

Realities, caring responsibilities and future aspirations of young carers in Cornwall: two critical case studies

Allister H. Butler, PhD and Gaynor Astbury, DPhil

Abstract

This paper will report on one aspect of a five-year (1999 – 2004) evaluation of the Cornwall Young Carers Project (CYCP), namely: a critical case study analysis of the experiences of two young carers living in Cornwall. The project lead, in consultation with the evaluators, made a decision as to which two young carers would form part of the critical case study. The criteria for inclusion were: voluntary participation, one male and one female, and involvement with CYCP since Phase 1 (therefore able to provide data with a longitudinal focus). The interviews covered topics such as demographic information and family circumstances, understanding of their roles and responsibilities as a young carer, biopsychosocial factors and future aspirations. This in-depth analysis will report on specific themes which emerged from the accounts of these two young people's everyday lives as young carers, namely: daily caring tasks, sibling care, role of the project, self-care and self-perception and their future aspirations. Conclusions and recommendations will also be discussed, from the perspective of the young carers themselves.

Key Words:

Young carers, Cornwall, case studies, caring responsibilities, daily tasks, sibling care, aspirations

INTRODUCTION

This paper will report on one aspect of a five-year (1999 – 2004) evaluation of the Cornwall Young Carers Project (CYCP), namely: *a critical case study analysis of the experiences of two young carers living in Cornwall*. For a comprehensive overview of the findings from this five-year evaluation see Butler and Astbury (2005).

For a historical overview of the CYCP please see the paper which was published with regards Phase 1 of the project's evaluation cycle, which was conducted from June 1999 to December 2001 (Butler and Astbury, 2004.)

The scope and magnitude of the evaluation in Phase 1 was relatively limited, due to the fact that the project was still in its early stages of development and implementation. However, the Phase 2 evaluation was more comprehensive as it included perspectives from all the major stakeholders, namely: the young carers themselves, parents, service providers and project leads. This evaluation focused on these perspectives and insights as articulated by the stakeholders, as well as mapping structural and programme changes, which had occurred since the project's inception (1996), operational status (1999/2000), and through the end of its five-year funding cycle (2004).

The CYCP works with young carers and their families, providing individual support and respite activities for young carers, and signposting them to the most suitable organisations to provide help and support for their individual circumstances. The guiding principle is the development of quality services and the provision of such services in supporting young carers. More specifically it aims to:

- maximise opportunities for the social, educational and personal development of young carers; and
- facilitate partnership building, which includes raising awareness, understanding and knowledge base among various agencies.

The last decade has seen a significant increase in the amount of research and project evaluation in the young carers field. This commitment to scientific investigation has slowly begun to move the needs and experiences of young carers from "invisibility" to a point where their needs are recognised through legislation, as well as their daily

caring roles and responsibilities being discussed as part of the national carers agenda. Numerous pieces of research have served as a catalyst in this paradigm shift, for example, Aldridge and Becker (1998, 1999), Becker *et al* (1998, 2001), Dearden and Becker (1998, 2000), Becker (2000), Dearden and Becker (2004), Frank *et al* (1999), Frank (2002), Underdown (2002), Eley (2004), Olsen (1996), and Banks *et al* (2001), amongst others. In spite of this increase in research output, Olsen (1996:49), in his critique of young carer research, argues that “practice has run ahead of knowledge in this area, and that in-depth, basic research, designed to enhance our knowledge of who young carers are, what they do, and how they do it, is urgently required.” This need for a more in-depth observation and analysis of young carers lives served as an impetus for this paper. Instead of reporting on all aspects of the Cornwall Young Carers Projects, this paper will offer a critical case study of two young carers. This in-depth analysis will focus on specific aspects of these two young people’s everyday lives as young carers, namely: daily caring tasks, sibling care, role of the project, self-care and self-perception and their future aspirations

Research estimates suggested that there are between 20,000 and 50,000 young carers in Britain. The Social Services Inspectorate report, “*Something to Think About*” (November 1999), revealed some of the effects that children and young people experience when they have been providing care: Isolation and social exclusion, stigmatisation; Problems at school, including bullying; Lack of time for play or leisure activities; Lack of self-esteem; Lack of recognition, praise or respect for their contribution and difficulties moving into adulthood, especially finding work, a career, further study and establishing relationships

Butler and Astbury (2004) found that young carers in Cornwall experienced similar effects to those mentioned above, with regard to their caring roles. Thus, it was concluded that while Cornwall was relatively unique in terms of its rural context and population size, it shared many characteristics with other young carers around the United Kingdom. Furthermore, this study found that the number of young carers identified by the CYCP had increased substantially over this five-year period, which reflects a similar increase at a national level. A recent survey (2004) commissioned by the Princess Royal Trust for Carers has found that a much higher proportion of young people are carers than reported by the census. The survey of over 1300 young people found that 12 percent of 7 to 19 year olds were looking after and caring for someone with an illness, disability or health problem. This would correspond to over a million people age up to 19 in the UK, which is dramatically higher than the census which found that around 225 000 people up to 19 were performing caring responsibilities for a family member

In the national strategy document “*Caring About Carers*” (National Strategy for Carers, HM Government, March 1999), the work that young carers do for members of their immediate family is acknowledged. It is also recognised that children with a parent in need of support are likely to spend a large part of their time providing care, and taking full responsibility for doing so. Children caring for parents who have mental illness can often suffer themselves from a mental illness. (Butler and Astbury, 2004).

The 1988 Griffiths report reviewed the way in which public funds were used to support community care policy, and to advise on options that would improve the use of these funds as a contribution to more effective community care (Young, 2000). The NHS and Community Care Act 1990 adopted many of the Griffiths recommendations, and established the legislative framework for supporting vulnerable people requiring residential, nursing home or home-based care in the community. Since the inception of this Act, guidance now confirms that carers should be fully involved in the assessment process of their disabled relatives, and that they are entitled to ask for an assessment of their own needs (Becker, Aldridge & Dearden, 1998). Two further pieces of legislation and a national assessment strategy also had an impact upon the way practice and policy has sought to address the specific needs of young carers; namely The Children Act (1989), The Carers (Recognition and Services) Act of 1995, and the National Services Framework for the Assessment of Children in Need and their Families (DOH, 2000). The Children Act 1989 and the Carers (Recognition and Services) Act 1995 state that young carers can receive support from local and health authorities. Furthermore, with Section 17 of the Children Act, Social Services Departments can assist young carers, by considering whether their welfare or development might suffer if support is not provided. Young carers are also entitled to request a comprehensive assessment of their needs.

This paper will report on critical case studies with two young carers from the Cornwall Young Carers Project. These findings will be contextualised within local and national trends relevant to the experiences of young carers. Amongst others, comparative references will be made to the findings from Dearden and Becker’s national 2004 survey report, in which 87 young carers projects were evaluated (with a total of 6,178 young carers).

METHODOLOGY

The approach adopted in this five-year evaluation study was triangulative, in that a variety of data capturing and analysis methods were utilised. Methodologies utilised were predominantly qualitative, however quantitative work was undertaken when considering categorical responses to questionnaires and considering the changes in demographic distributions from Phase 1 to Phase 2. However, in terms of the two critical case studies, the following methodological procedures were followed.

Sampling procedures/criteria for inclusion

The project lead, in consultation with the evaluators, made a decision as to which two young carers would form part of the critical case study. The criteria for inclusion were: voluntary participation, one male and one female, and involvement with CYCP since phase 1 (therefore able to provide data with a longitudinal focus).

Data collection and analysis

Both evaluators are health professionals, with training and experience in youth work. The evaluators are also CRB checked. The female evaluator interviewed the female young carer and the male evaluator interviewed the male young carer. As with the focus group interview, participants' rights were carefully explained and informed consent obtained (countersigned by project lead). An interview schedule was used to guide the critical case study interviews, submitted in advance to CYCP workers to ensure suitability for use. The interview covered topics such as demographic information and family circumstances, understanding of their roles and responsibilities as a young carer, biopsychosocial factors and future aspirations. Due to the anticipated depth and sensitivity of information shared, the interview schedule was intended for use as a loose guide, with the interviewers preferring to allow the participants to address their areas of need at their own pace. The interviews were audio taped, transcribed verbatim, and subsequently thematically analysed by both evaluators. Resultant themes were sorted into meaningful categories. Note that the two participants in these case studies have been given pseudonyms (John and Jane), so as to ensure confidentiality and anonymity.

RESULTS AND DISCUSSION

Case Study 1

The first critical case study focuses on the experiences of a male young carer, aged 14 years old. He will be given the pseudonym of John for the purposes of this discussion. He has been a carer since he was 8 years old and joined the CYCP five years ago. He has two older female siblings, who are also members of the CYCP. His parents were divorced five years ago, and he has no contact with his father. He lives with his mother and two sisters. His mother has been diagnosed with both physical and mental ill health. She was diagnosed with clinical depression shortly after her divorce, as well as suffering from severe arthritis. It is also important to note that his two older sisters have also experienced various illnesses. Three years ago, his second oldest sister was diagnosed with Myalgic Encephalomyelitis (ME), and his oldest sister has made numerous attempts on her own life.

Daily caring tasks

The evaluator asked John to describe an average day in his life, with specific reference to his caring roles and responsibilities. He provided the following synopsis:

"I am at up at 6 a.m.', sometimes a bit earlier, and the first thing is I get mum up and take her to the loo. I then get her dressed and make her breakfast. This can take quite

long. It depends on how sick she is that day. While she is having breakfast I take up mum's snacks for the day until I get home from school. It is important that she is not hungry. Sometimes I finish a bit of my homework in the morning. I then go to school once I have put mum back to bed. I come home at lunchtime and take care of mum. Then I go back to school and come home about 3. Sometimes a bit later. The first thing I do is the dishes from the morning and the night before. Sometimes I forget to do the dishes at night. I walk my dog every afternoon. I like going out with my dog. It gives me a break. I then may have to go to the shops and buy food for the next day. I start my homework at about 7. I am so tired by then. I make tea for my whole family and then at 10 I start getting mum ready for bed. I have to do loo, pyjamas and medication. Sometimes I have to do the budgeting and pay the bills. My sister used to help me with this but now that she goes to college all day I do the bills."

An interesting feature of this commentary is the systematic recitation of a typical day. It was evident that this was a well-rehearsed set of events. Each component of John's day is carefully allocated to ensuring that other people's needs are met, allowing little opportunity for spontaneity, self-expression or self-care. On a poignant note, even walking the dog (a chore that teenagers often grumble about) caters predominantly for the needs of his pet – although this is expressed as his one enjoyable activity of the day because it allows him to escape.

John also referred to the fact that when he was younger it was easier because he had two older sisters who did most of the work. However, as he gets older he feels that more and more of the responsibility of household management and caring for his mother is falling on his shoulders. This, in spite of the fact, that he is the youngest sibling. As John states: "*As I am getting older, the pressure is getting more and more.*" This pressure is exacerbated by the fact that his older sister attends college all day and his middle sister has her own mental health concerns to consider. John finds this pressure intolerable at times. Finances are tight in his family and John feels the burden of having to budget to meet the varying needs of the family and pay the family bills. This level of daily caring responsibilities is supported by Dearden and Becker's third national survey (2004). Dearden and Becker (2004) found that two thirds of young carers provided domestic help in the home, 82% provided emotional support and supervision, and 18% provided intimate personal care for their parent(s).

At 14 years old, John is well versed in his mother's medication regime: *"I make sure she takes her medication properly. I know all her pills and know which ones she takes when."* This regimented approach to administering his mother's medication stems from previous negative experiences, where his mother has mixed up her medication: *"I have always known about mum's pills because she used to take the wrong ones."* Various features emerge from John's comments about his typical day. His mature sense of responsibility and concern for his mother's well-being is self-evident (*"first thing is I get her up"*; *"depends on how sick she is that day"*; *"it is important that she is not hungry"*). A sense of exhaustion, but having to carry on regardless, emerges through his litany of chores and responsibilities. There is also a sense of each distinct area of responsibility having to synchronise into a carefully planned routine. Eley (2004:69) refers to the complex nature of young carers task in that "caring does have connected to it, responsibilities that frequently override other activities. Compromises need to be made and respite tends to come in the form of a few hours here and there." Eley (2004) further expands upon the complex balancing act which young carers have to juggle, especially between school attendance, doing their homework and carrying out the various caring responsibilities which are part of their everyday lives.

Sibling care

Providing sibling care and support is a major part of John's daily roles and responsibilities. John recalls, with vivid accuracy, how his family began to *"fall apart"* six years ago (i.e., when John was 8 years old), and the impact this has had on his relatively young life: *"Six years ago, my dad had a nervous breakdown and just walked out on all of us. I was quite young so did not know what was happening. My sisters protected me at first I think. My mum could not cope and she also had a breakdown. From then my older sister [name of sister] became suicidal and at the same time my second oldest sister was diagnosed with ME. I was 10 and 11 yrs old then."*

It is important to consider the physical and mental health impact this multi-dimensional provision of care for parents and siblings had on John. Following suicide attempts by his sister, John became increasingly afraid for her well-being. At the age of 11 he put himself on 'suicide watch', unable to leave his sister alone in case she

tried again. This meant being available throughout the night. As he says: *“When I was 11, I was on constant suicide watch for my sister. I used to sleep on a pillow in the hallway outside her room in case she did anything.”* For a child of 11 to be aware of the concept of suicide watch in itself is remarkable. Bearing in mind that John was already suffering from exhaustion and disturbed sleep with having to take his mother to the toilet in the night; having to try to sleep while remaining hyper-vigilant placed an intolerable amount of pressure on him. This also needs to be considered in light of the reality that if his sister had attempted suicide again, it would have been up to John to ensure her safety and obtain appropriate help. The Princess Royal Trust for Carers (2005) reinforce the difficulties which John had to endure in caring for his ill siblings. They refer to the vulnerability which young carers feel in their task of providing emotional support, namely: dealing with the aftermath of an overdose attempt, and worrying about someone in the home while at school or out of the house.

The debilitating chronic fatigue of Myalgic Encephalomyelitis is well-documented. Again, this resulted in John having to not only absorb roles previously occupied by his sister in the caring system, but also additional caring roles in ensuring her well-being. Instead of three young people caring for one adult, John was suddenly confronted by being an 11-year-old child, caring for three people. In a family context where three people were allowed to not cope because of their illness, John was expected to cope.

This issue of the complexity of sibling care was borne out by both the project lead and field worker, in that they regard sibling care as one of their new focus areas for CYCP. John further elaborates on this role by saying that *“although I am the youngest I always feel like I am the oldest.”*

He also explains the resentment he feels towards his father in terms of relinquishing his parental role: *“I was so sad when my father walked out on us. I am so angry at my dad. He should be caring for me and my sisters and my sick mum. But now I have to be the dad. I hate it sometimes.”* John has assumed the role of his absent father, without having adequate access to a well-modelled father role. His sense of anger towards his father is vehement. His sense of abandonment and loss were tangible. In

expressing these thoughts surrounding his father, John allowed himself to acknowledge (on the only occasion during this case study) that he needs care too.

Role of the project

As stated earlier John has been part of the CYCP since 1999. Social Services referred John and his sisters to the project. He refers to numerous ways in which the project has influenced his life. He reflects on CYCP as life-changing: *“The young carers project has totally changed my life.”*; *“I cannot remember what it was like before I met [name of project lead] and the project.”*

The supportive role of the CYCP workers has enabled John to feel that he has someone that he can speak to honestly about the way he is feeling. He feels secure in the knowledge that his feelings are not judged. *“At school I don’t want people to know my family business so I don’t tell them anything. I don’t tell them that I am a carer. But coming to the project is easier. I can be myself and tell people how I feel, even if I am feeling really down. Even if I want to say that I am mad at my mum.”*

John feels that CYCP has helped to keep his family intact and saved his sister’s life by providing appropriate support: *“If it wasn’t for the project [name of sister] would not be alive today. She would be dead. It saved her life. If she had died [name of older sister] would have been put in care and I would have just walked out. I would never have come back.”*; *“Just knowing that I can talk to [project lead and fieldworker] helps me so much. They are the only people I can be totally honest with. They know how I really feel.”* This enables John to feel a sense of pride and value in his role as a young carer: *“I see now that it is a privilege to be a young carer.”*; *“Coming to the project has made me proud of myself.”*

The positive way in which John refers to the impact that the CYCP had had on his life is echoed by Underdown’s (2002) national analysis of 1200 young carers experiences. Underdown (2002:60) stated that *“the young carers praised their voluntary support groups which offered emotional, social and personal support, understanding and fun.”* Dearden and Becker’s (1998:11) evaluation of the Sheffield Young Carers project bore similar findings, in that *“for many of the young people the Project offers the only*

opportunity for them to engage in social and leisure activities and to experience holidays.”.

Self-care and self-perception

As noted in John’s reflection on a typical day, there is not much time for John to “simply be”. This implies that he has little time to allow himself to give due cognisance to his own feelings and needs. John felt that he did not have the right to express when he feels down or sad, as it might impact negatively on the family members in his charge: *“I feel guilty when I feel down or when I feel a bit depressed.”*; *“I don’t tell my sisters because they are so stressed. Especially [older sister] ‘cos she is stressed from College and comes home late and is so tired.”* As a result John tends to hide his feelings from his family. He reports that he goes into his room and puts on a CD so that they will not hear, and expresses his emotions in isolation: *“I don’t want to stress out my mum or my sisters, so I go into my room put on a CD and just cry. They don’t really know how I feel.”*

John further explains how this style of isolated containment and self-management is reflected in his school setting: *“Teachers don’t understand my life as carer so I just don’t tell them.”* Unfortunately, this non-disclosure has resulted in negative school experiences which John has found deeply embarrassing and hard to cope with: *“Once a teacher embarrassed me in front of the whole class. He screamed at me because my PT kit was dirty. I didn’t want to tell him the truth. That I was doing so many other things that I did not have time to wash my kit. It was so embarrassing. I hate him.”*

Dearden and Becker (1998:10) found similar results in their Sheffield evaluation, by observing “bullying in school can compound educational difficulties and seems to be a particular problem for young carers. One of the reasons she kept her caring role a secret from friends in school was fear that bullying would be worse if people knew she had a parent with mental health problems. Any child perceived as being ‘different’ runs the risk of victimisation and this seems to be one of the reasons young carers do not openly discuss their family situations. In a sense they suffer stigma by association.” The “Too much to take on” study of young carers’ experiences found that one third of the 240 young carers studies believed that their teachers were not aware they were carers (Crabtree and Warner, 1999, in Eley, 2004). Eley (2004: 70)

further contends, “teachers were reported as being insensitive at times and that young carers felt that their confidences to teachers were often considered ‘stories’ or ‘excuses’”. Underdown’s (2002:58) study supports John’s self perception in his school context, by saying that “few of the young carers felt that schools had sufficient understanding of their situation and many felt stigmatised and isolated. Children said they often felt stigmatised at school and labelled as ‘problem children’ if they were unable to complete homework due to caring commitments.”

John notes that people tend to perceive him as: “... *serious, very mature and independent.*” He commented that his social circle is restricted, apparently by choice, stemming from his not wanting other people to know what his family circumstances are: “*I have one or two close friends, but not too many. I don’t want them all to know.*” His social life is also restricted by not having pocket money to spend on social activities (which he describes as “*waste*”): “*I don’t have money to waste on movies and stuff like that. I don’t mind really.*” This atypical adolescent attitude stems from his having to budget and ensure that priority household expenses are paid. High levels of caring can have an adverse impact on young carers, resulting in friendship difficulties, limited time for social and leisure activities, limited time for school work and homework, and can limit opportunities and make transitions into adulthood more problematic (Dearden and Becker, 2004; Aldridge and Becker, 1993, Dearden and Becker, 2000, Frank *et al.*, 1999).

As a 14 year old heterosexual male, John’s thoughts are naturally turning to girlfriends; but at present he feels he does not have the time or emotional resources to consider that option: “*Having a girlfriend would be nice, but caring for my sisters and my mum is enough. Caring for them is my priority. It might change.*”

Future aspirations

John also reports on the ways in which the project has enabled him to look at his life more closely, and plan for the future. He expressed that, although he has not had the opportunity to just be a child, he has gained ‘adult’ skills through being a young carer that he might not otherwise have developed. He recognises that these skills are not typically possessed by his peers outside of CYCP and this gives him a sense of pride: “*While I have missed out on so many things I have also learned so much. I can*

budget, pay bills, run a house, cook and clean, and I know how to care for people. I don't think any of my friends can do all of this."

Olsen (1996) support John's insights by offering a commentary with regard to the potentially positive aspects of caring. Olsen (1996: 45) states that "the inference repeatedly made is that young carers have lost their childhood (Dearden *et al.*, 1994:), or have been prevented from participating fully in childhood (Aldridge and Becker, 1993), or have been excluded in some sense (Aldridge and Becker, 1993). Anecdotal evidence points to some of the positive (as opposed to compensatory) benefits of caring, in terms of personal development, sensitivity, and self-esteem (Kornblum and Anderson; Segal and Simkins, 1993).

John has aspirations to become a skilled technician when he is older: "*When I am older I want to be a mechanic or a plumber. I think it is easier working with my hands.*" However, his sense of a future self is clouded by his caring role. He feels certain that he will always have to take care of his mother: "*Even when I am older I think I will always be caring for my mum. She will always need me. That won't change.*" John is not yet at the developmental stage of leaving home, starting his career or starting a family of his own; however, this sense of a lifelong responsibility has implications for his development into young adulthood. There is little sense, in what he expresses, of his sisters resuming an equal share of the caring responsibility in the future. Dearden and Becker's (2004:14) third national study concluded with a reference to this lifelong caring commitment in saying that "many children care for several years and some will be committed to caring for many years."

Case Study 2

The second critical case study focuses on the experiences of a female young carer, aged 17 years. She will be given the pseudonym Jane for purposes of this discussion. Jane has been a young carer since she was 7 years old and joined the project during phase 2. She has one younger brother, aged 10 years, who is also a member of the CYCP. When she was 7 years old her mother gave birth to her brother, and experienced postnatal depression. Shortly after her brother's birth, Jane's father committed suicide. Subsequently, her mother's condition deteriorated into clinical depression, requiring medication and hospitalisation at times. Jane experienced a stroke 18 months ago, leaving her with restricted mobility and loss of sensation on her left side. This particularly impacts her left arm and

hand. It has also left her with a slight speech impediment. Currently Jane lives with her mother and her new partner. Her younger brother now lives with their grandmother who, although in a different village, is relatively close. Her grandmother has offered support to Jane and her brother in their caring roles. While Jane experienced extensive school absences prior to her stroke, Jane has now had to leave school. Her younger brother has also left school due to illness (a non-diagnosed stomach complaint and depression), stress and simply not coping.

Daily caring tasks

Jane has been a young carer since the age of 7. She describes the aetiology of her mother's clinical depression as follows: *"My mum has been clinically depressed for 10 years. Well ... since [name of brother] was born. Well my dad died. Well he committed suicide not long after [name of brother] was born. Obviously that tipped it over, but she had the baby blues as well."*

She recalls the early days of being a young carer as difficult and expressed that it was a time of having to cope with three life changing events, namely the birth of her brother, her father's suicide and her mother's debilitating depression: *"It [reference to mum's illness] was hard for me. I was struggling with my dad being dead. And I had a new baby brother. I was 7."*

The Princess Royal Trust for Carers (2005) web page references the effects of being a carer at an early age. They refer to the stress and worry young carers experience and the that young carers often experience traumatic life changes such as bereavement, family break up or seeing the effects of an illness or addiction affecting their loved ones.

Jane's caring role has fluctuated as her mother's mental health has improved or deteriorated. During times when her mother is on her medication and is stable, Jane finds her caring role fairly easy. In this context she predominantly provides emotional support. She also finds the support of her grandmother to be valuable:

"Mum's actually ... she's quite independent. She likes her independence even though she's ill. She just can't make any decisions by herself. She's just very down. She gets depressed.

"When I get up in the morning she is already dressed, 'cos she can dress herself. I have a cup of coffee with her. It's just, she prefers company I think. That's what she really needs, is just someone to talk to. I have done the cooking and stuff before, when she was in hospital. But when she's home, she likes to do that stuff. When we were at school, the only thing I have really done is the housework. 'Cos we've got gran, and gran helps out and stuff.

Dearden and Becker (2004) confirm that Jane's experience is a reflection of national young carer trends in that emotional support is more common where a person with care needs has mental health problems – provide in 77% of such cases (from a sample of 6178 young carers).

Jane's mother appears to be relatively stable until she comes off her medication. According to Jane, her condition is exacerbated by the substance misuse. During the course of this discussion Jane disclosed that she too smokes cannabis in order to relax, and that she believes this has no negative

effect on her: *“She’s come off the tablets before but she smokes cannabis, and I do as well. But it doesn’t affect me. She thinks because it doesn’t affect me, she can do it. But it sends her funny. And that’s what starts every breakdown. She goes into psychosis or something they call it. And she gets really bad. It chills me out and helps me relax. But it makes people like schizophrenic and stuff.*

Jane commented that she had found it difficult to be at school at times, and that she felt that no allowances had been made for her when she had to assume a more extensive caring role (when her mother was in hospital). While Jane acknowledges that she was rude to teachers, a particularly upsetting event at school had triggered a feeling that she simply did not want to be there. This had resulted in her spending increasing amounts of time away from school; preferring to be down the village smoking with her friends. An alarming reflection by Jane was that she was often given detention because she was unable to fulfil school requirements and because her frustration sometimes spilled over into rudeness. This had typically taken place over lunchtimes. The Princess Royal Trust for Carers (2005) further reinforces Jane’s school experience in stating that some young carers protect their vulnerable parents from their negative feelings at home, but cannot “keep their feelings in” at school. The real reason for a carer’s school behaviour is rarely discovered until it is too late. Due to the frequency with which detention was allocated, Jane had lost weight and become quite skinny. Her mother had laughed at her:

“When I was at school the teachers didn’t understand. But I was like quite rude to them. I just went into school like really upset one day. Just like it was the death anniversary of my dad and I was crying and my teacher laughed at me. So I said, I like swore at him and just like left the room and said I’m not coming back. So he said ‘come back, you have to come back in the room’. Since then I just used to skive quite a lot. I just used to go down town and smoke with my friends.”

“They didn’t like to make allowances for me. I don’t know. I don’t think they make allowances for anyone really. It was just like you have to have homework in. The only time they didn’t ask me to do work was when I was in hospital having my stroke. Then I never got asked to do anything. I used to get detentions and stuff. Mum used to think it was funny. She was like ‘got another detention today dear’. I was like ‘yeah I missed my lunch again’. I got really skinny as well ‘cos I kept missing lunch.

Sibling care

Jane had assumed a caring role for her younger brother (with support from her grandmother), particularly during periods when her mother was hospitalised. However, her brother has now moved out of the home environment: “[name of brother] lives in [name of village] with my Gran. They [grandparents] divorced when mum was a child.”

There were reasons above and beyond their mother’s illness which had prompted her brother leaving. When Jane experienced her stroke, her younger brother had felt overwhelmed by caring for two ill relatives. Plus, during the last period of hospitalisation her mother had developed a relationship with a fellow patient. When she left hospital that relationship had developed, and he is now her partner. Jane’s brother had found this very stressful, finding the new partner to be scary and aggressive. Jane

reports that although she copes with the situation she is nervous about him and avoids him where possible: *“I don’t really speak to mum’s new partner. I just say ‘aright?’ and stuff. I am a bit nervous about him. I suppose so. Like we don’t really know anything about him or anything. Like he was in hospital when mum was in hospital. And he came out with her. It don’t really bother me ‘cos I don’t really see him or speak to him.”*

Role of the project

Jane had been involved with CYCP since phase 1 of the project. She did not report how she had been referred to the project, but commented simply: *“I’m involved with the CYCP because I help my mum.”*

Since joining CYCP, Jane has befriended another female young carer and they provide support to one another. Being a part of CYCP means that she has something to do outside of the isolation of the small rural village she lives in. Jane reports that she enjoys being involved and all of the trips. She also feels that if she does not attend she will be letting down her friend:

“I think CYCP is important for young carers. We all get to talk to each other and we help each other. I’ve made friends with [name of young carer involved with the project]. I think if I don’t come I’ll be letting her down. She’s lovely. She’s like ‘if you don’t come you’ll be letting me down.’ I only didn’t turn up once! It’s just something different to do, rather than like hanging around [name of village]. I went to Disneyland. That was really good.”

With regard to the future development of the CYCP, Jane would like to see more trips available to young carers. However, she recognises the funding limitations of the project: *“I think more trips would be good. But we are already struggling with funding so I don’t think we will get more trips.”* She also recognised the need for the identification of young carers who are not yet known to the project. She specified that she would like funders to be aware of the need to reach more young carers. When exploring why so many young carers were not yet identified, Jane felt that it was due to family fears regarding children being taken away from families if the extent of their caring role was known: *“Funders need to know that there are a lot of young carers here and there’s a lot more of us that haven’t been found yet. We get the help and support we need and we find it really useful. But there’s still lots of people who haven’t got nothing and still doing it all themselves. They don’t know about CYCP because their parents don’t want to say anything ‘cos they think their children will get taken away. They shouldn’t though. Unless they are like getting beaten up and stuff.”*

Jane has received additional support, external to CYCP. Some of which she had found useful, while other experiences were not so good. She had found that input from the CPN had been beneficial: *“We had a CPN that was very good.”* Jane also felt that her physiotherapist was approachable, but recognised that her role was to focus on Jane’s current physical difficulties rather than her mental health: *“I’ve got a physio, but she doesn’t support me mentally. She supports me physically. We always talk and stuff. We’ve become quite close. She’s lovely.”*

Jane reported feeling negative about the role a social worker had played in her life. It appears that the social worker had tried some bereavement therapy techniques which Jane had not been comfortable with. Jane had felt that the social worker had not understood her and was trying to pressurise her into doing practical exercises to work through issues: *“I used to have a social worker but I don’t have her anymore. I just didn’t see the point. I thought I may as well deal with it on my own. Rather than pulling someone else in that I don’t know, and don’t trust. I just don’t like being told what to do. I am just one of those people. I go and do the exact opposite. She was like ‘write a letter to your dad and put it on the fire’. I’m like ‘but he’s dead – he’s not going to listen to a letter, is he?’. She was like ‘he might be able to hear it’. I was like ‘but I don’t want to do that’. I found it pressured when she told me to like do stuff.’*

This experience had left Jane with a lingering dislike of social workers and mental health professionals. She feels that they do not have the experiences to understand her life as a young carer or the stressors that she has experienced during her life: *“I’d like them to see things from my point of view. I think social workers really should be people who have had experiences of their own. Like what people have gone through, so they actually know what they are talking about. But I’ve always said that since I was little. They don’t know nothing about me, and they probably don’t know nothing about what they are talking about either. They read it all from textbooks.*

However, despite these negative perceptions Jane had considered a career in social work. This will be discussed under the section ‘self care and self-perception’.

Self care and self perception

Jane appears to have a fairly healthy body image. However, at present her self-image is clouded by her experience of having a stroke and subsequent physical limitations. Despite these limitations she appears to have a supportive network of friends and aspirations for the future. She speaks about her prognosis for recovery in positive terms:

I’m 17 now. I’ve got blonde hair and blue eyes. I think I am about 5”1 or 2. And I enjoy horse riding and chilling out with my friends really. My friends would tell you that I’m naughty. Which, I can be quite as well. I don’t really do anything. I’m on disability benefits ‘cos I’ve had a stroke. When my hand gets better I shall go to college. Either travel agency or hairdressing or something like that. I would like to travel.

Jane also expressed that she feels proud of her role as a young carer: *“You feel proud sometimes ‘cos you know you’re doing something for somebody else. It’s not for you.”* Despite her young carer role, Jane feels herself to be similar to her friends. She feels that she is not ‘as much’ of a young carer as many of her peers within the CYCP. In recent times, due to having a stroke, this role has lessened considerably. This is an interesting dichotomy. While the stroke experience was clearly traumatic and has left Jane with physical restrictions, at times there is almost a sense of relief expressed in not being able to do as much and receiving support for her own needs: *“I think I’m quite the same as other*

people. I'm not like as much of a carer as some of the people around here are. And that might be because I've had a stroke as well. Yeah. When they need two hands on, I can't do it either."

The stroke had been caused by Jane falling down some steps when she was drunk at a party (age 15). Her friend had fallen on top of her, causing Jane's neck to be compressed. This had blocked the artery, resulting in the stroke:

"I fell over when I was drunk at a party, down a step. And my friend fell on top of me. Just landed awkward on my neck. A one in a million chance that it could have happened. I just blocked my artery in my neck. It got twisted or torn or something. It was like 2 years ago, maybe one and a half."

Jane speaks wistfully about her life before her stroke, describing herself as having been 'normal'.

"With what has happened to me ... I've seen how lucky I was being normal. Obviously I'm not like normal – but like I was before. I was so lucky to be how I was before." One aspect which had helped her to cope with the stroke experience was the much needed support of her mother: *"But mum was really good. We were getting on really well. So that helped."*

Jane reports that there have been times when the stress of being in the home environment was overwhelming. On one such occasion, at age 15, she had elected to leave home and had moved into a caravan in the middle of an isolated field. She lived alone in this context. Due to having the stroke and needing care herself, she has been forced to move back into the home environment. This is what she reported in this regard: *"I left home but I moved back in after the stroke. I left home and lived in a caravan on a campsite for a bit. It was just a field in the middle of nowhere, like ... just a caravan. It was quite good fun. I enjoyed it. Yeah, stuck in the middle of nowhere as well. But it was better than being at home. I just wanted my own space. When I was 15. I really enjoyed it."*

Jane experiences a sense of geographical isolation stemming from living in a small rural village. This sense of isolation is at present exacerbated by her restricted mobility. However, having a group of friends who live in the same village has made this easier:

I live in [name of village]. A little village in the middle of nowhere really. The shops are about a mile out, so I get my gran to go to the shops and so on."

"I love my friends. Because they are mine and nobody else's. They are a bunch of idiots really. I haven't really got many girl friends. I've got a couple. My girl friend, she's going to have a baby. But most of my friends are boys. I get on better with boys than I do with girls. 'Cos I find them not so bitchy. I see them everyday for at least half an hour or so. We all live in the same village. There is nothing to do in the village. We sit and smoke all day. There is a local pub, but it's a couple of miles away. And I can't walk all the way there. They are like 'we'll ride our pushbikes'. I'm like 'I'm not walking behind you'. My friend [name of friend] drives, but she lives over in [name of town], so I don't see her very often. I think I'll be able to drive in a couple of years. I can't get away from it. 'Cos there's nowhere to get away from it. We've got a post bus that goes to [name of town] in the morning, but there's nothing very near."

Jane expresses feeling fairly comfortable inviting her friends over to her home, despite the fact that her mother behaves in an over-excited fashion when they come round. Jane compensates for this by laughing with her friends at her mother's behaviour: *"They would say that my family are 'nutters', probably. 'Cos mum just makes a scene every time somebody comes around. She tries to be comical or something. Then people laugh at her. I don't get like embarrassed. I laugh at her as well. She just gets like really over-excited. Dances around and sings and stuff."* It is worth noting that, although Jane states that she is not embarrassed, her body language during this disclosure and her compensatory behaviour may indicate otherwise.

Jane has conflicting feelings regarding her mother which, under the circumstances, are probably to be expected. She expressed a growing resentment towards her mother during the earlier years of coping with her illness, which culminated in feelings of hatred and anger. Jane expressed that she and her brother had borne the brunt of their mother's declining mental health. In elements of what Jane was expressing, it emerged that she felt her mother was to blame for her health condition: *"I used to really hate and resent my mum for what she put us through and stuff. What she was doing to herself. 'Cos obviously we saw everything that was going on and stuff. And when she went 'funny' we were the ones she shouted at and stuff like that as well. I just grew to hate her."*

Now that Jane is older and approaching young adulthood, she feels that she is more able to understand her mother's illness: *"But since growing up I realised there is no point in hating her. 'Cos it's like an illness."* However, Jane wishes that her mother did not have mental health difficulties as she and her brother continue to feel the strain of this condition: *"I'd rather my mum was just more normal. Well, just the opposite really. So me and [name of brother] wouldn't be affected and I wouldn't have any stress there."*

Jane is not comfortable expressing emotion. She was quick to point out that she does not feel that there is anything wrong with crying, it was simply that she does not feel comfortable. Although this was not explicated, one wonders whether this has anything to do with the negative experience she had at school (around age 15) when she was laughed at by a teacher for crying on the anniversary of her father's death. She expressed that her friends view her not crying as strength, however she appears conflicted regarding her own feelings in this regard: *"All my friends say I am strong-hearted. They say I should cry more. And I'm like 'yeah but I don't like crying'. And like ... you should cry. There's no need, you don't have to hold all your feelings inside. But like I find it easier or something to not think about what's going on to me. I just live my life that way. Rather than thinking about what's been in the past. That's just the way I deal with it."*

Future aspirations

Jane intends to either study to be a hairdresser or a travel agent. While she is positive about the prognosis for her stroke recovery, she recognises that hairdressing training might not be possible at present: *"I don't think hairdresser will be possible but travel agent will yeah."* She feels that it will be

possible for her to attend college, but that it would be best if she does this before she is 19, so that she can get her tuition for free. However, she has been saving her disability allowance in case she has to pay for some of her college fees. She also expressed that college attendance might be problematic, simply because she does not see herself as a 'determined' person. Jane felt that she would need someone to insist that she attends classes: *I just need someone to shout at me the whole time to make sure I go. I'm not lazy, I'm just not a very determined person. Well, I've had to be with my stroke. But other things I don't really care about. I'm just really chilled ... like laid back. I don't really care. It's just I must go [to college], so I have to go. I think if I go before I am 19 I can still get my education for free. But if I go when I'm 19 it will be like a £1000 scholarship or something. But I've got some money saved up from my disability money so I will be able to pay for myself.*"

Jane also expressed that she had considered a career in social work, because of her strong feelings that social workers should have significant life experiences. However, a friend had put her off this idea by telling her she would not be suited for the career: *"I did think about social work. But my friend told me off. She was like 'do you really reckon you'd be able to like ... you've got enough problems of your own without having loads of children's problems on your head as well'. She's like 'I know what you'd be like – you'd be trying to solve all the crimes and get the children into new homes and stuff'. She's like 'you just wouldn't have any time for yourself anymore'. It would be a good job but I guess I'm not really cut out for it. I don't know. It [what friend had said] did put me off a bit.*

At 17 years of age, Jane is now considering her life options, including moving away from home and starting a career. She had already made the decision to leave home at age 15, due to overwhelming stress. Due to the circumstances in which she located herself (*"a caravan in the middle of nowhere"*) and her age, it is uncertain how successful this attempt would have been. Her attempt was cut short by her stroke, forcing her back into the environment in which she had felt overwhelmed. However, she is certain that she will be leaving home when her recovery allows for this. When this happens, Jane expressed that she will definitely keep in touch with her brother. However, she is conflicted about keeping in contact with her mother. In many ways she feels that not knowing how her mother is doing would alleviate much of the stress she experiences. But, she also feels that this may exacerbate her stress as she would want to know if something bad happened: *"I would always keep in contact with [name of brother]. But I'm not sure with mum. I think it would be like either no contact or lots of contact. It would be easier not to hear what she is up to so I wouldn't have to worry. I think I would feel awful if I didn't know what was going on at home though. She could be dead and I wouldn't know."*

In relationship to Jane's future aspirations as a young adult, Olsen (1996) expands upon the impact that the unpredictability of a parents illness can have on a young careers aspirations. Olsen (1996:46) explains that "a young carer of a mentally ill parent is likely to have particular problems in terms of the reliability and predictability of the condition, and the disruption and inability to plan and have a degree of control that this means (Parker, 1993, Mapp, 1994)."

Commonality of experience

While these young carers' stories are unique in terms of their life experiences, daily caring roles, geographical areas and family contexts; the evaluators found it interesting that several commonalities emerged. These are indicated below:

- Absent father
- Assumption of adult roles (being 'the responsible one' / 'making key decisions')
- A sense of loss and grief
- Internalising of feelings in social contexts and restricted affect
- An in-depth understanding of medications and medical conditions
- A sense of wanting to escape
- A sense of feeling overwhelmed
- A sense of having to put their own needs and feelings aside, and "get on with it"
- Caring for siblings with medical / emotional difficulties
- Negative and embarrassing experiences in the school context, resulting from young carer role
- A sense of dissonance when considering future opportunities for a career and a life separate from their family
- Deep seated anger and resentment directed at the people they care for, with a concomitant need to protect them
- Expressed perception that the only way to escape a carer role is to be ill yourself
- A developing sense of pride in their roles as young carers through being involved with CYCP
- A clash between their needs as adolescents and their roles as young carers
- The experience of suicide and/or suicidal ideation within the family context

CONCLUSION

In the first case study, we found that John presented as a quietly spoken, sensitive and intelligent young man, with a sense of maturity far exceeding his 14 years. His comments provide insight into a serious minded, caring adolescent; who has been forced by circumstances outside of his control to assume multiple adult roles and responsibilities. In many ways, his childhood has disappeared beneath his caring role: *"All I have ever known is being a carer. I don't remember anything else. I don't remember a time in my life when I was not caring for my sisters or my mum."*

It is encouraging to report that the CYCP has given this young adolescent numerous opportunities to 'escape' his assumed adult roles and to recapture a part of his childhood. John regularly attends outings and events. He has also contributed to the ongoing success of CYCP by communicating the needs of young carers to service providers in consultation exercises.

The isolation experienced by John outside of his CYCP involvement is far reaching. As his comments indicate, this encompasses his social, educational and family environments – all key contexts in the life of an adolescent. It is unfortunate that John does not feel adequately understood in his school context, to the extent of needing to hide why he is unable to fulfil certain tasks, as this environment could provide much needed support and encouragement. It is equally unfortunate that John does not feel able to express his feelings to his family, out of a sense of needing to protect them. John's sense of isolation was evidenced in the interview context when he became tearful at being given the opportunity to talk about how he felt. The evaluator, a clinically trained social worker specialising in youth work, felt it in the participant's best interests to suspend the interview schedule at this point. Professional support was provided as John was simply allowed to express what he was feeling at his own pace. Despite having been upset, John wanted his voice to be heard, and gave permission for his comments to be used in this regard.

John is developing future aspirations. However, his aspirations are still firmly enmeshed within the ever-present needs of his family. At present he expresses no sense of ever being separated from those demands. He will need support in order to fully develop a sense of his own right to be; both as a developing adolescent and eventually as a young adult functioning in separation from the demands of his nuclear family. This is essential if John is to be allowed to develop normative adult relationships.

In the second case study, Jane, presented as an attractive, eloquent young girl who had undergone numerous tragic life circumstances, faced the evaluators. Her attempts to escape her life stressors include rebellion, truancy, running away and substance misuse (alcohol, smoking and cannabis). It is perhaps most poignant that one of the tools she used to escape, namely alcohol, resulted in the tragic accident which placed further restrictions, isolation and stress on her already stressful life. There is no indication how early this substances misuse began; however it was present at age 15. It is evident that Jane uses cannabis with her mother's knowledge; who, in turn, also uses the substance. Jane expressed that cannabis has no effect on her, and this is why her mother thinks she can use it too. It is uncertain how much Jane blames herself for her mother's use of cannabis, in the light of her expressing that it triggers her mother's "*breakdowns*" and "*psychosis*". Jane recognised that she uses the drug to assist her to feel relaxed and less stressed.

Despite professions of anger, resentment, stress and anxiety, Jane presents as remarkably positive and pragmatic. However, one wonders how much of this is learned from having to internalise much of her pain as "*it is easier not to think about things going on in me*". Jane did not expand on her experience

of her younger brother leaving home due to her mother bringing in a new partner. This perceived 'loss' of a sibling to whom Jane had provided care from birth, may have invoked further feelings of resentment and anger, while at the same time a sense of relief that he was safe. It also needs to be considered that her illness was one of the triggers resulting in her brother moving out. This may be difficult to accept considering that she had been involved with providing care for him since she was 7 years old. With the exception of simply stating that her father had committed suicide and that she had cried on the anniversary of his death, Jane made no further reference to her feelings in this regard

It is alarming that Jane's school experiences were so negative. It is particularly worrying that unruly behaviour, truancy or not completing homework (resulting from being overwhelmed in the home environment) was not recognised as a cause for concern. This was instead punished by repeated detentions, causing repeatedly missed meals and resultant loss of weight. It is a point of concern that Jane found herself laughed at by a teacher (in front of her classmates) when she was upset about her father's death. The potential damage of this educator's insensitivity cannot be underestimated, especially in the light of Jane's electing to simply stay away from school and current inability to allow herself to cry. In Jane's life the home environment was overwhelming and sometimes abusive; which, unfortunately, appears to have been echoed in the school context. The only allowances Jane experienced were when she herself became ill. This is an interesting point, as it may go some way to explaining why her younger brother subsequently manifested a mysterious stomach complaint (which could not be diagnosed) resulting in him leaving school. While the pressures placed on educators can be appreciated, this speaks to the need for training in the roles expected of, and pressures placed on young carers.

While Jane minimises her young carer role, her commentary suggests that providing predominantly emotional support for a parent with mental illness and a vulnerable younger sibling, has impacted her life in significant ways. It is also evident that the CYCP have provided valuable support and a means of escaping from the home environment on occasion. This is especially important in the light of Jane's professed rural isolation and current restricted mobility. This paper concludes that the Cornwall Young Carers Project has made significant progress towards achieving all of its original aims and goals, and has exceeded a number of its targets. The continuous assessment of young carers' needs has also been a significant cornerstone of the overall success of the project. It is encouraging to note that this process has been conducted with constant service user feedback and consultation. The young carers are the major stakeholders and their input has been valued at every stage of the project's development.

The project has been able to respond to the needs of young carers by providing one to one mentorship, support services, as well as range of respite and educational opportunities. It is clear from feedback received in this evaluation that the CYCP provides a critical and valued service to a vulnerable group of young people.

Not only has the project increased its profile in Cornwall, but perhaps more importantly, the young carers have been granted opportunities to present their experiences and insights to local and national audiences. This has served to both empower young carers and encouraged confidence in their abilities to advocate on behalf of their own needs and rights. Furthermore, the project has placed a great deal of their work around holistic family care and support. No longer are the young carers viewed in isolation, but their needs are seen by CYCP within the context of their families.

REFERENCES

- Aldridge, J. & Becker, S. (1993). Children as Carers. *Archives of Disease in Childhood*, 69, 459-462.
- Aldridge, J. & Becker, S. (1988). *The National Handbook of Young Carers Projects*, Carers National Association, London.
- Aldridge, J., & Becker, S. (1999). Children as carers: the impact of parental illness and disability on children's caring roles. The Association for Family Practice. *Journal of Family Therapy*, 21, 303-320.
- Banks, P, Cogan, N, Deeley, SW, Hill, M, Riddell, S, & Tisdall, K. (2001). Seeing the Invisible Children and Young People Affected by Disability. *Disability and Society*, 16(6), 797-814.
- Becker, S. (2000). Carers and Indicators of Social Exclusion, *Benefits*, 28, April/May: 1- 4.
- Becker, S., Aldridge, J., & Dearden, C. (1998). *Young carers and their families* Oxford: Blackwell Science.
- Becker, S., Aldridge, J. & Dearden, C. (1998). *Young Carers and their Families*. Blackwell Science, Oxford,
- Becker, S., Dearden, C., & Aldridge, J. (2001). Young carers in the UK: research, policy and practice. *Research, Policy and practice*.
- Butler, A.H. & Astbury, G. (2004). The Caring Child: an Evaluative case study of the Cornwall Young Carers Project. *Children and Society*. Volume 19 no 5.
- Butler, A.H. & Astbury, G. (2005). *A five-year evaluation of the Cornwall Young Carers Project*. Commissioned report by the Cornwall Rural Community Council.
- Carers (Recognition and Services) Act 1995. London: The Stationery Office.
- Caring about Carers (National Strategy for Carers) (1999). London: Department of Health.
- Crabtrees, H. & Warner, L. (1999). *Too much to take on: a report on young carers and bullying*. London. Princess Royal Trust for Carers.
- Dearden, C., & Becker, S. (1998). *Young carers in the UK: A Profile*. Carers National Association: London
- Dearden, C. & Becker, S. (1998). *Sheffield Young Carers Project: The Evaluation*. Young Carers Research Group. September 1998.

Dearden, C. & Becker, S. (1999). The experiences of young carers in the UK: the mental health issues, *Mental Health Care*, Volume 2, No. 8, 273-276.

Dearden, C., & Becker, S. (2000). *Young carers' transitions into adulthood*. Can be found at <http://www.jrf.org.uk/knowledge/findings/socialpolicy/630.asp>

Dearden, C & Becker, S. (2004). *Young Carers in the UK: The 2004 national report*. Young carers research group. Loughborough University.

Department of Health (1989) *The Children Act 1989*. London: Department of Health.

Department of Health (1996). *Carers (Recognition and Services) Act of 1995: Policy guidelines and practice guide*. London: Department of Health.

Department of Health (1996). *Young Carers: Making a Start*. London: Department of Health.

Department of Health (1999). *Caring about carers: a national strategy for carers*. London: Department of Health.

Department of Health (2000). *The Framework for the Assessment of Children in Need and their Families*. London: Department of Health

Eley, S. (2004). "If they don't recognise it, you've got to deal with it yourself": gender, young caring and educational support. *Gender and Education*, Vol. 16, No 1., 65 – 75.

Frank, J., Tatum, C., & Tucker, S. (1999). *On Small Shoulders: learning from the experiences of former young carers*. London: The Children's Society.

Frank, J. (2002). *Young Carers and their families*. Paper presented at the Positive Links: a conference to explore positive links for young carers in Cornwall, 5 March 2002, Truro, Cornwall.

Kornblum, H. & Anderson, B. (1985). Parents with insulin-dependant diabetes: impact on child and family developments, in: S Thurman (ed.) *Children of Handicapped Parents: research and clinical perspectives*. London: Academic Press.

National Social Services Inspectorate (1999). *Young Carers, Something to talk about*.

Office of National Statistics (1996). *Young carers and their families*. London: The Stationery Office.

Olsen, R. (1996). Young carers: challenging the facts and politics of research into children and caring. *Disability and Society*, Vol. 11, No. 1, 41-54

Princess Royal Trust for Carers (2005). Can be found at <http://news.bbc.co.uk/1/hi/health/3614918.stm>. Last accessed 12 November 2005.

Segal, J. & Simkins, J. (1993). *My mum needs me: helping children with ill or disabled parents*. Harmondsworth. Penguin.

Underdown, A. (2002). 'I'm growing up too fast': Messages from Young carers. *Children and Society*, 16, 57-60.

Young, P. (2000). *Mastering Social Welfare*. Palgrave: Basingstoke, Hampshire

Dr Allister Butler currently holds tenure as the Professional Lead and Principal Lecturer in the Social Work Department at Canterbury Christ Church University, in the United Kingdom. Dr Gaynor Astbury is a community researcher in Cornwall, United Kingdom. Dr Allister Butler can be contacted at Social Work Department, Canterbury Christ Church University , North Holmes Road, Canterbury, Kent, CT1 1QU, United Kingdom, or by e-mail: allister@abutler.net