required). While ‘cared for’
parents and guardians do of course have an illness or disability, there is no suggestion that they are not capable of providing informed consent, either in respect of themselves or their children, as they continue to act as the parent or legal guardian in the normal manner. These issues were canvassed in an Ethics Application approved by the University's Ethics Committee. The Information Sheet and Consent Form for these parent/guardian interviews are at Appendices E-1 and E-2.

As was the case for their children, the parents/guardians were also invited to nominate their preferred location, date and time for the interviews. With one exception, they also choose their own home, which was likely due in large part due to them having an illness, a disability, or were frail. It should be stressed at this point that the ‘voices’ of young carers are overwhelmingly the focus of the research, and the use of data from the parent/guardians interviews was limited to providing context and to assist in the understanding of the material provided by young carers.

6.2 Working collaboratively

The methodological aims for this research were outlined in detail in Chapter 5. A major focus in seeking to work collaboratively with young carers was to ensure, as far as possible, that it be ‘driven’ by the young people. In the first instance this involved the young people being free to choose the level and duration of their own involvement in the project. It was expected that the level of commitment by the young people would vary considerably (Treseder, 1995). Young carers were offered the opportunity to have ongoing involvement throughout the research as it evolved, but at the same time it was recognised that some young people may wish to limit their involvement to an initial discussion, while others may wish to remain involved to varying degrees throughout research. Accordingly, the young people were free to decline to be involved in any particular discussion/s or to withdraw completely from the project at any time, including after the initial discussion. The young people were also told that if they did choose to
withdraw at any point, they would also be free to rejoin the project at any stage. It was
the intention that this group of carers would be supplemented with further recruitment as
required. These conditions were part of the ethics approval process and were included in
the Information Sheet and Consent Form provided to potential participants.

However, it eventuated that all 12 young people remained working with the project
throughout the duration of the 13 months over which the interviews were conducted, with
the exception of one young person who declined the final interview. Accordingly, it was
not necessary to supplement the group with further recruitment. This continuity of the
involvement of these twelve young people is considered to have been a significant
advantage in terms of building relationships and trust and strengthening the collaborative
foundation of the research. This was also reflected in the increasing openness of the
young people over the course of the research, particularly in regard to their discussion of
personal and family difficulties. This conforms with the comment by Liamputtong (2013)
that ongoing research will be more productive than ‘one-off’ events.

It was considered to be a positive outcome that all but one young carer chose to meet in
the family home. This is argued to make the participants feel more comfortable and more
in control (Liamputtong, 2013) and so may have contributed to the disruption of the adult
researcher-child participant divide. Importantly, it also provided the opportunity to
observe the young carer and their families in their homes. This provided context and
enabled valuable insight into the nature of the caring situation, the role of the young
carer, and family dynamics and relationships. In many cases it provided the opportunity
to observe very graphic demonstrations of what can be interpreted as ‘being a young
carer’. This included, for example, Jonathon skilfully ‘managing’ his parent’s emotional
unpredictability, Liam seemingly adopting an adult parent role in relation to his brother
who has autism, and Emma’s complex relationship with her ‘cared for’ mother. A
detailed discussion of my reflections on what I have termed ‘Being a young carer: Performativity’, forms part of the analysis and is in Chapter 9.5.

6.3 Engagement with young carers

Participatory research requires disruption of the power differential (R. Fox, 2013; Punch, 2002). Accordingly, a primary consideration was how to best engage with the young people. From the very first conversation I was open and candid with the young people about the participatory/collaborative expectations for the project with the view to providing the space for them to take a lead role and to initiate and drive discussions (Treseder, 1995). During all meetings with young carers there was an ongoing dialogue that sought to conscientise and to reinforce the expectation of a young carer’s ‘standpoint’ that is independent of the views of adults and services providers.

Discussions were informal, unscripted, and with the minimal appearance of note-taking (as suggested by Bagnoli & Clark, 2010; Vromen & Collin, 2010). This approach was adopted to provide a relaxed and flexible setting for the discussions, enabling the young people to speak openly and so aid the construction of collaborative interactions.

There is a difficult balance to be achieved between allowing young people the space to develop critical ideas about research methods, unhindered by existing dominant views, while also providing them with required information about the context of the project. In particular, it is recognised that young people may not be cognisant of the possibilities of participatory research, and be more likely to hold assumptions that reflect traditional research methods. Accordingly, possible methods were ‘floated’ in a way that sought to be neutral. This was done with the knowledge and experience gained in my past research with young carers (Watson & Fox, 2014) wherein they demonstrated a remarkable capacity to articulate deep insights into their lives and experiences as a family carer,
including the capacity to appraise the dominant notions of young carers portrayed in the literature.

I considered it to be particularly valuable to be able to work with young carers and the Respite Centre over such an extended period. The primary focus of much academic research is on literature and discussion of theory and, while not dismissing its importance, I would argue that the balance is often disproportionately skewed away from actual work with the people being researched. This research sought to achieve an appropriate balance as far as possible between theory and fieldwork. Prolonged fieldwork that enabled immersion into the home lives of young carer families, coupled with careful reflection and analysis, was considered to have the greatest potential for providing insights into, and understanding of, their experiences. It was recognised that immersion in prolonged fieldwork has the potential to inhibit the capacity to ‘stand back’ from, and question, the process. This was mitigated to some extent by allowing for a reasonable ‘break’ period between the three stages in order to reflect on both the emerging outcomes and fidelity to the collaborative aims of the research. This circular process of interlinking practice and theory (praxis), where each informs the other, was an important aspect of the ongoing development of this approach to conducting research with young carers.

Allowing the young people to take control of the process to the extent they were able or felt comfortable, was both unnerving and exciting, but was an important part of pursuing a young carers’ standpoint and fostering collaboration. Relinquishing some control of the research and the resultant uncertainty about its direction helped to diminish the power of the researcher as well as providing the environment where the new and the unexpected could emerge. This was of course of underlying importance to the poststructural aim of uncovering assumed and taken for granted knowledge. The value in seeking to relinquish control is suggested by the enthusiasm with which some of the young people embraced
the research. While most interviews went much longer than was planned, some young people largely took control of the interview and discussions extended beyond three hours.

In order to maximise my engagement with the young people it was also important that I was mindful of their possible expectations for the research. While I was completely open and forthright in explaining my plans for the research in the recruitment process, it is not possible to know exactly what expectations the young people had for the fieldwork.

While the young carers all volunteered, the level of engagement ranged from extreme enthusiasm to more muted, passive involvement. While the fieldwork was the most important thing happening in my life at that time, I was very conscious that this would obviously not be the case for the young people, regardless of how committed they were to the research project. Accordingly, I sought to manage my own expectations when, not surprisingly, their level of engagement and preparedness for an interview varied markedly, both between different young people and with the same young person at different interviews.

This variation in engagement brings into focus a further consideration. An important component of my engagement with the young carers was trying to be cognisant of the status of their family situation when both arranging and attending the home for interviews. On four occasions I gauged that the family was experiencing difficulties and proposed a postponement of previously arranged meetings, which was welcomed. On two occasions this occurred after I arrived at the family home. Demonstrating flexibility and understanding of the volatility in the family life of young carers was an important component of my engagement with the young people and one that seemed to be appreciated by the families.

The status of the family situation at the time of any particular meeting had important ramifications. It impacted on how ‘free’ their thoughts were, or whether they might be
pre-occupied with a serious family difficulty. Some families seemed to be on a roller coaster between ‘better times’ and crisis. For example, I arrived at one young carer’s home for a meeting to learn that his mother had just taken seriously ill and been hospitalised. While on the one hand he was presumably stressed by the event, he also seemed buoyed by his freedom from the responsibility of caring for his mother, at least in the short term. The young carer insisted that our meeting proceed. While this particular situation with this family was known, for many other interviews the family situation is known only to the extent that it might be inferred from the conduct of the interview. The difference in the engagement of both Rebecca and Mia in one of their three interviews was so striking as to strongly suggest that there were significant issues occurring in their lives at that time. The fact that the young carers will be in ‘different places’ at different times does add a complexity to interpreting and analysing the data. It does not however make the analysis less valid and is fully consistent with the epistemological position of this research. Detailed discussion of this issue is included in Chapter 7 (Methodology of analysis and the construction of knowledge).

6.4 Summary

The purpose of this chapter is to provide a clear and transparent understanding of the method and processes that were followed in conducting the fieldwork for this research. It has sought to provide context for the conduct of the research and context for understanding the lives and experiences of the particular young people who worked on the research. Importantly, this chapter has also sought to provide an understanding of my engagement with the young people and in particular how they were respectfully positioned as being central to the research and as the ‘experts’ of their subjective experiences.
PART IV

METHODOLOGY OF ANALYSIS

Chapter 7: Methodology of analysis and the construction of knowledge
Chapter 7: Methodology of analysis and the construction of knowledge

7.1 Introduction

This chapter sets out the position of this research on discourse, discourse analysis, and the process of analysis and the construction of knowledge that was adopted. The first section outlines my approach to discourse and extends into a discussion of Foucauldian Discourse Analysis (FDA) and its applicability to the research data. The second section steps through the process of the analysis and the construction of knowledge, detailing the ‘mechanical’ steps undertaken and, most importantly, the discussion seeks to make transparent the context of the analysis and the assumptions that underlie the analysis.

7.2 Discourse and discourse analysis

7.2.1 Discourse, knowledge and power

My approach to discourse is, in large part, informed by the writings of Foucault. The section extends the general discussion of Foucault’s work that was outlined in Chapter 2 (Theoretical literature). As has been discussed, Foucault provided a fundamental rethink of discourse which is very different from what had previously been the domain of structural linguistics (McHoul & Grace, 1992). The central aspect of Foucault’s theory of discourse is that power and knowledge are inextricably joined together: power and knowledge always imply one another since knowledge creates and reproduces power, and vice versa (Foucault, 1980a).

Discourses are considered to be sets of meaning which form to construct objects as well as subjects. Constructed objects are spoken about having some sort of ‘reality’ or ‘truth’. The notion of ‘objects’ is not restricted to physical, concrete items as might be commonly thought, but can refer to objects that are constituted or given a ‘reality’ by discourses
(Parker, 1992). For example, a theological discourse might create the soul as an object; a discourse on school discipline might construct regulations and rules as objects.

It follows therefore that discourses used to describe ‘reality’ are not always reflecting intrinsic and defining features of entities, but rather “bring into being the objects they describe” (Willig, 1999, p. 2): language constructs rather than represents (a fuller discussion of social constructionism and the critical realism epistemology I have adopted for this research was provided at Chapter 1.2 – Standpoint of the research).

“the will to exercise dominant control in society and history has also discovered a way to clothe, disguise, rarefy, and wrap itself systematically in the language of truth, discipline, rationality, utilitarian value, and knowledge” (Said, 1984, p. 216).

The above quote from Said artfully encapsulates the relationship between discourse and power. By making available “ways-of-seeing and ways-of-being”, discourses have important implications for how power emerges (Willig, 2001, p. 113). Discourses determine what is considered to be true and false in a particular field. Foucault describes discourse as sets of meanings which create opportunities for forms of power through processes such as shaping, regulating, and normalising: subjects are often constructed as normal-abnormal and qualified-unqualified within a discourse (Dreyfus & Rabinow, 1982; Foucault, 1980a). The concept of the ‘norm’ is used to evaluate and control people and to exclude those who do not conform to ‘normal’ categories. This is evident, for example, in discourses from developmental psychology where the ‘truths’ about children are presented (i.e., disguised, clothed, wrapped) in a discourse of knowledge produced by rigorous logic and rationality: this in turn provides the power to test and rank, and decide what is normal and abnormal (as discussed in Chapter 4.3). It is argued that the discourses that are the strongest are often those that seek to base themselves on scientific ‘truth’ and what is ‘natural’ and ‘normal’ and those of most significance to this research, which concern childhood and family, are some of the most dominant in Western culture.
Dominant discourses benefit those versions of ‘reality’ that maintain the status quo and it is very difficult to think, act and speak outside of these dominant discourses – a situation that has been argued to exist in relation to young carer research (Chapter 3).

The construction of subjects “make available positions within networks of meaning that speakers can take up (as well as place others within)” (Willig, 2001, p. 116). The subject positions people inhabit have implications for subjectivity and experience, providing certain rights and parameters for what people are able to say, think and act; that is, what is made possible and what is limited by this subject position. Positioning provides a perspective from which to view versions of reality. Willig (2001) gives the example of the subject position of patient within a medical discourse: the patient is positioned as a passive recipient of care under the direction and control of qualified experts. An example from this research might be to consider what experiences are compatible with being positioned as a compromised child carer or a member of a ‘not’ normal family?

It is difficult to resist dominant subject positions and there are negative ramifications for persons who are unwilling or unable to inhabit them. A parent who is unable to meet all the stipulations constructed for the subject position of ‘protector’ of their children (Wilbraham, 2004); that is, a good parent, will experience disapprobation and potentially face a legal apparatus that judges parenting (as was discussed in Chapter 1.1.5). People attempting to speak and act from outside the dominant subject position are marginalised; either constrained from speaking or not heard. It was discussed in the literature review (Chapter 3) that researchers and welfare bodies have constructed a dominant and negative subject position of a young carer as a compromised and tragic child. It was also discussed how young people resisting this negative subject position were constrained from discussing positive aspects of caring, and so their experiences went unheard and
were excluded (O'Dell et al., 2010). In a practical sense, there is also pressure to conform to the negative subject position of young carer to ensure services and support.

An important aspect of a Foucauldian approach lies in being able to ‘take apart’ dominant paradigms which have the potential to reduce problematic power. This is not to assume that a reality can be described and Foucault is not claiming that analysis is about establishing a final truth, but rather it is to question the truths that have come to be taken for granted and to “examine the discursive processes by which true and false statements become distinguished” (Willig, 1999, p. 10).

### 7.2.2 Discourse and Foucauldian Discourse Analysis (FDA)

Given the poststructural standpoint for this research, the ‘critical’ review of young carer research literature, and the preceding discussion of a Foucauldian perspective of discourse, my approach to discourse analysis is also informed in large part by the writings of Foucault, and more particularly as framed by Parker (1992, 2005) and Willig (2001).

This section will first expound on the rationale for the choice of FDA and its applicability to this research. While there are a number of other approaches to conducting qualitative analysis, other methodologies and methods were considered unsuited or problematic in relation to the standpoint of this research. The other major approach (apart from FDA) is the discursive analysis of Potter and Wetherell (Willig, 2001). It is appropriate to briefly mention why the latter approach has not been adopted for this research. Discursive analysis takes the position that participants use language as a tool or strategy to achieve interpersonal objectives. This position points towards an individualising account and as such does not accord with the epistemological position of this research. In addition, given the focus of discursive analysis on written or spoken interpersonal interactions, I would argue that Foucauldian analysis engages discourse at a more significant level for this
research. Foucauldian analysis provides for questioning the relationship between discourse and subjectivity and it is concerned with the relationship between discourse and practice (what can be done) (Willig, 2001). I consider these to be important factors for exploring the experiences of young carers.

As noted, a Foucauldian approach to analysis does of course also accord with my poststructural objective of questioning and challenging the ‘common-sense’ and taken-for-granted knowledge and assumptions about young carers, childhood, young people, parents, and families on which much of the mainstream research on young carers is founded. The Foucault approach questions how a particular phenomenon ‘came to be’ and provides for the deconstruction of dominant paradigms – how they have been created, elaborated, reified, and made to seem natural and to be taken-for-granted. A further important aspect of Foucault’s approach to discourse for this research is his focus on historical examination to uncover how discourses have evolved over time and to understand how the present taken-for-granted assumptions developed (as outlined in Chapter 2). The significance of these historical concepts to this research can be seen in my examination of the concept of childhood from a Foucauldian ‘genealogical’ perspective (see Chapter 4.2), which was a significant influence on my understanding of young carer discourse. As Parker (1992) has noted, discourse analysis must locate its objects in time and history.

In the discussion of Foucauldian Discourse Analysis, Parker (2005) has argued that searching for the contradictory, the unexpected, and what is different about what is being said, is fundamental to discourse analysis. Parker (2005) also describes searching for difference in a given text, and for points of contradiction and conflicting accounts. This is considered by Parker to be more important than searching for conformity, which is obviously the reverse of analysis in traditional research. These considerations support the
applicability of a Foucauldian approach to analysis of the young carer data. Indeed, it is argued that the choice of FDA for this research was informed by the young carers and driven in large part by the nature of the material that emerged from the fieldwork. The rich, diverse, contradictory and nuanced accounts that characterise the very detailed conversations with young carers could not be properly explored with a method of analysis other than FDA.

The nature of the research material was also a consideration. Importantly, FDA is not restricted to written and verbal forms, but can be applied to material that has “any tissue of meaning which is symbolically significant for a reader” (Parker, 1999, p. 4). Parker notes that discourse analysis can be applied to forms as diverse as an LCD Christmas game, bus tickets, fashion and architecture (Parker, 1992, pp. 6-7). The major focus of this analysis is the transcripts of the discussions with young carers, but other materials were also reflected upon, such as meeting notes with young carer agencies and organisations as well as my observations and interactions with young carers that have been recorded in my field diary. The analysis seeks to capture not just the content of the interviews, but also the performativity of the young people and the insight that this provided into ‘being a young carer’. The term *performativity* is used here with reference to what might be inferred from my interactions with and observations of the actions of the young people in their family home in the role of carer: this provides an understanding beyond their spoken words which is indicative of ‘being a young carer’\(^\text{13}\). Given the importance of institutional discourse to a Foucauldian approach, a further focus for the analysis was my interaction with government officials and respite centre staff, as well as the relationship between discourse and institutional practices.

\(^{13}\) The notion of *performativity* adopted here draws in part upon Butler’s work and her Foucauldian reading of the concept. Butler refers, inter alia, to actions, behaviors, gestures, and ways of speaking that enacts and consolidates a particular phenomenon (J. Butler, 1990).
It is also pertinent to discuss the use of FDA in relation to the research being grounded in a desire to make a positive difference for young carers. It is acknowledged that poststructural approaches have been criticised for being ‘un-empowering’ and have been characterised as “almost seems to mean ‘say what you like’” (Kagan et al., 2011, p. 12). As was noted in Chapter 1, poststructural approaches have also been questioned for their capacity to develop research methodologies and practices that can deliver on their aim of pursuing social justice (Goodley & Parker, 2000). I would however argue that FDA can provide a clear mechanism for empowerment and resistance and, in turn, the furtherance of social justice objectives. It is important to first distinguish my use of the term empowerment from the degraded concept that is prevalent in mainstream social sciences and welfare agencies which represents little more than a patronising exhortation for individuals to “pull themselves up by their own bootstraps” (McCubbin, 2009, p. 311). Notwithstanding possible good intentions, claims of empowerment often involve, at best, no more than condescending ‘helping’. I would also strongly argue that traditional research methods involving ‘subjects’ under the control of ‘expert’ researchers imposing their understanding of their world, as well as seeking to benchmark individuals against problematic notions of normal, is the antithesis of empowering research.

The poststructural approach of this research goes much further than a simple and vague notion of trying to help or being ‘on the side’ of young carers – it seeks to deconstruct and ‘take apart’ the discourses that affect the lives of young carers. By unmasking the constructed (and usually hidden) nature of phenomenon and identifying counter discourses, space is created for the telling and hearing of alternative understandings of what are taken to be ‘common-sense’ and essentialist ideas about young people, young carers and families. Willig (1999) has provided an extended argument for the use of discourse analysis as social critique, to empower by repositioning the subject and identifying counter discourses, and serve as a guide to reform. Furthermore, as has been
argued in Chapter 5, a collaborative/participatory approach which seeks to blur the divide between researcher and participants is an important component of research that seeks to empower.

Finally, it is important to acknowledge that Foucauldian analysis is always interpretative and that there are other perspectives from which analysis can be conducted and other epistemological and methodological standpoints from which to view material. The point however is that the version of ‘truth’ being pursued in this research is based on a different set of epistemological and methodological principles from previous research; positioning young carers as the experts of their own experiences, to make them central to the process, and produce outcomes that emanate much more directly from young carers.

Conducting Foucauldian discourse analysis

As has been well canvassed, there are no set rules or procedures for conducting FDA (e.g., Arribas-Ayllon & Walkerdine, 2008; Hook, 2001) and very few descriptions of carrying out actual methods of this form of discourse analysis. However, there are assumptions and considerations that are important to my approach to conducting FDA and the constructing of an account, which follow on from, or build upon, the preceding discussion.

A number of these points are drawn from the ‘criteria’ set down by Parker (1992), which in turn implicitly draw upon the work of Foucault. As has been discussed, discourses are considered to be sets of meaning which form to describe something which becomes an object: the object then comes to be spoken about as having some sort of ‘truth’ or ‘reality’. Discourse analysis is about discourses as objects. Consistent with the critical realism epistemology that I have adopted, some objects are seen as existing only as discourses, while other may have an independent reality outside discourses, and given another reality by discourse. The analysis is directed at concepts or notions about young
people, young carers, and families which become constructed through discourse, but appear as ‘truth’ and ‘reality’.

As outlined by Parker (1992), an important focus of the analysis is the examination of the various subject positions that emerge and consideration of what is made possible and what is limited for the young carers by these subject positions. The analysis must consider what discourses are ‘doing’ – what ways of speaking, thinking and acting become limited or available within particular contexts and discourses and how they create performances. This includes being mindful of what has not been said. This refers to what is impossible or unreasonable to talk about from within the subject positions of young carer or child. The analysis must consider the possibilities for control, resistance and compliance, and seek to understand what is being achieved and what purpose is being served by particular discourses and subject positions.

As has also been outlined by Parker (1992) and Willig (2001), an important focus is the way in which a discourse is located within other discourses and so the analysis examines the interrelationships, contradictions, and tensions between different discourses. For this research, this includes young carer discourses, child/adolescent discourses, familial discourses, and disability discourses. As previously mentioned, a further important focus for Foucauldian analysis is what is considered to be the powerful and dominating impact of institutional discourse (Parker, 1992). Accordingly, this analysis considers the institutional discourses (and practices) that function in relation to children, young carers and families.

I am also mindful that while young carers all share a common experience of caring for a family member, they are not a homogenous group and there is a wide divergence in their personal and family situations. The analysis aimed to ‘hear’ and capture the experiences
of all the young people and, as already noted, to be alert to differences and contradictions.

As has been outlined above, Foucault’s theories and understandings of discourse and discourse analysis, as elaborated upon by Parker and others, have informed my approach to the analysis for this research. I consider this approach to be the most consistent with my epistemological position (which has also been influenced by Foucault) and to be the most productive, given my aims for this research. My application of FDA to this research and the process of analysis is described in detail in the next section.

7.3 Analysis and constructing knowledge

7.3.1 Introduction

This section details the approach to analysis and the construction of knowledge that was developed for this research. It follows on from the preceding chapters and section and leads into and provides the foundation for the analysis that is presented in Chapters 8 to 12. In order to produce rigorous and persuasive analysis it is necessary to locate the research and the construction of knowledge in its context: this is described by Burman (2004) as “the stance from which the analysis is conducted” (section 4, para. 2). This context includes the literature which has influenced the research and the epistemological and methodological considerations that have been discussed in the previous chapters. Most importantly, the section seeks to make transparent and visible the processes that were central to producing the analysis; that is, the process of putting into practice the preceding theoretical discussion of FDA with the material co-produced with the young carers for this research. It will discuss the focus of my analysis and the assumptions behind what has been targeted in the analysis. The section will explicate why my approach to analysis and constructing knowledge is rigorous and why it makes for important research.
The section first provides an overview of the nature and extent of the data collected during the fieldwork. This is followed by a discussion of the transcription of interview recordings and immersion in the data. The process of analysing and developing the account is then discussed. This includes the integral role of critical reflexivity in that process. In order to further aid transparency, the chapter concludes with some brief illustrative discussion of the main considerations that underlie my analysis from which some major discourses emerged.

7.3.2 The research data

In keeping with the underlying rationale for the research, the primary focus of the analysis was the interview transcripts with young carers; that is, to listen to and understand their ‘voices’. I have also drawn on the diary I maintained over the two years of fieldwork. This included notes on my attendance at young carer events and, importantly, my observations, thoughts and impressions about each of my meetings with young carers, as well as descriptions of my subjective experiences as a researcher. I recorded instances where I was surprised by unexpected comments and actions by the young carers, as this was indicative of challenges to my own pre-existing assumptions. These field notes are not considered to be either comprehensive or conclusive, but rather are a subjective reflection on what I experienced at that particular time and in that particular situation. The notes provided useful context for issues that emerged from the analysis. For example, entries drew attention to ways the young people were often in a ‘different place’ at different times during the fieldwork (the significance of this variability is discussed in section 7.3.4). They provided important material for my understanding of the ‘performativity’ of young carers (as will be discussed in Chapter 9.5). The field diary also served as a valuable reference point for my evolving understanding of the experiences of young carers and for reflexivity about these changes in understanding.
My field diary included notes of my meetings with government officials and respite centre staff which contributed to constructions of the institutional structure within which the young people experience being a family carer. The transcripts of interviews with the parents of young carers were used to a limited extent to provide some context to their (young carers’) experiences and in relation to some specific discourses, such as the adult-child binary and the Western family. However, the focus of the analysis remained overwhelmingly the ‘voices’ of young carers.

The data collected totalled 595 pages of transcripts from the recorded interviews, 39 pages of notes made after the (unrecorded) initial consultation round of interviews, a field diary of 67 pages, and 24 pages of notes on meetings with staff and officials from respite centres and government agencies, as well as those taken on young carer trips and activities. There were also a small number of emails and documents that emanated from my interactions with respite centres. This inventory of data produced is not listed to attach undue significance to ‘quantity’, but rather to acknowledge the extent of the input of young carers once they were provided with the space to more freely pursue issues that were of interest and significance to them. As a consequence of the amount of data collected, not all potential themes/discourses could be included in the thesis. The issues ultimately pursued were those considered to be the most significant to the lives of young carers: this consideration was in turn directly influenced by the views that emerged from the discussions of young carers about the preliminary analysis (Stage 3).

7.3.3 Immersion in the research data

The transcription of the recorded interviews was performed by me and, when possible, within days of a particular interview. This provided valuable immersion in the data. I made notes throughout the transcription of any emerging thoughts and ideas that might be significant in later analysis work. It was also useful in considering my performance in
the conduct of the interviews so as to assist me in subsequent interviews. Thoughts on ways in which I could change my own actions and performance during future interviews were also recorded in my field diary. This included consideration of the level of engagement with the young person (and their family) and the extent that the collaborative aims of the research were being met. A particular focus of this reflection was my interaction with the younger children and whether the level of my discussion and use of language was appropriate to stimulate their engagement and participation. This was a particularly important focus during the first round of discussions when my relationship with the young people was in its infancy.

After the completion of the first two stages of young carer interviews and the parent interviews, I immersed myself in the transcripts, re-reading them multiple times, making notes and generally making myself thoroughly acquainted with the data. As has been well canvassed in earlier chapters, a major aspect of the collaborative aim was to have young carers involved in the analysis. It was felt that taking transcripts back to the young people for some sort of analytic work was too onerous: they are time poor and this would likely have been counter-productive to the engagement of young carers in the research. Instead the decision emerged to first produce a tentative, preliminary analysis. This was a very considered decision: presenting a full analysis may have given the impression that outcomes had been settled before being considered by the young carers, impairing collaboration. It was also an emergent decision to present this preliminary analysis to the young carers in the form of written questions. This provided a focus for the discussions and something concrete the young people could consider and disagree or agree with as they felt appropriate. As was discussed in more detail in Chapter 6, the questions were offered to the young people prior to our meetings so they could be contemplated at length if desired. These decisions were based on what was thought most effective to engage with the young people and facilitate discussion and feedback. This approach also
recognised that the young people ranged in age from 12 to 17 years and had different skills and preferences.

Following the completion of the Stage 3 discussions on the preliminary analysis, I engaged in a thorough and very deep immersion in all the data. NVivo, a computer software package developed for qualitative data analysis, was used to code the data. It was useful for coherently organising the very large amounts of material gathered during the project. It was also useful for being able to return time and again, after reflection, for further analysis. It was not however used as the exclusive tool in the analysis, but rather as an aid. I was conscious of not being excessively guided by the software so as not to produce a ‘mechanical’ construction of knowledge, given its many quantitative components. The coding was not solely limited to deciding that a piece of text was important because of a particular word or sentence, but rather the context of surrounding discussion was also a factor.

During the early stages of the analysis I simultaneously re-read theoretical writings that were important to the research (that were discussed in Chapters 2, 4 and 5). This was to ensure that I remained grounded to the theoretical basis of the research, as well as to assist in providing some distance from the emotional content of the interviews and move my ‘headspace’ from two years of fieldwork. It is also argued that simultaneous engagement with the theory and the process of analysis is an important component of the construction of knowledge. While it is obviously fundamental to consider the research material in the context of the theory, it is also important to reflect on the theory in light of the material that is emerging from the analysis: that is, allowing the theory and the research material to reciprocally inform each other. Critical reflexivity was fundamental throughout the process of analysis and constructing knowledge. Maintaining the diary during analytical stages was an important component of the reflexive process.
7.3.4 The approach to analysis and knowledge construction

This section explicates my approach to ‘doing’ the analysis for this research and constructing the account presented in the next five chapters. It describes why the approach is integral to producing research that is important, creative, and rigorous. An important part of this explanation is to make very visible and transparent the assumptions that underlie my approach. There is little research literature that explores in any great depth the process of knowledge construction involved in analysis, which accentuates both the difficulty and the importance of doing so.

The starting point for the analysis and the construction of knowledge is Foucauldian theory. A general overview of the applicability of Foucault’s work to this research was outlined in Chapter 2 and more specifically his work on discourse and Foucauldian Discourse Analysis (FDA) have been described earlier in this chapter. This described not only the applicability of FDA to this research, but that the research material could not be properly analysed using any other method. I argued this was informed by the young carers and the nature of the data that we co-produced.

It has been widely discussed how Foucault purposefully did not detail a method of conducting discourse analysis (Arribas-Ayllon & Walkerdine, 2008; Graham, 2005) and his dislike of being prescriptive about what “must be” and what “must take place” (Foucault, 1988a, p. 197). The response from researchers has often been to ignore the issue or to adopt the risible refrain that to articulate a method of analysis would be un-Foucauldian. Graham (2005, p. 15) also notes that many researchers lay claim to using Foucault by making some loose connection to power relations with a “few quotes from Foucault thrown in”.

These outcomes can give rise to the impression that ‘anything goes’ for analysis when using Foucault. The process is opaque, with few researchers seeking to address the
question and none fully explicating the process. Fryer and Nic Giolla Easpaig (2013) refer to researchers offering post-analysis rhetoric to suggest a rigorous process of analysis but which does nothing to demystify the opaqueness of how they are ‘doing’ analysis. Those researchers who do seek to tackle the question of conducting analysis drawing on a Foucauldian framework are faced with a confusing array of supposed precedents and more particularly a lack of a coherent description about how to proceed.

Notwithstanding the perceived constraints on being too prescriptive, as Graham (2005, p. 5) has noted, being prescriptive about how analysis must be done is quite “different from being explicit about what one is doing” [italics in original]. Graham (2005) has usefully outlined the goal of engaging with the work of Foucault while seeking to produce a scholarly account of the analysis – but which does not seek to be prescriptive about a model for others to follow. This section seeks to demonstrate rigour and transparency in articulating an approach to Foucauldian analysis for this research.

It is the case that all research has a specific focus that is based on assumptions: these assumptions are mostly hidden and often grounded in what is considered to be ‘natural’, as in the case of common understandings about childhood. This discussion seeks to be very transparent about the specific focus and targeting of this research and the assumptions that lie behind this focus.

There are a range of issues to be elaborated upon in terms of the context and background to how the process of analysis emerged for this research. It is axiomatic that the analysis did not commence at the time I physically commenced studying the transcripts and writing the text. In a very broad sense, my analysis is grounded in critical psychology and the poststructuralist aim of challenging the status quo and ‘accepted’ knowledge and assumptions, specifically those about young people and young carers (as discussed in the Introduction at Chapter 1.2.2). To restate a key point from the discussion earlier in this
chapter, this poststructural perspective of challenging the status quo and assumed knowledge has a focus on discourse that constructs notions or concepts that are spoken about as being ‘real’ and self-evident ‘truths’. This also includes attention to ‘what is talked about least’; that is, discourses that are not heard or are silenced. This entails, inter alia, a particular focus on content that I found to be unexpected, surprising or confronting that un_masks my own internalisation of deeply embedded conventional discourses and assumptions about young people and being a young carer. If content surprised me, it meant that I had assumed something different; it did not conform to internalised cultural constructs. Of course it is not only unexpected content that was the focus, nor was being unexpected the only conclusion that could be drawn from such content, but it informs about embedded assumptions. My critical psychology perspective incorporates a social justice concern and accordingly I am alert to structural discourses that might have problematic outcomes for young carers and their families, and might conceal inadequate policy and support. Relatedly, I also have a focus on what might be transformative: to identify counter discourses and create space for the emergence of alternative understandings of young people, young carers and families.

Making transparent the assumptions underlying the analysis requires mention of the methodology and the methods, as has been described in Chapters 5 and 6, respectively. This research, like all research, was targeted, but targeted to look at things differently from mainstream research. Part of this includes methodology and methods that more fully complement theory and epistemology. The theoretical standpoint that young people are not incomplete and incapable therefore informed methodology and led to the use of participatory methods. Accordingly, one context for the analysis is that the data has emerged from a participatory, collaborative framework driven to the extent possible by young carers, a marked contrast to much of the past research that is adult designed and
led. This produces a better opportunity for the young people to be involved in the construction of knowledge.

A further overarching influence on the analysis was the huge amount of variation in the accounts of the young people. There was difference and contradiction within a single transcript of an individual, within a series of transcripts of one individual, with different individuals in the same family, and between different young carers and young carer families. Apart from adding to the complexity of interpreting their comments and the analysis of the data, this variation provides an important backdrop to the understanding of the data (and the lives of young carers). The volatility in the accounts is an outcome of there being many different ways of ‘being a young carer’. Contrary to the implicit assumption in much research, young carers are not a homogenous group – variation is not something to be ‘ironed out’ of the data during the analysis. There is a myriad of ways of that young people experience caring for a family, as there is a myriad of caring and family situations in which the young person is located. This understanding provided important context for the analysis.

This discussion of variation highlights the significance of the epistemological position of this research. The analysis, and the research generally, is not proposing that there is an absolute and fixed position held by young carers to be captured. It is not proposed that an opinion expressed at a particular time is held to be a universal belief for that young carer. This research attaches importance to the fact it is possible for a particular discourse to emerge, not whether it is permanent or universal.

In developing an account of the analysis it is also pertinent to discuss the recognition of texts and discourses: that is, to address the question as to why I chose to focus on particular pieces of text, drawing inferences from utterances, when performing formal analysis. This entails understanding how particular objects of discourse are recognised. J.
Butler (1997, p. 5) discusses how there is a prior step to being recognised; “by being recognizable” [italics in original]. This refers to something that comes before recognition: the construction that has already occurred, which was evident on a number of levels for my analysis. There were already constructions and ideas that I held before consideration of the transcripts.

To recognise pieces of texts as depicting particular discourses it is first necessary to already have some knowledge of these discourses. A knowledge of particular discourses is acquired from the reading of research and theoretical literature which serves to render the researcher receptive to recognising and focusing on pieces of text that relate to these discourses. As has been described above, I was informed in large part by poststructural and postcolonial literature relating to children, childhood and developmental psychology (e.g., Burman, 1994; Cannella & Viruru, 2004). For example, when young carers speak of feeling like an adult, this is not simply taken to be the emergence of a theme that ‘young people feel like adults’. This analysis pursues a more sophisticated understanding that is informed in part by the literature described above: this outcome is the result of a Western cultural discourse of an adult/child binary that positions young carers to feel like an adult.

From previous research I had already formed an understanding of the subject position of young carer. It has been discussed how the literature was informing me and prompting questions and that is the start of the process of the analysis. In turn, as has also been discussed, my epistemological and methodological standpoints were factors in ‘recognition’. It will also be discussed in section 7.3.5 how my subject position as researcher, and the re-subjectification of this subject position over the course of the research, are important factors in the constitution of ‘recognizable’. It should also be mentioned how the act of being ‘recognizable’ can be problematic. Parker (2005, p. 27)
writes that as researchers “what we find … [is] always a function of what we thought we would find”. This can be mitigated to some extent by affording close attention to what is found to be surprising and unexpected. In particular, this often included young people unexpectedly resisting or overtly rejecting notions that I presented and strongly advancing contrary positions.

It is undoubtedly the case that some pieces of text strongly ‘leap out’ as being important, a situation described by Fryer and Nic Giolla Easpaig (2013, p. 71) as “erupt[ing] as if under great pressure”. There is something recognisable about these pieces, or something not recognisable about them, which draws upon and reflects all that came before. While it is important to acknowledge the existence of this pre-construction, it is equally important to acknowledge the complexity behind this act of recognition – a complexity involving a myriad of considerations that cannot be fully explicated in terms of all the outcomes of the analysis. While not purporting to be comprehensive, section 7.3.6 provides a brief overview of the factors involved in the emergence of the major discourses from the analysis. This seeks to make less abstract the preceding discussion.

This section will now turn to discuss a key component of both the process of the analysis and the collaborative research project as a whole. Analysis of research data should ideally be done in consultation with those being researched and this is particularly salient in this collaborative work. This was achieved as far as possible. Firstly, while indirect and iterative, each interaction with young carers and their families and each interview further informed me and provided new understandings which could be discussed and explored with the young people on an ongoing basis throughout the course of the fieldwork. More directly, it was of major importance that I was able to bring the preliminary analysis back to the young people for their consideration and feedback (Stage 3). To repeat a reference made in an earlier chapter: “the people best equipped to
… explain and address any issue are those who experience it every day” (McAlpine, 2006, p. 10). Apart from being an opportunity to clarify my own understanding of the outcomes of the analysis process, of much greater significance was allowing the young people to further develop the analysis or to challenge and present different interpretations of the data. The collaboration in the analysis further extends the role of young carers in co-constructing knowledge. This relates back to goals of this research project outlined in Chapter 1 of seeking to produce a final outcome that can better reflect a young carer’s standpoint.

Finally, in discussing influences on my analysis, mention should be made of the role of supervisors. It is important in producing sophisticated research that reflexivity is not performed in isolation. While young carers impacted on this reflexive process and were also directly involved in co-constructing the analysis as just discussed, the ‘outside’ perspective of supervisors, removed from direct involvement with young carers, was also important for challenging and uncovering my own internalised assumptions. By way of example, I provided an extract of a transcript along with my analysis of the transcript to a supervision meeting for discussion. This provided questioning and challenging of my assumptions and interpretations: explaining and justifying my findings both expanded and consolidated my thoughts and ideas. Analysis is usually assumed to be performed individually by a researcher without outside influence. Rather than being considered problematic, this interaction is a valuable part of sophisticated research: to have other subject positions outside the research process and outside the lives of the young carers enter into and disturb my process of constructing knowledge. It is important to make transparent my standpoint that the researcher does not (and should not) construct knowledge in isolation. I would argue that it is particularly important to have ‘outside’ perspective when the researcher is immersed in deep ethnography which has the potential to impair the capacity to stand back from the process and reflect on the data. A process
where the researcher is challenged and interrogated allows for other ideas and possibilities to emerge and is a valuable aspect of constructing knowledge.

7.3.5 Subjectivity and re-subjectification

“what we find and the sense we make of it are always a function of what we thought we would find and the position we try to make sense of it from” (Parker, 2005, p. 27).

There has been discussion of theoretical and methodological considerations that influenced my understanding and accordingly my analysis and construction of knowledge. What is alluded to by Parker in the above quote extends beyond expectations derived from the literature: it included the totality of my own subjectivity from which ‘recognizable’ is constituted. My position in society, my familial, cultural and historical experiences have shaped me and my expectations. This section discusses the subject position of researcher and the re-subjectification that resulted from immersion in the ‘space’ of young carers and the importance of this process to analysis and constructing knowledge.

It has become commonplace in qualitative research to catalogue life time personal experiences under the banner of disclosing ‘the position of the researcher’, a practice which has been characterised by Parker (2005, p. 28) as writing a “confession”. I would argue that personal journey narratives are open to criticism for being excessive and indulgent, while not assisting the reader’s understanding of the research. For this research there is also the risk of individualising subjectivity, which would be contrary to Foucauldian work. Accordingly, this discussion of my subjectivity is focused only on those considerations that may provide insight into the analysis process: why some issues were embraced while others were not taken up. Importantly, this section will also address the re-subjectification of my subject position as researcher as I have progressed through the fieldwork, the analysis, and developing and writing the thesis.
An important point has been made by Fryer and Nic Giolla Easpaig (2013) about the re-subjectification of the researcher. The subjectivity of the researcher at any point of time does of course influence the forming of knowledge, but this very experience changes the researcher; that is, the researcher is being continually re-subjectified (remade) throughout the fieldwork and the production of a thesis. There is a symbiotic relationship wherein my subject position as researcher at any given time is being impacted by the things that I was experiencing, causing a re-subjectifying at that same moment. Thus there was a bi-directional change process whereby the research was changing me which in turn was altering the research.

It may be helpful to illustrate this process with some significant examples. When undertaking the preliminary analysis, a lifetime of strongly positivist, quantitative studies (including psychology) made it very difficult to disengage from notions of searching for consistency and uniformity when considering the data. However, over the course of the interviews and the analysis, with overwhelming instances of difference and complexity and diversity, automatic positivist inclinations were profoundly diminished; that is, my immersion in the lives of young carers and in their data produced a powerful process of re-subjectification.

Mention must also be made of my own very conventional Western family and childhood experience in a small rural community that was very homogenous in terms of seeking to portray idealised notions of family and childhood. I came to the research with my own very clear understanding of childhood and family. The expectations that have been created by this experience was, as noted above, tempered by reading of the literature, but overwhelmingly the immersion in the family home of young carers, subsequently reinforced by studying the transcripts, was very significant in how my subject position as researcher was re-subjectified by the research. The experience of developing
relationships with a diverse group of young carers in their homes was confronting to my own experience and evolved my understanding of childhood and family.

It is also appropriate to mention my experience of more than three decades as a public servant in the Australian (Federal) Government in the context of my analysis in Chapter 8 (Institutional/structural context). This experience grounds my strong understanding that the administration of policy and funding by governments is extremely problematic. This perspective underlies my analysis in that chapter and it is acknowledged that the data would likely be interpreted much differently without this background.

7.3.6 The emergence of the major discourses

I would argue that for such a complex task of analysis that was inherent in this research, it is not possible to completely disperse the opaqueness from the process. It is also not feasible or desirable to seek to describe every thought and nuance that contributed to the analysis. It may though be useful to aid transparency and make the foregoing discussion less abstract by very briefly discussing some of the main considerations in the emergence of four major discourses in this research. The full analysis in relation to these discourses are provided at Chapters 9-12, but the following, which is intended to be illustrative rather than exhaustive or comprehensive, provides some insight and understanding of my process of analysis.

1. Being a young carer

As will be discussed in detail in Chapter 9, there were a range of subject positions of ‘young carer’ that emerged from the analysis. There were a number of considerations in seeking to ‘make visible’ the analysis, some being paradoxically oppositional. Initially, there was difficulty overcoming ingrained positivist thinking of looking for uniformity and consistency in the subject position of young carer. As the interviews progressed, the diversity and complexity of young carers’ experiences was overwhelming. The nuanced
and sophisticated positioning of some young carers was a jarring contrast to the
simplistic portrayal in the literature of a homogenous group of compromised and tragic
young people. This experience with young carers built upon my pre-existing
poststructural standpoint to challenge assumed knowledge about young carers. The
diversity and complexity of positioning by young carers was compelling, which
demanded the construction of the range of subject positions of young carers (as detailed
in Chapter 9). The development of various different subject positions and the exposition
of how the young people inhabit one or more positions in different ways at different
times, was significant in allowing the analysis to capture and convey the level of
complexity and difference involved.

2. Adult-child binary

The adult-child binary was a dominant discourse that emerged in many aspects of the
lives of young carers (Chapter 10). While it is the case that I was aware of issues
concerning the adult-child binary from reading the literature, it fundamentally emerged
as a major discourse from the fieldwork when I spent extended periods of time with
young carers in their family home. This presence in the home provided the opportunity to
observe young carers interacting with family members and performing the role of carer.
One notable example occurred in the early stages of the fieldwork when I met with (then)
16-year-old Emma: her adult presence in the family home and her assumption of the
adult role was striking. It also unfolded as time went on how her ‘adult role’ conflicted
with the family’s understanding of her position as a child/teenager and was a source of
tension. The surprise that I experienced and the conflict and tension of this adult/child
binary being displayed was so pronounced that it could not be ignored. This can be
likened to the description by Fryer and Nic Giolla Easpaig (2013, p. 71) of what is
important appearing as “ruptures”.
It has previously been noted that all the experiences of research create analysis. This is an important example of how fieldwork, and ethnography in particular – the being in a place and being with people in the field – has informed my construction of knowledge. This outcome also illustrates the significance of the methodology. The adult-child binary might not have emerged as a major discourse had there been one-off meetings with young carers outside their family home.

3. *Western familial discourse*

An awareness of the construct of the idealised Western family, and its problematic use in the negative positioning of young carers, initially developed from consideration of the research literature (Chapter 3). This awareness was profoundly magnified from the very first meetings with young carers in the family home where it was striking how the construct impacted their experience as carers. When they spoke, the ‘normal’ Western family was often the overt point of comparison against which they judged themselves and their family. This was reflected in a range of positions, including lamenting that they were missing out on the (idealised) ‘normal’ family experience and defensiveness that their family was not normal in terms of the dominant construct (which was sometimes recast as their family being better than the normal family). This pronounced focus on comparison with the ‘normal’ family again brought into consideration my earlier discussion of the work of Foucault (Chapter 2) which noted that people are regulated by the creation of the desire to be ‘normal’; a normality that is constructed by the relevant discourse. While the discourse was well understood in literature, the impact of it on the lives of the young carers was not. The emergence of this major discourse can therefore be described as a coming together of the previous research literature, the theoretical literature (Foucault), and most particularly the very pronounced impact on the experience of young carers that was evident from the fieldwork. The strength of this discourse could not be ignored.
4. ‘Normal’ child/teenager discourse

The discourse surrounding a ‘normal’ child/teenager was also a significant point of comparison for young carers and accordingly affected how they experienced being a carer. There were many considerations in relation to the emergence of this discourse. There was an overarching mindfulness from the literature of the construct of ‘normal’ Western children (as outlined in Chapters 3 & 4) which sets up the oppositional construct of the abnormal childhood. It became very pronounced early in the fieldwork that young carers were placed in the position of having to explain and justify themselves against the implication that their childhood was abnormal. As for the discussion of Western familial discourse above, this invoked consideration of the work of Foucault: norms are concepts that are constantly used to evaluate and control and exclude those who are unable to conform to ‘normal’ categories. In this instance, young carers are required to compare, evaluate and judge themselves against the construct of the ‘normal’ child/teenager. Accordingly, this outcome emerged from a confluence of my consideration of research and theoretical literature and my experience of fieldwork wherein young carers were very clearly constrained by the construct of a ‘normal’ child/teenager. Again, I would describe this emergence as a ‘rupture’.

7.4 Summary

To summarise, this analysis, as with all analysis, has not arisen in a vacuum. It has arisen from a very specific set of epistemological and methodological assumptions and a very deliberate method of engaging collaboratively with young carers. As a consequence of these epistemological and methodological underpinnings, there is a particular focus and target when analysing the research data.

This chapter has sought to explicate and make visible the process of analysis and the construction of knowledge. This process has emerged from postcolonial and
poststructural works and is based on a Foucauldian understanding of discourse, knowledge and power. The chapter has traversed the assumptions and influences behind the epistemology for this research and the methodology and methods that have been adopted to complement this epistemology. This includes a critical psychology perspective on social justice issues and the poststructural goal of challenging dominant discourses about young people, which have provided a specific context and focus for the analysis. Young people being provided with the opportunity to participate in constructing knowledge was a key consideration: that is, there is the assumption that young carers should be central to the analysis and the construction of knowledge (and to the research process generally). Issues concerning the influence of my subject position as researcher, and the impact of my experiences during the fieldwork in the re-subjectification of this position, are also a factor in the analysis. These, and the other factors and processes discussed in this chapter, have all overtly contributed to the analysis. It must however also be acknowledged that analysis is an extremely complex process and it is not one that can be completely captured in a linguistic account. Some aspects of the process remain outside the capacity to describe in the written word. Notwithstanding this qualification, by making transparent the context and assumptions behind the research and more specifically the focus and target of the analysis, the aim is to provide a clearer understanding of the importance of the research and the rigour and sophistication of the analysis presented in the following five chapters.
PART V

ANALYSIS

Chapter 8: Institutional/structural context

Chapter 9: Analysis – Discourses on ‘being a young carer’

Chapter 10: Analysis – The adult-child binary

Chapter 11: Analysis – Familial discourse and the Western family

Chapter 12: Analysis – Discourses on the ‘normal’ child/teenager
Chapter 8: Institutional/structural context

8.1 Introduction

An understanding of the institutions, agencies and organisations, and government bodies involved in young carer services and support provides an important context for the experiences of young people in a caring role. This chapter seeks to provide such an understanding and is based on my observations and experiences as a volunteer at young carer events, meetings with respite centre staff and Australian Government officials, as well as young carer and parent interviews. Informal discussions were also held with a person who was manager of a Commonwealth Respite and Carelink Centre at the time the Australian Government commenced funding support for young carers and gave the centres responsibility for developing and implementing young carer programs. This fieldwork was more fully described in Chapter 6.

This chapter does not purport to be a presentation of analysis in the usual sense and in large part is not a representation of the ‘voices’ of young people. It is primarily a narrative that seeks to describe the institutional/structural setting and context that will connect with the analysis in the following chapters. It is however important to note that this chapter is more than providing background and context. By developing and incorporating into the narrative an account of discursive practices, based to the extent possible on young people’s experiences of these practices, it also seeks to construct knowledge, albeit in a manner that would not usually be characterised as conventional analysis. The approach to analysis taken in this chapter comes within a Foucauldian understanding of knowledge construction (as outlined in the previous chapter); one which offers a discursive, structural context that is analytical in a poststructural sense. The account that is presented here is not portrayed as ‘concrete reality’ but as one possible interpretation; an approach that is consistent with, and justified by, the epistemological
and methodological underpinnings of the research which have been made transparent in previous chapters.

8.2 How young carer support developed and operates

In many important aspects the development of young carer support and services in Australia mirrors the motivation and aims of the UK agencies, as has been discussed in the review of literature (Chapter 3). In the late 1990’s the Australian Government, through the then Department of Family and Community Service and Indigenous Affairs (FaCSIA), argued that an increasing number of young people were becoming involved in caring for a family member. In a context that these young people were considered to be in a compromised situation, particularly in relation to schooling, funding from the Australian Government was allocated for the support for young carers. It is not unexpected that schooling should be a focus of support as it is the cornerstone of the Western constructs of the child and adolescent and, as such, a compromised education is a significant component of the negative paradigm of young carer research (as discussed in Chapter 3). This funding was in turn distributed to Commonwealth Respite and Carelink Centres for developing and implementing young carer programs. As noted earlier, there are 58 such centres across Australia, ten of which can be considered as serving regional and rural NSW. The respite centres were chosen as the vehicle for young carer support on the basis that they already provided temporary emergency respite services for adult carers, despite having no existing background or experience with young carers or young people generally. Funding was allocated on the basis of the population of the region for which a particular respite centre had responsibility, assuming that young

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14 This description of the introduction in Australia of funding for young carer support was provided by a former manager of a Respite Centre who was responsible for implementing the program.

15 Derived from a map of the regions covered by the ACT/NSW Commonwealth Respite and Carelink Centres. The map was produced by the NSW Managers Committee in 2010.
carers were uniformly spread throughout regions. This was described by one respite centre manager as “absolutely plucking it out of thin air”.

The Commonwealth official responsible for funding the respite centres for young carers was sympathetic to how difficult it was for centres, noting their previous responsibility for aged care and emergency respite for adult carers and, despite having no link with young people, had to “come up with programs for young carers”. The voices of the young were very distant from this process.

It was noted in Chapter 3 that the first government program for young people with a caring role was titled *Young people at risk*. Implicit in this title is the understanding that being a young carer is synonymous with the young person being compromised and ‘at risk’. As was discussed, the inherent negativity attached to this program was also stigmatising for parents, given the implication that they were bad parents for placing their own children at risk. It is likely that this negativity would have deterred parents from seeking support. This program is indicative of the mindset in which service and support agencies first engaged with the notion of young people having a caring role for a family member.

Once the perceived need for young carer support had been identified, funding was allocated, but without a clear idea how it would be expended. I argue that this unsound approach to funding programs to be commonplace, a conclusion that is based on extensive experience of government (as was referred to in Chapter 7.3.5). Giving responsibility to individual respite centre managers for developing and implementing programs for the expenditure of funding meant “it absolutely differed from region to region as to what the response was” (Respite Centre Manager). While there were FaCSIA guidelines, it was “big picture stuff … a lot of it was at our discretion, definitely” (Respite Centre Manager). Accordingly, support is often ad hoc and arbitrary, although
over the years, most likely as a result of Managers (NSW) meeting together four times a year, some common programs have evolved across regions. These include tutoring, young carer camps, and funding for ad hoc school-related matters. There is however a very stark difference between regions in designating young people as carers. While some centres have children as young as five years old registered as carers, other centres have a minimum age of around 12 years for a person to be considered to be a young carer. The major reason for this disparity is that some (and perhaps most) respite centres register young people as carers on the basis of them having a sibling with a disability/illness, regardless of whether they have direct involvement in caring for their sibling:

“some respite centres were taking on people as young as five and calling them carers, which is a complete joke … it brings in child welfare issues” [former Respite Centre Manager].

“it was very arbitrary and some centres were doing things they probably shouldn’t have … a lot of services didn’t draw a distinction, yeah … they didn’t … no question about it” [former Respite Centre Manager].

It is axiomatic that the statistics provided by respite centres to FaCSIA on young carers are inconsistent and unreliable, which has problematic implications for governments and agencies when considering funding and the development and targeting of programs.

While emergency and temporary respite is available from the centres, young carer camps are the highest profile support provided to young carers. My attendance as a volunteer at some of these camps was detailed in Chapter 6. They comprised three and four day trips to a holiday or tourist destination. The rationale for the camps is to provide the young people with a holiday away from caring and to allow the opportunity for them to meet and talk with other young carers. My experience of these camps was that the young people who were able to attend greatly appreciated the camps as an opportunity to ‘get

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16 In this thesis, the insertion of three ellipses points (…) in a transcript extract simply indicates pauses by the speaker. For the few instances where an extract is not a continuous portion of the transcript, omissions will be indicated by the use of four ellipses points (……).
away’ from their family caring situation. It was surprising to me however that there was no discussion, or even mention, of their lives as a carer, one of the primary reasons for these camps. This was later explained to me by a number of attendees as reflecting their desire to completely leave ‘behind’ that aspect of their lives for a few days, and if they were to talk about being a young carer it would negate their reason for coming to the camp. Jack explained as follows: “...I don’t want to talk about it because that’s why I went on the camp ... not to talk about it”. Kate offered a different explanation, based on not wishing to discuss their family member in terms of their disability: “it’s also not something that you really talk about much ... because they are your brother, they are not somebody who has a disability as such…”

From my interactions with the young people attending these camps, it seemed that in many cases it is those with a smaller caring role (i.e., siblings of a person with a disability as discussed above) who attend, because those primary carers with the most demanding caring situation feel unable to leave the ‘cared for’ person. One teenager spoke of how their family avoided contact with welfare agencies but he had been registered as a young carer by his mother solely to enable him to attend camps. This is not to suggest that any of these less difficult caring roles are unimportant or that those attending are undeserving, but rather it raises questions about the targeting of very limited funding when those most in need are effectively excluded. Young people caring for parents who have little or no outside help may not be able or may not wish to leave their family for several days. Jonathon for example, who has an extremely difficult caring situation with two parents with disabilities, rejects the idea of young carer camps and argues for more help at home. Commonwealth officials also expressed scepticism to me of their value in terms of being the best use of funding. Despite these doubts, the continued funding of these trips has not been seriously questioned, which can be positioned as a maintaining of the status quo and a level of indifference.
The role of the respite centres in relation to young carers is largely passive and reactive. There is no funding for field workers or other capacity for direct contact with young carers and their families. Those respite centres with whom direct discussions were held, advised that they were only able to devote part of one staff member to young carer work. It may be useful to briefly provide some context for the nature of the interaction between the centres and young carers. An awareness of the centres (and hence potential support) most often comes through the ‘cared for’ person’s contact with disability support agencies. It is almost always the parent who contacts a respite centre seeking to have their child registered as a young carer. Details are collected about the nature of the disability/illness of the ‘cared for’ family member, the family’s structure (i.e., other support available within the family), the nature and extent of the child’s caring and domestic tasks, and the impact of these tasks on the child’s ‘normal’ activities. Once registered, the child is placed on the young carers’ mailing list and receives notification of events and activities¹⁷. However, it is incumbent on the family to seek out any other support beyond these limited publicised activities and events.

Two of the young people positioned service providers as homogenous and inflexible, and unresponsive to different needs:

“…they just need to tick their little boxes, and once their boxes are ticked, anything you say after that … if there are no boxes to tick, it’s not relevant…” (Emma).

“it [support] doesn’t necessarily fit with to the individual’s need, but if you are a service provider and you want to provide a service it is a lot easier to just say ‘this is what we are doing’ … even if they don’t use it!” (Kate).

These two comments offer a similar perspective of agencies with which young carers are involved: they are seen as one amorphous, indistinguishable, ‘welfare’ body that is bureaucratic, unhelpful, and lacking understanding. Many of the other young carers have

¹⁷ The specific processes adopted vary between respite centres. This description is a generalisation of the process which is based on discussions with a number of centres and from a written “Assessment Tool” used by another centre.
no dealings with, or knowledge of, service and support agencies, or vaguely perceive them as a generic body that exists somewhere ‘out there’. There is a wide divergence in the awareness of families of potential support that might be pursued through the centres and an even greater variation in the expectation of young carers about entitlement and deservedness of support. This is a significant point given that these bodies are largely reactive and passive, and one that has significant implications for young carers needing support.

“It is very sad for the people that don’t know how to be proactive, because they weren’t given the skills…” (Emma).

This comment by Emma is significant in that it encapsulates what seems to be a key factor in young carer families accessing support. There is a discourse of an assertive, articulate parent that some parents are able to access through various resources and which create an opportunity for their families to access greater levels of service support; that is, in a Bourdieu sense, the level of support received seems to depend to a significant extent on the family’s social and cultural capital (see Chapter 2.3). The mothers of three young carers positioned themselves as assertive, tenacious, and with the ability to navigate bureaucracies in pursuing and obtaining support for their children. They spoke of receiving support that appeared to be ad hoc (and often unusual); support that would not be contemplated by young carers in families with little social and cultural capital, and who most often seemed to have a greater need for support. One mother of young carers was particularly notable in having agitated to be included in a pilot program, had registered her children with all possible relevant organisations, and managed to have neighbourhood friends classified and paid as respite workers.

While Emma raises an important issue, it is necessary to extend the interpretation of her comment. It is not necessarily that parents lack skills or knowledge but rather are excluded from the opportunity or ‘space’ in which to exercise these capabilities. This can
be demonstrated with reference to Mitchell’s mother, who holds postgraduate qualifications and before her illness held a managerial position. Because she is living in a remote area, has a chronic illness, and is mostly unable to drive, she is shut out from the possibility of being proactive and assertive in pursuing services.

Conventional institutional discourse tends to position individual parents and families as lacking in the skills and articulateness to access services, which are positioned as effective. I would argue however that the perceived dysfunctions described above are a legacy of how governments have constructed young carer policy. While all the major players – the Australian Government, FaCSIA, and the respite centres – are all genuine in seeking to help young carers, what has emerged are programs developed from an adult-led bureaucratic process that are largely detached from the lives of young carers. This situation brings to mind Foucault’s description of a network of powers that together produce outcomes that can be quite different from intentions (Foucault, 1980a).

8.3 Where the young carer ‘industry’ meets young carers

A number of young carers spoke of having attended young carer conferences. These conferences, which are organised by a central body in a major capital city, are interesting to consider from the perspective of being one of the few instances where young carers come directly into contact with the young carer ‘industry’. To place this discussion in context, it may be useful to briefly restate the background to the expression ‘young carer industry’, which was outlined in the literature review at Chapter 3. The term is used to encompass the research and young carer bodies that have grown around young people providing care for a family member. As was detailed in that chapter, there often exists a conflating of research goals and outcomes with competition for government funding for young carers. Researchers and service and support agencies are supported by a discourse positioning young carers as compromised ‘little heroes’, a subject position which they
also promote and seek to impose. This positioning of young carers supports their role, authority and rationale for funding. An Australian Government official responsible for managing funding of young carer programs volunteered the comment that a “young carer industry was [also] developing”, echoing comments made in the literature review about the situation in the UK.

These conferences differ from the young carer camps that have previously been discussed. These conferences appear to be structured in a way that very consciously promotes and enhances the understanding of young carers as very special people suffering under great hardship. A forum is provided where young carers are expected to speak publicly about their family’s situation in an environment which encourages them to be emotional and to emphasise the difficulties of their family and their caring role.

For young carers such as Melissa, these conferences seem to provide great validation and she spoke with great excitement about being able to publicly tell her story about being a carer and her family’s difficulties.

“[the young carer conference] was the turning point for me” “…I felt empowered … I didn’t feel like I was alone and to find out … to sit down and to hear about, you know, the statistics [on young carers]” (Melissa).

Melissa also spoke of being inspired and given hope and how she subsequently identified more strongly as a young carer after attending her first conference. To a lesser extent, such events were also described as impacting positively on Emma and Rebecca, with references to feeling “good” and “special”.

In stark contrast to these positive experiences, many other young carers described these conferences as distressing:

“… I tried talking about it [caring and her family situation] but … I dunno … I got really uncomfortable and had to walk out” (Allison).

This view was expressed more forcefully by Jack who shouted with annoyance:
“…and that [event] was terrible … because all we did was sit around and talk about it [caring] … and WE DIDN’T WANT TO TALK ABOUT IT” (Jack).

A conclusion that might be drawn from the above discussion is that for some young people there is great value in going to an event and discussing their family life, while others find them distressing and would greatly prefer to go on trips where they can (temporarily) forget their caring role. Other young carers are effectively excluded from attending. As will be pursued in the next section (8.4) the more significant point to be made here is that none of the young people have been asked what activity or support they want or need.

It was suggested above that the discourse promoted at conferences may provide important validation for young carers. It can also be suggested, albeit, far more tentatively, that there may be a further outcome from institutional discourse positioning young carers as special and remarkable people. Those young carers who were most vocal about being unrecognised and unappreciated in the wider community, mainly seemed to be those who had attended these conferences. Accordingly, the discourse promoted by the young carer industry might be having both a positive and negative impact on how young people experience their role of family carer.

Relatedly, there is the possible suggestion that some of the particular discourses that emerged from the accounts of some young carers may be linked with their attendance at these conferences. While not wishing to overstate this possible connection or its significance, the accounts of some young carers included ‘institutional discourse’ on young carer statistics, the magnitude of the ‘problem’, and the retelling of stories presented at conferences. In the example below, Melissa is describing information provided at young carer conferences:

“I found out the statistics of 85% of young carers not knowing that they were a carer… (Melissa)”
“…that is something that is going very [sic] unnoticed, there [are] 100,000 young Australians [caring]” (Melissa).

It will be recalled that in Chapter 3 there was discussion of how it was in the interests of researchers, government agencies and service providers to promote both the significance of young carers and the difficulty of their lives, since it has implications for funding and resources. Alternatively, the emergence of this discourse in the accounts of young carers may simply be a reflection of the validation that it provides them in undertaking the role that has been imposed on them.

In the context of understanding the self-promotion of the ‘industry’ there are also other accounts from young carers that may possibly be pertinent. Emma presents an account of conference organisers promoting what she labelled as young carer “celebrities” for appearance in newsletters, promotional material, and magazines to overtly advance a particular subject position of young carer. Emma also recounted how the conference atmosphere gave rise to competition amongst young carers, and she mockingly quoted others: “I am caring twice as much [as you]” ... “My family member is more disabled than yours!” Accordingly, young carer institutions and related discourse provide an important context when considering the accounts of young carers.

It should be noted at this point that Emma and Melissa are the young carers who feature most prominently in this section as they presented as having the most experience of attending conferences and were definitely the most vocal in expressing their opinion of them.

8.4 Young carer support: An adult agenda that disconnects with young carers

A further outcome of the discourse surrounding children is that it does not allow young carers a voice on the matters that most directly affects their lives – how they can best be supported. While trumpeting the ‘adult’ roles and responsibilities of young carers, the
‘industry’ paradoxically positions them as partially competent children. This allows for the control of the young carer agenda and decision-making on the basis of their (adult) perspective – the underlying assumption being that ‘we know what is best for young carers’. The positioning of young people in this way would also seem to be problematic by acting to stifle the very attributes they need to perform a caring role: “assertiveness, knowledge and status” (H. Rose & Cohen, 2010, p. 478).

The problematic impact of adult perspectives on young carer programs can be well illustrated with a number of examples of discursive practices. As part of my ethnographic work I spoke at a meeting of the managers of all the respite centres in NSW and asked to be notified of any suitable young carer activities I could attend as an observer. On a majority of occasions when arrangements had been made for me to attend a function, I was notified a few days beforehand that it was now cancelled because of a lack of numbers. In one case, just two people nominated from a potential group of attendees of more than 60 young people. It would seem inescapable that adults are making incorrect assumptions about the needs and interests of young carers in planning events – they are based on adult perspectives of what they consider is ‘good’ or ‘best’ for young carers.

I also attended, as an observer, a planning meeting held by two respite centres to organise a joint young carers’ camp. It was striking that no consideration was given at any stage to consulting with young carers about what sort of camp, venue and activities they would like to attend. Instead, there were four adults making statements such as ‘the kids would love to do that’; ‘they would have a ball at…’ without the slightest recognition that they may not know what the needs and desires are of young people in a caring role. Once more it eventuated that one of the respite centres withdrew from the proposed joint camp because there was no interest from young carers in attending. Again, the inference that can reasonably be drawn from this outcome is that the adults assumed they knew at least
as well, or better, than the young people. A failure to question this assumption can be seen as particularly surprising given the previous camp planned for a few months earlier had to be cancelled because an insufficient number of young people were willing to attend. It does demonstrate the strength of the assumptions adults hold about children and their understanding of children.

While some young people had no expectation of being consulted about support, services or activities, for others it was deeply felt:

“[they] do not listen to kids … kids don’t have a say, because kids have never had a say”; “they are the child but they are the primary carer and we don’t get taken seriously” (Emma).
“we are seen as kids”; “I’m sick of their shit”; “those organisations have NO IDEA [strongly emphasised] what it is like to care for somebody [as a child]” (Jack).

In large part the separation of young people from any decision making or consultation on what young carers support or services they need is in effect a collaboration with parents who also consider it a matter for adults to decide. This point is raised directly by Emma: “other adults always just ask my Mum … they are not asking the right person … and they don’t even realise!” The comments of Emma and Jack are very similar to those made by the young carers quoted by Underdown (2002, p. 59): “they were excluded from discussions and decision making processes, as they were considered too young to be involved”. In some cases, this exclusion even extended to young carers having no knowledge of the support they were receiving: while Jack advised that he received no support as a young carer, his mother commented “He doesn’t know about that [support] ... it is behind the scenes stuff that I organise for him”. Ironically, Jack was one of the most vocal about not being consulted. This situation was recognised by one respite centre manager: “often it is the parent who is calling the shots, even when they are the person cared for by the young person … we were in the position that if the person was underage we had to go through the parent”. In a significant way, parents act as gatekeepers
between their carer children and support agencies. The outcome is there is little or no direct contact between young carers and agencies, and hence they [young carers] have no ‘voice’ in matters which directly concern them.

It should not however be concluded from this discussion that it is always problematic for adults to be the decision makers in relation to support and related activities for young carers. At times it can be a positive for young carers, most particularly from the perspective of them having one less issue to manage. Relatedly, it can be suggested that in some instances the parent’s gatekeeping actions are motivated by a desire to lessen the burden on their children, a situation described by O. Prilleltensky (2004). Nonetheless, it does highlight that the positioning of young people by service agencies (and usually parents) has consequences, and many times these are negative consequences for young carers. It further reinforces the notion that young people are not fully competent and do not need to be included or consulted, even on matters that dominate their lives. This discussion on young carers being marginalised from the ‘conversation’ on support is extended in Chapter 10 (Adult-child binary).

8.5 Agencies and the ‘norms’ of the Western family

“The judges of normality are present everywhere. We are in the society of the teacher-judge, the doctor-judge, the educator-judge, the ‘social worker’-judge” (Foucault, 1995, p. 304).

There is an implicit acceptance by government and agencies of the ‘norms’ of the idealised Western family. As noted earlier, the origins of young carer programs reside in a mindset of ‘children at risk’: this arises in part from the ‘norms’ of family being deviated from, which is considered to be inherently problematic. This construction places young carer families in a difficult situation: it requires them to position themselves as having problems in order to assess services, while not being too different from a ‘normal’ family so as to invite (further) monitoring and surveillance. Young carers and their
families are often required to maintain a defensive stance in constantly managing and negotiating their roles and interactions. This situation is well captured by Emma who talks of her frustration, and how she is made to feel defensive in trying to get agencies to understand the extent of her mother’s mental health problems. Emma quotes a service agency: “so you are saying your Mum is not a good Mum”. In a related vein, Jack describes an intervention by a school counsellor who judged that he was in an abusive caring situation: this assumption was based on a minor behavioural matter that would have gone unnoticed had he not been seen as an ‘at risk’ young carer.

Another young carer, on the condition of complete anonymity, spoke of his dichotomy – a fear of being removed from the family home while simultaneously needing to argue for greater support. This fear of separation and the reluctance to disclose the family situation is consistent with the findings of H. Rose and Cohen (2010) who argued it to be a major concern of young carers. These difficulties for young carer families was recognised by a former respite centre manager: “The other thing that was scary for some parents … was it a welfare situation … will you take my child off me if I really tell you what my child has to do for me every day”.

While in many cases this would likely be a huge consideration for families in contemplating accessing services, except for the one instance mentioned above, the fear of being declared a child at risk was not raised by any of the young people. Consequently, there are no other comments from young carers to include here. There are a number of potential explanations for this outcome. Particularly in the early stages of the fieldwork, I would have been seen as an outsider with whom they would not feel confident in sharing such a profound and personal concern. Equally, there may also be reticence in acknowledging to others that their family situation appears to be so dire, or that they might be perceived as an abnormal family. Of course it may be that these
concerns did not exist for the other young people, since it is likely that most families who hold this fear would not have volunteered to participate in the research.

Underlying these experiences is the understanding that young carer families do not conform to the ‘norms’ of the Western family and therefore they must be in a compromised situation. This understanding is both overt and latent in service agencies and also one that is internalised by many young carers and their parents and would seem to impact on their willingness to engage with service providers. The impact that this understanding has on young carers is discussed further in Chapter 11 (*Familial discourse and the Western family*).

### 8.6 Summary

As was noted in the introduction to the chapter, this discussion does not purport to be a presentation of what is usually considered analysis. Equally, however, it is argued to be much more than a description of the operation of institutions and structures that are impacting on the experiences of young carers. By drawing together understandings obtained through my ethnographic work with agencies and institutions, supplemented where possible by the accounts of young carers, the chapter constructs knowledge concerning some important issues that impact in significant ways on the lives of these young people. Summarised below are the key points to emerge in this chapter.

It can be suggested that the introduction and implementation of support for young people caring for a family member was a process which reflects the workings of a government/bureaucratic network. It was, and remains, a process that is disconnected from the voices of young carers. Accessibility of services depends in some important ways on a family’s *capital* (in the Bourdieu sense) and whether they have the opportunity to utilise their capital.
As was argued in respect of the UK (Chapter 3), there is a suggestion of the emergence of an Australian young carer ‘industry’ wherein a particular discourse of a young carer is promoted which positions them as special, but compromised young people enduring hardship. This is suggested as having both a positive and negative impact on how they experienced being a young carer.

The choosing and planning of specific activities and support is notable for the exclusion of young people. It can be suggested that these matters are assumed to be only for consideration by adults: this includes both agency staff and parents. This reflects an implied understanding that young people are not competent enough to have an input, even on matters that most directly affect their lives. This conclusion is perhaps not surprising, given the previous discussion of the research literature (Chapter 3) and the Western construction of children (Chapter 4).

Perhaps one of the concerning issues to emerge was the suggestion that young carer families may feel constrained from seeking access to services for fear of coming to the attention of welfare authorities, and the related fear of their child being removed from the family home. This concern is based, at least in part, on these families departing from what is considered to be a ‘normal’ Western family and childhood and the notion of what is a ‘normal’ level of tasks and responsibilities for young people.

In some significant ways this chapter links with the conclusions that emerged from the previous research literature and theoretical works that were discussed in earlier chapters. At the same time the issues that have emerged provide important context and connection to the analysis of the ‘voices’ of young carers that is developed in the following chapters.
Chapter 9: Analysis – Discourses on ‘being a young carer’

9.1 Introduction

This analysis is primarily based on transcripts of three rounds of interviews with young carers conducted over a 13-month period. It does however also draw upon notes and observations recorded in my field diary of ethnographic work as a volunteer at young carer events and activities. I have also drawn what might be termed ‘performative inferences’ from my observations of, and interactions with, young carers over the two years of fieldwork. While at the most fundamental level this research was driven by the young carers and has a rationale of listening and understanding their ‘voices’, the analysis is also cognisant of the interviews with their parents when it was judged to be important for providing a better understanding of the accounts of young carers. The epistemology for this research maintains that an understanding of experience is enhanced by consideration of the context and for young carers a significant part of this context is the parent, particularly since in most cases they are the ‘cared for’ family member.

As will be developed throughout this chapter, the analysis in the first instance is based on the first two rounds of interviews with young carers. The preliminary and tentative outcomes which I developed from these discussions were the subject of a collaborative analysis with the young carers in a third round of discussions. This third round was largely focussed on involving the young people in the analytical process, and less on their particular experiences as young carers, as was the case for the preceding discussions.

There were four major discourses that emerged from the analysis:

- Being a young carer.
- The adult-child binary.
- Western familial.
- The ‘normal’ child/teenager.
The most significant of these discourses was that which offered subject positions for young people who cared for a family member: subject positions which offered particular experiences of ‘being a young carer’. This discourse of a young carer was interrelated in important ways with those of the adult-child binary, the Western family, and the ‘normal’ child/teenager. This chapter will firstly explore the discourse of ‘being a young carer’ and the following three chapters will expand the analysis by developing an understanding of these three related discourses and the complex interactions, tensions, and contradictions that confront young carers. The very evident complexity involved in seeking to provide an account of the experiences of young carers serves as an appropriate reminder at the commencement of the analysis to reiterate that this research does not seek to uncover a purported representative or universal position of a young carer.

### 9.2 Being a young carer

The subject positions that emerged from analysis of conversations with young people in a caring role can be categorised in four ways:

1. A better/special young person: “a higher calling”.
3. Not a carer – just being a proper family member.
4. A carer, but still a regular, normal young person.

“I am an odd person ... different ... sort of person …. most carers I have met are somewhat odd…” (Emma).

This comment by Emma reflects an understanding of the young people that seemed evident from the very beginning of the research: that they were looked upon by others as being different. There was an awareness, in varying degrees that, as young carers, they were considered to be one or more of the following: odd, nerdy, different, exploited, tragic, compromised, stigmatised by their association with illness/disability, heroic, and
the object of patronising sympathy. My presence as a researcher would have presumably heightened this awareness of being different, given my interest in exploring their experiences of being a carer. Accordingly, the subject positions presented should be seen in the context of ‘being different’. This emphasis of difference potentially sets up a dialogue which invites justification of life as a family carer and thus defensive descriptions.

In very general terms, with the exception of the second subject position of a compromised child/teenager, the other three subject positions enabled the young people to consider themselves as ‘normal’ or as better than ‘normal’, avoiding the alternative of being abnormal or a ‘lesser’ young person. The dominant subject position which emerged from an individual young person was generally (but not always) reflected in whether they positively or negatively described their lives, and the context of their lives. As will be discussed, the accounts of the young people were notable for identifying with different subject positions at different times. This included simultaneously advancing accounts that they were ‘better than’ and ‘better off’ for being a young carer, while also presenting as having a bad and compromised childhood and teenage years. Each of these subject positions will now be explored in greater detail.

9.2.1 A better/special young person: A “higher calling”

“…it’s like you feel like you’re doing something … you feel like you have a higher … not to sound religious as an atheist, but you have a higher calling than all the other teenagers … sort of…” (Emma).

This statement by Emma captures, at the extreme, the position of young carers as better people. Emma’s reference to a “higher calling” has an almost evangelical flavour of being special and of being chosen.
Accounts which presented young carers as ‘better’ people, whose lives were enhanced by their caring experience, volunteered an extensive catalogue of positive qualities which were attributed to being a carer for a family member. These embraced both practical skills and what might be considered personal character traits, values and principles. The range and depth of positive attributes could perhaps be indicative of the perceived need to portray themselves as having good lives; this being a result of the dialogue that was taking place in a research and cultural context and anticipation that I might focus on the negative outcomes of being a young carer that dominate the accounts provided by researchers, the media, and service agencies (as discussed in Chapter 3).

_A positive construction of a young carer_

“well, we understand more than people ... and can deal with situations better ... and are totally different to the normal kid ... the average kid...” (Mia, 13 years old).

Like Mia, almost all the young people described having increased maturity and sense of responsibility, as well as being more caring, empathetic, compassionate and understanding, particularly in relation to disability and marginalised people. Mia also speaks of how being a young carer had taught her “to look after people”, “not to judge”, and to “understand disabled people”. Similarly, in Liam’s account an advanced understanding of people with disabilities emerges:

well, I feel normal about it [disability] ... cause my little brother’s autistic ... it’s just like ... I just feel normal ... like I go ... like my friends would be sort of avoiding them ... but I would just walk straight up ... straight past them ... would ... would just treat them normally .... doesn’t bother me at all, seeing someone who is mentally or physically disabled … I can just treat them as a normal person… (Liam, 12 years old).

Perhaps the most poignant comment that related to a special and exceptional position was made by Jack in inferring a selfless altruism:

...I’ve never really thought about what ... [long pause] ... never really thought about what I ... want in life ... it’s been about what I need to do for Kathleen [sister with a disability] ... what I need to do for Mum [mental health issues] ... I think it’s the same with Emma ...
it’s been about everybody else but YOU ... it’s just part of the job I guess (Jack, 12 years old).

This understanding of themselves as caring and loving persons who are able to make sacrifices for others, was a further factor in some young people positioning themselves as special and having a “higher calling”.

*Jumping the barrier to adulthood*

...but [I am] more realistic in that ... umm ... I’ve come to understand that life is no smooth sailing .... I think it sets me up to better deal with the adversities of life ... and I think that ... I’m ... going to be much better able to deal with life ... especially at an earlier age ... than say my friends (Jonathon).

This quote from Jonathon encapsulates a prominent theme, particularly among the ‘older’ young people, of positions which possess adult-like qualities. This is implicitly being contrasted to an idealised child’s understanding of a ‘rosy’ world, which a wiser Jonathon knows not to be true. The comment by Jonathon suggests a greater and more realistic understanding of the world and the capacity to deal with adversity, which is implied to be necessary for dealing with his more realistic understanding of that world.

The ‘adultness’ of young carers is further extended by Mitchell’s bewilderment at the lack of understanding of other young people about what he considers to be life in the real world, as opposed to a child-like understanding. In the comment below, Mitchell presents a stark contrast between young carers and other teenagers who do not appreciate, or even recognise, that they have “perfect” family lives:

…like young girls putting shit up on Facebook … ah, like, ‘I just want to end it all’, and they may, like come from a perfect background, and you just feel like telling them to shut up, you know … umm, just that sort of stuff, you know, I think it [being a young carer] has made me stronger … like character wise… (Mitchell).

This positioning by some of the young people brings into focus the discussion of the literature in Chapter 4 about adulthood being the point of reference against which all
others – children, adolescents, and the elderly – are judged. The definition of these groups is relational: they exist in relation to adults. There are accepted markers and attainments, which purport to constitute the status of adulthood. Adolescents, in particular, are positioned as being “citizens in waiting” in a state of ‘becoming’ and taught (Western) adult knowledge and forms of thought to ensure they pass the divide into responsible adulthood (Arneil, 2002, pp. 70-71). It can be suggested that some young carers, such as Jonathon and Mitchell, are in effect positioned as having ‘jumped ahead’ by already possessing the qualities of an adult, which is the central and desired position in our society.

...it’s set me up with a lot of skills ... I can already cook a meal for five ... I know how to make a small budget stretch over five people ... I know how to bathe a wriggly child ... and probably one of the most horrible thing that first time parents face is nappies, and I have been changing nappies for 12 years! (Emma).

Emma was one of a number of those who positioned young carers as having the life skills of an adult in terms of resources rather than values. Interestingly, Emma is portraying these skills in terms of a traditional Western mother, suggesting that the role of carer is conflated with being a mother, drawing upon Western familial discourse that positions the mother as being primarily and ultimately responsible for a child’s ‘normal’ development (as discussed by Burman, 1994).

Issues surrounding the position of young carers as adults and, assuming ‘adult’ roles and responsibilities in the family, also brings into focus the discourse surrounding the adult-child binary, which in turn interrelates with parent-child roles that have been laid down by familial discourse, often with problematic outcomes. These interrelationships and outcomes will be explored in Chapter 10 (Adult-child binary) and Chapter 11 (Familial discourse and the Western family).
An investment for the future

…it’s actually rather good the way it has turned out … it is sort of an investment, but … really good … would you rather just miss out on a few years of childhood, or grow up being very mature … or would you just rather have those couple of years of childhood and be up a little snob … brat when you are older (Liam).

The above quote from Liam captures the notion of young carers positioned as having an enhanced future as a result of their experience as a family carer. While Liam is acknowledging he has missed a few years of his childhood (a point he contradicts at other times), it is presented as an investment for the future. Interestingly, there is also the suggestion that it is an either-or situation: the alternative to being a carer is to grow up a “snob” and a “brat”. A similar position is expressed by Melissa, who suggests that the alternative to being a carer would have likely resulted in her “going down a bad path”.

This clear statement of a polarising binary serves to enhance and emphasise the understanding that the benefits of being a young carer are long term, life-changing, and set them apart from their peers. This discourse of such a strong binary may also reflect some defensiveness and serve to counter an expectation that researchers might view young carers as having lesser lives than their peers.

The idea that caring is also a positive for the long-term future builds on the other positives such as life skills, maturity, and capacity for dealing with adversity. This positioning as ‘better’ goes beyond the opportunity to feel good about being a carer. Rather than missing out, their future is brighter because they are a carer. For young people with fewer material resources, this investment for the future can importantly be seen in the Bourdieu sense as cultural capital. It can also be suggested that this understanding is reflected in the ambitious plans of many young carers for the future. For example, Jonathon and Kate have set goals to study law at university, Emma to study psychology, and Liam to be a pilot. Interestingly, Jonathon attributed his ambitious plans
to his family situation, in particular seeing what his parents have been able to achieve while experiencing disability. This very positive standpoint of these young people conflicts with research literature which positions young carers as having their futures jeopardised because of disrupted education, fewer social skills, and mental health problems (e.g., Cree, 2003; McAndrew, Warne, Fallon, & Moran, 2012; Warren, 2007).

To summarise, a number of the young people in this research put forward a strong understanding of being a better person for being a carer. This understanding incorporated a very positive description of the outcomes of being a carer, based on possessing personal qualities and adult-like skills and capacities, and an enhanced future.

9.2.2 A compromised childhood

While the above discussion of the positive positioning of some young carers is very important, it is not intended to downplay what is still a very difficult experience which at times is described very negatively by some young people. Some rejected the positive positioning of young carers described above, and for others the positive elements were not sufficient to overcome the understanding that they were missing out and their future lives might be jeopardised. This viewpoint is very succinctly captured by Mitchell:

“[my home life] just sucked … it just sucked” (Mitchell).

Mitchell was one of a small number of young people who were almost entirely negative about their experience caring for a family member. Here the understanding of being a young carer excludes the possibility of having a ‘normal’ childhood and hence involves ‘missing out’. The tenor of the discourse about missing out and ‘what if’ things had been different, is well captured by Melissa in reflecting upon missed opportunities for school honours and the opportunity to attend university, which are indirectly connected with caring duties:
…I had a lot of people actually in-boxing me saying ‘you should have got school captain … if you were here you would have got it’ … and so the thought of thinking ‘what if’ … if I hadn’t have had those things … (Melissa).

It is significant to note that in the previous section Melissa described very positive constructions of being a young carer. These divergent comments by Melissa are an example of the ‘roller-coaster’ of positioning that commonly featured in the young carers’ accounts, both within one interview and between the interviews over the period of the fieldwork. In the preceding section, it was described how very positive subject positions emerged from the young people’s accounts of their role as family carer. Many of these same young people were, at other times, positioned as having a compromised and abnormal childhood, describing what they had missed out on by being a carer. This duality was, at times, also exemplified by Emma who has simultaneously extolled positives of being a family carer and how she had a “higher calling” and “a privileged life”:

…it gets very overwhelming, I can get resentful … it does make me angry … and I see … like I see other children who don’t even clean their rooms or take the bins out, their mothers do it … and why can’t my mum do that… (Emma).

The subject position reflected in these comments by Mitchell, Emma and Melissa can be likened to the dominant negative paradigm as portrayed in the research literature with discourse about burden, resentment, and being overwhelmed (e.g., Aldridge & Becker, 1993; Thomas et al., 2003) and the negative impact on schooling and the future (e.g., Cree, 2003; Warren, 2007).

It is interesting however that the tenor of this negative discourse is not directed to the inherent difficulties of a caring role, but rather to making comparisons to the lives of peers and missed opportunities in relation to peer-related activities. It can be suggested that a major factor in young carers (mostly) being positioned as being compromised and missing out relates to lives being in conflict with the dominant Western discourses.
concerning a ‘normal’ childhood/teenager and family, which will be discussed fully in Chapters 11 and 12.

A negative construction of a young carer

“You see the bad times and you think, you know ‘why me, does God have no heart ... why have I been put in to this role’...” (Jonathon).

The above comment by Jonathon is an example of the very negative portrayal presented by some young people in relation to their situation as a family carer. In striking contrast to the catalogue of positives outcomes described earlier, the role of caring was for some accompanied by a miasma of despair, anger, isolation, and the idea of a person whose life is defined by bad luck.

It is important to note that this negative portrayal was not usually expressed in terms of education or social activities (the focus of much of the research literature), but rather what most often emerged was a discourse characterised by expressions of isolation, being trapped, and feeling unappreciated and unrecognised. Revealingly, when Mitchell was asked what the term ‘young carer’ meant to him, his despairing response was that it was a young person who had “bad luck”; “bad things in life happen, you just have to keep going”; “I used to be pretty angry about it ... or like, you know, why us, why do I have to do this, this is bullshit, you know...” (Mitchell).

Particularly strong for these young people was the experience of being isolated and not understood:

“...you think you are alone ... because you think, ‘oh, everybody else is so much better off; nobody knows what I am going through’...” (Stephen).

...because they didn’t get it ... and that was the worst part for me, was not having people who understood and that is where a lot of young carers get frustrated as well .... Because a lot of the time when you are a carer, you feel alone, you feel like there is nobody you can relate to ... or you can talk to, you know... (Melissa).
For those young carers whose family structure provided no other options for caring support, such as being the only other member of the family, there was a discourse of being trapped in a family situation with no foreseeable end that would not entail guilt about abandonment. This was a specific concern for Jonathon, Stephen and Mitchell:

“...I’m stuck here ... looking after two disabled parents” (Jonathon).
“I knew I didn’t have a choice” (Stephen).
“…so I’m stuck here” (Mitchell).

It is important however to consider the context within which this discourse of being isolated and trapped takes place (consistent with a critical realism epistemology). Firstly, these three young people are all sole carers and they are the only other family member apart from the ‘cared for’ parents/guardian, and hence they have no family support. The three families appear to be experiencing some levels of poverty with very limited provision of support services. It is argued here that these contextual factors play important roles in the experience of being trapped and isolated. The importance of this lack of support services can be illustrated by accounts of different times from both Jonathon and Mitchell. Jonathon describes how at an earlier time his family had a dedicated case worker who dealt with agencies on their behalf and was their ‘problem solver’: “it made things a lot easier and it reduced a lot of the stress” (Jonathon). The position of their case worker was subsequently axed by the relevant government agency. Similarly, Mitchell discusses how good it was when they received the support of a part-time housekeeper, but this service had to be ‘traded’ to obtain a computer for his school work. These examples are suggestive of institutions being predisposed to attribute young carers’ feelings of isolation to their difficult family situation, ignoring the importance of support in mediating their experience. This conclusion is also supported by the predominant focus on events and activities for young carers, which could be characterised as seeking to treat the ‘symptoms’ and not addressing the cause of the isolation (which is seen as an unavoidable consequence of caring). This is a concern
raised by Olsen and Parker (1997): agencies are tinkering with ad hoc support for young carers to the exclusion of support for the family that would greatly reduce the caring role of the young person.

It follows that the isolation experienced by some young carers is exacerbated by being inadequately supported by government and, in fact, unrecognised and unappreciated by the community as a whole. This belief was specifically articulated by Jonathon and Melissa:

“…people just don’t care, the government doesn’t care … a lot of people don’t care, and that’s where … just … they are focused more on funding for ‘better’ things like roads” [sarcastic tone] (Melissa).

…it’s a taboo topic … there’s not very much recognition at all. You know, nobody wants to go out and talk about how one person’s doing society a favour by looking after someone who can’t always look after themselves (Jonathon).

It seems clear that a significant aspect of the negativity expressed by young carers was a belief that governments were indifferent to their situation and that they were not being supported. Lack of support services can be a particularly significant concern in rural and remote regions, although for some young carers there were advantages in being connected to a small community.

In marked contrast to young people, such as Jonathon and Melissa, who are positioned as being trapped and isolated, there were other young people whose experience was quite different because of what might be termed ‘external connectedness’ beyond the family. An important example is Kate and Sam who lived in a very small rural community and felt very connected to the people in that community. Their community neighbours were seen as a source of both practical and emotional support and back-up that might be likened to an extended family. In one small coastal village, there was a long standing relationship with a doctor and a pharmacist that could be relied upon to provide Emma
and Jack’s family with a personal service that enhanced a sense of connectedness and being supported. Conversely, for others such as Mitchell who lived in a small, remote community with no apparent connections to that community, there was a pronounced sense that he felt isolated and with an added responsibility of coping alone.

Disability and illness: Stigmatised by association

“...I do think I have missed out on some very important things ... not having ... umm ... friends ... I can’t ... I can bring my friends home but ... it was hard to sort of...”; “I am not ashamed of my brother, but...” (Mia).

“…well I’m not embarrassed about him being my brother or his disability, but when he goes ‘off’ … crying, slamming … stuff all the time …. which is why I barely go anywhere with him anymore…” (Liam).

These quotes from Mia and Liam highlight aspects of young carers negotiating discourses of disability. Mia’s quote has its origins in a much earlier incident that occurred when she brought a friend back to her home; the friend referred to her half-brother, who has the condition cerebral palsy quadriplegia, as “disgusting”. In light of the negative effect of this incident on Mia, her mother places tight restrictions on the young people who come to the home and the quote from Mia alludes to her exclusion from this common reciprocal social activity with friends. The context of Liam’s quote is the disruptive behaviours of his brother who has profound autism. The embarrassment that Liam feels about his behaviours in public, referring to “staring, teasing”, constrains him from attending age-related social activities. Liam’s disclaimer about not being embarrassed by his brother evokes a discourse of family loyalty, which is in tension with a negativity surrounding disability which comes from peers and the general public.

Mia and Liam are examples of how, at times, the positioning of young carers as compromised appears to be significantly influenced by their connection with disability and illness. Most particularly, young carers often felt constrained about socialising and
bringing friends to their homes, perceived to be an essential aspect of teenage activities suggested by the dominant discourse of a ‘normal’ child/teenager. The experience of Mia and Liam is consistent with the descriptions by Keith and Morris (1995) of the prejudice suffered by young carers because of disabled family members.

Attitudes to disability were often a difficult area for the young carers to negotiate. As was discussed earlier (section 9.2.1), for many young carers it was portrayed as a point of distinction from their non-caring teenage peers, as well as a general positive of being a carer; they were understanding of disability, non-judgmental about difference, and supportive of those who were marginalised from their peers for whatever reason: “I can understand …. like whereas the normal person wouldn’t know … have any idea, wouldn’t have the slightest idea” (Liam).

Notwithstanding the position as a better person because of a positive attitude and approach to disability, at the same time they often ‘shielded’ their family member with the disability and kept their family situation secret. The tension can be illustrated with reference to Jack who gained some notoriety at school for regularly and aggressively responding to people teasing or bullying children with a disability: “…yep, so I hit him … in the face … [long pause] believe me, he never made fun of any disabilities again, or in front of me, at all … so”. At the same time, Jack largely keeps secret the physical and mental health problems of his sister and mother. One potential consequence for Jack of keeping the family experiences of disability and illness a secret may be a distancing and dissociation from the strong underlying and stigmatising discourse about disability and, perhaps more particularly, mental health problems. This allows for loyalty and protectiveness to be maintained while creating distance from perceived stigma in the community about disability and mental illness.

These tensions experienced by Mia, Liam and Jack are suggestive of a mostly latent
stigmatising discourse on disability in the community that gives rise to embarrassment, fear, and misunderstanding. In all but very small communities, the young people characterised community attitudes to disability as lacking understanding and often entailing staring, teasing or patronising sympathy. This discourse adds further tension and complexity to the construction of some young carers’ lives as compromised.

Worry about the future

...not only am I worried about what will happen to Justin ... I’m not ... I’d want to know where I stand about looking after him ... I don’t know what’s going to happen to him, because I don’t want him to have to go to a nursing home ... I don’t know what ... I deserve to have ... my life ... like everybody else ... so I don’t know what I’m going ... I don’t know... (Mia).

In some family situations the sense of being trapped was exacerbated by concern about future care of their family member that could potentially consume a large portion of their lives. The above comment from 13-year-old Mia is perhaps the most striking portrayal of ‘future worry’. She longingly spoke of plans to leave home, to have a good career and to travel, but was uncertain about responsibility for the long-term care of her half-brother who has a profound disability. This was a particularly prominent concern for some of those young people contemplating university; Emma, who has positioned herself as a quasi-mother speaks of “abandoning her children” (which interestingly included her mother as well as her half-sister). Jonathon, although only in Year 10, was already contemplating the problems that would be involved with him being a carer and attending university. A point to be noted here is that this ‘worry for the future’ is of an entirely different nature to that portrayed in the research literature, which suggested that the future lives of young carers are imperilled by compromised education and physical and mental health issues. Instead, the concerns of these young carers related to ongoing caring responsibilities that may hold back their ambitious plans for the future. The worries of these young carers may also reflect their awareness that there is no
government facility or capacity to ‘step in’ should families be unable to provide care for their parent or sibling; to repeat a comment from Chapter 1.1.4, under deinstitutionalisation there has been a normalising of the view that a government ‘caring for its citizens’ now means ‘caring by the family’.

To briefly summarise this section, there are a number of elements to the positioning of young carers as compromised. Most particularly, there was a strong discourse of ‘missing out’ in terms of childhood and family life. A number of young people also detailed feelings of being trapped, isolated, and not being understood, which emerged in a context of the young carers receiving very limited support in managing extremely difficult situations. For some young people, the difficulties where compounded by a (mostly latent) discourse in the community that stigmatised their association with disability and illness. Finally, for those caring for siblings, there was an additional concern about long term responsibility for their care and the potential for a whole of life impact on their future. All these elements contributed to the subject position of compromised child.

9.2.3 Not a carer – just being a proper family member

you don’t really think of yourself as a young carer ... like you do, because that is the label, like you said, that has been put on us, but it’s not really, we don’t think of Briony ... that she’s my ... care-ee [laughs] (Kate).

Kate is one of a small number of those young carers who consistently rejected being positioned as a young carer. Furthermore, the implication of Kate’s comment is that the notion of her being a ‘young carer’ would not have arisen had the label not been applied to her by external agencies. It was discussed in Chapter 3 how the term ‘young carer’ is a label that was created and applied by researchers and service agencies. Kate’s comment resonates with the findings of Morris (1997, p. 55) who noted that young people did not describe themselves in this way until they came “into contact with researchers or professionals”.

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The rejection of the subject position of young carer also appears to stem, at least in part, from the notion that a child being a family carer conflicts with the roles and responsibilities of parents and children that are prescribed by Western familial discourse. There was an overt focus on maintaining traditional family roles and so the child is not acknowledged as being a carer. In order to incorporate this understanding of family roles into a very different situation that exists in their home, some young people were positioned as a helpful child/sibling, rather than as a young carer. This was expressed by Kate as “we just have to be brother and sister … [that] do a lot of chores”. Their caring role was positioned as just being a natural and appropriate part of being a family member, which was presenting as not being particularly special or demanding. The positioning of these young people in this way enables both the family and the young person to accord with Western discourses of normal family and normal child/teenager, minimising any suggestion that they are ‘different’.

This subject position of not a young carer, but rather a helping family member, is an important part of the discourses of ‘being a young carer’. While it is appropriately raised here as being of the four subject positions that emerged from the analysis, it has its genesis in the cultural norms of the family and, will accordingly, be discussed more extensively in Chapter 11 (Familial discourse and the Western family).

9.2.4 A carer, but still a regular young person

In the previous section it was described how the positioning of young carers as a helpful family member constructs a ‘normal’ young person whose lives are routine and not different or special. A fourth subject position that emerged from the analysis also positioned young people in this way: while they were a carer for a family member, their lives were fundamentally no different, and they remained a regular young person.
The emergence here of a discourse about normalcy was an important outcome of these initial two rounds of conversations with young carers. It is very apparent that the strong Western constructs of a ‘normal’ family and ‘normal’ child/teenager invites comparisons with, and judgments of, the situations of young carers. With the lives of these young carers of necessity differing quite markedly from those of their peers, this subject position of a ‘regular young person’ brings a strong focus to the ways the construct of ‘normal’ emerged. As has been discussed in Chapter 1.2.1, this research takes a social constructionist position and considers ‘normal’ to be a construct that is both temporal and culturally based. Rather the focus is the consequences of discourses of ‘normal’ and, from a critical realism epistemology, the context which enables or disenables such discourses.

The accounts of the young carers that relate to this subject position were notable for the frequency with which issues concerning ‘normal’ emerged, the different ways in which ‘normal’ emerged, and, in turn, the questions that are raised by the discourse surrounding normal. The quotes below from five of the young people are indicative of how strongly a discourse of normalcy emerged:

“…well, I just DON’T KNOW [emphasised] any different now …. this is the only life I know” (Allison); “it becomes the normal … you get used to it” (Sam); “…this is normal” (Stephen); “…so it becomes normal” (Liam); “this is normal” (Rebecca).

This emergence of a subject position of a ‘carer who is a regular young person’ can possibly be interpreted in the context of young carers being required to be defensive about the normalcy of themselves and their families which, at times, this research may have created. Additionally, however, this positioning makes possible a resistance to cultural constructions of a normal family life, with the strong stance of some young people that their life and that of their family were normal and routine, notwithstanding major differences from the conventional construct.
Deflecting the magnitude of the caring situation?

One possible consequence of these accounts of their situation as ‘being normal’ is that it may deflect the magnitude of the caring situation and suggests a more ‘matter-of-fact’ status that is not particularly special or different. A discourse of ‘all I have known’ may strengthen the understanding of these young people that their caring role makes them no different, either in a positive or negative way. The context of the above quotes of the five young people referred to above is that they grew up with their family situation as it currently exists and so it has the status of being routine and the ‘norm’. Rebecca, for example, who has been a carer since the age of eight years, considered her family situation to be ‘normal’ although her father has a major mental health issue which disrupts the family in a very substantial way every few days and which prevents him performing what would be considered a ‘normal’ parental role and maintaining the expected father-daughter relationship. Of course from the social constructionist standpoint of this research, the portrayal of their experience as being routine and normal can be understood as their ‘reality’ and is not surprising, but their accounts do raise issues about the construct of normal.

Even Mitchell, whose accounts of his experience as a carer for his mother were very negative, at one point also described his situation in terms of a regular lifestyle:

“…like if you haven’t experienced anything different, like me … like me, I grew up like that … then it is your regular lifestyle” (Mitchell; 17 years old, who has been a carer since he was 12 years old).

Interestingly, Mitchell often speaks of his experiences as being abnormally bad, but here he also describes them as being “regular” (normal). These variations and contradictions in the accounts of the young people suggest that ‘normal’ is being used in different ways at different times. The context of these quotes is that ‘normal’ is not referencing the constructs of the Western ‘normal’ child, teenager and family, but rather their ‘reality’.
There is a certain paradox in this outcome: normal will always be whatever life (reality) is being experienced. This understanding of normal positions their experience as a young carer more positively in the face of the implication, perhaps also prompted in part from my presence as a researcher, that they had a lesser life because they were caring for a family member.

Comparisons with other young carers

Another aspect (or variation) of the normalising discourse which emerged was the accounts of many young people which described their situation positively compared to other young carers.

“I don’t have it as bad as other people ... it’s not like I have anything to complain about when other people [young carers] have it much worse” (Rebecca).

“...there is people [young carers] out there that have it a lot worse than myself” (Allison).

These quotes capture part of the discourse surrounding the subject position of ‘a regular person’. Rebecca and Allison were two of the many young people who suggested that the situation of other young carers was much worse than their own. These accounts of their comparatively better situations has the potential to position their own lives as ‘more regular’.

Complexity and variation surrounding ‘normal’ further emerged in relation to Mitchell’s account. As the sole carer for his chronically ill mother in a remote area with no support network, his situation seems extraordinarily difficult and he most often was extremely negative about being a carer. However, in seeming contradiction, Mitchell declined to go on young carer camps because:

“…if I didn’t go maybe it would help someone else more … that was more deserving … that was the sort of conclusion I reached, you know”.

Notwithstanding Mitchell’s overwhelmingly negative account of being a carer, on the other hand he refers to his situation as being better than that of other young carers. This
contradiction highlights the complexity and variation of the discussion surrounding normal. It can perhaps be tentatively suggested that his account of other young carers being in a much worse situation, may potentially help him understand his position as ‘not so bad’ and less difficult than would otherwise be the case.

As will have been noted, in addition to discourses relating to normalcy, the other significant issue to emerge in relation to this subject position was the variation in accounts of the young people, both within one interview and between different interviews, as well as the variation between the accounts of different young people. The subject position of a regular young person whose life is ‘nothing special’ was usually ephemeral, with the young people often returning to themes about what they were missing out on because of their caring role. These contradictions most commonly involved the young carers reflecting upon their exclusion from participating in what are understood to be the fundamental components of Western teenage and family life. These exclusions appear to invite judgments that they were not experiencing a ‘normal’ childhood or family life. From unpacking this subject position of ‘just a regular young person’, what begins to emerge is a complicated narrative and construction of ‘normal’ which, in turn, was notable for its significant variation.

To summarise section 9.2, four subject positions of ‘being a young carer’ have emerged from my analysis of the first two rounds of discussions with the young people: (1) A better/special young person; (2) A compromised child/teenager; (3) Not a carer, just a proper family member; (4) A carer, but a regular, normal young person. While the first three of these subject positions emerged in part from comparisons with non-caring young people and their families, the position of being both a carer and a regular young person has revealed more complex normalising discourses. The tentative outcomes discussed in this section were the subject of further direct discussions with the young carers in the
third round of interviews (as part of the collaborative methodology) in order that they could challenge, extend and develop my initial analysis (section 9.4).

9.3 The influence of parents on the positioning of young carers

There was discussion in Chapter 6.1.9 about interviews being conducted with the parent of seven young carers at the suggestion of their children. I also had lengthy interaction and discussions with the other parents when meeting with their children in the family home as well as when arranging these meetings. Parents are of course also impacted by dominant cultural discourses and, in almost all instances, particular subject positions for their children were advanced in my discussions with them. This presumably occurs to some degree in all families. It is also pertinent to note that most of the young people in this research were caring for a parent (or grandparent). There were however two young people, aged 12 and 13 years, who were caring for siblings with disabilities and this arrangement can be expected to result in a much different understanding of the situation than when a child is caring for a parent.

There were instances of both a congruence and a divergence in how parents and their respective children understood the subject position of young carer. While there was considerable variation in these subject positions, a common understanding in the family seemed to be a significant factor in how the child understood her/his experience. Where there was not a common understanding between parent and child, this seemed to produce mostly problematic outcomes. At one extreme, very similar views were expressed which included the independent use of identical phrases in their discussions with me: for example, Jonathon and his mother both referred to young carers as being “used and abused”. At the other extreme, a mother and child even differed on who they considered to be the ‘cared for’ person in the family. Reflecting on the concordance of views
between parent and young carer provides further insights into the themes that have emerged.

“…being a young carer has given her these gifts and strengths” (Allison’s mother).

“…I don’t think it harms them to give them responsibility ... I think its ok, I’ve never felt like ... it’s bad...” (Allison’s mother).

I’ll often say that to Allison, you know ... you think they have a perfect life, across the road in that house ... or something like that family, they’ve all got a good car and this and that ... and you think ... but behind those closed doors ... you don’t know ... so many people ... everybody ... life has its ups and downs and its challenges” (Allison’s mother).

The above comments from Allison’s mother presents the role of young carers as unproblematic, seeks to diminish differences between their family and others, and even suggests that the responsibility of caring is a positive for young people. Indeed, her tone of annoyance at the time suggested umbrage at the implication that Allison has been disadvantaged by being a carer. A different but related position is presented by Mia’s mother, who adamantly argues that their family situation provides her daughter with valuable life lessons: “…it is very important that Mia knows that life isn’t easy” (Mia’s mother). This positive parental discourse resonates with the study by McDonald et al. (2009) wherein parents identified no negative outcomes from their children caring, but rather talked of positives.

Accepting that being a young carer may, as claimed by Allison’s mother (above), have few negative outcomes, there are a number of possible purposes that could be served by a parent describing their child’s situation in this way. It can first be suggested that the context for this positioning is parents being made to feel defensive about imposing a role and responsibilities on their child that is contrary to those of the ‘normal’ family and contrary to what is considered appropriate for a child. Accordingly, this positive discourse allows for assuaging feelings of guilt and inadequacy as parents in imposing on their child a demanding caring role. Secondly, a parent, by promoting a positive
positioning of their child and their family, may serve to enhance the child’s own understanding of her situation (or it may be vice versa). Allison, for example, mostly speaks of her situation as being nothing particularly special, notwithstanding her very difficult caring role and the high level of responsibility she assumes within the family. She adopted a very similar positive discourse about being a carer to that of her mother, noting that: “you kind of just have to look at it in a positive way...” (Allison). This suggests that a parent’s positioning may be a significant influence in mediating a young carer’s understanding of their situation.

In contrast to the relatively positive positioning of Allison by her mother, in some families the parents view their children’s experience as carers extremely negatively. Again, it may not be a coincidence that it was the children of these parents who most often described their situation negatively. Jonathon’s mother captures this negative sentiment below:

“…it does [adversely] affect Jonathon as a young carer in a MAJOR, MAJOR way [emphasised] … physically and mentally” (Jonathon’s mother).

These views might be characterised as the negative paradigm of young carers as was discussed in the literature review. In particular, the mothers of both Jonathon and Melissa were very vocal about the plight of their children and some of the exact phrases from the research literature emerged in positioning their children as compromised and failing to have a normal childhood (e.g., Melissa’s mother: “…grow up too fast …. haven’t had that normal growing up experience”; Jonathon’s mother: “has he had a childhood?”). It was perhaps not surprising therefore that the discussion with these parents was dominated by their exhortations for much greater levels of support for themselves and their children. Without doubting that the parents’ comments were motivated by genuine concern for their children, it also seemed I was positioned as a young carer ‘expert with contacts’ and seen as a potential abettor in their pursuit of more support. The focus of
these parents on positioning young carers so negatively can therefore be understood, in part, as enabling justification for claims for more support. It is however likely that this very negative positioning by the parents of Jonathon and Melissa also had the effect of enhancing how negatively their children understood their own experience as a family carer. In particular, there was an overwhelming and suffocating discourse of negativity and complaint from Jonathon’s parents, which could not have done other than to add to Jonathon’s negativity and despair.

“...we just have to be an older brother and sister ... and be a bit more responsible” (Sam).

Mention was made earlier how Kate and Sam are positioned as a helpful child/sibling in the family, rather than as a young carer. It was also specifically mentioned by both Kate and Sam that this subject position of ‘helpful sibling’ was actively promoted by their mother. Their mother also openly expressed the need to maintain what she considered to be an appropriate ‘normal’ family structure and roles and relationships between parent and child and between siblings. This positioning by parents can be attributed to the strong interrelationship between the discourse of being a young carer and Western familial discourse, a topic that will be explored in detail in Chapter 11.

The above discussion illustrates three mostly clear subject positions of young carers that have been promoted by parents that also accord with how their children describe themselves as carers. These can be understood as important examples of the influence parents may be having on how young carers understand their position in the family, and in turn how their children experience being a carer. There were however also other, more nuanced, subject positions of young carer that were presented by some parents.

Two young people (Liam and Mia) share with their sole parent a caring role for a profoundly disabled sibling. It was evident from my discussions with these young people, and their respective parent, that their child’s role as a carer was positioned as minor, and
hence as not having a significant adverse impact. This positioning by parents may have the potential to deflect any sense of guilt about their child needing to be a family carer and the notion that they may not be providing them with a proper childhood experience.

This positioning appears to impact on the child’s understanding of their situation. Liam and Mia also identified less as a ‘young carer’ and, in general, did not reproduce the negative discourse about the impacts of being a carer. The subject position that was more accessible to Liam and Mia was that of ‘child with a disabled sibling and a single parent’, which it can be suggested was conflated with, but dominated how they understood being a young carer.

Apart from being the carer for their sibling, there was expressions of jealousy and annoyance for what was seen as their sibling being the favourite child and receiving favoured treatment by their mother. Both Liam and Mia openly discussed how their sibling with the disability is the favourite and receives preferential treatment and attention from their parent. Mia often argues with her mother that “… he’s [brother with disability] your favourite” and refers to herself as “the forgotten child” and spoke with some annoyance how “it’s always ‘how’s Justin?’ … it is never ‘how are you Mia?’” Similarly, Liam argues that “I never got as much attention …. I think that was maybe why I tried really hard at school … just to try and get my parents’ attention” (Liam). For Liam there was also open expressions of bitterness about being in a one parent family, for which he attributes blame on his sibling for his parent’s divorce, and that “he is stealing attention with my mother” (Liam). The conflation of being a family carer with the experience of being in a one parent family with member/s of that family having a disability or illness, adds another layer of complexity to understanding the experiences of young carers.
Further to the parents of Liam and Mia dismissing, or at least downplaying, the significance of their children’s caring role, there was a starker disconnect between young carers and parents: that is, those parents who understand their children’s experience of being a young carer quite differently than do their children. This can firstly be illustrated by reference to Stephen’s situation with his ‘cared for’ grandmother. In her discussions with me, the grandmother criticised Stephen as a carer for being “lazy” in completing household chores, which is the terms in which she saw his role of a young carer. However, for Stephen household chores and tasks were not a factor in how he understood being a young carer. Stephen described his situation as a young carer in terms of the sense of (sole) responsibility that had been imposed on him, a responsibility for which he often feels ill-equipped to handle, and the feeling of being alone and isolated and not knowing what to do: “…it’s like ‘I don’t know what to do’ … You have no idea what you are doing” (Stephen). A disconnect between the understanding of the parent and their child carer was also suggested by Emma at the first interview when she spoke against interviewing parents and in the final interview she commented: “oh god, imagine if you asked my Mum about me”. The different perspectives of parents and young carers is even more graphically illustrated by Emma and her mother not even agreeing on who is the ‘cared for’ person in the family.

The negative impact of this disconnectedness can be contrasted with the strength that Melissa drew from her shared understanding of being a carer with her mother. Melissa and her mother independently presented very similar accounts of Melissa’s experience of caring and “…if it wasn’t for my Mum I probably would have just given up a long time ago” (Melissa).

It might tentatively be argued that concordance between parent and child on the subject position of young carer can provide for a more harmonious caring and family situation,
as was generally the case for Melissa. This also appeared to be very much the case with Kate and Sam. Conversely, the opposite situation appeared to apply to Emma and her mother who clashed about Emma’s position of carer and their relationship experienced difficulties.

Although more indirect, one final matter for reflection regarding the influence of parents is whether young people downplay the difficulty of their caring situation, and promote the positives of their situation because of their acute awareness that their parents harboured guilt and regret about their children being their carer. The comment below by Melissa encapsulates this awareness:

“[parents] don’t think that their children should be relying on them ... yes, my mother had had her meltdowns ... like ‘you shouldn’t be doing this for me’” (Melissa speaking about her mother).

It is suggested that the positivity expressed by some young people may perhaps, at least in part, be seen in the context of children seeking to ameliorate their parent’s concerns.

It is appropriate to conclude this section by commenting on the use of parent interviews. While the very basis and rationale of this research is about collaborating with and listening to young carers, an understanding of their experience is enhanced by consideration of the context, and a significant part of this context is the parent. It is also pertinent to note that the context will necessarily be different depending on whether or not the parent is the ‘cared for’ family member. As has been noted, those two young people not caring for a parent were only 12 and 13 years old, so there is an intersection between age and caring situation. This is not a straightforward issue and it is not possible in this research to make a conclusive statement about how the impact on young carers might differ depending on the context that arises from particular parental caring situation.

9.4 Collaborative analysis with young carers: Feedback on subject positions

After two rounds of discussions with young carers about their experiences (and to a much
lesser extent with parents), there was a desire to involve young carers in analytical conversations (consistent with the collaborative methodology for this research). It was decided therefore to conduct some very tentative preliminary analysis of the data to use as the basis for discussions with the young people (this process was described in Chapter 6.1.8). A series of questions were compiled, incorporating these preliminary findings, which were provided to the young people. A copy of the questions is at Appendix G. The use of questions was carefully reflected upon, given that they were likely to influence the way in which the young people would consider and talk about the issues. It was however very clear that it was not feasible or productive to provide raw interview data to the young carers for analysis, particularly given the already prohibitive demands on their time. The use of questions was seen as the only feasible way to move from my preliminary findings to more collaborative analysis. However, on-going reflexivity was an important part of these ‘analytical’ discussions to minimise the authority of my preliminary analysis and allow the young people to be unconstrained in expressing their own views and ideas.

As the starting point for these analytical discussions, the following question on the four subject positions, as discussed in the preceding sections, was provided:

*In general terms, the young people I have spoken with, seem to think of themselves predominantly in one of four ways (although lots of young carers describe themselves as more than one of these at different times): (i) a young carer who feels as though they are ‘missing out’ and their lives are worse off; (ii) a young carer who feel they are better off for being a carer; (iii) as young people who feel their lives are normal and routine, that is, they are a regular teenager; and (iv) those who don’t consider themselves to be a young carer; they are just being a family member. What do you think about these categorisations? Are there other more important categories I should have included? Are there things that affect how much you feel like one of these at different times?*

While acknowledging that the question invited consideration of a narrow range of labels, the four subject positions were effectively confirmed by most of the young people. They
were also not able to identify any additional ways in which young carers could be positioned. Mitchell and Liam were however incredulous at the suggestion that any young carer could consider themselves to be better or better off because of their situation. Most young carers considered there to be some negatives and some positives to being a young carer, and could at least appreciate that some would nominate positive (better than) and negative (missing out) subject positions. At the farthest end, Emma considered that she felt like all four categories at the same time.

However, the most significant outcome from the third round collaborative discussions was the nomination by the young people of the subject position that they considered most pertinent to themselves, which was overwhelmingly ‘a regular teenager whose life was routine and normal’. For most of the young people, this sharply conflicts with the subject positions that had emerged from my preliminary analysis of the first two rounds of interviews. Perhaps the most striking example was Jack: he had previously lamented that he was not able to play like a normal kid, that he did not have normal family holidays, and that he did not have normal mother-son time, and at times explicitly states that he is not a normal teenager – yet in responding to the specific question, he chose to nominate as “a carer, but still a regular, normal young person”.

From a critical realism standpoint, it is the case that a life as a carer is, for these young peoples, their ‘norm’ and their reality. It is not surprising that when asked about themselves being different, the response from young carers is that the situation is normal. It would seem however that this outcome also reflects the young people raising the issue of ‘normal’ in different ways at different times. It is also the case that their realities are mediated by cultural constructs. It is possible that this withdrawal or stepping back from their previous accounts could be attributed to the difficulty in being directly confronted with occupying a subject position that is at odds with some of the most powerful
constructs in Western society and, in turn, the implications of being identified as abnormal.

The collaboration also included seeking their views on the ‘negative paradigm’ of young carers that underpins much of the existing body of research that was discussed in Chapter 3. Direct questions on this issue were also presented, which included the following:

_The research on young carers mostly portrays their situation in a negative way – in addition to focusing on what they feel are problems with education, social activities and health (and they don’t tend to say positive things), it also talks of young carers as having missed out on childhood and/or teenage years; it uses phrases such as ‘robbed of childhood’, ‘forced to grow up too fast’. What do you think about the portrayal of young carers in this way?_

“I think it is silly to suggest that there is a certain way to grow up” (Emma).

Firstly, the comment from Emma above is significant in that it directly challenges a dominant understanding of young carer research literature; that there is only one normal way to grow up and the transition from childhood to adolescence to adulthood is compromised by caring responsibilities (see for example Harstone et al., 2010). Emma’s comment is an implicit rejection of any notion that her life as a family carer has any long term negative implications.

All but two or three of the young carers disagree with the negative portrayal of young carers, or at the very least suggested it was too strongly negative. This is similarly judged to be somewhat of a ‘step-back’ from the overall tenor of the earlier interviews, which again can perhaps be seen in the context of being confronted with a direct question that portrays their lives so negatively (and as not normal).

Melissa who, as previously noted, very strongly identified with being a young carer, was the one whose account was most congruent with the negative portrayal of their lives. Mitchell also holds very negative views and Emma also implied congruence to some extent with the negative portrayal. It is perhaps pertinent to note that these three young
people have all attended at least one young carer conference which, as has been discussed, are notable for promoting a discourse of carers as suffering great hardship. However, without wishing to make judgements about the relative caring situations of the young carers, it can be suggested that these three teenagers are in very difficult circumstances. Perhaps of more relevance is that the relationship of both Mitchell and Emma with their respective mothers was firstly complex, and then became toxic and fractured, culminating in them moving out of the family home towards the end of the fieldwork. Family connectedness, which seems to be an important factor in how these young people experience being a family carer, has seemingly dissipated for Emma and Mitchell. As might be anticipated, those young people like Stephen, Kate and Sam who did not consider themselves to be young carers, were dismissive of the portrayal of young carers as either brave little heroes or negatively as burdened young people who were compromised by their caring duties.

To summarise, the extent to which the accounts of these young people are congruent with the negative paradigm of the research literature is, as would expected, an outcome of the various complex factors that have been discussed. At one extreme was Emma who has recognised and rejected the cultural construct implicit in the paradigm, through to Melissa who perhaps exemplified the young carer paradigm. However, it was also notable that all the young people, including Melissa and Emma, varied significantly in how negatively (and positively) they described their experience as a carer.

*The effect of the label of ‘young carer’*

“it didn’t matter whether I was a young carer or not, I was still going to have to look after Mum” (Mitchell).

The issue alluded to in Mitchell’s comment is the impact, or otherwise, of young people with a caring role being labelled as a ‘young carer’. This was also an issue on which the views of the young people were sought. It was mentioned in the literature review
(Chapter 3) that the term ‘young carer’ is a label developed and used by researchers and service agencies, but may not necessarily be one with which young people, with a caring role, identify (Morris, 1997). For some young people, such as Melissa who spoke of being inspired by her attendance at young carer conferences, the label was a positive and a source of pride. Mia similarly spoke of being positively affected when she was first labelled ‘a young carer’: “... I did feel different ... yeah, better I suppose, now that I knew that I wasn’t just helping Mum for no reason [chuckle]” (Mia). It has also been mentioned how some young people, such as Sam and Kate, do not identify as young carers, but have been registered with the Respite Centre as young carers by their mother in order to access services and programs. Accordingly, for them the label was relevant only to the extent that they were not positioned in their families in this way.

The feedback from the young people on the appropriateness of the label ‘young carer’ was notable for its variation – many people have no view, some reject the label, others consider it to be irrelevant (Mitchell), while yet others see ‘young carer’ to be an important label which makes them feel recognised and proud of their role as family carer.

While it was never articulated in these terms, it can perhaps be suggested that those who rejected the label (as well as those who accepted the label but still described themselves as regular young people) are at some level reacting against what is being presented as a total characterisation of their lives – a characterisation which ignores other aspects and features of their identity as a child/teenager. This can be understood as the opposite position from Melissa, whom it is argued essentially defines her life in terms of being a young carer. As has been stated many times, this research does not seek a representative view and, in any event, it is evident that ‘difference’ is a defining characteristic of the experiences of young carers.
One further issue arises in relation to the use of the label of young carer. An obvious ramification of Sam and Kate’s situation is that the extent to which ‘young carer’ is seen as an appropriate label is disguised by the need for those caring to accept the designation and register as same in order to access funding and services. The positioning of Sam and Kate as not being a young carer also highlights the problems inherent in defining a young carer; an issue that was raised as being problematic for young carer research in the review of literature (Chapter 3). Kate and Sam, with a younger sister with Downs Syndrome, a mother with cancer, and a young brother with developmental difficulties, would seem to quite obviously qualify as a young carer. The other aspect of defining a young carer has centred on an abnormal level of caring and domestic chores, but Kate’s discussion of this issue serves to further underline the vagaries about what defines a young carer: “what’s normal … Mum would decide that” (Kate). The comment illuminates the point that the level of chores undertaken by young people varies dependent on the arrangement in the particular family, regardless of whether or not a child is a carer. Hence, it can be suggested that while chores are often a main focus in young carer research, they are not necessarily a defining feature of a young person being a ‘young carer’.

The central issue that very strongly emerged from the collaborative analysis with young carers was a complex narrative and construction of ‘what is normal’. These discussions added considerable complexity to the understanding derived from my preliminary analysis. Both directly and indirectly, the concept of ‘normal’ repeatedly arose as a point of discussion, reference and comparison. There is also a narrative about the complexity of their lives that makes ‘normal’ problematic, while the rules of what is ‘normal’ are imposed on young carers from ‘outside’ in various ways. This can even extend to the micro-level with a determination of what is a normal level of chores (Kate’s mother).
These outcomes would suggest that understanding ‘being a young carer’ must account for constructions that involve actions imposed from the outside.

To summarise this section, an outcome of bringing the young carers into the analysis process is that discourses surrounding normalcy have emerged even more strongly and with greater complexity. This builds on and extends the strong line on ‘normal’ that first began to emerge in section 9.2.4 with the discussion of the subject position of ‘a young carer who is a regular person’. Similarly, and also extending the work in section 9.2.4, the collaborative analysis was notable for highlighting the great variation in the accounts of individual young carers.

9.5 Being a young carer: Performativity

The involvement of the young people in the analysis of the data about their own experiences provides an appropriate point to consider what might be inferred from the performativity of young carers. It is suggested that there are a number of aspects from my interactions with and observations of how the young people acted and presented, beyond an understanding of their spoken words, that are indicative of ‘being a young carer’. This included extended periods in the family home, observing their interactions with family members and undertaking caring tasks, extensive contact during young carer camps and, to a lesser extent, contact at other young carer activities. Consideration of performativity can also be useful in ‘unpacking’ assumptions about young people.

Unlike other chapters and sections of analysis, this section does not focus on what has been talked about by the young carers, but reflects on their actions, their way of being, and the way matters are presented. This section does not seek to be representative or to demonstrate concrete absolutes, nor does it seek to delve into every action observed during the fieldwork. It seeks to draw and reflect upon a small number of important examples of performativity that provide insights into young carers and young people.
more generally. An important component of this section is reflexivity in relation to my reactions to their ‘ways of being’ and how I have interpreted these actions.

Perhaps the most surprising, and consequently instructive example of performativity was my observation of the role of a 16-year-old young carer. The particular incident ‘brought to life’ his discussions about being a carer and relates to him performing a role of mediator and counsellor for a parent who, amongst other conditions, was highly excitable with anxiety issues. I observed with some amazement his skills in quietly talking his parent through an issue, presenting options, and ultimately dissipating their agitation and anxiety. While this aspect of a caring role was later seen in other families, this was the first instance where I observed a complex, demanding, and emotional function from a young carer. There is a strong tendency, particularly in the research literature, to view young carers in terms of household chores and overlook the non-physical aspects of caring for a parent. The reason for my amazement was that I had not expected that a person of this age could possess such high level skills.

A further incident that reinforces this understanding was mentioned in Chapter 6 where, at our first meeting on a young carer trip, a 12-year-old boy took me aside from the group to gently point out that he prefers to be addressed by an abbreviated form of his name. This level of confidence in interacting with an adult and his nuanced handling of a social situation disrupted my own internalised understanding of the position of child. In addition, what is not captured for the reader in my description of the incident is the in situ impact on me of confronting the visual aspects of a small 12-year-old child, which serves to reinforce notions of vulnerability and partial competence, but which contrasted so starkly to his ‘way of being’. On reflecting on this incident, my shock was an indication of the degree to which my own expectations of young people had been challenged. I noted at the very beginning of this thesis (Chapter 1.1.1) that the impetus for this
collaborative research was my recognition from previous research of young carers’ sophisticated insight and understanding of their situation. I have also been exposed to poststructural literature on the construction of children (Chapter 4). I should not have been surprised. My reaction is indicative of the powerful assumptions and discourses that are attached to our internalised understanding of young people.

Young carers have been placed in adverse positions by circumstances over which they had no control. They would of course greatly prefer that their family member/s did not have a disability or illness or, even more obviously, that a parent had not passed away. It is also axiomatic that people generally do not consider adversity to be an enjoyable experience. However, there is a context to Melissa’s comment that: “...like now I wouldn’t change anything for the world”. She is pleased and proud of the person she is, which she attributes to the adversity she has confronted and the caring role she has been able to undertake in the family. Emma wants to be the person she has become because of the adversity she has experienced.

Equally illuminating was the young carers’ independence of thought and capacity to provide their own sophisticated analysis of their own situation and that of their family. Jonathon, for example, has two disabled parents that has resulted in him being teased and bullied, but he was still able to give an insightful and forgiving explanation of community attitudes to disability. Emma was able to recognise and argue against the negative impact on young carers of cultural constructions of the Western family and childhood.

In the consultative discussions carers as young as 12 years did not present as being at all ‘suggestive’ and felt entirely comfortable in rejecting ideas floated by me, who is positioned as the ‘expert’ researcher, and to argue for their own suggestions. Most of the young people, including some of those who were only 12 and 13 years of age, were
articulate, confident, very talkative, and sometimes raw and brutally frank. Two young carers largely controlled and dominated their interviews. Emma felt comfortable in offering a critique of the ethics Information Sheet that I provided: “It is really well written”. This is not only unexpected from young people, but it rarely happens with adult participants who are usually accepting of views put forward by ‘professional’ researchers and published research. It is acknowledged however that as the researcher I was in a position of power and it is likely that at times the young people were ‘suggestive’ or felt uncomfortable in offering alternative views.

Mention should also be made of the ‘adult’ stance many young carers adopted in the family home. One of the very first meetings was in the home of a 16-year-old girl, and I was taken aback by her assumption of an adult role in the family, both in her interactions with her siblings and her mother. Perhaps more surprising was that, based on our meetings in the family home of 12-year-old boy, I judged that he has positioned himself in the role of adult male. It may be that this positioning was a direct outcome of being a family carer, although of course it would also seem to be related to the absence of his father in a single parent family. However, the question that arises from all these observations and inferences is ‘what do they tell us about being a young carer’? Are these characteristics indicative of operating in an adult world and dealing with service, medical and welfare agencies?

Perhaps the obvious conclusion is that their self-confidence, insightfulness, and independent thinking result from being a carer, as the young carers themselves have more or less suggested (as was discussed in section 9.2.1 above). However, it could also be seen as revealing the arbitrary nature of the adult-child binary in designating these characteristics as adult qualities which underestimates the capabilities of young people. There is the general assumption that young people are inherently incapable, a view also
shared by many of these young carers about their non-caring peers: they discussed how their peers are not able to do all the things that they, as young carers, are able to do.

However, it can be argued that this ‘incapability’ of other young people is not inherent, but rather because they have not been placed in such a position of adversity in order to demonstrate their capability. It is also the case that there is no expectation that young people are able to do sophisticated things, but the outcome with young carers is that they most certainly can. It is simply that for most young people most of the time, they are not provided the opportunity: it is only is this forced situation of being a young carer that these capabilities can emerge. This also brings to mind the argument presented by Lansdown (1995) that young people are construed as vulnerable and in need of protection, denied the opportunity to participate in decision-making and gain experience of independence, and hence are made more vulnerable. The outcome when young people are given independence and responsibility for decision making, as is the case with young carers, would seem to support Lansdown’s argument.

The conclusion that can be drawn from this discussion on performativity is that while young people are constructed as vulnerable, partially competent, and in need of protection, the experiences of young people with a caring role demonstrate that this construction is not valid. While there is a specific context to these experiences – families struggling with disability and illness – I would argue that this conclusion speaks more generally for young people. The assumption that young people are not capable is disrupted by the ‘ways of being’ that has been very evident throughout the fieldwork for this research. Consideration of performativity supports the arguments of Boyle (2003), Lansdown (1995), and Burman (1994) that were earlier discussed in Chapter 4.

9.6 Summary

“...if you asked me that every day for a week I would probably give you a different answer every time...” (Jonathon responding to a question about how he feels about being a carer).
The statement by Jonathon above very adroitly encapsulates the fluidity and variability in the subject positions of young carers. It can be suggested that a defining characteristic of the accounts of young carers, both within the one interview and between different interviews, was inconsistency and contradiction. At times, one subject position was predominant for a particular young person, while at other times one or more of the other three positions emerged. At the extreme the accounts of some young people suggested opposing positions; that is, as being both compromised and better, and one person claimed that all four subject positions were appropriate for her caring situation.

As has also been briefly touched upon, and will be further elaborated upon in following chapters, the positioning of young carers described above was strongly interrelated with, drew upon, or was in tension with other discourses, including familial discourse, the adult/child binary, and the discourse that creates the ‘normal’ (and abnormal) child/teenager. The complexities, contradictions, and tensions that emerged were at times obvious; at other times they were rich in subtlety and nuance as a result of these young people being confronted with the most powerful discourses in Western society. In less significant, but still important ways young carers are also impacted by a discourse on disability, institutional discourse, and discourse related to being a neighbour in a small community. Interwoven into all these discussions was a prominent narrative about ‘what is normal’. Consideration of these various discourses that are faced by young people with a family caring role provide significant explanatory power in understanding their experience.

There are indications that in a number of families (but definitely not all) the young people were influenced by the subject position that emerged from their parent. This suggests that the parent, who is also navigating the dominant discourses about families and the role of parents, can play a significant role in how young people are positioned as
a young carer. This in turn greatly impacts how young people experience being a carer for a family member.

The comment from Jonathon also insightfully alludes to part of the explanation as to why the accounts of young carers are characterised by inconsistencies and contradictions. Each account is provided at a given point in time over the course of the fieldwork, which will reflect the state of family dynamics and relationships and the state of the caring situation at that moment. Not least of all, the condition of the ‘cared for’ person often varied greatly between interviews. It was common to encounter the same family to be in a very different ‘place’ at each interview – this varied from crisis to quietude. It was also the case that my relationship developed over the two years of the fieldwork. For example, a number of young carers became increasingly frank in the final interviews, speaking for the first time of tension and deteriorating family relationships. However, while each successive interview brought new insights, it is not suggested that this was closing in on some ultimate truth, rather to acknowledge that each interview will be different, as would any future interview.

To conclude this chapter, it is suggested that the major factor in these varying subject positions stem from the young people having to confront the most powerful discourses in our society that tell them that their lives are so opposite to what they are ‘supposed to be’. The manner in which they were positioned often changed because they were negotiating the conflicts and contradictions of their situation with powerful discourses about adults, adolescents, children, and family. At different times these discourses were accepted, ignored, rejected and resisted. These discourses will be explored in the next three chapters.
Chapter 10: Analysis - The adult-child binary

10.1 Introduction

In the previous chapter there was an explanation of the major ways in which the subject positions emerged for young carers. In a very significant way, these subject positions drew upon, were interrelated with, or emerged from contradictions and tensions with other discourses that are dominant in Western society, these being:

- The adult-child binary.
- Familial discourse and the Western family.
- Discourse of the ‘normal’ child-teenager.

These discourses and their impact on how young people experience being a carer for a family member will now be explored in further detail in this chapter and the following two chapters.

It is appropriate to commence with the adult-child binary as it forms part of the foundation of those discourses concerning the family and young people. Further elaboration of the adult-binary is also appropriate given that it was a consideration in a number of issues discussed in the previous two chapters. In Chapter 8 the existence of the adult-child binary emerged as a factor in the exclusion of young carers from having input into the adult-driven provision of support services and respite activities. The adult-binary was also implicit in the discussion in Chapter 9 of some young carers describing their ‘adult’ capacities, which positioned them as ‘jumping’ the divide from childhood/adolescence to adulthood.

The chapter will first consider the respective roles and responsibilities for adults and young people that have been constructed as part of the binary and their implications for young carers. The following section will discuss young carers being positioned as an adult and the impact that this can have on the family of a young carer. Finally, the
chapter will discuss the predominantly negative consequences when young carers are positioned as a ‘child’, most particularly in being marginalised from decision making in relation to their role as a young carer. The discussion of the binary in this chapter is largely based on the analysis of the first two rounds of discussions with the young people.

10.2 Adult-child binary: Roles and responsibilities

As foreshadowed, this section considers the situation of young carers in relation to the culturally constructed roles and responsibilities that are expected of adults and young people. Young carers are, of necessity, usually in conflict with these expectations. This raises for consideration how young carers understand adult/child roles and the impact of these constructs on their experiences as a family carer.

I ... the thing is, children should be able to do ... like, within reason, within reason obviously, what they want to do, when they want to ... like sports ... I want to play outside ... fine, go ... I could never just go and do something” (Emma).

In the above comment Emma is describing an assumed position that children should have some form of spontaneity and freedom in their everyday experiences – this is tied however to play, being outside, and sports, rather than other possibilities for freedom that might be adult domains. This encapsulates what is perhaps a defining characteristic of the positioning of a child against that of an adult. There is a wide separation between the child and adult because the child is grounded in the discourse of play while adults function in the world of work and responsibility. Play is what children do; work and responsibility is what adults do. Emma’s discussion on what children ‘should be doing’ resonates with the postcolonial writings of Cannella and Viruru (2004) about the linking of play/work and adult/child binaries, with play being argued to be the work of (Western) children.
A corollary of this division between work and play is the perceived division in capabilities and capacities, with roles that an adult can perform but that young people cannot perform, as noted by Jonathon:

...because there is plenty of things I can do, but just by virtue of being young ... under 18, I can’t do everything (Jonathon).

Even though Jonathon cares for both his parents, a role which includes inter alia, personal care, mediation, and being the family spokesperson, he still defers to perceived constraints based on an arbitrary age that places him on the child side of the binary. Jonathon’s situation illustrates the very evident point that a child caring for an adult is in conflict with the respective roles and responsibilities established by the binary, but one that continues to be accepted.

10.3 Young carers positioned as ‘adult’: Tensions and conflicts

In Chapter 9 it was discussed how some young carers are positioned as adults, or at least as possessing ‘adult’ qualities and characteristics. This section will explore the consequences of young carers being positioned in this way.

At first thought it might seem that the existence of young people who undertake ‘adult’ caring roles (i.e., young carers) represents a challenge or even a breakdown of the adult/child binary. It can however be argued that the opposite is the case. The comment below from Emma is very significant.

“I’m their mother …. I was never going to be a child” (Emma).

The important point suggested by this comment is that the binary is in effect further entrenched by the existence of young carers. Taking on all the work and responsibilities of her mother as a young carer does not diminish or blur Emma’s distinction between child and adult, as might be expected, but paradoxically sharpens the binary. Rather than being positioned as a child performing adult roles and responsibilities, Emma is elevated
into the position of the parent; that is, her situation does not challenge the binary. The discourses of adult and child are not blended or intermingled in the descriptions of young carers but rather are polarised and, as has been discussed in relation to Emma, an adult discourse emerges from the young people.

It is possible that this adult positioning has some positive consequences for young carers. It may provide them with a sense of status, authority and knowledge: attributes that were noted by H. Rose and Cohen (2010) as being important for performing a caring role. However, there does seem to be some negative consequences from young carers being positioned as adults. It was evident that tensions and conflict emerged in a number of families because of the discord with the expectations of other family members that control and decision making must reside with an adult. These tensions emerged between young carers and their siblings and young carers and their parents.

In the first instance these tensions seemed to arise when a sibling carer was ‘in control’ of another sibling. While a ‘normal’ adult/child relationship provides a clear binary in the exercising of power and control, these boundaries become blurred in relation to a child with a caring responsibility for her/his sibling. Emma, for example, perceived the non-acceptance of her exercising ‘adult’ authority as the cause of a diminished relationship with her two siblings; that is, by being positioned in this adult role it is not possible for her to maintain a relationship with her siblings that conforms to that of a ‘normal family’:

“…so I’m always the bad guy …. oh, I [Emma] just looked like a giant bitch” [to my brother and sister]. Similarly, I observed Liam adopting an ‘adult stance’ in disciplining his brother who has autism, and at times this seemed to be a source of tension in the family. Liam’s mother spoke to me of her concern about Liam thinking he was the male adult in the family, feeling Liam challenged her authority and inappropriately disciplined his brother. The situation appeared to be a similar one for Emma and her mother:
“she won’t DAMN [emphasised] admit it [tone of annoyance] ... she [mother] thinks she is in control but she’s not” (Emma).

This comment by Emma also reflects the disharmony with parents that can arise from young carers needing to be positioned in an adult role, contradicting the adult’s adherence to the adult/child binary which places the adult in control and the child in a subservient position. It can also be suggested that what emerges here is not just Emma adopting an adult role, but an expectation that her mother adopt a child role. This point is made explicit by Emma speaking of her mother in the manner that would be expected of a parent referring to their child. A similar tension was evident with Melissa and Allison, who also clashed with their parent over control issues. It should be noted at this point that the situation is much more complex than the young carers always taking adult roles. At other times Emma and Melissa wanted to be positioned as a ‘child’, lamenting what they perceived to be missing out on from being in an adult role.

The adult/child binary was not always a source of open conflict. In some young carer families there was a more complex, nuanced relationship. In Chapter 9, there was discussion of Jonathon’s complex and challenging situation in caring for two parents with disabilities. This included a description of my observation of Jonathon skilfully mediating his mother’s emotional volatility (and my surprise at the level of complexity of this aspect of his caring role). Perhaps not surprisingly, Jonathon describes his major and most difficult role as effectively acting as a counsellor to mediate his parent’s volatile emotional states, as well as being an interpreter for his father who has aphasia:

... there is also a lot of ... umm ... [long pause] counselling, I guess you could say ... because it doesn’t take much for either of my parents in a stress situation ... to just ... you know, go all over the place, forget things, lose things, get frustrated when they are talking to people ... especially my Dad because he has got aphasia (Jonathon).

yeah, it’s especially ... umm ... difficult when I’ve got to speak for someone like my father, to someone important ... because, he can’t speak, he wants me to speak, but I’ve got to say
the right thing ... and if I don’t say the right thing, then it can have a larger impact [tone of despair] (Jonathon).

Jonathon’s situation is also much more complex in terms of the adult/child binary: he is often positioned simultaneously as an adult and as a child. Not only does his carer role entail providing emotional support, which is seen as the essence of an adult caring for children, he is also required to perform this function while simultaneously trying not to compromise or disrupt the standing of his parents. While adult actions and adult decision making emerge from Jonathon’s accounts, they do so in a manner that does not overtly challenge his parents’ performance of adult roles and allows them to interact with him as a child. This ‘juggling’ role takes place in an environment where the father acts as a strict and vocal disciplinarian (which I observed on my visits to the family home). The reference in the above quote to “can have a larger impact” alludes to his father’s anger should he be dissatisfied with Jonathon’s performance as his spokesperson. The inherent conflict with the adult/child binary does however have problematic outcomes for the family, with the mother claiming that having a child as her carer has caused her “loss of self-confidence”. Similarly, the father’s strict discipline can perhaps be seen in the context of him not being able to perform other roles that are usually the domain of the adult male in the family.

The situation with Jonathon and his parents is a striking example of the power of the adult/child construct, how ingrained it is in Western society, and how it clashes directly with experiences of young carers and their families. The tension between adhering to powerful cultural adult-child constructs and managing day-to-day life as a carer adds to the inherent difficulties that exist when young people are caring for adults. As an aside, Jonathon’s situation is also a graphic example of how the role of a young carer extends well beyond physical chores and tasks, which has been the major focus of much of the previous young carer research.
The experience of Jonathon merits further reflection. Having worked with many young carers in both the current research and previous research (Watson & Fox, 2014), I have become very accustomed to young people caring for their parents in terms of chores and tasks and, even in some cases, undertaking caring tasks of a very personal nature. However, Jonathon providing emotional support and quasi-counselling to his parents struck me as being totally unexpected and surprising, as well as being a strikingly complex role. In reflecting on my own surprise, I would also seem to have internalised an understanding that this function assumed by Jonathon was not something that was within the capability of a 16-year-old teenager, but rather an adult role; that is, I have reproduced the assumptions of the adult-child binary. Indeed, in reflecting upon my surprised reaction to Jonathon’s role, it is apparent I also assumed that he is unique; that is, I assumed that other young people do not ever perform some kind of counselling role in relation to their parents from time to time, which is not the case. It is also important to record that Jonathon is prodigiously thoughtful and articulate in speaking about the complexity of his role and it may be that the situations of other young carers are equally complex in either similar or different ways, but they do not verbalise their understanding of their situation as Jonathon has done.

It is very evident from the analysis to date that there is great complexity in the lives of young carers. Some of these complexities stem from the adult/child binary. This brings into focus the argument presented in Chapter 4.4.4 that the adult/child binary is a method of both denying complexity and stifling alternate viewpoints. This argument would seem to be very apt in relation to young carers, although it might be argued that the complexity in the case of young carers is so striking that it cannot be denied or stifled.
Young carers positioned as ‘child’

In the previous two sections the positioning of young carers as adults was discussed. However, this was not always the case as, not surprisingly, young carers were often positioned as a child. This section will explore this alternative positioning of young carers and reflect on the implications for their experience as carers.

...like I feel like ... you are talking to me like I could be your age ... I could even be older than you ... you just talk to me like a normal person, whereas everybody else in my life ... you know... (Emma).

In the above comment Emma is referring to having equal status in her communication with me (an adult researcher). Emma’s reference to “I could be your age” is defining this equality as being related to, and dependent upon, age. She is being positioned in the dialogue as an adult, as being older, and as more equal. Emma contrasts her equality in our communication against her experience with “everybody else in my life”. There was a level of frustration evident in Emma’s comments, suggesting she considers that her views are not heard or accepted because of her young age (which she also contrasts with her experience with this research). Because she is a teenager she believes herself to have an unequal ‘voice’ and is disempowered. The acceptance of an adult/child binary (and other binaries) can place a boundary around what may be said and by whom, and indeed voices from the non-dominant side of the boundary may be silenced completely. It can be suggested that young carers are for the most part silenced.

There is a very evident paradox that young people are on the one hand being acknowledged as a carer who is performing an adult role, while at the same time being positioned as children who are not capable of operating in the adult world or being involved in decision making, even on matters that so directly and profoundly affect their lives. There is however an important distinction to be made about the use of adult and child discourses. The adult discourse comes mostly from the young people themselves.
This emerges from their adult experiences and ways of being, such as taking responsibility and being accountable for the consequences, and of talking and negotiating in adult ways. Conversely, the child discourse is largely imposed from external sources, such as welfare agencies, service providers, parents, and schools, accompanied by the assumption that adults must make decisions and deal with other adults. It can also be suggested that the discourse emerging from the young people represents a more sophisticated understanding of ‘adult’ compared to a more reductive and essentialised version of ‘adult’ and ‘child’ that is presented by external discourses and which seems to be based on a binary understanding of the role of adults and children (e.g., work or play).

A consequence of the positioning of young carers as ‘child’ can be illustrated by reference to a comment made by Jonathon:

...let them [young carers] choose what it is that they want to do ... because the time that we get outside of caring is rare and valuable and we should be able to spend it in ways that we would like to ... rather than having someone decide for us (Jonathon).

Jonathon is discussing how adults at the Respite Centre make unilateral decisions about how to support young carers through the provision of respite activities. The exclusion of young carers from any involvement in what support and respite activities are provided is instructive of the adult-child binary. There is no recognition that young carers know best what they need, but rather it goes unquestioned that it is a matter for consideration and decision by adults.

While Jonathon (and also Jack and Stephen) recognise that this adult process is problematic, more revealing was that the majority of the young people are indifferent and even bemused by the thought that they, as children/teenagers, should be consulted or have any say into their needs as young carers and how they should be supported. An analysis of the comments by these other young carers show how deep is the understanding and acceptance of the adult-child binary. In the final round of
collaborative interviews when feedback was sought on my preliminary analysis of the earlier interviews, a direct question was put as to why they thought they were not consulted or involved in matters that dominated their lives:

*In terms of support for young carers, it would seem that service/support agencies do not seek any input from young carers about what support they need or want, and probably that young carers themselves do not have any expectation of having a say on what they need. (1) Do you think this is correct? (2) If so, why do you think it is like this, given that you as a young carer would know better than anybody what support would be best for you?*

“I don’t expect to be able to choose what we [young carers] do” (Mia).

The response from Mia reflects a viewpoint common to many of the young carers; they have no expectation that they should have any involvement in these matters. When I suggested to Mia it might not be choosing as such, but rather to have some input into her needs as a young carer, she deflected the conversation to another matter. It may be possible that Mia did not consider that this was a matter of significance, or perhaps did not even fully recognise that there was an issue that might be explored. Rather, implicit in the understanding of Mia and others is that adults are appropriately seen as the decision makers and young people are not, even on matters that directly affect young people.

For Mitchell, despite seeming to be in an extremely difficult caring situation, it had not occurred to him that young people should have an input into issues that are so fundamental to the quality of their lives: “… like I don’t think I ever thought of that [being consulted]” (Mitchell). After I provided some context to why young carers might be consulted, Mitchell acknowledged that the situation was “pretty stupid”, although I still inferred he was bemused that it had been raised as being problematic.
All the young people acknowledged that they have never been consulted by carer services about what support or activities they needed or wanted. Beyond that, some of their responses, in spite of their frustration with services, were conventional, problematic ideas about the scope of agencies. Rebecca, for example, suggested that it would be impractical for agencies to consult young carers, while Kate noted that it was “easier” for agencies to make unilateral decisions. These suggestions were presented without indication that either Rebecca or Kate considered their exclusion to be problematic. Their insouciance about involvement can be suggested as being indicative of the discourse surrounding the decision making responsibilities of adults to be so entrenched that for most of the young people it is unrecognised as an issue. The following comments from three young carers indicate the extent to which they remain positioned as a child for whom adults will consider and make decisions.

“Mum made a point of keeping us out of that [young carer support needs]” (Sam).

“...but Mum would be able to tell you about that [availability of young carer support] ... I don’t really know” (Allison).

“I dunno ... I think Mum knew ... or something” (Rebecca responding to a question about how she came to be enrolled in a young carer camp).

Despite being fully cognisant of their adult roles and responsibilities as carers, the above comments reflect the role of adults in making decisions for the young carers, particularly in relation here to young carer services. Parents usually collaborated with services with the result that their children had no involvement in, or awareness of, support services that were or were not on offer or received. Parents ‘protected’ or shielded their carer children from contact with service agencies which, while well intentioned, was based on the assumption that they [the adult] knew the needs of their children as well as, or better than, their children.

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18 It was the case that Kate referred to receiving a flyer from the Respite Centre inviting suggestions for a young carer camp. However, this flyer was sent by the Centre at my suggestion after the previous camps had to be cancelled because too few carers nominated to attend.
As has been noted, this was not widely recognised by young carers as an issue, but in those instances where concerns were expressed, it was mostly by those young people who were caring for a parent; that is, in this particular caring situation the consequences of the binary may be most deeply felt and resisted. It can be suggested that an outcome of this exclusion and denial of agency for young carers is firstly disempowerment and secondly that support services often do not meet the needs of young carers. This positioning as a ‘child’ provides part of the explanation for the disconnect that exists between the support and activities offered by agencies and the needs and desires of young carers that was first discussed in Chapter 8 *(Institutional/structural context)*.

It should however be acknowledged that being positioned as a child may not always be problematic for young carers. Being positioned in this manner may, at times, be beneficial in reducing the heightened sense of responsibility that many young carers experience. This subject position of child may, in a sense, be experienced as some level of respite from the adult responsibilities of being the family carer.

The exclusion of most of the young carers by adults (both parents and staff of service, welfare and government agencies) from being consulted or involved in decision making on matters affecting their lives, also reflects the aspect of the adult/child binary that construes young people as vulnerable and in need of protection with adults being strong and protective (Lansdown, 1995). The strength of the binary is evidenced by the failure to recognise that the positioning of both the child and the adult is totally at odds with the situation where a child is the carer for an adult.

### 10.5 Summary

An important outcome of the analysis in this chapter is that young carers experience being positioned both as an adult and as a child at different times and in different contexts, and this sometimes occurs simultaneously. Given the blurring of the boundaries
between the role of an adult and a child, it might be expected that young carers disrupt
the adult-child binary. However, it is argued that the opposite is the case, with the binary
being further entrenched by the polarising of the ways of being either adult or child.
While there was some evidence of the young people (such as Jonathon) negotiating both
positions simultaneously in subtle, sophisticated ways, which suggests that the situation
may sometimes be more nuanced, the power of the binary may limit opportunities for
reducing this polarisation.

Being positioned as an adult had various consequences. In particular, tensions and
conflicts arose with parents and siblings because often the young carers could not
conform to traditional child and sibling roles. At times these tensions were skillfully
managed, but at other times the effects of the contradictions were very evident. It may
however also be the case that being positioned as an adult can have a positive impact for
young some carers: by providing a sense of status and authority that is important for
undertaking some aspects of caring, such as dealing with service providers.

Being positioned as a child appeared to have a number of important, and mainly
negative, consequences for the young people. Significantly, the young people tended
most often to be positioned in this way by service providers and parents, leading to their
exclusion from a role in decision making about support or respite activities. This has
meant that there is often a disconnect between the support being offered by providers and
the needs of young carers, which is obviously a negative consequence. One underlying
reason for support being provided to young carers is that they are portrayed in the
research as imperilled by the notion of damaged transitions to adulthood (e.g., Aldridge
& Becker, 1999; Earley & Cushway, 2002) and “crossing adult/child boundaries” which
is argued to endanger their mental health (Byng-Hall, 2008, p. 147). It is not surprisingly
therefore that the adult-led process of providing support to young carers reflects the same
assumptions that saturate the research literature: young people are partially competent which renders them both vulnerable to damage from caring as well as disqualifying them from needing to be consulted about their needs. This outcome extends the argument presented in Chapter 8 (Institutional/structural discourse) that young carer support is often misconceived and inappropriate.

It has, however, also been noted that being positioned as a child may at times be a positive outcome for some young carers by dampening the high level of responsibility they can experience as a family carer.

It has also been discussed how, importantly, there was evidence of ‘child’ assumptions emerging from the young people’s dialogue, meaning they too seemed to assume they should not have a role in decision making on matters that affect them. This speaks to the strength of the adult/child binary: there is no recognition by most of the young people that the status quo is problematic.

The strength of the adult-child binary that emerged from this analysis supports the discussion in Chapter 4.4.1. It was noted in that chapter that the strongest discourses are often those that seek to ground themselves as being both scientific and natural (Hook, 2001). It was also noted that there is a ‘scientific’ view of children and adolescents that draw upon binary opposites with adults, while Lesko (1996, p. 155) argues that young people are understood to “naturally and inevitably possess certain characteristics and behaviours” that are different from adults. The characteristics of the binary place adults in an absolute and largely unquestioned position of control and decision making about young people. Accordingly, the adult-child binary is argued to be a powerful, unquestioned construct in society and one that is extremely significant for the experiences of young carers and, by extension, young carer research.
As noted at the beginning of this chapter, the adult-child binary also provides part of the foundation for Western familial discourse and, most particularly, discourses about children and adolescents which have a major impact on the experience of young carers. These are, respectively, the subject of the next two chapters.
Chapter 11: Analysis – Familial discourse and the Western family

11.1 Introduction

There were two significant discourses relating to family that emerged from my discussions with young carers: both have important implications for how the young people experience being a carer for a family member. The first discourse relates to the idealised ‘normal’ Western nuclear family and the associated understandings about the roles and responsibilities of family members, as well as the ‘normal’ family structure and the activities that families are ‘meant to do’. The emergence of this discourse was not unexpected as the construct of the idealised ‘normal’ Western family was dominant in the literature review (Chapter 3) and was suggested as being the bedrock of much of the research on young carers. The pivotal position of the Western family, and the understanding that what constitutes the family is ‘natural’ and without a history, are captured by the following quote from Parker:

[familial discourse] includes a history of the family and the way that history is reinterpreted to legitimate the Western nuclear family form …. to reinforce the notion of the family as natural, as going back to the beginnings of civilisation. (Parker, 1992, p. 16)

More particularly, the construct underlies much of the negative portrayal of young carers in the literature, with their caring role perceived to violate the ‘natural’ role and responsibilities of family members, as well as the ‘normal’ family structure and family activities. My identification of this discourse in the literature review as being problematic for young carers was very likely a factor in how it ‘jumped out’ in the analysis process.

There was also an additional discourse about the Western family that unexpectedly emerged – a discourse about family loyalty, obligation, and mutual support. This discourse was not something that was encountered in previous research literature, but rather strongly emerged from the interviews with young carers. It seems to be informed by ‘nuclear family’ assumptions which at times offers young people supportive and
valuable family interactions but for some it led to resentment because of unmet expectations.

Both these discourses constructed notions of a Western family that have been internalised by most of the young carers (and their parents) and were important to how they experienced their lives as carers. These two discourses concerning the ‘normal’ Western family will now be discussed in detail, followed by an exploration of how young carer families are positioned in relation to these constructs and how this has affected their experiences.

11.2 Roles, responsibilities, structure and activities of the Western family

The discourse surrounding the Western family as natural and without a history embraces understandings about what are the ‘appropriate’ roles and responsibilities for family members and the structure and activities of a ‘normal’ family. The significant roles and responsibilities in the context of young carers include being parent and child and, at times, sibling. While at times these roles emerge in conventional ways, young carers and their families are not always positioned to engage in them conventionally.

Young people as carers

“…because parents care for children, siblings don’t care for children [shrill voice] … in your black and white, SUV, 2.5 children world, children don’t care for children…” (Emma).

In this extract Emma presents a powerful contrast in critiquing societal assumptions of normal families. The tone of Emma’s voice in making this statement very strongly suggested an analytical and mocking critique of these assumptions. The statement firstly deals with the relations within a family and the action of ‘caring’: that caring is an action performed by parents for their children rather than by children for siblings. The accepted understanding of family roles and responsibilities dictates that young people should not be caring for a sibling. Interestingly, Emma only refers here to caring for a child, rather
than a parent, as elsewhere Emma describes her major caring role as being for her mother.

Emma’s description of ‘normal’ familial discursive assumptions is implicitly contrasted with young carers’ experience of family. Perhaps assuming a shared understanding with me (the researcher) based on previous meetings, Emma leaves unspoken suggested opposites to her statements: family situations that are complex and ‘grey’, less financially well off, with complicated structures and arrangements, and with the children as carers.

Emma’s comment commanded my attention because she was the only person to very directly confront and challenge the understandings and the stereotypical ‘trappings’ of a Western nuclear family. She is reacting to and rejecting the notion that her family is an oddity because it does not conform to this model.

The strength of this accepted understanding of these parental/sibling roles is perhaps even better captured by Kate who makes strong polarising statement about these roles:

“If I’m looking after her I’m like a parent rather than a sister”; “…parents care for children, children don’t care for siblings” (Kate).

While using very similar words to Emma, the tone and intent of this conversation were most serious (i.e., not intended as sarcasm as with Emma): she seemed far more to be making an unequivocal statement of what she understands to be a clear fact, and that she felt this distinction when performing family roles. In the review of literature (Chapter 3.2), it was discussed how children caring for a parent is seen as a reversal of the natural order, which is argued by Keith and Morris (1995) to account for much of the fascination of researchers and the popular media with young carers.
Western familial discourse also establishes the appropriate family structure for a normal family, elements of which are captured in the comments by 12-year-old Liam (whose parents are divorced), reflecting a stereotypical structure and features of the ‘normal’ nuclear family:

“well, a normal family would probably be … umm, two parents who aren’t divorced …. maybe one or two kids and a dog or a cat … that would probably be considered normal” (Liam).

While most families do not meet this structure, it is axiomatic that young carer families certainly cannot match this idealised construct. As was discussed in detail in Chapter 6, for most young people positioned as a young carer, there are one or more family members with a disability or illness, they are almost always part of a single parent family, and are almost always without the financial resources to engage in what are seen to be typical family activities. This is partly because young people in two parent families are not usually required to be carers and a single parent with a disability or illness invariably means there is no adult wage earner and the family is subsisting on welfare benefits. In some cases, there is a straightforward attribution to being a carer for ‘missing out’ on normal family activities; for example, Jack’s talks about not having family holidays, the quintessential family activity: “…you don’t get holidays when you are a young carer”. Jack’s tone and agitated manner at the time when talking about this concern, suggested it was a source of some bitterness. It should be noted here that greater financial, material and caring supports for these families could potentially alleviate much of this ‘missing out’ on activities.

While Jack’s concerns related mostly to family activities, more common was young carers reacting to being positioned as not being part of a traditional two parent family structure. Mitchell, who has no father in his life, comments about his friend’s family: “…
[he] had a great father, sorry … he was actually sort of one of my father figures for a while there to be honest … but yeah, it was just a nice happy family”. In this comment, Mitchell is suggesting that a traditional structure, in particular one with a father, is necessary for a family and children to be happy; that is, Mitchell is reproducing Western familial discourse that a normal and natural family has two parents. Familial discourse also establishes expectations about what is a ‘normal’ family relationship between a mother and child, which are seen by some of the young people as not being met due to the caring situation. Jack attributes the stresses and constraints flowing from being a carer for him not participating in mother-son activities and not having a normal mother-son relationship.

*Parental feelings of inadequacy*

The perceived disparity between their own family life and the idealised Western family is also one of the main mechanisms for some, but definitely not all, parents feeling guilty and inadequate for failing to provide what is understood to be a normal and proper family environment. Melissa speaks about her mother’s feelings of guilt: “she cries all the time, and says ‘I’ve let you down’”. Jonathon has also been made very aware of his parents’ feelings of guilt: “…I think both my parents … at times … in fact, I don’t think … I KNOW [emphasised] … they verbalise it … you know, my mum often talks about … that I wasn’t born as slave labour…”. There are two aspects of parental guilt that require comment. Firstly, the way in which some parents so openly expressed their feelings of guilt to their children about them having to be carers was surprising to me. While perhaps a reflection of the openness between parent and child in young carer families, it might also be suggested that it may serve to accentuate their children’s understanding that their family is different. While there are many complex factors at play, it was certainly the case that Jonathon and Melissa very clearly understood their families to be ‘different’. The second point to note refers to the argument presented in the literature review positing
that the negative portrayal of young carers engender guilt and diminishes disabled and ill parents (Keith & Morris, 1995; Newman, 2002). At least for some parents, this guilt and stigma is very evident.

Parental authority and control

“...and I think as a carer they ... umm ... they like to be in control and take control of the situation .... and I go ‘hang on a minute, no you’re not [taking control], you are still my daughter’” (Melissa’s mother).

The conflict that can arise over ‘normal’ parental roles and responsibilities has important consequences for the experiences of some young carers. The above transcript extract – and in particular the reference to “you are still my daughter” – very clearly illustrates what is considered the unassailable notion of the parent ‘being in charge’, notwithstanding how diminished their physical and mental capacities might be, and notwithstanding what level of caring and other responsibilities have of necessity been assumed by the child. This aspect of familial discourse intersects with the discussion of the adult-child binary in the preceding chapter. There is an unquestioned assumption in familial discourse and in the discourse of the adult-child binary of a parental monopoly of authority, power and decision making. Tensions and conflict arose when this assumption was necessarily challenged by the practicalities involved when the child is caring for the parent. This tension was evident through my talks with both young people and their parents, and perhaps is more of an issue for young carers:

what she wanted me to do was say ‘I’m sorry, I’m going to do things your way’ … I’m just … I was never going to be that child … I was never going to be what she wanted me to be, so it was never going to work out … us having a parent-child relationship … whereas, like if she stopped controlling me and talked to me like a normal person .... she thinks she is in control but she’s not (Emma).

The difficulty for young carers in managing the familial discourse of parental control and authority with the requirements of caring is well illustrated by Jonathon’s situation. As was detailed in the previous chapter, while Jonathon’s parents have disabilities, the most
challenging aspect of his caring role is the management of their volatile emotional states. In my presence his father openly displayed an authoritarian approach as both husband and father: this went unquestioned by Jonathon who instead sought to manage the conflicting requirements through a nuanced approach that would allow him to be able to undertake the necessary functions as his parents’ carer, while not overtly threatening or disrupting his father’s position of control and authority. The following extract captures the subtlety that he is required to employ:

[I] get them to calm down and sort of ... umm ... think a bit before they do anything ... prompt them into thinking about what it is they are doing ... is this really what you want to do ... is that what you wanted to achieve in the first place or are you going off on a different track because your minds not in the right place (Jonathon).

It is the case that Jonathon’s description of his discussions with his parents could be read more as an adult talking with another adult, or even parents talking with their child (rather than vice versa). However, what it does demonstrate is Jonathon’s ability to manage difficult family situations in a manner that does not directly challenge his parents’ position as parents. This would seem to be a very important factor in Jonathon being able to manage the unusual and difficult situation of being the carer for both his parents.

In reflecting on the difficulty for young carers in managing the contradiction between the familial discourse of parental control and authority and the practical requirements of children caring for their parent/s, it is perhaps pertinent to record that towards the end of the fieldwork, when my relationships with the young carers had developed most fully, a number of other ‘older’ young carers also began discussing their deteriorating and, in some cases, fractured relationship with their parent. This can perhaps be attributed in part to the difficulty in reconciling these issues. It must though be acknowledged that there are other possible factors involved with these parent-child relationship difficulties, not
least the likely cumulative effect of the stresses involved in being a long term carer for a parent that, in most cases, commenced at around 10 to 12 years of age.

To summarise, it is suggested that familial discourse presents an understanding of the roles and responsibilities in a Western family as natural and normal, but that are at variance with the situation that must necessarily exist in young carer families. Accordingly, the construct of the normal Western family is a major factor for many young carers feeling bad about being a carer for a family member; their perception of being in an abnormal family and thinking they are missing out on the ‘normal’ family experience. While not always verbalised, implicit in the understanding of many young carers was an underlying assumption that children need to be in a certain type of family for their proper development and a happy childhood and teenage years. In establishing the idealised nuclear Western family as the desired ‘norm’, familial discourse impacts in many significant and often problematic ways on how young carers experience being a carer for a family member.

11.3 Family loyalty, obligation and mutual support

“[Caring] is not a negative thing! [emphasised] Caring for your sister or your brother, or your Mum is very rewarding...” (Jack).

The experience of young carers was also mediated in a very different, but very significant way by another dominant discourse about the Western family – a discourse about the existence of a strong bond between family members that encompasses obligation, mutual support and loyalty. This aspect of familial discourse is heavily drawn upon by some young carers in accepting the responsibility for caring for a family member; it allows them to position themselves as the good and dutiful son, daughter or sibling, and this mediates or eclipses feelings of being compromised and ‘missing out’ on a normal family life.
This positioning was raised by many young people, with the construct being so strong that the mention of the familial relationship was considered sufficient explanation for why a caring role was right and proper for them. For example: “it doesn’t matter what’s the matter with him, he’s my brother I’ve got to help” (Liam): “it’s [caring] not a brunt, she’s my sister” (Jack). Jonathon explicitly discusses: “… you just want to see the best for them ... and if you can help them [parents] get the most ... the best out of life”. Even in situations where there was some resentment about the caring role, the situation was accepted because “it’s just what families do…” (Mia). At the extreme, the discourse of family loyalty was reflected in some young carers referring to the responsibility for caring for, and being able to help, a family member as a positive opportunity: “most of the time I am grateful for it [the responsibility]” (Melissa).

The impact of the familial discourse on allowing young carers to feel positive about their situation was strongest when there was a feeling of reciprocal support in the family. It was perhaps no coincidence that those most accepting of their situation often used the phrase ‘team effort’. “It’s a team effort around here ... everyone, everyone helps each other” (Jonathon).

Conversely, those who often felt compromised by their caring situation experienced no such sense of mutual family support and team work: “she wasn’t there when I needed her, and that I needed to be there when she needed me” (Emma). The difficulties appear to be compounded when there is an unmet expectation, as per familial discourse, of a greater family bond in times of hardship:

“I think it’s true … you know, you bond more, better family connection and everything … umm, my experience was just completely different, you know…” (Mitchell).

In the above comment, Mitchell is referring to his understanding that families become closer and more connected when confronting difficult times, while lamenting how the opposite occurred with him and his parent, who have a very difficult relationship. A more
graphic example of the impact of an unmet expectation of the ‘normal’ construct of loyalty, obligation and mutual support, is illustrated by Stephen’s discussion of the response by his extended family when his grandfather died and he was forced to become sole carer for his chronically ill step-grandmother. Stephen considers that he and his step-grandmother were deserted by the family and he spoke of them angrily: “… ‘god I hate you’ [members of extended family] … but you abandoned us; that was what I was thinking, you have abandoned us [very passionate tone]”. While familial discourse that has constructed notions of family loyalty and mutual support was very important for most of the young people feeling better about being a family carer, for some it appeared to have exacerbated feelings of despair.

A parent discussing their feelings of guilt with their children did, for some, appear to further engender family loyalty. As was mentioned above, some parents were consumed with guilt and spoke openly to their children about the perceived loss they had brought upon them. It was notable that many parents, unlike their children for the most part, adopted the discourse of the negative paradigm of young carers that was discussed in the review of literature. This included adopting many of the clichéd phrases that are used by researchers (e.g., Charles et al., 2009; Charles et al., 2010) and the media in reported on young carers: “forced to grow up too quickly …. childhood stolen” (Mitchell’s mother); “she’s lost that childhood …. growing up too soon…” (Melissa’s mother). Perhaps paradoxically this acknowledgement seemed to engender further family loyalty from their children, and some spoke of very deliberately trying to prevent their parents feeling guilty or feeling that they had deprived them of a ‘proper’ childhood. It can be suggested that this discourse of family loyalty and obligation was a factor in many young carers appearing to downplay the difficulty of their situation, to focus on the personal positives from being a young carer, and even to claim they “wouldn’t change a thing” (Melissa).
It was mentioned in the *Introduction (11.1)* that the strong emergence of this discourse of family loyalty and obligation came as a surprise, and that it was not one that had been evident in previous research literature. In reflecting on the emergence of this discourse from the discussions with the young carers, there are a number of considerations to be explored. Firstly, I am reminded of discussion in Chapter 1 relating to deinstitutionalisation and the role of governments in normalising caring by families by promoting a discourse of family obligation and family values. It is not however suggested that it is as simple as young carers just reproducing the institutional discourse; rather the situation is far more complicated. Family loyalty and obligation is an extremely old and strong discourse. There is a deep understanding of what a family ‘is’; an understanding that has existed for a long period, is deeply ingrained, and has a broad cultural understanding and meaning. It may be considered as a high level, overarching cultural discourse. Accordingly, on reflection the emergence of this discourse may not be surprising, and can be suggested as emerging more from within young carers’ family experience of caring, and less so from the outside. While notions of family loyalty and obligation are deep in people’s understanding, it is a mutual understanding that is not overtly discussed like the practical aspects of caring that are often included in quantitative research as a tick-off list. It is a concept that is linked to emotion and something that is less easily describable or verbal. It can also be suggested that the notion of family loyalty and obligation is, in the main, *only drawn upon in times of adversity*; it exists as a latent understanding that is assumed but not spoken about, and does not explicitly emerge until there are serious difficulties that require help and support from family members.

The question as to why this discourse has not emerged in the research literature can perhaps be attributed to the theoretical assumptions of previous research and the methods that have been adopted, which are much different from the poststructural epistemology
and collaborative methodology of this research. Failing to explore family loyalty and obligation may be a result of more positivist methodologies which construct more essentialised and less nuanced understandings and theoretical expectations about childhood which positions it as a less complicated experience. As discussed in Chapter 3, much past research has involved quantitative studies focussing on practical aspects such as chores, skills, homework, and social activities. These, in a sense, may be seen as ‘surface’ level or superficial aspects that do not provide for the emergence of deeper considerations of being in a young carer family. Research has also traditionally focused more on negative aspects of young people caring whereas the notion of family loyalty and obligation relates more to positive and strong emotional bonds that seem to be particularly evident in young carer families.

There are significant parallels between this discourse of family loyalty and obligation which emerged from working with these young people, and the language used by government to position care as a family responsibility, which was first raised in Chapter 1.1.4. This appears at first glance to be contradictory to the claim in this section that the young people draw on the discourse from within family, from deeper cultural roots, rather from government influence. However, unlike the discourse of ‘being a young carer’ for which governments, institutions and services have had a strong influence, I would argue government is not heavily implicated in families’ experiences of the loyalty and obligations discourse. However, as was described in Chapter 1, government does simultaneously draw on this deep cultural discourse which has considerable consequences for young carers. Government use of this very deep and emotional familial discourse can be argued as having the divisive result of disadvantaging families with a disability or illness. Family loyalty and obligation are factors that reside within the family, and so negate any government responsibility. The focus on these family aspects diverts attention from the practical support that governments could provide, such as home
help, nurses, case workers, and material resources. While it is not suggested that this outcome was the result of an explicit government design, it can be likened to the description of Foucault (1980) of power being exercised thought a network that comes together to produce effects that neatly fall into place. In any event, as Foucault (1980a) has argued, it is not intentionality but affects which are central, and this discourse has certainly been useful for governments.

To summarise, aspects of familial discourse that establish loyalty, obligation and mutual support as a hallmark of the Western family have allowed some young people to feel good, or at least more positive, about being a carer; as well as allowing for a lessening of their parent’s guilt. The same discourse has however enabled governments to ‘step-back’ from their role in supporting people with disabilities and illness. At this point it is again important to stress that the subject positions that emerged for young people were often ephemeral and/or contradictory, both within the one interview and between different interviews, which was indicative of the complexities that exist between their own family situations and those presented by Western familial discourses.

Having outlined the two familial discourses that are suggested as impacting most significantly on the experiences of young carers, these will now be explored in more detail and, in particular, how young carers position their families in relation to this idealised construct of the Western family.

11.4 The positioning of young carers families in relation to the ‘normal’ family

Drawing in large part upon the two constructs of a normal family as discussed above, the families of young carers were positioned in a number of ways; these are discussed below in a number of ‘loose’ categories, while again stressing that these positions were different at different times, in ways that were often contradictory and complex.
11.4.1 The rejection of the idea that the ‘normal’ family exists

For some young carers, such as Emma, the construct of a ‘normal’ family was seen to be false and was vehemently rejected:

“it’s a lie …. it doesn’t exist [tone of exasperation] …. It’s insulting ... it’s insulting to suggest there’s a normal family…. like the idea of a family is not even real ...” (Emma).

Emma’s thorough critique and rejection of normalising familial discourse demonstrates that the young carers were not simply burdened by the discourse, but were sometimes actively engaged in problematizing and resisting it (both for this research and more widely). One consequence of this critique and resistance is that it offers the position that young carers are not ‘missing out’ on normal family life. In some cases, this entailed construction of an alternative and problematic ‘normal family’ against which young carers are positively compared:

...because in all honesty, people who think they are the perfect family, who have two parents … and you know, have the family and everything, and go to sporting events … most of the time behind closed doors they are not happy …. because you know, their parents were alcoholics, their fathers were never home, their Mum was having an affair on their husband … you know, they didn’t care, they didn’t take their kids to sporting events, they didn’t, you know, care about their grades or anything like that, they just didn’t care… (Melissa).

In demonstrating the many variations in family problems, this critique provides a sound and often used argument for rejecting normalising discourse. The construction of the alternative problematic ‘normal’ family can perhaps also be seen in the context of discursive forces that require young carers to be defensive when there is comparison being made between their families and so-called ‘normal’ families. This defensiveness and critique was reflected in repeated comments such as “behind closed doors they [‘normal’ families] are not happy” (Melissa) and “everybody has their own problems in their families” (Allison).
Mia was an example of a young carer who rejected the construct of a ‘normal’ family (“…I don’t think there is a so-called normal family”) while also positioning her single parent family as normal. Her unsolicited discussion of statistical information to demonstrate that single parent families were now very common, was a valid and conventional normalising technique to position her family as normal.

The contradiction that emerges from Mia’s account highlights the need to once again reiterate that in most instances there was no consistent positioning of the family. Young carers who dismissed the construct of a normal family did, at others times, lament missing out on many of those aspects of ‘normal’ family life that constitute the construct, and at other times claim their family was normal. This included those who were the most vocal in denying the existence of a normal family. As such, familial discourse was a very significant source of complexity, contradiction, and tension for young carers. Dominant family constructs were at different times selectively accepted, resisted, or ignored.

### 11.4.2 Positioned as being in an abnormal family

“I know we are not normal. This is not a normal family” (Jack).

Jack was one of a number of young carers who were acutely aware that their family differed from the construct of a normal Western family and readily identified as being in an abnormal family. Being in a single parent family and with two family members with significant disability/illness did not conform to an idealised ‘normal’ family with the roles, responsibilities, and activities that are inherent in the model.

There are however quite different perspectives on being in an abnormal family: those young carers who described themselves as compromised by being in an abnormal family and those who position themselves as better than the normal family. Not surprisingly, these opposing positions have a significant impact on how young people experience being a family carer.
“...you know you are different from other kids when ... you go to school ... and you’re the only one with two parents that are different to everybody else” (Jonathon).

The understanding that they were not experiencing a ‘normal’ family environment, as constructed by Western familial discourse, was experienced by some as a strong sense of missing out and despair. For Mitchell this seemed to be at the crux of his unhappiness and disenchantment as he expressed his yearning for an idealised ‘normal’ family: “…[it] did make me sad …. I just wished she could be better so we could be like a normal family and stuff” (Mitchell). For some young carers there is a deliberate strategy of keeping their family situation secret in order to feel more normal. In discussing his reason for not telling people about his family, Liam explains: “[I] didn’t want to feel different ... that’s the thing ... I just want to feel as normal as I humanly can” (Liam).

It can be argued that the negativity experienced by some about being a carer is conflated with, or perhaps significantly a result of, their experience of being in a single parent family. It is relevant to note in this regard that most of the young carer families in this research (and probably more generally) were single parent families with the one parent being the mother. This version of family structure, which is so often culturally positioned as being abnormal, was often, to varying extents, a direct result of the caring situation in the family and so the two were related and could create intersecting discourses of an abnormal family.

Mitchell, for example, does not have a relationship with his father and speaks with some poignancy about being from a “broken home”. When he was younger he attributed his workload at home to being normal for a single parent home, rather than a consequence of being a young carer. His expressed admiration for, and envy of, a friend’s family with the ‘normal’ family structure and a “father figure”, which reflects the largely unquestioned
assumption of Western family discourse that a father figure is necessary for the proper
development of a male child.

In addition to an understanding of being in a ‘different’ family, for some young carers
there are additional layers of complexity in terms of family relationships. It was
discussed in Chapter 9 how there can be some level of jealousy and hostility about
perceived favoured treatment of a sibling with a disability, as well as young carers being
made to feel embarrassed and secretive about their family’s situation because of negative
community attitudes about disability and mental illness. Feelings of being in an
‘abnormal’ family were therefore intersected with a discourse that portrayed disability
negatively. In all but very small communities, the young people characterised community
attitudes to disability as lacking understanding and often entailing staring, teasing or
patronising sympathy. Again, family relationships are the crux of how young carers
perceive their experience, and in these cases the experience of being a carer is conflated
with having a family member with a profound disability in the family. These are further
complexities in family relationships that have seemingly been ignored in previous
research, but impact significantly on young carers’ lives.

To summarise, those young carers who experienced caring for a family member very
negatively often felt in conflict with the dominant aspects of familial discourse that
established an idealised Western family. This interrelated with discourses about disability
and more significantly, as will be explored in Chapter 12, discourses that construct the
normal childhood/teenager.

Abnormal, but superior to non-caring ‘normal’ families

    I was able to spend so much time with my family, and that’s why we are so close …
    because of that … so, because I know certainly that my friends aren’t as close to their
    parents as I am, so that’s one thing that is, sort of a blessing from it all” (Melissa)
“... you also develop a lot more respect for each other ... which is something that you don’t necessarily get in a normal child relationship ... ah ... a parent-child relationship... (Jonathon).

These comments are indicative of a number of young people who at times described their families as ‘better off’ by drawing on those aspects of familial discourse which incorporated family loyalty, obligation, and mutual support. In response to the idea that they were not a normal family in terms of the Western construct, some young carers described themselves as being superior to other families because caring had enhanced these family attributes. There were a number of areas in which young carers considered their families to be superior to their peers, including mutual respect, closeness, trust, openness, and stronger relationships where family members help and support one another. These factors are powerful and important positives for young carers. They allow for the situation of young carers to be framed more positively; for them to feel good about being a carer, while negating the notion of missing out from not being in a normal family.

11.4.3 Positioned in the family as a ‘helpful’ sibling or child, not as a young carer

“…if I’m looking after her I’m like a parent rather than a sister” (Kate).

The above comment encapsulates the view of some young people about the mutually exclusive family roles of parents and children. A child being the carer for a family member is explicitly seen in some families as being incompatible with Western familial discourse about the appropriate role and responsibilities of a sibling or child. Accordingly, as was mentioned in Chapter 9.2, some young people rejected being positioned as a young carer. In order to incorporate this understanding of family roles into a very different situation that exists in their home, the young people were actively positioned as a ‘helpful’ child or sibling, not as a young carer. This familial discourse,
establishing ‘proper’ roles for parents and children, overlaps in part with the earlier discussion in Chapter 10 of roles that emanate from the adult-child binary.

Kate implies that being a carer for her sister would detract from, jeopardise, or would be incompatible with a proper sibling relationship. This position seemed to be quite strongly promoted by her mother, with Kate commenting that “she [her mother] just wants me to be a sister”. Implicit in this positioning is the idea that there is something wrong or perhaps harmful about siblings providing caring roles, or children ‘crossing the boundary’ into a parental role. As was discussed in Chapter 3, this position can be contrasted with families in many non-Western societies children where young children take on so-called ‘adult’ responsibilities within the family that includes care of younger siblings, which is considered both normal and important for children’s development (East, 2010; Whiting & Edwards, 1988).

This positioning can allow both parents and young carers to feel their family is normal and, in the case of Kate, to feel she is maintaining a ‘normal’ sibling relationship with her ‘cared for’ sister. While this did seem to be a significant concern for some young carers, it would also seem to be driven more by parents who may feel even more strongly the familial discourse that positions parents as having responsibility for providing a ‘normal’ family structure within which to raise their children.

11.5 The importance of family relationships in mediating the experience of being a young carer

It will now be very evident that there is a complicated and complex family life and family relationships in which young carers experience their lives as carers. The importance of family relationships and the notion of family loyalty and support inherent in familial discourse appears to be the major factor in the acceptance of young people
about being a carer in the family and, for some, having very positive feelings about being able to help their families.

The importance of family relationships is also suggested by the seeming lack of concern or focus by the young people on the caring and household chores and tasks that are required of them as a family carer. In general, the young people did not speak about the caring and household chores and tasks (except when responding to a direct question). Rather their narrative was dominated by their relationship with their ‘cared for’ family member, that person’s wellbeing, and relationships within the family more generally. This contrasts significantly with much of the research literature which largely focussed on completing caring and domestic chores and the impact of this on homework and social activities (e.g., Thomas et al., 2003; Warren, 2007).

Accordingly, it can be suggested that caring is not seen by young carers only in these terms. Rather it is about the difficulties and complexities of family life and family relationships, many of which arise from their conflict with the discourse of a normal Western family, as has been discussed. Most particularly, it is very difficult for the young people to see a family member unwell and not be able to fully participate in society.

Support for this finding was found in the third round of fieldwork. As has been mentioned previously, part of the collaborative methodology was to involve young carers in discussing the analysis of the data. The questions compiled for this purpose included one which very directly sought their views on the body of research that bases its idea of young carers mainly on coping with caring, chores and homework. Their views were also sought on whether the research sufficiently considers family relationships and the more difficult things for young carers beyond chores; for example, how difficult it is to see a family member unwell and the complications of their family’s life.
This understanding was supported by the young people in discussing what they found to be the most difficult aspect of being a family carer:

“... I think the most difficult thing actually is just watching someone you love not being able to have that full quality of life as you are having” (Melissa).

“…it is very hard to see my Mum not being a Mum” [tone of sadness] (Emma).

“…I don’t really have it as hard as some people might make it out to … umm, I just think, well what about Ryan [brother] … poor Ryan does [emphasised] have it hard like…” (Allison).

“Watching somebody you love … and known [emphasised] all your life, just get worse and worse … it’s like … ‘oh yeah, I will go do the chores’ … you know, so…” (Stephen).

To summarise the above discussion, it is suggested that many of the young people understand their experience as a carer in terms of family relationships. These relationships are impacted in large part by familial discourse that establishes notions of loyalty and mutual support, which often seems to overshadow concerns about chores, homework and missed social activities. What seems equally clear is that family life and family relationships in young carer families are complex, as will now be further discussed.

11.6 Complexity, contradiction and tension: The power of the construct of the ‘normal’ Western family

“Even when … even though you know there is no such thing as a normal family, it’s still on TV … it’s still on movies, and when you’re a little kid, you’re like, that’s real life, TV is real life when you’re ten, eight, thirteen, sixteen...” (Emma).

In the above transcript extract, Emma, who has rejected the notion of a normal family as a cultural construction (“the idea of a family is not even real”), critiques the insidious persuasiveness of how the construct of the normal family is maintained and reinforced in our society. This leads Emma to challenge the validity of the construct as “insulting” and to refute it as a basis for making negative comparisons with young carer families (as occurs in much young carer research).
However, notwithstanding Emma’s recognition and insights, there is nonetheless a sense of loss in her dismissal of the insulting notion of a ‘normal family’, as well as from positioning herself in a parent role in the family. Emma describes with some poignancy her loss and feelings of jealousy in missing out on what are considered ‘normal’ aspects of a family and child/parent relationships ([to be able to] “go home crying to my Mum like everybody else”); “I felt I was missing out maybe because my Mum and I weren’t girly enough”. While Emma mostly resisted and rejected notions of the ‘normal’ family, here she reproduces them. The same tension appeared to exist for others – Mitchell stated that he did not think about being in a normal family, but later extolls and envies his friend’s apparently ‘normal’ family.

As is very evident from the discussion to date, the issues surrounding young carer families are complex and contradictory, with young carers being pulled between various subject positions and understandings of their situation as a family carer. As has also been stressed, young carers are positioned in different and often contradictory ways at different times and there is no representative model of a young carer.

There are other similar examples which illustrates the manner in which the young people are sometimes able to recognise cultural constructs, but are not always able to resist.

While the young people were often made to feel defensive about their family’s ‘normalness’, at other times they were able to ‘stand back’ from their own situation and demonstrate an awareness of the mechanism for how they had been made to feel bad – maintaining the appearance of being part of an idealised normal family:

…they [young carers] get embarrassed … some … a lot of people, a lot of kids and teenagers get embarrassed about their … back to the whole ‘normal’ family thing … they want to portray the image, like ‘no, I don’t have these problems at home’… (Melissa).

This tension illustrates the extent to which these constructed family subject positions are entrenched in our understanding. No matter how people may recognise, and intellectually
dismiss concepts such as the Western family as cultural constructions, these notions are ingrained in our understanding and emerge at different times.

The contradiction and tension in relation to family constructs is also suggested by young carers who argue that the ‘normal family’ does not exist while simultaneously positioning their families as normal or abnormal. The concept of an abnormal family can of course only exist by virtue of a comparison to a normal family. This non-sequitur is perfectly captured in the following extract:

“…so I do think there is no such thing as a normal or perfect family … and we would probably be the most abnormal [laughs] … god, yes (Melissa).

It was perhaps also telling that in the earlier rounds of discussion most of the young carers talked about how different their family was from that of their friends, in ways both positive and negative, wherein it was either explicitly stated or could be inferred that they considered their family not to be ‘normal’ as per the Western model. When this interpretation was directly put to young carers in the final round of discussions, many young carers rebuffed the implication that their family was in some way inferior or differed from the ‘norm’. This speaks to the strength of the discourse on the Western family in constraining the young people from positioning their families as other than normal.

11.7 Summary

In Chapter 9 the range of subject positions available to young carers was discussed. It was also examined how the positioning of young carers was usually not consistent, with differences and contradictions emerging within a single interview, between different interviews with the same young person, between different carers in the one family or, of course, between different carers. Similarly, there was inconsistency and contradiction in how the families of young carers were positioned in relation to the construct of a normal
Western family. At times it was a source of pride to be coping with the difficulties of an ‘abnormal’ young carer family and being the good family member, and at others times this was submerged by the losses perceived to be associated with their disparity from the normal family.

Without wishing to dwell on the narrative of any one or more individuals, it is useful to reflect on the tensions and contradictions that emerged from Emma’s account of her experience. She has perfectly encapsulated the way in which a person can stand back and analyse their own situation but then at other times can completely reproduce cultural constructs. Emma criticises the whole notion of the culturally constructed ‘normal family’ and very clearly demonstrates an awareness of its mechanism and power, but then at other times reproduces these same constructs. This contradiction is informing who she is at different times. This research, in producing an account of young carer experiences, seeks to explore these different ways of being and speaking that are evident in the same young person and between different young people. It raises questions as to why the idea of a normal family is reproduced at one time and vehemently rejected at other time. These contradictions speak to both the complex family lives of young carers and the power of Western familial discourse which they are required to negotiate.

While the considerations outlined above offer an important understanding of the constructs under which these young people experience their lives caring for a family member, it is of course too simplistic to interpret the experience of young carers solely through the prism of Western familial discourse. This discourse interrelates with that of the adult-child binary (as discussed in the preceding chapter) and operates through similar considerations of the discourse that defines a ‘normal’ childhood/teenager, the subject of the next chapter.
Chapter 12: Analysis – Discourses on the ‘normal’ child/teenager

12.1 Introduction

As foreshadowed, this chapter discusses discourses relating to the ‘normal’ child/teenager and how they have affected the young people’s experience as a carer. The participating young people had two very contrasting discourses available to them about this period of their lives (i.e., childhood and teenager years) which appears to profoundly influence how they experience caring for a family member.

Not surprisingly, one of these discourses is the dominant understanding of childhood and teenagers that is entrenched in Western society – it is a time of play, fun, and no responsibility (as described in Chapter 3). More surprising was a second discourse that positions young people as trivial, mean and selfish, and who are involved in drinking, drugs and promiscuity. These two discourses will now be described in detail, followed by an exploration of how these discourses position young carers in relation to their peers and how this may affect their experience of being a young carer.

12.2 Childhood/teenage years: An idealised fun time of life

“I just wanted to be a kid and have more fun…” (Melissa).

In this comment, Melissa is very explicitly linking the notion of ‘being a child’ with the assumed understanding that it means having fun. This encapsulates a key aspect of the discourse of childhood that dominates Western society – the expectation that childhood is a time of freedom, fun and play. In a related vein, a comment by Emma that “children should be able to do ... like, within reason, within reason obviously, what they want to do, when they want to”, invokes the notions of spontaneity and no responsibility.

As was extensively described in Chapter 3, there is a discourse which promotes an idealised childhood and teenage years, assuming it is a period of life without difficulties or responsibilities (Lansdown, 1995). For young children this includes play (and certain
types of play) which is seen as necessary for a child’s happiness, and implicitly, normal growth, development and health (Cannella & Viruru, 2004). There is a similar understanding in Western society of the ‘normal’ and necessary range of activities for adolescents to transition from childhood to adulthood, based around social pursuits, friendships and schooling. It is seen as a time limited period during which young people need to meet milestones necessary for them to progress through to attain adulthood (Lesko, 2001).

Some young carers, as reflected in the above quotes from Emma and Melissa, are deeply aware that their lives differ greatly from the idealised Western notions of childhood and adolescence, as has been constructed by these discourses. The subject position available to them in this discourse is young people who are deprived, compromised, and ‘missing out’, which can have a major impact on how young carers experience their lives.

12.3 Childhood/teenage years: A period characterised by irresponsibility, selfishness, triviality and bad behaviour

“…in all honesty, my generation disgusts me [emphasised] with some of the stuff that they do …. and as I said, all my friends who are out partying and drinking, doing drugs, having sex…” (Melissa).

In striking contrast to the dominant discourse of childhood/teenagers outlined above, many young carers also presented a very different understanding of their peers. The above quote from Melissa is indicative of the disdain often expressed at times by young carers about teenage peers. They were variously described as: “very immature”, “nasty” and “pathetic” (Emma); or “stupid” (Jack). Stephen characterises the teenage years as a time to experience “the joys of being irresponsible and foolish …. to be a bit selfish”.

The emphatic use of this negative discourse by many young carers about their peers was both jarring and surprising. This understanding about young people was not however universally held, nor was it always consistently expressed. This suggests some
ambivalence in the belief about the ‘bad’ teenager. Nonetheless, while the use of this discourse was surprising and at times ephemeral, it did not arise in a vacuum. As has been discussed in Chapter 4, there is a well versed narrative in the community on ‘troubled’ teenagers which draws on a discourse of adolescents erratically under the control of hormones, lacking judgment and stability, and being vulnerable to peer pressure and risk taking (Lesko, 2001; Wilbraham, 2004).

It is useful to reflect on how this construct of the ‘bad’ teenager has emerged in a very emphatic and strenuous manner in the dialogue of some young carers. In considering my surprise at the way this discourse was presented, it can be suggested that these negative discourses about peers position young carers as ‘better than’ and ‘better off’ and also deflects the notion that they were compromised by not experiencing the life of a ‘normal’ child/teenager. The intensity with which some young people criticised their peers could perhaps be seen in the context of resistance to the implication they were missing out on what is perceived to be an important, natural, and even critical phase of their life.

The discussion of these two contrasting discourses will now be developed to explore their effect on the positioning of young carers in relation to their peers. These discourses operate in significant and complex ways, including interrelations with discourses about disability and family, as well as institutional discourse.

12.4 Young carers positioning in relation to their peers

These two very different discourses about childhood and teenagers form the basis of how young carers are positioned in relation to peers. Similar to the analysis of familial discourse, these can be loosely categorised in the following three ways:

1. Not a normal teenager and missing out.
2. Better than a normal teenager.
3. Remains a normal teenager/rejects the notion of a normal teenager.
In general terms, the first of these subject positions involves anger at missing out and being made to feel defensive about not being a ‘normal’ teenager. The last two positive subject positions make it more likely that the young people will feel more positive about their experience as a family carer. More particularly, the latter position also enables young carers to reject the notion that they are, in some way, abnormal. There is tension for young carers in negotiating these discourses – at times ignoring, challenging or resisting, and at other times accepting – giving rise to complexity, contradiction and nuanced positioning. Significantly, most young carers at different times are positioned differently; for some this included either explicitly or implicitly being identified with all three subject positions. These considerations will now be discussed in detail.

12.4.1 Missing out on being a ‘normal’ child and teenager

I was taking the bins out … you know, doing chores … as usual … while Mum yelled at me for not doing the chores … in the correct fashion … she was very unwell then … even more unwell … and … umm, and I could see my friends playing, and I asked Mum if I could go play with them … and she said ‘have you checked on Kathleen yet; have you changed Kathleen’s nappy yet; what’s Jack up to; are you going to take Jack; can you take Kathleen with you’ … so I decided not to go … it was just easier to stay at home… (Emma).

...there were some people my age ... there were two people my age over there ... and them and their siblings were playing outside and ... but I had to look after Kathleen, so I couldn’t go out and play ... and that’s the best ... I guess even an analogy, for how it can feel ... you know, inside a fence ... you can see people through a fence... (Emma).

These experiences from childhood, described by Emma many years later, poignantly reflects her sense of loss at her exclusion from play, perceived as the natural and necessary activity of a child. Her analogy of looking through a fence captures perfectly the notion of looking out to an idealised childhood world of play, a world of which she is not a part. While not described with the same powerful imagery and detail, many other young carers expressed the same view as Emma. Jack, for example, equates not being able to play with not being a ‘kid’:
The comments by Emma and Jack reflect one of the most powerful constructs in Western society – that childhood is a time of play and no responsibility (Cannella & Viruru, 2004). The conflict with this understanding of childhood is a significant factor in how some young people experience being a carer. There was the feeling they had missed out on critical developmental stages – there was a sense of loss about their childhood and a concern about a compromised future (this contradicts statements at other times about gaining important life skills that better prepare them for the future). The extreme ‘either-or’ position is presented below by Emma: you cannot be a carer and still have a childhood. She suggests that she has sacrificed her childhood and that she has taken the brunt of caring for her sister and her mother so as to allow her brother to have a childhood:

I was never going to be a child anyway … umm, because I’ve borne the brunt of that … ah, and the caring role and bearing the brunt of my Mum … I’ve sort of made it so my brother could have a childhood (Emma).

For the ‘older’ young people, the perceived departure from norms relates to not engaging in teenage social activities, and these were also deeply felt. Often these difficulties were imposed because of their caring responsibilities or the disability of the family member, as discussed by Mitchell:

…the only thing that I ever thought about was ‘oh, I wish I could go to my friends tonight’ … but I wouldn’t be able to because Mum wouldn’t be able to drive me, you know … I never really thought about being a carefree teenager (Mitchell).

An important aspect of young carers’ disengagement from their teenage peers also seems to stem from the expectation that they are perceived negatively because of their association with disability. This consideration was detailed in the previous Chapter 9,
most particularly, how young carers often felt unable to socialise and bring friends to their homes, which is seen as a very important aspect of normal teenage activities.

Without repeating the discussion in Chapter 9 about attitudes to disability, it is useful to consider the issue specifically in relation to childhood/teenage discourse. It was portrayed as a point of distinction from their ‘bad’ teenage peers that young carers are understanding of disability, non-judgmental about difference, and supportive of those who were marginalised from their peers for whatever reasons: “I can understand …. like whereas the normal person wouldn’t know … have any idea, wouldn’t have the slightest idea” (Liam).

The tension is well illustrated by 12-year-old Jack. It was discussed in Chapter 9 how he is well known at school for his vigorous defence of children with a disability, but he also speaks of keeping his family’s situation as secret because he wants to ‘fit in’ with his peers:

  umm … yeah, ‘fitting in’ is a big thing though … that’s probably part of the reason I haven’t told people [about his mother and sister’s illness and disability], because I feel kind of normal [tone of equivocation] … (Jack).

These contradictory comments by Jack are suggestive of a strong latent discourse on disability that gives rise to embarrassment and a fear of being stigmatised, and which acts to constrain some young carers from pursuing aspects of a ‘normal’ teenage social life. Jack’s comment brings into focus a discourse that positions adolescents as being particularly susceptible to, and driven by, peer group pressures, a community stereotype that is discussed by Lesko (2001). It is noted that Jack, Mia and Liam (discussed in Chapter 9), who all either expressed embarrassment or sought to shield their family member from peers, were all aged around 12-13 years, which might suggest that ‘fitting in’ with peers was a particular concern for this age sub-group. However, it might equally be said that this age sub-group were simply more frank about their situation and willing
to make statements that others might see as socially undesirable. These tensions between discourses of disability, being a ‘better’ child/teenager, and perhaps that of the peer driven adolescent, adds a further layer of complexity to understanding the experiences of young carers and their understanding of ‘missing out’ when compared with the idealised construct of a Western child/teenager.

12.4.2 Better off for being a young carer

“I am sure that you can see just from talking to me that I am not anything like my generation” (Melissa).

The above quotation is very revealing in that Melissa considers the difference between young carers and the average teenager to be so striking that it is self-evident. This positioning of young carers versus the normal teenager enables some young carers to be positioned as superior, which in turn mediates in a positive manner their experience as a carer.

This positioning drew heavily on the discourse of a teenager that portrayed them as trivial, immature and mean and who were mostly involved with drugs, alcohol, and were promiscuous. Jack very explicitly and emphatically states that he is not a ‘normal’ teenager and that he is much better for not being so. He also offers a damming critique of his peers: “I know what stuff is wrong ... like drinking and stuff at my age ... I wouldn’t do it ... I think it is disgusting that people aren’t virgins at my age and drink ... and smoke...”. He positions himself on a higher plane and, like others who positioned themselves as ‘better than’, being different from his ‘bad’ teenage peers was seen as a positive and even a source of pride.

This discussion by Jack reflects intensely polarising discourses about ‘good’ young carers and other ‘bad’ teenagers. This polarisation can be suggested as having a powerful impact on how some young people understand their experience as a family carer; an
impact that goes well beyond the (unlikely) accuracy of the claim that 12-year-old children are generally promiscuous and involved in drugs and alcohol.

The contrast between young carers and ‘normal’ teenagers is extended further by Melissa to evoke a very problematic portrayal of her peers, while also describing young carers as being under-supported, a theme which often dominates her discussions.

but what blows my mind is that they want to pay … literally dole bludgers … teenagers who don’t want to work, don’t care … spend it on cigarettes, alcohol and drugs, and then they pay someone who is caring, you know, who is a hard worker, a lot less … that’s what blows my mind … or the assistance, the money that teenage pregnancies get, you know (Melissa).

In this extract Melissa draws on a political discourse that advances a ‘blaming’ perspective on issues of social justice and poverty. It positions particular marginalised groups of young people as being lazy, profligate, responsible for their own plight and as undeserving of government assistance. This discourse also serves as a point of comparison to position young carers as being inequitably treated and deserving of more financial assistance. This discourse of the problematic teenager that allows some young carers to be positioned ‘better than’, was also further accentuated by the contrasting of traits and behaviours of the ‘bad’ teenager with their own social maturity, compassion, and sense of responsibility.

…like normal people, they just don’t seem to have as much of a social conscience …. I feel more responsible, I am more responsible; I tend to put others before myself …. if somebody says something horrible to someone else, I can’t sleep that night if I didn’t stick up for them. So if someone said something nasty to someone … I’d be like ‘wait a second, you’re being a jerk... (Emma).

…the friends she had at primary school were just mean to her … she was just by herself, and I just felt bad for her, so I just started talking to her and we become friends (Mia).

The comments by Emma and Mia (above) are examples of the many accounts presented by young carers of be-friending marginalised young people and young people with
disabilities, and standing up for the under-dog. For some young carers these qualities were described as a major point of difference with teenage peers. It will be recalled that an extensive catalogue of positive personal qualities, which the young people attributed to being a young carer, have been detailed in Chapter 9.

Interestingly, those most critical of their ‘bad’ teenage peers and who described themselves as better people, were those most strongly identifying as a young carer, such as Melissa, Jack and Emma. As has been discussed in Chapters 8 and 9, young carer discourses position young carers as special and remarkable young people. It can be suggested that the discourse of the ‘bad’ teenager is then contrasted with the discourse of young carers as exceptional young people, compounding the perceived polarising differences between young carers and the ‘normal’ teenager. This understanding of a ‘gulf’ between young carers and their teenage peers is also seen by Melissa in the context of a lack of support for young carers, which she contrasts with the funding available for (bad) teenage dole bludgers and for teen pregnancies. This builds on the understanding of many young carers that they are not appropriately recognised, appreciated or supported. This tension between the respective treatment of young carer and ‘bad’ teenagers would seem to mediate in a negative way the experiences of young carers.

For some young people the differences they described between young carers and other teenagers was so great that they also spoke of being alienated from their peers because of this difference:

“… I just sit there and look at them … ‘you are an idiot’ … like half the time, so … and that was a problem … that was actually why I dropped out of school really …. was, yes, I couldn’t handle the pressure of the HSC by being around, you know, immature kids who didn’t respect their families…” (Melissa).

This discourse about being alienated from her peers because of what she describes as their idiocy and immaturity, and hence being driven from school, can be considered in
the context of Melissa’s many references to not completing secondary school, which she explicitly refers to as a fundamental milestone for young people. It seemed very clear that Melissa thought it necessary to discuss why this milestone was not obtained: this perhaps reflects a cognisance that education is the major component of the Western construct of children and adolescents (the “work” of children; Robb, 2001), although it was also clear that Melissa held very understandable concerns about being disadvantaged by not finishing secondary school. While disruption to education is often a focus of young carer research (as discussed in Chapter 3), it has always been based on forced school absences and time constraints, rather than being a result of alienation from school peers. This alternative explanation can perhaps be considered in the context of Melissa not wishing to directly attribute non-completion of school to having to care for family members: this would be consistent with her notion of family loyalty and wanting to lessen her mother’s feeling of guilt, as discussed in the previous chapter. It can therefore be suggested that Melissa is being impacted by a number of discourses about the Western child/teenager, as well as family.

This provides a suitable segue to a discussion of the interactions, tensions and contradictions between multiple discourses that emerge when young carers are positioned as better than their peers. It is instructive to use as examples the position advanced by Jack and Melissa, whose strident criticism of their peers has already been fully described, as has their positioning as ‘better than’ their peers and feeling good about not being a normal teenager. Notwithstanding these very clear and explicit positions, Jack at other times explicitly nominates himself as a “normal teenager” and Melissa laments with considerable sadness how she has missed out on the important normal teenager milestones, citing as examples, missing school graduation and prom night, and her alienation from friends.
These are just two examples of the many tensions that emerged from the discussions about the lives of young people and which were laden with contradictions. At times, many of the young carers claimed to be happy they are not a normal (bad) teenager, while at other times complained about missing out on being a normal teenager. At yet other times they claimed to be a ‘normal’ child/teenager. This rollercoaster of positions can be expected to result in a corresponding high degree of variability in how young people like Jack and Melissa understand their experience as carers. These changing and conflicting positions, together with the need to manage the feelings that accompany these different subject positions, creates new and additional difficulties in the lives of young carers. The emergence of these negative consequences from consideration of the discourses surrounding young carers, extends our understanding well beyond superficial notions of young people caring, which most often focus on extra chores and missed social activities.

While there is often resistance to the dominant Western discourses, enabling young carers to feel better about their lives as carers, the contradictions are suggestive of the strength of the discourse of ‘normal’ in our society, as will be discussed further in the following section.

12.4.3 Positioned as normal children and teenagers/rejecting the notion of normal teenager

This section seeks to unpack two opposing positions for young carers in relation to the construct of a normal child/teenager. While some young people described the desire to feel like a ‘normal’ child/teenager, others expressed resistance to normalising discourses that are calling on them to conform to notions of the Western child/teenager.

Liam captures the first of these: a desire expressed by the young carers to feel like a normal child/teenager:
“...I’m like ... I just want to ... feel normal so I do ... just like anyone else ... I just want to feel normal .... oh ... I just ... I just try to be as normal as possible” (Liam).

This comment can be related to the discussion of Foucault’s work on normalisation and the desire to be ‘normal’ that was discussed in Chapter 2. Some young people such as Liam were very open and explicit about their desire to feel normal, which suggests an acknowledgement at some level that they do not currently, or always, feel this way.

However, to further reference the work of Foucault, “there is no relations of power without resistances” (Foucault, 1980a, p. 142). Notwithstanding that the lives of many young carers seem to differ in significant ways from that of their peers, some young people described their resistance to being positioned as other than a ‘normal’ child/teenager. Given the power of the discourse about young people in Western society that establishes what is normal for young people, this is perhaps unsurprising given that to do otherwise is to accept the alternative that you have an abnormal life. This resistance took a number of forms which, in effect, were critiques of the problematic limits placed on what constitutes a ‘normal’ child/teenager. For some young carers there was (at times) the outright rejection of the cultural construct of a normal child/teenager, at least in the terms described by the discourse. This point was very explicitly made by Allison and Liam:

“I don’t think there is such a thing as a normal teenager…” (Allison)

“…there is no such thing as a normal teenager (Liam)

It will first be noted that two comments by Liam (above) have been used to illustrate contradictory positions in this discussion: firstly, that he wants to feel like a normal child/teenager and then he later rejects the idea of there being such a thing as a normal teenager. This again highlights the tension between powerful normalising discourse and the resistance to these discourses.
Allison’s rejection of ‘normal’ is further reinforced by also downplaying and diminishing the difference between the lives of young carers and those of so-called normal young people suggesting their lives are not substantially different from their peers.

... I don’t really miss out on anything, I can do everything I want to do normally and when I’m needed here I’ll do it ... yeah ... but a lot of time teenagers just sit at homes on their computers and stuff anyway ... like they’re [young carers] not missing out on anything [laughs] (Allison).

Allison’s stated position is different from the other young people, who all described missing out on some important aspects of childhood or teenage life. It is significant that in this excerpt Allison is positioned as similar to other teenagers in the first part of her comment, but then in contradiction brings in a negative discourse on teenagers to argue that when she does miss out it is not anything worthwhile. While not directly articulated in these terms, it might also be inferred that Allison recognises the ‘normal child/teenager’ as being a cultural construct, and is making a sophisticated critique of the notion. This is suggested in her quote below, describing her understanding of how some young carers would think that it is ‘real’: a comment which also captures the idea that it is a powerful construct:

... they [young carers] might really think that there is a ‘normal’ teenager ... ... like there is others out there that get to do things that they don’t get to do ... yeah, some might ... but I don’t, I definitely don’t [emphasised] think it is. (Allison).

While the construct of ‘normal’ child/teenager is stated by Allison as being rejected, it could also be suggested that it is actually being redefined to suggest that the life of other teenagers is not greatly different from their own, and hence they are not actually missing out on much at all; that is, the discourse of the normal teenager as including the idea of endless fun and social activities, with no chores or responsibilities, is not accepted.

The desire to be seen as ‘normal’ was perhaps best revealed in the third round of interviews. As has been mentioned a number of times, an important aspect of the
collaborative methodology for this research was to involve young carers in the analysis of the data and for this purpose a series of questions were compiled which incorporated the findings of the preliminary analysis of the preceding rounds of interviews and ethnographic work. Specifically, the suggestion from the analysis that young carers’ experiences of caring were negatively affected by them not considering themselves to be a normal child/teenager was directly presented:

Just following on from the talk of a so-called ‘normal’ family, do you think there is also an understanding about what is a ‘normal’ teenager? Do you think that young carers don’t feel like they are a normal teenager, and for some that makes them feel badly about being a carer?

The response to this question was very similar to other ‘collaborative’ questions concerning the constructs of ‘normal’, as has been discussed in Chapters 9 and 11. Again, in general, there was a retreat from what had often been very explicit and strong views in previous discussions about not being a normal child/teenager. This outcome can be insightfully unpacked by reference to a comment made by Melissa in our final discussion:

“you know, I want to be a normal teenager, I get that…” (Melissa).

The significance of this comment is that the analysis prior to this point has been replete with Melissa’s strident criticism of the normal teenager, and indeed she often spoke of how being a young carer had “saved” her from being a normal teenager.

These very contradictory statements are indicative of the power of the normalising techniques of dominant discourses, in this case the dominant discourses about the normal teenager.

12.5 Parents and the discourse of a normal child/teenager

it’s sad ... you know, she [Melissa’s mother] feels like I should be able to save my money and I should be going out with my friends all the time ... and be a normal teenager (Melissa).
The above comment by Melissa suggests that the discourse of a normal teenager is also a strong influence on parents. It gives rise to a belief by parents that their children are not having a ‘normal’ childhood/teenage experience and, by implication, they were not fulfilling the role of a good parent. This concern also draws, in part, upon familial discourse about the role and responsibilities of parents, as was explored in Chapter 11. This includes the fundamental requirement of parents to safeguard the well-being of their children.

The coming together of discourses about family and young people was very much reflected in the parent interviews. It was discussed in Chapter 9 how parents reproduced the stock phrases that punctuate the dominant research literature and which portray young carers as compromised (e.g., Charles et al., 2009; Charles et al., 2010). The comments below are examples that reflect the accepted understanding by parents about both the nature of childhood and the negative impact of caring on childhood:

…forced to grow up too quickly …. childhood stolen (Mitchell’s mother).

…has he had a childhood? Is he going to have mental issues, is he going to fit into society? (Jonathon’s mother).

…she’s lost that childhood …. growing up too soon …. too much responsibility for a young person (Melissa’s mother).

These extracts from interviews with the mothers of Mitchell, Jonathon and Melissa bring together elements of childhood discourse with familial discourse, which stipulate ‘appropriate’ roles and responsibilities for children (as has been described in Chapter 11). Their comments are also indicative of the profound guilt felt by these parents about their children being their carers. The worry expressed by Jonathon’s mother (above) includes his possible alienation from society and mental health problems as a consequence of being a child carer, which align with the more dire aspects of the negative paradigm that dominates much of the young carer research (e.g., McAndrew et al., 2012).
This understanding by parents of their children’s experience comes together with the cultural expectation that you are not a good parent unless you are providing your children with a ‘normal’ childhood and, more particularly, that a good parent will ‘make it better’. Accordingly, it appeared that some of the young people were under close surveillance by their parent (in addition to the surveillance of young carers and their families by welfare and service agencies, as discussed in Chapter 8). During the period of the fieldwork, all the young people mentioned how at some stage they had received, or were receiving, counselling. The reason for the young people receiving counselling was not always discussed, but in a number of cases it was stated that parents were concerned about the mental health of their children. Discourses stipulating what constitutes a normal (and abnormal) childhood comes together with the cultural understanding that counselling is the required response if a person is not considered to be having a normal experience. In the case of young carers, counselling is assumed to be what a good parent does to address the perceived adverse impact of caring on what they understand to be a normal childhood.

The outcome was somewhat paradoxical. Counselling was emphatically rejected by the young carers: while in some cases this was based on perceived lack of efficacy, others refused counselling because they did not want to feel (or seen to be) abnormal, as was made explicit by Liam:

“...well I don’t like talking to people who will think I am crazy if I tell them stuff...”

(Liam).

Liam’s comment represents one explanation for the divergence with parents about counselling – he is impacted by a negative understanding of what receiving counselling suggests about him, and his mother is impacted by a discourse about being a good parent that requires her to ‘fix’ her child. These respective attitudes to counselling might be seen as reflecting the tensions that exist for young people seeking to straddle the subject
positions of (normal) teenager and carer, and for parents negotiating the subject positions of (good) parent and a person with a disability/illness. There is also a deeper interpretation that can be explored in relation to all the young people being required to participate in counselling (at some stage). It can be suggested that there is a strong cultural drive to address, as an individual’s mental health issue, problems that can be argued to be of a practical nature that stem from, or are exacerbated by, a lack of adequate services and support. This is supported by a critical inquiry made of mainstream psychology where there is seen to be an excessive focus on the individual while ignoring material conditions in society that disadvantage marginalised groups.

The assumption by most parents that their children were missing out and that their lives had been compromised was openly discussed by some parents with their children, and for some was implied by their insistence that their children receive counselling. These considerations bring a focus to the role of psychology in how young carers are treated. As was discussed in Chapter 4, psychology has come to form the foundation of community policies and practices concerning parenting, education, and the treatment of young people. Parents and the staff of young carer agencies and service providers are, like the community generally, subject to the same constructs about the treatment young people require when their lives deviate from a normal childhood. It can therefore be argued that psychology is a central influence on the response by parents and the community to young people being carers, which in turn impacts on their understanding of the situation and their experience as a family carer.

12.6 Summary

The discourse of the Western child/teenager is a powerful construct against which young carers are compelled to compare and judge themselves. The subject position available to young carers under this discourse is one of being different from their peers, of missing
out, and having a compromised childhood and teenage years. Conversely, the discourse of the ‘bad’ teenager provides an alternative subject position against which young carers judge themselves very positively, and which in turn enables a more favourable understanding of their experience as a family carer. At times young carers rejected the construct of the normal child/teenager or diminished the differences between their lives and the defining features of the construct.

However, as has been evident throughout the discussion, the situation is complex. As with the discussion of the other major discourses, the most striking feature of the discussions with young carers about themselves and ‘normal’ young people was inconsistency and contradiction. At the most straightforward level there was the forceful rejection of a position that was at an earlier time emphatically proclaimed, to subtle, nuanced changing of positions at the other extreme. These tensions were numerous, both simple and complex, and difficult to fully encapsulate. The discourse of the fun, carefree Western child/teenager is in tension with the discourse of the ‘bad’ teenager, which in turn stands in contrast to the positioning of young carers as exceptional young people. This perceived ‘gulf’ between young carers and their ‘bad’ peers, positions young carers as unappreciated and unrecognised. At various times these discourses on young people also interact with familial discourse and a discourse on disability. Psychology is very much implicated in determining what constitutes a departure from a ‘normal’ childhood and the response to perceived departures. There is a cultural expectation that young carers need counselling because they are not experiencing a normal childhood. The conclusion that clearly emerges is that young carers are impacted by, and striving to negotiate, a number of discourses.

Consideration of the discourses that impact on young carers presents a much more complex understanding of their lives: one that extends beyond a superficial focus on
chores and caring tasks. It is evident that the variation and conflict surrounding the positioning of young carers adds to the difficulty of their role as family carer, and are important considerations.

Relatedly, and perhaps the most compelling outcome from this section, is the powerful processes of normalisation that demand allegiance to the construct of ‘normal’ child/teenager, while on the other hand compel resistance. Similar considerations about normalisation and resistance emerged from the earlier discussion of ‘being a young carer’ (Chapter 9) and the Western family (Chapter 11), and can be seen as a significant outcome of the analysis. These issues will form an important part of the discussion in the next and concluding chapter.
PART VI

DISCUSSION AND CONCLUSIONS

Chapter 13: Findings, critical reflections, and conclusions
Chapter 13: Findings, critical reflections, and conclusions

13.1 Introduction

This chapter seeks to draw together the knowledges produced through the research project as a whole, and to reflect on the understandings which have emerged of the experiences of young people with a family caring role. The project commenced with a particular poststructural and postcolonial epistemological position that challenged the existing research and understandings of childhood and young people and that consequently evolved into a very particular collaborative methodological approach to young carer research. It is therefore important to discuss not only the findings of the analysis, but also to review all the knowledge that emerged from a very specific research journey that culminated in working with young people as co-researchers and where the knowledge was constructed from a Foucauldian perspective.

13.2 Reflections on collaborative research with young people: Theory meets practice

13.2.1 Pursuing collaborative goals: What actually happened?

As one of the primary concerns of this research was to work collaboratively with young carers, this section will reflect extensively on the collaborative methodology and process. The starting point for research is rarely young people themselves and this project was no different: time spent in the initial phases reviewing literature and producing research plans, no matter how fluid and critical, were adult-led and theoretical. This aspect was itself reflected upon carefully and there was a desire for the young people to challenge and disrupt this planning on meeting with them. Planning was therefore undertaken with the expectation that, as far as possible, it would be undone by working with the young carers. This had some surprising consequences for the project and, as was hoped, led to innovative research in quite unexpected ways.
As has been discussed in detail in Chapter 6, the initial step was a series of ‘consultation’ discussions with each young carer to obtain their input in developing the format and design of the research – which methods they thought would be most appropriate, what issues they thought might be most important, and who should be involved. It has also been discussed how the young people were able to choose their own manner and level of involvement and to be part of as many or as few stages of the research as they wished. Many young people took dominant roles, while some were more passive and reactive. Some strongly advocated their parent being interviewed (“I definitely think ... talking to the parents would be a great thing as well”: Melissa), while others were horrified at the prospect (“oh god, imagine if you asked my Mum about me”: Emma).

In seeking to conduct this participatory research with young people there were tensions that are important to reflect upon. In providing the space for young people to choose their preferred method (or methods) of participating in the research, I had fully anticipated working with the young carers in exciting and, perhaps, even radical ways. It was assumed that not only would multiple methods be chosen, but also that the young people would favour non-traditional, and so called innovative research techniques. Drawing on the participatory research literature discussed in Chapter 5, possible methods ‘floated’ by me included such things as video diaries, Internet-based methods, social media, interviewing each other, and group meetings. It was earlier discussed how this assumption was comprehensively (and surprisingly) contradicted. Instead, I was faced with a group of young people who all just wanted to meet in their family home and have a series of one-on-one conversations; that is, the traditional method of interviews that I was trying to avoid! My related assumption that young people, particularly the very young, would not be comfortable being interviewed by an adult researcher was also emphatically rejected. The prevailing sentiment was well captured by 12-year-old Liam who said he “liked to talk” and felt “absolutely comfortable being interviewed by me”.
My initial struggle with this ‘consultative’ outcome is an important episode to recount. My initial reaction was disappointment and the feeling that this outcome indicated a failure as a participatory researcher. While it was difficult to overcome my reservations, in particular the feeling that their choice may have been related to internalised assumptions they held about the nature of traditional research, I did recognise that it was of utmost importance to maintain my original standpoint and not lose sight of my participatory goals. I needed to adhere to my desire to listen to and promote the rights of young people and not seek to make the young people participate in ways that matched my expectations. No research outcome is ever going to be perfect; nor was it important that my preconceived ideas had not eventuated.

While it may be seen as counter-intuitive, the radical aspect of this research was to employ conventional methods, which conflicts with the notion portrayed in the literature that participatory research with young people can be expected to pursue different and exciting methods (e.g., Bagnoli & Clark, 2010; Dona, 2006; Holland et al., 2010). This research argues that the important thing for researchers is to listen to and act upon what the young people want to do; sometimes, as in this case, they just want to have a conversation! An important point to take from the surprising outcome of young carers choosing the traditional research method of interviews is not to presuppose a particular view about how young carers want to be involved and end up with ‘directed’ collaboration and participation that may inadvertently impose an unwanted research relationship on the young people. This outcome has reinforced my underlying criticism about adult researchers making assumptions about how participants should participate in research and what is ‘best for them’.

It is also valuable to reflect upon what may have underlain my (and others) expectations about the preferred methods of the young people. At some level there is the assumption,
particularly for the younger children, that they are often not very verbally literate and they require non-discursive methods in order for them to participate in research. It is of course also the case that some young people or particular groups of young people would not wish to involve themselves in discussions about their lives because they are unhappy, and even angry at the world. However, while some of the young people in this research were undoubtedly angry with the world, they *did* wish to discuss their lives and had much they wished to discuss. This is one further instance of how this research has challenged the understanding of young people as a homogenous group.

The fluidity that strongly characterised this research is argued to be a very positive outcome for participatory work with young people. The research was improved because it was, as far as possible, inclusive of difference: allowing the space for the young people to engage with the project as they wished. It is unarguably a positive for the young people that they were not constrained by a researcher’s limited set of questions, and conversely others were not coerced into trying to discuss issues they did not wish to, or could not, address. Some young people spoke to a wide range of issues; others were more limited in their discussions. While the expected non-traditional, multiple methods approach did not eventuate, as was noted earlier, it has been argued that it is not the kinds of methods that make research participatory, but rather having the participants involved in the process of choosing the methods (Kindon et al., 2010).

It is also useful to reflect generally on the role of young carers as co-researchers. Many of the young people’s interviews were profoundly notable for being articulate and thoughtful, and for providing great insight into the complexities of their caring situation and family life. Importantly, there was generally positive engagement with the project with few obvious signs of suggestibility; that is, the young people being influenced by me, the adult researcher. The young carers’ agency was evident in many interactions and
expressed in many ways – sometimes subtly and sometimes very overtly. Certainly all the young people were at times openly dismissive of viewpoints that were ‘floated’ (e.g., Mitchell: “I don’t think like that AT ALL [emphasised]”; Emma: “I don’t believe in that … I think that is a complete joke”) and presented and argued alternative viewpoints. In a number of cases, the young people largely took control of interviews. However, given my position as an adult researcher, it is recognised that some young people would at times have been inhibited or led.

The young people were also for the most part remarkably cheerful, engaged and open about their personal lives, family relationships, and the physical and mental health problems of family members. One of the most important collaborative outcomes of the research was being able to take preliminary analysis back to young people to review and critique my understanding and so co-produce the findings. As has been extensively outlined in previous chapters, the young people often provided sophisticated feedback on my preliminary analysis, which included putting forward opposing interpretations of the data. This was also an important aspect of seeking to develop a young carer’s standpoint.

As a researcher, this participatory project was exciting, surprising, and often unnerving: however, encouraging the young people to take control of the process was an important part of fostering participation and seeking a young carers’ standpoint. There was a sense that passing some control to the young people, and the resultant uncertainty about the direction the research would take, helped to diminish my power as the researcher. Ultimately it was very rewarding to be able to work closely with these young people and be able to provide them with the opportunity to directly participate in researching the issues which dominate their lives and to tell their own stories. In reflecting on the outcomes from this project, I arrived at the paradoxical position of wanting a greater level of collaboration while at the same time being surprised at the high level of
engagement and commitment to the project. This provides a suitable segue to a discussion on the obstacles that were encountered in conducting collaborative research.

13.2.2 The obstacles to achieving meaningful collaboration with young people

As has been discussed at many points throughout this thesis, the research project sought to change how young people, and in turn young carers, are positioned. It sought to use a methodology that allowed young people to be central to the research. This collaborative approach was not considered as being simply a method, but rather as a methodological principle to be pursued in working with young people that allowed them to be central to the research. Notwithstanding some very positive outcomes (as discussed in the previous section), there are significant barriers to achieving meaningful collaboration with young people: however, what can make the research especially meaningful is the careful reflection on the barriers that have been encountered and the implications of these barriers.

Adult-child binary

A significant constraint on collaboration was the cultural expectation that young people defer to adults. The strong adult-child binary in Western society has been extensively discussed in the context of being a young carer, but it also exerts a strong influence on young people as research participants, clearly acting as a barrier to collaborative research with young people. As has been discussed, young people are marginalised in an adult-centred world (Lansdown, 1995) and there is a largely unquestioned assumption that adult knowledge is superior to that of young people. Adults exert influence on young people simply by their ‘adultness’, and this impacts negatively on young carers feeling able to embrace the collaborative intent, no matter how well intentioned is the researcher. This divide was seemingly evident in my inability to gain the full understanding of a small number of the younger children as to what I was seeking with collaboration. This
adult-child binary is compounded and conflated with the researcher being positioned as the ‘expert’ (as is also the case with adult participants). The subject position of university researcher carries with it the assumption of expert knowledge and skill and it seems unavoidable that they are seen as ultimately directing the research, detracting from the level of collaboration that can be achieved. It has been noted, for example, that when I sought their views on my preliminary analysis some of the younger children seemed bemused that I (an adult researcher) was seeking their advice (as children) on such matters.

The impact of the adult-child binary as a barrier to genuine collaboration also manifested itself in young people making choices that where seemingly at odds with the intent to develop a young carers’ standpoint. This was most obviously an issue when the majority of young carers proposed the inclusion in the research of young carers’ parents. Despite knowing and accepting the rationale for the research, the young people still positioned adults/parents as experts on the lives of a young carer. It transpired that many parents had very different and often sharply conflicting perspectives to their carer children, reflecting their own interests and agendas. The adult-child and researcher-participant divide cannot be completely overcome, which has obvious implications for the degree of collaboration that could be achieved.

*Ethics and parents as gatekeepers*

There was discussion in Chapter 6 of the extensive ethics approval processes that were undertaken for this research. Ethical requirements are set by the Australian Psychological Society, the ethics committee of the University and, for this research, the stipulations of the Respite Centre also needed to be met. These ethical requirements in turn draw upon a legal framework, cultural and societal understandings of what is ethical and moral, and a medical perspective on ethics. They are bound up with the notion of participants being
vulnerable and weak, with the researcher/psychologist having the knowledge and power. The idea that participants are weak and vulnerable is particularly significant for young people and, as has been a prominent argument throughout this research, is powerfully bound up in societal beliefs that adults know what is best for young people.

While the intention of these bodies is, understandably, to ensure proper practice in relation to ethics, it can be suggested that the requirements can be an impediment to the fidelity of collaborative research. To some extent, the theoretical stance of the research, which positions young people as competent social actors and as subjective experts in their own lived experiences, clashes with the ethics approval requirements for research with young people. These ethical guidelines, which have been derived from an adult perspective, require parental consent for people under 16 years of age. As such, the final decision on whether a child participated almost certainly came from a parent/guardian, which means the possible exclusion of young people who were very keen to participate, while those who were less interested may have been influenced by their parent to participate. In circumstances where young people may have been influenced by their parent to participate, there is possibility, or even likelihood, of some level of passive resistance which would obviously have a negative impact on the degree of collaboration achieved. While there were no overt indications that this occurred, it was a possible factor in the lower level of engagement of some of the younger children.

*Internalised understanding of traditional research*

As has been discussed, all the young people were given the opportunity to nominate their preferred method/s of participation so as to maximise the possibility for them all to find the space to work comfortably with me (the researcher), as well as to cater for different communication preferences and competencies across a range of ages. It has also been discussed how I had assumed, supported by some literature on conducting research with
young people (discussed in Chapter 5), that the young carers would favour non-traditional, innovative research methods but that this was comprehensively contradicted, with all the young people expressing a firm preference to be involved through a series of one-on-one discussions. Even gently raising potential limitations and drawbacks of interviews was responded to by a 14-year-old boy mounting a cogent argument against my ‘devil’s advocate’ position: he proposed “open” discussions (in effect unstructured interviews) which he suggested would allow more control by young carers over the direction and content of interviews.

The question that arises is the extent to which the young people have internalised an understanding of traditional research methods, limiting consideration of methods other than interviews, which in turn potentially impacts on the level of collaboration that can be achieved. This would be consistent with the argument by Smith (1997), referred to in Chapter 5, that people being researched have often internalised assumptions about conventional research which lead them to make conventional decisions about participation.

It should though be noted that for many young carers the rejection of non-interview methods may have a practical basis. For young people who professed little interest in school, the notion of completing diaries, journals, or inputting material via internet-based techniques, was seen as too much like school assignments. Some young people who were otherwise eager to be involved, were time-poor and interviews were considered to be less demanding in terms of time and organisation. For some young people there seemed to be concerns about adopting unfamiliar methods which may have been perceived as more demanding in terms of time and complexity. Many young carers would also not have been able to nominate methods that would require them to leave the family home.
As the research progressed it also became clear that even when a researcher is willing to relinquish significant control of his/her project, not all participants have an expectation, or desire, to engage in collaboration to the full extent intended. It seemed likely that an internalised understanding of traditional (non-collaborative) research methods was brought together with discourses on adult-child and researcher-participant binaries to limit the level of collaboration that could be achieved with some young people.

13.2.3 Involving young people in the critiquing of the methodology

The collaborative methodology adopted for this research has been at the forefront of the discussion throughout the thesis. This approach commenced with the first round of discussions which sought the advice of young people on the conduct of the research and the terms of how they wished to participate, through to their participation in the analysis of the data. I also considered that it would be an elegant conclusion to the collaboration to seek the views of the young people on the collaborative methodology. For this purpose, the following question was presented to the young people as part of the Stage 3 discussions:

The final thing that I wanted to get your thoughts on – as you know, my fundamental aim with the project was to collaborate as much as possible with young carers like yourself, since you are the experts with the experience – I started by seeking input from young carers about how to conduct the research, through to now in seeking views on some of the possible outcomes. As a final step to complete the circle, I would really like to hear any thoughts you had about this approach, my methodology for the research.

The feedback from the discussions on this question were overwhelmingly positive. A sample of the tenor of the comments is listed below:

“…everybody’s different, but honestly this sort of approach just works great for me … because, you know, I am really open with it…” (Mitchell).

“…I think it is really good to have that [discussions] multiple times … you build up the relationship trust, and as you said, you see people on different days and things happen … our lives changed over two years” (Melissa).

“…it’s been a good way that you’ve done it” (Allison).
It is acknowledged that perhaps some (but definitely not all) of the young carers may have felt constrained from offering criticism, particularly given that at this concluding stage of the fieldwork I had developed a strong working relationship with most of the young people and their families. Perhaps more limiting though in terms of receiving feedback was, for the most part, a lack of direct engagement with the intent of the question; that is, to focus specifically on the collaborative nature of the research. The clear exception was Emma who very directly spoke to the collaborative aims of the research. This is a compilation of her comments in responding to the question:

…that’s [collaboration] so smart; …that’s all any of us ever wanted; …young carers are the verified experts; …you’re consulting with experts on the topic [laughing]; You talked to us like normal people … nobody [else] ever asked me the questions I wanted to answer; We all like to be talked to like normal people … and I liked it that you didn’t really want to hear what my Mum had to say … you weren’t there to talk to her … that is like the first time ever! (Emma).

While less direct, there were two other young people whose comments may be taken as tacit acknowledgment of the problematic nature of previous approaches and the merit of the collaborative approach taken in this research. Jack, in rejecting the negative portrayal of young carers as being compromised, noted: “I reckon this is research done by … just … not actually talking with young carers”. In a similar vein, Stephen commented: “So, I don’t know, it seems really weird that people who make up all these books about young carers and they don’t even go straight to the source” (Stephen).

For most young people it was evident that the opportunity to be central to the research was appreciated and it was acknowledged as being important to understanding their experiences. This was well captured by Emma’s expression of appreciation for the equality of communication that was enabled by this research: having somebody “talk to me like a normal person” and like a contemporary. It is though suggested that for some, particularly the younger children, that the significance of collaboration was not fully
recognised. Again, this might be attributed to the adult-child binary which produces an entrenched understanding that the knowledge of young people is inferior to that of adults, even on the matter that most directly impacts their lives.

### 13.3 Overview of the findings

#### 13.3.1 Western discourses and the subject positions of ‘young carer’

“Each society has its regime of truth, its 'general politics' of truth; that is, the types of discourse which it accepts and makes function as true” Foucault (1980a, p. 131).

Rather than simply summarise the findings that emerged from the analysis in the preceding five chapters, this section will build upon, develop and consider the implications of what has already been presented. The starting point for this discussion is the major cultural discourses surrounding the family, childhood and adolescence that are dominant in Western society. The above quote of Foucault has been used to highlight the pivotal role of major Western discourses in producing ‘truths’ about the family and childhood: these ‘truths’ have consequences for young carers. These discourses construct knowledge about the role and responsibilities of adults and children, the structures and activities of the ‘normal’ family, what responsibilities and tasks are appropriate (play) and not appropriate (caring) for young people. They specify what a child needs for proper development to progress through to adulthood and to have a sound future. These discourses are particularly powerful because they are grounded in a ‘natural’ and ‘scientific’ view of children and adolescents (Hook, 2001) that draws upon binary opposites with adults. These cultural discourses are heavily implicated in the four subject positions that emerged as being available to these young carers, which were explicated using a Foucauldian Discourse Analysis.

The negative subject position of young carers that emerged in this research was not surprising: not just because caring is difficult but also because the impacts of caring on young people have been portrayed so negatively in the research literature and by young
carer bodies. This thesis argues that this negative positioning does not emerge from the inherent difficulties of a caring role; that is, the household chores and the caring tasks, but rather from the comparisons that are made between young carers and a subject position of the ‘normal’ young person (and their respective family). Most significantly, young carer families are often not able to engage with the constructs of the Western family model in conventional ways and so the young carer is positioned as missing out on normal, natural, family life: a major factor in the negative subject position relates to the presentation of their lives as being in conflict with dominant Western discourses. However, what is missing from this understanding is a recognition that the lack of financial, material and caring support is often the basis for young carers missing out on a ‘normal’ family life. Young carers are almost always part of a single parent family with no wage earner, often have very substantial medical expenses, and so are usually without the financial resources to engage in what are seen to be typical family and teenage activities (Chapter 11.2). It has also been discussed how young carer families are often marginalised from accessing support networks and that inadequate support often prevents them from engaging with the community as a family (Chapter 8.2).

A particularly important outcome of this research was the emergence of a positive subject position of young carers, a position that has gone largely unrecognised in young carer research. This subject position provides an important counterpoint to the portrayal of young carers in the literature and more generally “in almost wholly negative terms” and as “tragic victim[s] of circumstance” (O'Dell et al., 2010, p. 650). It is important to understand that this positive subject position emerged in large part from different aspects of Western discourses which have not previously been considered in young carer research. This subject position draws largely on a discourse that encompasses notions of family loyalty, mutual obligation and support. This discourse appears to mediate the experience of young carers in a very positive way, as does those concerning close family
relationships and connectedness. These familial discourses are powerful and important positives for young carers, providing a context in which young carers were able to describe feeling good about what they were doing in helping the family and to describe their family as better than those of peers. The importance of this family discourse was suggested by the way many young people described their experience as a carer largely in terms of family relationships, rather than concerns about chores, homework or missed social activities. This outcome was a significant point of departure from previous research.

A second discourse exercised alongside the positive subject position of young carer was the portrayal of teenage peers as mean, trivial, out-of-control and uncaring. This discourse of the ‘bad’ teenager provides an alternative subject position against which young carers can be judged very positively, and which in turn can enable a more favourable understanding of the experience of a family carer. The understanding of young carers as being mature, capable, and principled, is contrasted with the traits associated with the ‘bad’ teenager. The two subject positions of good young carer and bad teenager were intensely polarising, to the extent that some young carers even described feeling alienated from peers. An institutional discourse that positioned young carers as special and exceptional young people may have contributed to this polarisation. Again, this perspective has not been evident in past research.

The subject position of young carers as normal and regular young people who are no different from peers was also very significant: in particular, by highlighting how some young people were able to recognise and at times explicitly reject the notions of a normal family life and a normal child/teenager, critiquing them as being cultural constructions. While this rejection may reflect some element of young carers being made to feel defensive about the normalcy of themselves and their families, this sophisticated
understanding of cultural constructs belies the suggestion that young people are partially competent, dependent and need not be consulted about matters affecting their lives (or be co-researchers).

While the fourth subject position – not a young carer, but positioned as a helpful family member – was initially surprising, it can also be well understood in the context of Western discourses about the family and children. Being a young carer conflicts with the ‘proper’ role and responsibilities of a child that are prescribed by these discourses. The emergence of this subject position was also important in highlighting a point discussed in Chapter 3.2: the term ‘young carer’ is a label developed and applied by researchers and young carer bodies and is not necessarily how young people with a caring role understand their situation (Morris, 1997).

As has been earlier discussed, the adult-child binary forms a significant foundation for discourses of family, childhood and adolescence. The importance of the binary on the experience of being a young carer needs to be highlighted. Assumptions about what children should be doing (playing) and should not be doing (caring) derives, in part, from this binary. It also gives rise to conflicts in families when siblings or the parent (or both) have difficulty in accepting their child or sibling exercising what is considered to be an adult responsibility of control. Perhaps paradoxically, it is also argued that young people undertaking ‘adult’ roles and responsibilities does not diminish this binary, but rather further entrenches by the polarising of the ways of being either adult or child. Of particular significance is that in some cases young carers are required to employ a very subtle, complex and sophisticated role in providing a personal and adult caring role for their parent while carefully avoiding what might be seen as usurping their parent’s control. This suggests that the situation may at times be very nuanced; the strength of the binary would however seem to limit the opportunities to reduce the polarisation. This
juggling in the face of the powerful cultural discourse of the adult-child binary and the roles of parent-child, adds to the inherent difficulties for young carers.

It is also important to consider how some discourses seemingly have a contradictory impact on the young people, while others combine in such a way as to produce very negative outcomes for young carers. It has been noted how the notions of strong family loyalty and obligation have had a positive effect on how young people experience caring. While in the main this discourse seems to stem from latent understandings that are only drawn upon by families in times of adversity, it is suggested that governments have simultaneously tapped into this powerful family discourse to normalise the understanding that caring for those with a disability or illness is a family responsibility. However, at the same time as having been included in a family caring regime by government, discourses about the adult-child and parent-child binaries have left young people excluded from being involved or consulted on issues of being a carer; for example, how government resources should be provided. These discourses have meant that decisions about young carer support and activities are considered to be matters for service providers and parents (adults); that is, it is not considered appropriate or necessary to seek input from young people, even on these matters which so very directly and significantly affect their lives. This situation exists despite young people paradoxically being recognised as performing adult roles and responsibilities in the family in obvious contradiction of the binary. As a result, support programs and activities reflect an adult perspective and are often disconnected from what most young carers want or need, and often exclude those who most require help and support.

Even more telling was that most (but not all) young people, for the same reason, did not recognise they should be involved – they are positioned as ‘only children’ and there is an unquestioned assumption that these are matters for adults to decide. This situation
reflects the same assumptions that saturate the research literature – young people are partially competent which renders them vulnerable and legitimately disqualified from needing to be consulted about their needs (or to be directly involved in research). There is the suggestion that the problematic outcomes from this exclusion are compounded by the emergence of a young carer ‘industry’ that is bureaucratic and detached and, in some cases, those families with little social and cultural capital (in the Bourdieu sense) are marginalised from being able to access support networks. It was also discussed earlier in this section how a lack of financial, material and caring support has prevented young carer families from engaging conventionally in the constructs of the ‘normal’ family. The overall outcome is a social justice problem for young carers and their families.

13.3.2 Findings in the context of previous research

Previous research

The section above touched on a number of areas in which the findings of this research differ from or contradict the previous research literature (as was outlined in Chapter 3). Indeed, it will be very evident that the outcomes from this research are very different from the previous body of work on young carers. This is not surprising given that these research outcomes (like all research outcomes) are produced in a particular context and the context of this research was fundamentally different. This research has a very different (poststructural) epistemological approach, which itself aimed to challenge the dominant assumptions that underlie much of the previous research. This study aimed for a Foucauldian approach in young carer research, providing a focus on discourses, power and knowledge, and subject positions that impact on the lives of young carers. The unpacking of dominant discourses enabled by a Foucauldian approach has provided an understanding of how they enable and constrain what can be thought, said and felt as a young carer. This is a perspective not previously pursued. A participative methodology has allowed the young people to ‘drive’ the project where possible; that is, this research
is much less adult-driven and much less reflects an adult perspective. Young carers have
had the opportunity to talk about things that mattered to them. In turn, this has allowed
for the emergence of more of the complexities of how young people experience being a
young carer, rather than the simplistic portrayal of a tragic and compromised young
person doing chores and missing school. While seemingly obvious, the research has also
explicated the effects on young carers of the paradox where they are fully recognised as
performing ‘adult’ caring tasks and responsibilities, but in all other contexts they are seen
as dependent, vulnerable and partially competent.

It was noted in the previous section that notions of family loyalty and obligation were
perhaps the most important factors in how young carers understand their experience;
factors that have not been evident in previous research. This particular outcome is a
useful example to demonstrate some fundamental differences in the theoretical
assumptions, focus, and methods that have been adopted in past research. Positivist
methodologies can be argued to construct more essentialised and less nuanced
understandings of childhood. Theoretical expectations in past research can also be argued
to position childhood as a less complicated experience. In addition, much of the past
research has focussed on quantitative inquiries into practical aspects such as chores,
homework, and social activities (e.g., Thomas et al., 2003; Warren, 2007). These, in a
sense, may be seen as superficial aspects that do not provide for the emergence of deeper
considerations of being in a young carer family. In addition, past research, conducted
from an adult perspective, has tended to focus on negative aspects of young people
caring, or relatedly, assumed that there are only negative aspects (see Chapter 3),
whereas the notion of family loyalty and obligation is about positive and strong
emotional bonds that seem to be particularly evident in these young carer families.
Further to the above, what strongly emerged was the rejection of the notion that ‘being a young carer’ revolves around chores and caring tasks, the primary focus of much previous research. Emanating from a discourse of family loyalty and connectedness, the most difficult and most important aspect of being a young carer was described as having a family member with disability or illness; seeing them not be able to fully participate in society and enduring some level of suffering. As has been discussed, this discourse was important at a number of levels, which adds to the significance of its absence in previous research.

*Potential areas for further research*

To conclude this section, there are issues that arose from the review of the research literature (Chapter 3) that could not be included in this research. The issue of ‘hidden’ carers is widely discussed in the research literature with estimates of large numbers of young people who are family carers but who are not identified as such for various reasons (e.g., Banks et al., 2002; Smyth, Blaxland, et al., 2011). This issue was discussed in respect of this research in Chapter 6. While working with the Respite Centre, some attempts were made to locate and include young carers who were ‘hidden’, but these endeavours simply highlighted the seemingly intractable nature of the issue. For example, it was learnt that five young people with a family caring role were using computers at a local youth centre to complete homework. Staff at the youth centre passed on information to them about receiving support from the Respite Centre, but all declined to make contact. It has previously been discussed how some families are likely to be deterred because they are concerned about coming to the attention of child welfare agencies. There can also be cultural and privacy concerns that cause young carer families to remain hidden. It would be ethically problematic to ‘expose’ families that wish to remain ‘hidden’ and so there are considerable difficulties in seeking to include these young people in research.
It may be recalled that part of the quote below from Heaton (1999) was included in Chapter 1. The complete quote references a particular focus on women as carers, which brings into consideration the issue of gender and caring.

“the contemporary policy discourse ... reinforces an ideology of welfare which places a moral imperative on families, and women in particular, to function as carers” [italics added] (Heaton, 1999, p. 764).

It has been noted in a number of young carer studies (Eley, 2004; McDonald et al., 2009) that because of gender assumptions, girls are more likely to be young carers than boys, even in situations where there is an older male sibling. In this research some limited aspects of gender did emerge, such as Emma directly equating caring to the role of a mother (noted in Chapter 9.2.1). However, overall there was not sufficient pertinent material to enable gender to be incorporated into the scope of this thesis, but it is flagged as an important issue which warrants further development.

Finally, it is appropriate to reflect on the implications of the quite specific demographic of young carers that worked with this research. It was discussed in the Introduction (Chapter 1.1.2) and elsewhere throughout the thesis that the young people all lived in small communities in rural, coastal, or remote regions. It will also have been noted that minimal issues emerged in the findings that directly related to rurality. It was the case that the young carers largely did not speak of their experience as young carers in terms of living in small rural communities and accordingly could not constitute significant findings. Outcomes relating to rurality were essentially limited to the suggestion that more positive outcomes were sometimes experienced in very small communities through greater connectedness and support from neighbours and friends. For the same reason there often seemed to be less of a stigma surrounding disability and illness in these small communities. On the other hand, it seemed from anecdotal information that the availability of services was very limited in these rural areas. This research did not include
young carers who live in metropolitan areas and obviously it cannot, and does not seek to, make any comparisons between their experiences and those of counterparts in small rural communities. This is a subject that was beyond the scope of this research. It is nonetheless a potentially important issue and is also an area that can be suggested for future research; in particular, the implications for young carers living in rural areas in terms of availability of services.

13.3.3 Understanding the contradictions, complexities and tensions in the accounts of young carers

There has been considerable discussion about the variation that is present in the individual accounts of the young people and between the accounts of different young people. It has been noted how there was difference and contradiction within a single transcript of an individual, within a series of transcripts from one individual, and within different individuals in the same family. Different subject positions emerged at different times. Some of the most significant outcomes to emerge from the analysis were the tensions, complexities and contradictions inherent in the accounts of the young people of their experiences caring for a family member. There was discussion in Chapter 7.2.2 of the argument by Parker (1992) that analysis needs to pay particular attention to the differences and contradictions in how a phenomenon is described, as this opens up considerations of what other discourses are involved and the interrelationship with these other discourses. It is therefore important to reflect on this variability and what it might suggest in terms of understanding the experiences of young carers.

As has been noted, the variability does result, in part, from the diversity in the young carer community, with a myriad of caring situations in terms of illness and disability, ‘cared for’ person, family arrangements, availability of support networks, and socio-economic status. There was also significant diversity in how the various young people understood the difficulty of their caring and family situation. These components of the
variation would seem to have been captured quite completely in this research. A point for consideration is whether there is more variation in this young carer research than with research on other issues with other groups of people. While it is not necessary to seek to provide a definitive answer to this point, it is useful to consider why it might be the case.

It seems very evident from the analysis that has been developed in Chapters 8 to 12 that the major factor in the heavily varied and contradictory accounts is that young carers are immersed in and struggling to negotiate some of the most imposing discourses of Western society: the family, and those surrounding childhood, children and adolescents. The cultural norms that are constructed by these discourses are powerful forces, and the ways in which the young people are positioned and the ways in which they are forced to respond, give rise to complexities, tensions and contradictions – and, as a consequence, variation in their accounts. There are very great levels of contradiction between these discourses and the situations they are dealing with in their lives: simultaneously attempting to perform what is understood to be a parent-like (adult) role and being a ‘normal’ child. A child who grows up completely located within the discourse of being a child does not feel negative consequences, but rather is able to smoothly progress through a childhood of play, with no responsibilities. Such a child experiences no ambivalence, tension or struggle with the discourse of childhood. This is the childhood that Emma imagines and describes when she spoke of longingly watching neighbourhood children play from her front window. However, a child who is a young carer, and has imposed on them a life so completely opposite from what dominant cultural discourses stipulate it is ‘supposed to be’, is excluded from this construct of childhood. This emphasis on ‘difference’ can establish a situation where young carers are ‘required’ to defend themselves and their families for not engaging conventionally with these dominant discourses about a normal family life and a normal child/teenager. The variation in accounts of the young people relates in part to the consequences of dealing
with some of the most imposing discourses of Western culture.

A further layer of complexity in understanding how young carers and their families are positioned relates to the dichotomy that can exist where families need to present as requiring support, but not so needy so as to risk coming under the scrutiny of child welfare authorities. Again, this fear can arise because the family’s situation is seen as differing so markedly from the Western discourse of the ‘normal’ family, the ‘normal’ childhood, and the ‘good’ parent. Notions of a Western family also underlie the approach of government welfare agencies, service providers and school authorities. Young carer families feel they are under the ‘normalising’ gaze (as per the discussion of Foucault’s work - Chapter 2) of welfare authorities and that they have to appear as the ‘normal family’; the parent has to present and speak as though they are ‘in control’ for fear that they may come under the scrutiny of welfare services. In these circumstances there may be a risk for families to resist the constructs set down by Western familial discourse.

Overlaying these discourses is an institutional discourse. It was discussed in Chapter 7 that an important focus for Foucauldian work is discourses that are implicated in supporting or subverting institutions (Parker, 1992). It was noted in Chapter 8 that there is an institutional discourse which promotes the positioning of young carers as special and exceptional young people, suffering under great hardship. While this discourse might be seen in the context of young carers bodies seeking funding, status and authority, it also has the effect of providing important validation for some carers. It can be suggested that the institutional discourse about the exceptionalism of young carers is a significant factor in the positioning of some young people as ‘better than’ peers and, as Emma has noted, responding to a “higher calling”. At the same time this institutional validation seemingly gave rise to feelings of being unrecognised and unappreciated in the wider community,
once again demonstrating the unexpected outcomes that can emerge and the disconnect that can arise between intentions and outcomes (Foucault, 1980a).

A further layer of complexity and contradiction emerged from discourses surrounding disability and illness. On the one hand young carers, drawing upon their own experiences and notions of family connectedness and loyalty, described themselves as very positive, supportive and protective of those with a disability. However, at other times their accounts were suggestive of being made to feel defensive and of ‘managing’ a stigma they experienced from their association with disability and mental illness. This was indicative of an underlying negative discourse about disability that affected young carers, particularly in larger communities; one that adds to the difficulties of the lives of young carers.

A further source of tension that affected some of the young people was how they were positioned as carers by their parents. Parents, like their children, are faced with negotiating the same dominant Western discourses about family and childhood and, in particular, those concerning parental roles and responsibilities. While not always the case, in some instances, concordance between parent and child on the subject position of young carer provided for a more harmonious caring and family situation. Conversely, in situations where there was a different understanding, particularly in relation to parental control and authority, for some families there was conflict, and in two cases a breakdown in the relationship between parent and child. In can be argued that in these cases the positioning of young carers as an adult in the family caused conflict because they are seen as not adhering to what is understood to be proper parent/child and sibling/sibling roles and responsibilities in the family. It is however important to provide some context to this finding. Firstly, disagreements between parents and their children over subject positions and roles are also common in non-caring families. Secondly, these
disagreements should not be characterised as always being a negative outcome. There is value in young people developing the voice and the confidence to argue their position.

These difficulties are in addition to the stresses and tensions at play in young carer families, not least of all being the health status of the ‘cared for’ family member at a particular time, which impacted on relationships. There has been discussion in Chapter 9 about each account being provided at a given point in time over a lengthy period of fieldwork and it will reflect the state of family dynamics and relationships and the state of the caring situation at that moment. It was noted in particular that the condition of the ‘cared for’ person often varied greatly between interviews. It was also discussed how it was not uncommon to encounter the same family to be in a very different ‘place’ at each interview, which varied from crisis to quietude.

It is also useful to reflect on the ongoing series of interviews with the young people over a lengthy period that allowed for the continual emergence of different and additional information and perspectives. It is important to note that conducting three rounds of interviews over 13 months opened up further ways of considering and understanding the experiences of young carers but, perhaps paradoxically, produced more complexities and contradictions. While each successive interview brought additional and different insights, this is not to suggest this process represented a closing in on some ultimate truth and arriving at the endpoint. Rather, it is acknowledged that each interview will be different, as would any future interview. It is not the case that any one outcome is either right or wrong, but the young people are impacted by different discourses, perhaps reflecting matters happening in their lives at that time. The point being made here is that the research is not seeking to capture some kind of representative or universal young carer, nor to definitively characterise the experience of any single young carer. Rather, this research explores what is possible for young people to think, say, and experience as
carers, while negotiating the various discourses and subject positions that are available (or not available) to them. Revealing this complexity can better allow for the standpoint of a young carer to emerge.

There is also the process of subjectification and re-subjectification of both the young people and the subject position of the researcher that was taking place throughout the period of fieldwork. It is acknowledged that with my subject position as the researcher being continually re-subjectified throughout the process, my understanding of the data and my analysis will be changing (Fryer & Nic Giolla Easpaig, 2013). My expectations and understandings were continually in a state of flux with each experience of the research – from meeting with each young person and with each discussion, through to conducting the analysis. In addition, perhaps a small part of the explanation for the differing accounts presented by young carers at successive interviews, was my closer relationships with the young people and perhaps increasing trust being developed over the two years of the fieldwork. This is not to suggest however that this necessarily produced a greater ‘truth’, but rather different outcomes. For example, while a number of young carers appeared to become increasingly frank in the final interviews (speaking for the first time of tension and deteriorating family relationships), others may have become less comfortable in talking openly as our relationship developed and I became less of a ‘stranger’. This is another illustration of the continuing process of re-subjectification that was occurring both with myself as researcher and the young people as the research progressed; the prolonged fieldwork and the resultant lengthy engagement with the young people provided for the emergence of new and different perspectives.

It is important to place the variation in the context of the methodology and epistemology adopted for the research. This research resisted the need for a ‘uniform set of data’ that is usually considered a standard requirement for traditional research where differences are
assumed to need ‘smoothing out’. Instead, this project assumes that differences are very significant and non-uniformity is embraced as an important part of seeking a genuine participatory approach with young people. This approach placed additional onus on me to carefully interpret the often widely varying accounts and to be very careful not to privilege the accounts of those young people who are the most talkative and articulate. However, while a methodologically fluid approach created some increase in labour for the researcher, it importantly provided an enhanced role for young carers in the construction of knowledge.

13.3.4 A complex narrative of normalising discourses and resistance

The knowledges produced around a position of young carer can be characterised as a complex narrative and in many ways a construction of ‘what is normal’. This outcome can be very directly related to the work of Foucault discussed in Chapter 2 on the desire to be ‘normal’ and how normality is constructed by the relevant discourses. This, in turn, can be linked to the quote earlier in this chapter about society establishing “discourse which it accepts and makes function as true” (Foucault, 1980a, p. 131). It is the discourses of the ‘normal’ family, the ‘normal’ childhood and adolescence that society has established as ‘truths’ against which young carers are required to compare and judge themselves.

Both directly and indirectly, the concept of ‘normal’ repeatedly arose as a point of discussion, reference and comparison. There is a discourse emanating from researchers, service providers and parents about the ‘different’ lives of young carers which makes feeling ‘normal’ problematic, while the rules of what is ‘normal’ are also imposed on young carers from ‘outside’ in various ways. As has been discussed, the lives of young carers of necessity must differ from these purported ‘truths’, and so they are made to feel defensive and not normal. At times there is resistance: ‘truths’ are rejected as cultural
constructs and caring situations are reframed. This rejection included the construction of an alternative and very problematic ‘normal family’ and ‘normal teenager’ against which young carers could be positively compared. These critiques represent a commonly used and valid argument against normalising discourses. Ultimately, however, often there was a negative impact on these young people from having imposed on them a life that so markedly contradicts these dominant discourses.

The notion of the ‘desire to be normal’ also emerged in the discussions surrounding disability. The young people spoke of a mostly latent, but sometimes an overt stigma associated with disability and a number described maintaining a level of secrecy about their family member’s situation. This was directly addressed by one child’s comment: “I just want to feel as normal as I humanly can” (Liam).

Discourses of ‘normal’ also strongly emerged from discussions with parents. Some parents discussed their profound feelings of guilt for having deprived their children of a normal life, as prescribed by the dominant discourses. They often reproduced the negative discourse of the young carer as portrayed in research literature. This guilt intersects with the cultural expectation that it is the parent’s role to protect and safeguard their children and provide them with a ‘normal’ childhood; the understanding that good parents make things better when there are difficulties. It can be suggested that this understanding is implicated in the fact that, at some stage, all the young carers had been required to attend counselling. Psychology and the psy-complex are implicated in this outcome: in addition to providing the foundation for parenting practices and the treatment of children, psychology has generated the cultural expectation that counselling is the necessary response when there is deviation from a ‘normal’ childhood. Perhaps of even more significance, is the suggestion that practical problems which stem from lack of
support and services for young carers, are not recognised as such, but rather are addressed as being a mental health issue of the individual carer.

There was discussion in Chapter 2 of Foucault’s argument about power and resistance: power, being neither simple nor unidirectional, offers the possibility for resistance (Foucault, 1980a). The outcomes of this research are congruent with this argument. As has been outlined in the preceding chapters and briefly noted earlier in this section, various forms of resistance were evident, including commonly used arguments against normalising discourses. The tensions between normalising discourse and resistance were also evident in the final collaborative round of interviews which considered the preliminary analysis of the material. There was, in general, a retreat from earlier strong and explicit characterisation of their childhood and family experiences as abnormal and ‘missing out’. This is suggestive of the strength of normalising discourses and as noted earlier, “the desire to be normal” (Cannella & Viruru, 2004).

Young carers experience great tension in confronting powerful cultural discourses that stipulate ‘what is normal’. Consideration of Foucault’s work on normalisation and resistance has allowed these tensions to be explicated and has provided insights into the lives of young carers that have not previously considered.

13.3.5 Performativity of young carers

There was discussion in Chapter 9 concerning the performativity of young carers. It was discussed how performativity is not about what was said by the young people, but rather reflects on their actions, their ways of being, and the manner in which they presented. This included observations of young people undertaking very complex and nuancing roles, such as being a counsellor and mediator for parents, and the display of very sophisticated social skills in children. There were many examples of young people being articulate, confident and brutally frank in providing sophisticated analysis of their own
lives and of social issues. Importantly, there were a number of examples of young people dominating and taking control of discussions, as was intended for this collaborative research. There were significant examples of young people presenting their own critical analysis when discussing their lives.

It is suggested that the inferences that can be drawn from the performativity of the young people are important outcomes of the research. The above examples are a very graphic demonstration of the capabilities of young people and it can be argued that this outcome emanates from the decision to work collaboratively with them. Providing the ‘space’ for young carers to work collaboratively has produced a context in which their capacities and abilities can come to the fore, a situation that has largely not existed with previous approaches to young carer research.

13.4 Concluding discussion

Given the underlying rationale for this research, it is appropriate that this concluding discussion should focus solely on the lives of young carers. In turn, a prominent aspect of this discussion must be the social justice issues that often impact very negatively on young carers.

Consideration of the outcomes of this research must be based on the impact of dominant cultural discourses about family and childhood on how young people experience caring and, in particular, the problematic influence of normalising discourses that position them as not normal; as compromised and missing out on an idealised and culturally constructed Western childhood and family life. There were many tensions and complexities as the young people sought to negotiate these discourses while undertaking an ‘adult’ role which was in conflict with these discourses. At times, a powerful polarisation emerged between the positioning of adults and young people, between young carers and other young people, and between young carer families and other families. To a
significant extent the outcome of this research can be seen as a complex narrative about normalisation and resistance, as the young people were forced to confront constructs of ‘normal’. An understanding that young carers’ lives are not homogenous is missing from literature and public discourse. There is a need to move the conversation away from negatively comparing young carers with cultural constructs of the family, children and adolescents. These young people should not be required to shape their lives to some idealised notion of what is considered normal, or alternatively be made to feel abnormal. Their caring responsibilities should not be complicated by having to navigate subject positions that are based on temporal and culturally-specific constructs.

Those who are often labelled ‘children’ should not be excluded from the ‘conversation’ and consequently impacted negatively by an institutional discourse which draws on these same dominant discourses and produces mostly problematic outcomes in terms of the support and services for young carers. There would also seem to be a predisposition by agencies to assume support services are effective and that problems experienced by young carers are unavoidable consequences of their caring situation or, even more problematically, that difficulties should be addressed as a mental health issue of the individual young carer. It is also argued that the deep and emotional cultural discourse surrounding family loyalty and obligation has enabled governments to distance themselves from responsibility and to divert attention from the practical support they could provide. This in turn has contributed to the young people experiencing a sense of being isolated, unsupported and unrecognised.

The dominant discourses concerning young people stand in stark contrast with the findings of this research in relation to performativity (as was discussed in Chapter 9 and briefly in the preceding section). The performativity of young carers that emerged in this research is a major outcome which warrants further unpacking. It might be thought to be
an obvious conclusion to make that these young people have such abilities and capacities as a result of their experience as a carer, which is what many of the young carers suggested. It can however be argued that this outcome is applicable in general to young people; that is, all young people possess these capabilities. For most young people, most of the time, they are not in situations of family adversity; it is only in this forced situation of being a young carer that these capabilities are able to emerge and be demonstrated. In Chapter 4 the argument of Lansdown (1995) was presented, suggesting that young people are construed as vulnerable and in need of protection, denied the opportunity to participate in decision-making and gain experience of independence, and hence are made more vulnerable. The outcome when young people are given independence and responsibility for decision making, as is the case with young carers, would seem to support Lansdown’s argument. This outcome suggests a very different understanding to that presented by the dominant discourses that construct the adult/child and parent/child binaries (an outcome moreover that has general applicability to conducting research with young people). It is also important to highlight that while young carers have developed abilities and strengths through their caring experiences, which they regard very positively, this shift away from the ‘normal’ vulnerable, innocent and dependent child has not translated into positive outcomes more generally. Young carers are still marginalised from decision making on matters that affect them, they have no agency with support services, and their voices are largely not heard, including within their own family. This represents a failing in social justice for young carers, their families and society more generally.

Finally, it is important to emphasise that the young people value their family and willingly accept the role of carer. It is also the case that they accept that there will be difficult periods and negative aspects to cope with, most particularly witnessing chronic illness or disability in family members. It is however not acceptable that they have had
this responsibility imposed upon them without adequate support and without support that could largely ameliorate the difficulties of being a young carer. Of further concern is that cultural constructs have marginalised young people from having a voice on these matters which so massively impact their lives. Social justice for young carers will only be fully realised with the advent of a new discursive paradigm; social reform requires the unmasking of the culturally constructed nature of the dominant discourses and the creation of space for alternative understandings (Willig, 1999). This research seeks to contribute to that reform process.
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APPENDIX A – Information Statement: Ethnographic work through the Respite Centre

INFORMATION STATEMENT

Name of project: An examination of the experiences of young carers providing care to a family member.

Name of student and contact details: Lester Watson
Ph: 0407 432 286
Email: lester.watson@ozemail.com.au

Name of Supervisor: Dr Rachael Fox
Ph: (02) 6933 2840
Email: rfox@csu.edu.au

This information sheet outlines proposed arrangements for my attendance at young carer functions which is a preliminary stage of a research project I am undertaking at the Charles Sturt University for the award of a Doctorate of Philosophy (Psychology).

The project is an extension of a small study completed last year - with the assistance of the Commonwealth Respite and Carelink Centre (Southern Highlands) - as part of an Honours degree in psychology. The current research project seeks to extensively develop research in the area. It will involve the development of methodologies for working with young people, ethnography in rural NSW, and using a range of methods in collaboration with young carers which will include interviews, focus groups, observation and discursive analyses.

As a preliminary step in the project, I wish to attend suitable young carer functions organized by the Respite Centre. My purpose in attending is to build relationships and to use my interaction with young carers to help inform decisions that I will take in the development of the research process. The choice of functions that might be suitable for me to attend is, of course, totally at your discretion.

I intend to maintain a fieldwork diary that might be used for analysis or to provide narrative accounts of the research process. The notes would be subjective accounts from me and would not include direct quotations nor the names or personal details of any individuals. The fieldwork diary would be written away from the field so as not to be intrusive, but it would be very transparent to both adults and young people that notes were being taken, and they would be available to be read for those interested.
My presence and role would be mentioned at the introductory part of a particular function. In particular, it would be explained that while no quotes, names or personal details would be recorded, the young carers should feel free to indicate at any time that they do not wish to be included. I would take great care to ensure that no notes are taken relating to people who have indicated that they do not consent.

My involvement in young carer functions requires the approval of a detailed Ethics Approval Application by the University’s Human Ethics Committee to ensure stringent requirements are met. If you were to have any complaints or reservations about the ethical conduct of the project, you are able to contact the Committee through the Executive Officer:

<table>
<thead>
<tr>
<th>The Executive Officer</th>
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<tr>
<td>Human Research Ethics Committee</td>
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<tr>
<td>Office of Academic Governance</td>
</tr>
<tr>
<td>Charles Sturt University</td>
</tr>
<tr>
<td>Panorama Avenue</td>
</tr>
<tr>
<td>Bathurst NSW 2795</td>
</tr>
<tr>
<td>Tel: (02) 6338 4628</td>
</tr>
<tr>
<td>Fax: (02) 6338 4194</td>
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</tbody>
</table>

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.

I hold a current ‘Working with Children’ check.
APPENDIX B-1 – Information Statement for initial consultation stage

INFORMATION STATEMENT

Name of project: An exploration of the experiences of young people providing care for a family member.

Name of student: Lester Watson
PhD student

Contact details: Ph: 0407 432 286
Email: lester.watson@ozemail.com.au

Name of Principal Supervisor: Dr Rachael Fox

Contact details: Ph: (02) 6933 2840
Email: rfox@csu.edu.au

Name of Co-Supervisor: Dr Maree Bernoth

Contact details: Ph: (02) 6933 2492
Email: mabernoth@csu.edu.au

My name is Lester and I would like to invite you to help me in the planning of a study about the experiences of young carers. It is very important to me that the design and conduct of research on young carers takes into account the views of young carers. If you agree to take part, you would initially have a discussion with me. I do not expect that this would take longer than 40 minutes. The discussion would be held at a time and place of your choosing. Where it is feasible to do so, the discussion could be held jointly with other young carers, however, you would be free to choose whether you would wish to meet individually or take part in a group discussion.

I am interested in hearing your views and ideas, as a young carer, on any and all matters that you think might be relevant to conducting research with young carers. This might include, for example, what issues about caring you think should be researched, what methods you think might be best for working with young carers (for instance, it has been suggested that video diaries or internet-based methods might be favoured by young people over traditional research methods). It might include suggestions for interviews and questions, or indeed quite different ideas that I (as an adult, who is not in a caring role) have not considered – which is exactly the reason for consulting young carers!

Please note that the discussion does NOT require you to talk about your own caring and family situation and no personal details or information will be recorded. The interview will not be audio-taped but hand-written notes may be taken by me on ideas and views about the research that result from our discussions. No personal details or information about you will be recorded.
You are free to choose your own level of participation in the project. After the initial discussion referred to above, there is intended to be a follow-up discussion/s to obtain young carers’ feedback on the ideas and suggestions that have emerged. Should you wish to, you may remain involved over the course of this consultation stage (which is planned to run over approximately three months) and have input into how the research plan evolves from the initial discussions. It is understood that some people may wish to limit their involvement to the initial discussion, while others will wish to remain involved to varying degrees throughout the consultation stage. You will be free to decline to be involved in any particular discussion/s or to withdraw completely from the project at any time, including after the initial discussion. If you did withdraw, you would also be free to rejoin the project at any stage.

Based on my discussions with you and perhaps fifteen other young carers, a plan will be developed for research that will be conducted throughout 2013. A thesis will subsequently be written that will be assessed for the award of Doctor of Philosophy at the Charles Sturt University. Neither your name nor any other identifying information will be used in the research thesis (however, if you wished, you could be included in a general acknowledgment of those who contributed to the development of the research plan). It is intended that articles based on the research will be submitted to academic journals to be considered for publication.

If you agree to be involved with this consultation stage of the research as outlined above, there is a Consent Form that would be signed by you (and a parent or guardian if you are under 16 years of age). This Information Statement is to be kept by you.

Thank you for agreeing to help with this research.

NOTE: Charles Sturt University’s Human Research Ethics Committee has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Executive Officer:

The Executive Officer
Human Research Ethics Committee
Office of Academic Governance
Charles Sturt University
Panorama Avenue
Bathurst NSW 2795
Tel: (02) 6338 4628
Fax: (02) 6338 4194

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.
APPENDIX B-2 – Consent Form for initial consultation stage

CONSENT FORM

Name of research: An exploration of the experiences of young people providing care for a family member.

Name of student: Lester Watson
PhD student

Contact details:
Ph: 0407 432 286
Email: lester.watson@ozemail.com.au

Name of Principal Supervisor: Dr Rachael Fox

Contact details:
Ph: (02) 6933 2840
Email: rfox@csu.edu.au

Name of Co-Supervisor: Dr Maree Bernoth

Contact details:
Ph: (02) 6933 2492
Email: mabernoth@csu.edu.au

Please read and consider the following statements carefully before signing this consent form and participating in the research.

1. The purpose of my involvement in this research project has been explained to me and I have read and understood the Information Statement given to me. I have had the opportunity to ask questions about the research.

2. I understand that I am consenting to participate in a discussion about young carer research and I am free to withdraw at any time and, if I do, there will be no adverse consequences for me.

3. I understand that I am not required or expected to discuss any aspect of my own caring and family situation. I understand that I do not have to discuss any matters or answer any questions I do not want to.

4. I understand that any personal information or details that I might disclose in the course of the project are confidential. I understand that neither my name nor any identifying information will be used in the research report.

5. I understand that the discussions will not be audio-recorded but that handwritten notes will be made to record ideas and suggestions for young carer research that result from the discussions.
6. I understand that there is intended to be a follow-up meeting/s that I may be invited to participate in and that I am free to accept or decline without any adverse consequences for me. I understand that I am free to choose my own level of involvement in the project, which can be varied at any time, including withdrawing. I understand that if I did withdraw, I would also be free to rejoin the project at any stage.

7. I note that the Charles Sturt University’s Human Research Ethics Committee has approved this study. I understand that if I have any complaints or concerns about this research I can contact:

   Executive Officer  
   Human Research Ethics Committee  
   Office of Academic Governance  
   Charles Sturt University  
   Panorama Avenue  
   Bathurst NSW 2795  

   Phone: (02) 6338 4628; Fax: (02) 6338 4194

Name: ............................................................

Signature: ............................................................

Date: ...............  

If you are under the age of 16 years, approval of a parent/Guardian is required:

Parent/Guardian

Name: ............................................................

Signature: ............................................................

Date: ...............
Appendix B-3 – Ethics approval for initial consultation stage

24 May 2012

Mr Lester Watson
PO Box 426
ERINDALE CENTRE ACT 2903

Dear Mr Watson,

Thank you for the additional information forwarded in response to a request from the Human Research Ethics Committee (HREC).

The CSU HREC reviews projects in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Research Involving Humans.

I am pleased to advise that your project entitled “Examination Of The Experiences Of Young Carers Who Care For A Family Member With A Physical Or Mental Illness” meets the requirements of the National Statement; and ethical approval for this research is granted for a twelve-month period from 24/5/2012.

The protocol number issued with respect to this project is 2012/072. Please be sure to quote this number when responding to any request made by the Committee.

Please note the following conditions of approval:

- all Consent Forms and Information Sheets are to be printed on Charles Sturt University letterhead. Students should liaise with their Supervisor to arrange to have these documents printed;
- you must notify the Committee immediately in writing should your research differ in any way from that proposed. Forms are available at: http://www.csu.edu.au/__data/assets/word_doc/0010/176833/ehrcauaprep.doc
- you must notify the Committee immediately if any serious and or unexpected adverse events or outcomes occur associated with your research, that might affect the participants and therefore ethical acceptability of the project. An Adverse Incident form is available from the website; as above;
- amendments to the research design must be reviewed and approved by the Human Research Ethics Committee before commencement. Forms are available at the website above;
- if an extension of the approval period is required, a request must be submitted to the Human Research Ethics Committee. Forms are available at the website above;
you are required to complete a Progress Report form, which can be downloaded as above, by 24/5/2013 if your research has not been completed by that date;

you are required to submit a final report, the form is available from the website above.

YOU ARE REMINDED THAT AN APPROVAL LETTER FROM THE CSU HREC CONSTITUTES ETHICAL APPROVAL ONLY.

If your research involves the use of radiation, biological materials, chemicals or animals a separate approval is required from the appropriate University Committee.

The Committee wishes you well in your research and please do not hesitate to contact the Executive Officer on telephone (02) 6338 4628 or email ethics@csu.edu.au if you have any enquiries.

Yours sincerely

Julie Hicks
Executive Officer
Human Research Ethics Committee
Direct Telephone: (02) 6338 4628
Email: ethics@csu.edu.au

Cc: Dr Rachael Fox

Version 3

FIA
Hi - my name is Lester. I am doing research at the Charles Sturt University into the experiences of young carers. I would like to invite you to help me in the planning of the project. It is very important to me that the design and conduct of research on young carers takes into account the views and ideas of young carers.

I am interested in hearing about matters that you think might be important in conducting research with young carers. This might include, for example, what issues about caring you think should be researched, what methods you think might be best for working with young carers (for instance, it has been suggested that video diaries or internet-based methods might be favoured by young people over traditional research methods). It might include suggestions for interviews and questions, or indeed quite different ideas that I (as an adult, who is not in a caring role) have not considered – which is exactly the reason for consulting young carers!

Please note that the discussion does NOT require you to talk about your own caring and family situation and no personal details or information will be recorded. The discussion will NOT be audio-taped.

I do not expect that the discussion would take longer than 40 minutes and would be held at a time and place of your choosing. Where it is feasible to do so, the discussion could be held jointly with other young carers, however, you would be free to choose whether you would wish to meet individually or take part in a group discussion.

If you would consider helping me with this project, please contact me by email, text message, or telephone (details below), and I can provide further information. Your participation would be greatly appreciated as I am hoping that the project can help young carers.

Thanks for your consideration.

Lester Watson

Email: lester.watson@ozemail.com.au
Mob: 0407 432 286
APPENDIX C-2: Letter from Respite Centre to young carers inviting participation in research

COMMONWEALTH RESPITE AND CARELINK CENTRE

Dear [Name]

Invitation to help with some important research

The Commonwealth Respite and Carelink Centre is assisting a student who is planning some important research into the experiences of young carers.

The project is being undertaken by Lester Watson who is doing post graduate research at Charles Sturt University. He wishes to talk to young carers about ideas for doing research with young carers. This will not involve talking about your own caring and family situation.

Participation is voluntary. Your participation or non-participation will not in any way affect your relationship with the Centre. Information provided to Lester will be treated confidentially and will not be provided to the Centre.

Attached is a leaflet from Lester that outlines the process for consulting with young carers and includes his contact details.

We hope that you will contact Lester and help with his important project.

Yours sincerely,

[Name]
Manager
Regional Respite and Carelink Centre

February 2013
INFORMATION STATEMENT

Name of project: An exploration of the experiences of young people providing care for a family member.

Name of student: Lester Watson
PhD Student

Contact details: Ph: 0407 432 286
Email: lester.watson@ozemail.com.au

Name of Principal Supervisor: Dr Rachael Fox

Contact details: Ph: (02) 6933 2840
Email: rfox@csu.edu.au

Name of Co-supervisor: Dr Maree Bernoth

Contact details: Ph: (02) 6933 2492
Email: mabernoth@csu.edu.au

Alternative opening paragraphs

I would like to thank you for your previous involvement in our research on young carers and invite you to take part in the next phase:

OR

My name is Lester and I would like to invite you to take part in research about young carers.

If you agree to take part, you would have a discussion with me. I do not expect that this would take longer than 40 minutes. The discussion would be held at a time and place of your choosing. Where it is feasible to do so, the discussion could be held jointly with other young carers, however, you would be free to choose whether you would wish to meet individually or take part in a group discussion.

Should you participate in the interviews, they will be audio-taped and transcribed and the resulting data will be kept for 5 years in a secure location and then destroyed at the end of 5 years.

You would be free to withdraw from the research at any time, and if you did, there would be no adverse consequences for you. You would also be free to withdraw and rejoin the research
at any time if you so wished, and indeed are free to choose your own level of participation in the project.

This discussion represents part of an ongoing research process and you may be invited to participate in a subsequent discussion or activity. It is understood that some people may wish to limit their involvement to this discussion, while others will wish to remain involved to varying degrees throughout the subsequent stage. You will be free to decline to be involved in any particular discussion/s or to withdraw completely from the project at any time, including after this discussion. If you did withdraw, you would also be free to rejoin the project at any stage.

Based on the research with you and other young carers conducted over approximately the next nine months, a thesis will be written that will be assessed for the award of Doctor of Philosophy at the Charles Sturt University. Neither your name nor any other identifying information will be used in the research thesis (however, if you wished, you could be included in a general acknowledgment of those who contributed to the research). It is intended that articles based on the research will be submitted to academic journals to be considered for publication.

While it is considered unlikely, if you should experience discomfort as a result of your involvement in the research, you could contact Kids help Line (1800 55 1800), which is available 24 hours a day, or the Carer Line with Carers NSW (1800 242 636), if you feel it necessary.

If you agree to be involved with the research as outlined above, there is a Consent Form that would be signed by you (and a parent or guardian if you are under 16 years of age). This Information Statement is to be kept by you.

Thank you for agreeing to help with this research.

NOTE: Charles Sturt University’s Human Research Ethics Committee has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Executive Officer:

The Executive Officer
Human Research Ethics Committee

Office of Academic Governance
Charles Sturt University
Panorama Avenue
Bathurst NSW 2795

Tel: (02) 6338 4628
Fax: (02) 6338 4194

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.
APPENDIX D-2 – Consent Form: Stages 2 and 3

CONSENT FORM

Name of research: An exploration of the experiences of young people providing care for a family member.

Name of student: Lester Watson
PhD Student

Contact details: Ph: 0407 432 286
Email: lester.watson@ozemail.com.au

Name of Principal Supervisor: Dr Rachael Fox

Contact details: Ph: (02) 6933 2840
Email: rfox@csu.edu.au

Name of Co-supervisor: Dr Maree Bernoth

Contact details: Ph: (02) 6933 2492
Email: mabernoth@csu.edu.au

Please read and consider the following statements carefully before signing this consent form and participating in the research.

1. The purpose of my involvement in this research project has been explained to me and I have read and understood the Information Statement given to me. I have had the opportunity to ask questions about the research.

2. I understand that I am consenting to participate in young carer research and I am free to withdraw at any time and, if I do, there will be no adverse consequences for me.

3. I understand that I do not have to answer questions, discuss, or otherwise provide information, on any matters that I do not want to.

4. I understand that any personal information or details that I disclose in the course of the project are confidential. I understand that neither my name nor any identifying information will be used in the research report.

5. I understand that the discussions may be audio-recorded and that resulting data will be kept for 5 years in a secure location and then destroyed at the end of 5 years.
6. I have been provided with the names and contact details of psychological services in my area that I can contact if I suffer any discomfort as a result of the interview.

7. I understand that this discussion is part of an ongoing research process and I may be invited to participate in subsequent activities. I understand that I am free to accept or decline without any adverse consequences for me. I understand that I am free to choose my own level of involvement in the project, which can be varied at any time, including withdrawing. I understand that if I did withdraw, I would also be free to rejoin the project at any stage.

8. I note that the Charles Sturt University’s Human Research Ethics Committee has approved this study. I understand that if I have any complaints or concerns about this research I can contact:

   Executive Officer
   Human Research Ethics Committee
   Office of Academic Governance
   Charles Sturt University
   Panorama Avenue
   Bathurst NSW 2795

   Phone:   (02) 6338 4628; Fax: (02) 6338 4194

Name:   ..............................................................

Signature:   ............................................................

Date:   .................

If you are under the age of 16 years, approval of a parent/Guardian is required:

Parent/ Guardian

Name:   ..............................................................

Signature:   ............................................................

Date:   .................
Appendix D-3– Ethics approval for Stage 2

15 January 2013

Mr Lester Watson
PO Box 426
ERINDALE CENTRE
ACT 2903

Dear Mr Watson,

Thank you for the additional information forwarded in response to a request from the Human Research Ethics Committee (HREC).

The CSU HREC reviews projects in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Research Involving Humans.

I am pleased to advise that your project entitled “An exploration of the experiences of rural young people who care for a family member with a physical or mental illness” meets the requirements of the National Statement; and ethical approval for this research is granted for a twelve-month period from 15 January 2013.

The protocol number issued with respect to this project is 2013/007. Please be sure to quote this number when responding to any request made by the Committee.

Please note the following conditions of approval:

- all Consent Forms and Information Sheets are to be printed on Charles Sturt University letterhead. Students should liaise with their Supervisor to arrange to have these documents printed;
- you must notify the Committee immediately in writing should your research differ in any way from that proposed. Forms are available at: http://www.csu.edu.au/_data/assets/word_doc/0010/176833/ehrc_annrep.doc
- you must notify the Committee immediately if any serious and or unexpected adverse events or outcomes occur associated with your research, that might affect the participants and therefore ethical acceptability of the project. An Adverse Incident form is available from the website: as above;
- amendments to the research design must be reviewed and approved by the Human Research Ethics Committee before commencement. Forms are available at the website above;

Version 3

www.csu.edu.au
CRICOS Provider Numbers for Charles Sturt University are 00005F (NSW), 01947G (VIC) and 02950B (ACT). ABN: 83 878 708 551
• if an extension of the approval period is required, a request must be submitted to the Human Research Ethics Committee. Forms are available at the website above;
• you are required to complete a Progress Report form, which can be downloaded as above, by 15 January 2014 if your research has not been completed by that date;
• you are required to submit a final report, the form is available from the website above.

YOU ARE REMINDED THAT AN APPROVAL LETTER FROM THE CSU HREC CONSTITUTES ETHICAL APPROVAL ONLY.

If your research involves the use of radiation, biological materials, chemicals or animals a separate approval is required from the appropriate University Committee.

The Committee wishes you well in your research and please do not hesitate to contact the Executive Officer on telephone (02) 6338 4628 or email ethics@csu.edu.au if you have any enquiries.

Yours sincerely

Julie Hicks
Executive Officer
Human Research Ethics Committee
Direct Telephone: (02) 6338 4628
Email: ethics@csu.edu.au
Cc: Dr Rachel Fox

Version 3

FIA
Appendix D-4 – Ethics approval for Stage 3

10 July 2013

Mr Lester Watson
PO Box 426
ERINDALE CENTRE ACT 2903

Dear Mr Watson,

Thank you for the additional information forwarded in response to a request from the Human Research Ethics Committee (HREC).

The CSU HREC reviews projects in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Research Involving Humans.

I am pleased to advise that your project entitled “An exploration of the experiences of rural young people who care for a family member with a physical or mental illness (stage 3)” meets the requirements of the National Statement; and ethical approval for this research is granted for a twelve-month period from 10 July 2013.

The protocol number issued with respect to this project is 2013/126. Please be sure to quote this number when responding to any request made by the Committee.

Please note the following conditions of approval:

- all Consent Forms and Information Sheets are to be printed on Charles Sturt University letterhead. Students should liaise with their Supervisor to arrange to have these documents printed;
- you must notify the Committee immediately in writing should your research differ in any way from that proposed. Forms are available at: http://www.csu.edu.au/__data/assets/word_doc/0010/176833/ehrc_annrep.doc (please copy and paste the address into your browser);
- you must notify the Committee immediately if any serious and or unexpected adverse events or outcomes occur associated with your research, that might affect the participants and therefore ethical acceptability of the project. An Adverse Incident form is available from the website: as above;
- amendments to the research design must be reviewed and approved by the Human Research Ethics Committee before commencement. Forms are available at the website above;

Approval_after_further_information.doc Last updated: February 2013
Next review: February 2014

www.csu.edu.au
CRICOS Provider Numbers for Charles Sturt University are 00009F (NSW), 01941G (VIC) and 00968B (ACT). ABN: 85 878 708 561
• if an extension of the approval period is required, a request must be submitted to the Human Research Ethics Committee. Forms are available at the website above;
• you are required to complete a Progress Report form, which can be downloaded as above, by 16 May 2014 if your research has not been completed by that date;
• you are required to submit a final report, the form is available from the website above.

YOU ARE REMINDED THAT AN APPROVAL LETTER FROM THE CSU HREC CONSTITUTES ETHICAL APPROVAL ONLY.

If your research involves the use of radiation, biological materials, chemicals or animals a separate approval is required from the appropriate University Committee.

The Committee wishes you well in your research and please do not hesitate to contact the Executive Officer on telephone (02) 6338 4628 or email ethics@csu.edu.au if you have any enquiries.

Yours sincerely

Julie Hicks
Executive Officer
Human Research Ethics Committee
Direct Telephone: (02) 6338 4628
Email: ethics@csu.edu.au
Cc: Dr Rachel Fox Dr Maree Benneth

This HREC is constituted and operates in accordance with the National Health and Medical Research Council’s (NHMRC) National Statement on Ethical Conduct in Human Research (2007)
APPENDIX E-1 – Information Statement: Parent/guardian interviews

INFORMATION STATEMENT

Name of project: An exploration of the experiences of young people providing care for a family member.

Name of student: Lester Watson
PhD Student
Contact details: Ph: 0407 432 286
Email: lester.watson@ozemail.com.au

Name of Principal Supervisor: Dr Rachael Fox
Contact details: Ph: (02) 6933 2840
Email: rfox@csu.edu.au

Name of Co-supervisor: Dr Maree Bernoth
Contact details: Ph: (02) 6933 2492
Email: mabernoth@csu.edu.au

I would like to invite you to take part in research about young carers. If you agree to take part, you would have a discussion with me. I do not expect that this would take longer than 40 minutes. The discussion would be held at a time and place of your choosing.

I wish to discuss your perceptions of your child’s experience of being a young carer and what this means for him/her and your family.

Based on the research with young carers and other parents/guardians of young carers conducted over approximately the next nine months, a thesis will be written that will be assessed for the award of Doctor of Philosophy at the Charles Sturt University. Neither your name nor any other identifying information will be used in the research thesis. It is intended that articles based on the research will be submitted to academic journals to be considered for publication.

Should you participate in interviews, they will be audio-taped and transcribed and the resulting data will be kept for 5 years in a secure location and then destroyed at the end of 5 years.
You would be free to withdraw from the research at any time, and if you did, there would be no adverse consequences for you.

While it is considered unlikely, if you should experience discomfort as a result of your involvement in the research, you could contact the National Carer Counselling Service (1800 242 636), the Commonwealth Respite and Carelink Centre (1800 052 222), **Lifeline’s 24 hour telephone support line (13 11 14)**, if you feel it is unnecessary.

If you agree to be involved with the research as outlined above, there is a Consent Form that would be signed by you. This Information Statement is to be kept by you.

Thank you for agreeing to help with this research.

**NOTE:** Charles Sturt University’s Human Research Ethics Committee has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Executive Officer:

The Executive Officer  
Human Research Ethics Committee  
Office of Academic Governance  
Charles Sturt University  
Panorama Avenue  
Bathurst NSW 2795  
Tel: (02) 6338 4628  
Fax: (02) 6338 4194

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.
APPENDIX E-2 – Consent Form: Parent/guardian interviews

CONSENT FORM

Name of research: An exploration of the experiences of young people providing care for a family member.

Name of student: Lester Watson
PhD Student

Contact details: Ph: 0407 432 286
Email: lester.watson@ozemail.com.au

Name of Principal Supervisor: Dr Rachael Fox

Contact details: Ph: (02) 6933 2840
Email: rfox@csu.edu.au

Name of Co-supervisor: Dr Maree Bernoth

Contact details: Ph: (02) 6933 2492
Email: mabernoth@csu.edu.au

Please read and consider the following statements carefully before signing this consent form and participating in the research.

1. The purpose of my involvement in this research project has been explained to me and I have read and understood the Information Statement given to me. I have had the opportunity to ask questions about the research.

2. I understand that I am consenting to participate in young carer research and I am free to withdraw at any time and, if I do, there will be no adverse consequences for me.

3. I understand that I do not have to answer questions, discuss, or otherwise provide information, on any matters that I do not want to.

4. I understand that any personal information or details that I disclose in the course of the project are confidential. I understand that neither my name nor any identifying information will be used in the research report.

5. I understand that the discussions may be audio-recorded and that resulting data will be kept for 5 years in a secure location and then destroyed at the end of 5 years.
6. I have been provided with the names and contact details of psychological services in my area that I can contact if I suffer any discomfort as a result of the interview.

7. I note that the Charles Sturt University’s Human Research Ethics Committee has approved this study. I understand that if I have any complaints or concerns about this research I can contact:

   Executive Officer
   Human Research Ethics Committee
   Office of Academic Governance
   Charles Sturt University
   Panorama Avenue
   Bathurst NSW 2795

   Phone: (02) 6338 4628; Fax: (02) 6338 4194

   Name: ..........................................................

   Signature: .....................................................

   Date: .................
APPENDIX F-1 – Information Statement: Respite Centre staff

INFORMATION STATEMENT

Name of project: An exploration of the experiences of young people providing care for a family member.

Name of student: Lester Watson
PhD student

Contact details: Ph: 0407 432 286
Email: lester.watson@ozemail.com.au

Name of Principal Supervisor: Dr Rachael Fox
Contact details: Ph: (02) 6933 2840
Email: rfox@csu.edu.au

Name of Co-Supervisor: Dr Maree Bernoth
Contact details: Ph: (02) 6933 2492
Email: mabernoth@csu.edu.au

As you are aware, I worked as a volunteer with the Commonwealth Respite Centre over a period of 18 months at events and activities conducted by the Centre for young carers. This work was undertaken as part of my field work for the doctoral research I am undertaking on young carers. As you are also aware, during my work with the Centre I had considerable interaction with staff, including discussions about the practices and procedures followed by the Centre in providing support for young carers.

In accordance with the initial ethics approval process, it was explained at the time that handwritten notes may be taken by me for background material for the research in relation to young carers. Any personal details or information about staff or about young carers and their families that may have been mentioned in these discussions were NOT recorded in these notes.

In the course of writing of the thesis it has become apparent that it would be very valuable to include a small number of specific comments contained in discussions you had about the operation and procedures/practices of the Centre as they relate to support provided to young carers.
carers. In order to include your comments, it would be necessary for you to give your written consent.

As indicated above, a thesis is being written that will be assessed for the award of Doctor of Philosophy at the Charles Sturt University. Neither your name nor any other identifying information will be used in the research thesis. It is intended that articles based on the research will be submitted to academic journals to be considered for publication.

You are of course free to decline this request and, if you do, there would be no adverse consequences for you of any kind. If you do agree to the use in the thesis of the material described above, there is a Consent Form that would be signed by you. This Information Statement is to be kept by you.

Thank you for agreeing to help with this research.

NOTE: Charles Sturt University’s Human Research Ethics Committee has approved this project. If you have any complaints or reservations about the ethical conduct of this project, you may contact the Committee through the Executive Officer:

The Executive Officer
Human Research Ethics Committee
Office of Academic Governance
Charles Sturt University
Panorama Avenue
Bathurst NSW 2795

Tel: (02) 6338 4628
Fax: (02) 6338 4194

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.
APPENDIX F-2 – Consent Form: Respite Centre staff

CONSENT FORM

Name of research: An exploration of the experiences of young people providing care for a family member.

Name of student: Lester Watson
PhD student

Contact details: Ph: 0407 432 286
Email: lester.watson@ozemail.com.au

Name of Principal Supervisor: Dr Rachael Fox
Contact details: Ph: (02) 6933 2840
Email: rfox@csu.edu.au

Name of Co-Supervisor: Dr Maree Bernoth
Contact details: Ph: (02) 6933 2492
Email: mabernoth@csu.edu.au

Please read and carefully consider the following statements before signing this consent form.

1. The purpose of this research project and what has been requested on me in respect of the project has been explained to me and I have read and understood the Information Statement given to me. I have had the opportunity to ask questions.

2. I understand that I am consenting to material provided by me in discussions about this research project, which relate to the operations of the Commonwealth Respite and Carelink Centre in providing support for young carers, being used in the research report. I understand that I am free to decline this request and, if I do, there will be no adverse consequences for me of any kind.

3. I understand that any personal information or details that I may have disclosed during my discussions are confidential and will not be used. I understand that neither my name nor any identifying information will be used in the research report.
4. I note that the Charles Sturt University’s Human Research Ethics Committee has approved this study. I understand that if I have any complaints or concerns about this research I can contact:

   Executive Officer  
   Human Research Ethics Committee  
   Office of Academic Governance  
   Charles Sturt University  
   Panorama Avenue  
   Bathurst NSW 2795  
   Phone: (02) 6338 4628; Fax: (02) 6338 4194

Name: ..........................................................

Signature: .........................................................

Date: .....................
APPENDIX G – Questions guide for discussions with young carers on preliminary analysis of data: Stage 3

Questions guide for discussions on preliminary analysis

Preamble

Briefly review previous stages and discussions about the collaborative nature of this project to provide the context for this final round of discussions – I have been through what people have said and made these preliminary notes. I stress that these thoughts are not in any way presented as fact or ‘how it is’, but rather it is only an account and you should feel very free to disagree. ‘Opinions’ or ‘how things are’ can be quite changeable and slippery – people can feel differently from one another, and the same person can feel differently at different times – there have been descriptions coming up of things being ‘bad’ or ‘good’, but I am aware things can be both – the ideas that are being presented are simpler ways of describing things but I know that things are complicated. If these are things you don’t have an opinion about, that’s fine.

Interview notes

1. In general terms, the young people I have spoken with, seem to think of themselves predominantly in one of four ways (although lots of young carers describe themselves as more than one of these at different times);
   
   (i) a young carer who feels as though they are ‘missing out’ and their lives are worse off
   
   (ii) a young carer who feel they are better off for being a carer
   
   (iii) as young people who feel their lives are normal and routine, that is, they are a regular teenager; and
   
   (iv) those who don’t consider themselves to be a young carer; they are just being a family member.

   a. What do you think about these categorisations? Are there other more important categories I should have included? Are there things that affect how much you feel like one of these at different times?

   For participants who previously explicitly identified with (4) above, the following question could be introduced here:

   b. One of the things you talked about previously was that you don’t really think of yourself as a young carer, but rather you were just a sister/brother/daughter/son. Can you talk further about what you mean by that? (Possible ideas for discussion: do
you see them in any way as incompatible? Is there something about being a young carer that you think detracts from being a sibling?) [Note: may be their Mum’s influence – a subject position that is imposed]?

2. It seems to me that in Western societies such as ours there are strong ideas about a so-called ‘normal’ family; that it has two parents and children, particular roles for parents and children, and the notion of ‘normal’ family activities. In most cases this is not the situation in a family with a young carer.

   a. Do you think there is this view in our community about what a ‘normal’ family is?
   b. Do you think this affects how young carers feel about their situation, that they feel they are not part of a so-called ‘normal’ family and/or not being involved in so-called ‘normal’ family activities?

3. We have just talked about some of the ideas that may be behind the notion of a so-called ‘normal’ family. I also think there may be a view that there is a special kind of loyalty and obligation that happens within families. Many of those young people who spoke very positively about their situation seemed to me to be drawing on a view of family loyalty and obligation, and mutual support between family members. Do you think this might be a factor in some young carers feeling good about their situation?

4. Just following on from the talk of a so-called ‘normal’ family, do you think there is also an understanding about what is a ‘normal’ teenager? [Possible points for discussion: no responsibility; care free; fun time, etc.]. Do you think that young carers don’t feel like they are a normal teenager, and for some that makes them feel badly about being a carer?

5. Conversely, quite a number of young carers have expressed very negative views about teenagers; their fellow teenagers were described as immature, irresponsible, selfish, trivial, mean, and promiscuous, into drugs and drinking, and stuff like that.

   a. What do you think about this view of teenagers?
   b. One of the thoughts I had was that on one hand, not being a ‘normal teenager’ might feel like a bad thing (even though there might not be really a ‘normal teenager’) – on the other hand there might not be this ‘bad normal teenager’ either, but it does allow young caring to seem much more positive – for those who
are young carers and for other people – it might be a way to set young caring apart and show it to be special?

6. Some of the young people have spoken of a negative attitude by people in the community about disability and illness, and have mentioned staring, patronising sympathy, teasing and so on.

   a. Do you think that there is this attitude in the community?
   b. Do you think this could be why some young carers feel different from their peers, and even keep secret that they are carers, because of their association with disability through their sibling or parent?

7. In terms of support for young carers, it would seem that service/support agencies do not seek any input from young carers about what support they need or want, and probably that young carers themselves do not have any expectation of having a say on what they need.

   a. Do you think this is correct?
   b. Why do you think it is like this, given that you as a young carer would know better than anybody what support would be best for you? (Ideas: seen as an ‘adult’ concern, something for adults to decide; we are seen as kids; we are just kids).

8. One of the things many young carers have spoken about was talking with others and confiding about their caring situation and their difficulties. It seemed to me, from what people said, that there is a belief that there is a gender difference i.e., that girls are happy to talk with their friends and peers about personal problems etc., but boys believe that boys don’t talk about personal stuff and keep their problems to themselves. What do you think?

9. (a) When we spoke last time you mentioned that some of your friends had some mental health issues or were in disadvantaged situations. Do you think these friendships arose by chance, or that there is some other reason for this? (Possible ideas for discussion: young carers relate to people who feel themselves to be different from their peers; alienated from other peers; have embraced the role of being a carer; like to help people).

   OR (for those who did not talk about this in earlier discussions)

   (b) I don’t know if this applies to you, but quite a number of young carers have mentioned that most of their friends had some mental health issues or were in disadvantaged
situations. Do you think that young carers might intentionally initiate these friendships?  
(Possible ideas for discussion: do young carers relate to people who feel they are different from their peers? Feel alienated from other peers? They have embraced the role of being a carer? They like to help people?).

10. [THIS QUESTION IS NOT APPLICABLE TO ALL]  
Going back to what we first talked about – that is, how young carers see themselves; it seems to me that you very strongly identify with the experience of being a young carer, perhaps more than some others I have spoken to. I remember you spoke to me about attending young carer conference/s, where you shared your experiences with the group, as did others.  
a) Do you think that your involvement with these conference/s, or young carers’ events generally, has influenced your perception of your situation and about being a young carer? (Further talking points - it would seem that some young carers who have had no or minimal contact with young carer organisations do not identify strongly as young carers. Or do you think the extent of identifying as a young carer relates to the difficulty of the caring situation?)

[ALTERNATIVE QUESTION]

11. Going back to what we first talked about – that is, how young carers see themselves. Some young people I have spoken with do not strongly identify with the experience of being a young carer, while for some others it has seemingly defined their entire lives.

Do you think that involvement with young carer conferences or young carers’ events generally, has influenced young carers’ perception of their situation and about being a young carer? Further talking points:

   i. it would seem that some young carers who have had no or minimal contact with young carer organisations do not identify strongly as young carers.  
   ii. or do you think the extent of identifying as a young carer relates to the difficulty of the caring situation?  
   iii. does the attitudes and/or mutual support of parent/s, family have an influence?

12. [for Mitchell and Emma only (pseudonyms)] Now that you are living away from home, has your view about your situation as a young carer changed at all?
13. (a) [This could be introduced in the discussion on (1) above, depending on the direction taken by the young carer.] The research on young carers mostly portrays their situation in a negative way – in addition to focusing on what they feel are problems with education, social activities and health (and they don’t tend to say positive things), it also talks of young carers as having missed out on childhood and/or teenage years; it uses phrases such as ‘robbed of childhood’, ‘forced to grow up too fast’. What do you think about the portrayal of young carers in this way?

(b) The research seems to base its idea of young carers mainly on coping with chores and homework and caring and the like, and it seems to me that the research doesn’t look much at family relationships and the more difficult things for young carers than just chores, like how hard it is to see a family member unwell, how complicated family life gets, apart from just chores. What do you think of this?

14. The final thing that I wanted to get your thoughts on – as you know, my fundamental aim with the project was to collaborate as much as possible with young carers like yourself, since you are the experts with the experience – I started by seeking input from young carers about how to conduct the research, through to now in seeking views on some of the possible outcomes. As a final step to complete the circle, I would really like to hear any thoughts you had about this approach, my methodology for the research.