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# **THE CORNWALL YOUNG CARERS PROJECT: PHASE TWO EVALUATION**

**February 2005**

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Dr Butler has worked in various social work capacities (practitioner, researcher, evaluator, lecturer and academic) in the area of children, youth and families for the past 15 years. He has worked in different international settings, namely: South Africa, United States of America, Taiwan and the United Kingdom. Upon completing his Ph.D. in South Africa in 2000, he took up the post as programme evaluator for the CloS Health Action Zone. He supported research and evaluation capacity building with children and young people's project leads from the various statutory and voluntary sectors, including the Cornwall Young Carers project (CYCP). As part of the University of Plymouth evaluation team Dr Butler was commissioned to conduct the first evaluation of the CYCP. For further details of this evaluation please see (Butler and Halliday, 2001), and Butler and Astbury (2004). Thereafter Dr Butler was employed as a Senior Lecturer in the Department of Social Work at Sheffield Hallam University. Dr Butler has been published in a wide range of specialisms, ranging from young carers, gay and lesbian youth and international social work practise. He has been invited as an international Socrates scholar to teach at various higher education institutions in Europe (Sweden, Holland, Denmark and Norway). Currently, Dr Butler holds tenure as the Professional Lead in Social Work at Canterbury Christ Church University College. Dr Butler can be contacted at: Social Work Department, Canterbury Christ Church University College, North Holmes Road, Canterbury, Kent, CT1 1QU or via e-mail at: [ahb4@cant.ac.uk](mailto:ahb4@cant.ac.uk)

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Dr Astbury began her career in South Africa as a pastoral community worker, specialising in youth work. She subsequently trained as a generalist psychologist in her B.A. and B.A Hons degrees before specialising as a Research Psychologist to doctorate level. Following 8 years of working in the academic arena (lecturing, skills development, researcher and practitioner) at the University of Port Elizabeth (South Africa), Dr Astbury moved back to the U.K. Upon relocating to Cornwall in 2001, Dr Astbury began working once again in the community-based sector, focussing on the field of back-to-work initiatives (Cornwall Action Team, SureStart for Employment and Neighbourhood Pathways/Pathways Plus projects). She currently manages a back-to-work project based in Falmouth, Cornwall, offering holistic support to disadvantaged service users wishing to return to work or training. In addition to this work, Dr Astbury has published and offered conference work and training in the fields of health psychology, social psychology and pastoral psychology. Her current research interests include young carers and gay/lesbian issues.

## 1. INTRODUCTION

This paper will report on a three-year (2002 – 2004) evaluation of the Cornwall Young Carers Project (CYCP). This time period is referenced as 'phase 2'. Comparative references will be made to phase 1 of the project's evaluation cycle, which was conducted from June 1999 to December 2001. Please see Butler and Astbury (2004) for an overview of the findings from the first phase of the project.

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 is more comprehensive as it includes perspectives from all the major stakeholders, namely: the young carers themselves, parents, service providers and project leads. This evaluation will focus on these perspectives and insights as articulated by the stakeholders, as well as mapping structural and programme changes which have occurred since the project's inception (1996) and operational status (1999/2000). Furthermore, this report will assess which recommendations (policy and practice) have been adopted and integrated since the initial evaluation, and propose new recommendations based on phase 2 of the CYCP evaluation process.

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.

In 1996, Social Services, the Youth Service, British Red Cross and the Cornwall Rural Community Council worked together to set up a young carers support group. This was intended to be a pilot project to assess and demonstrate the need for support to this particular group of young people. Funding was provided (Cornwall Social Services and Cornwall and Isles of Scilly Health Action Zone) for a full time project lead in mid 1999 to develop and manage the CYCP. The project only became fully operational in 2000.

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 1995), 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
- 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 report will discuss how the number of young carers identified by the CYCP has increased substantially over the last three years, 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 (<http://news.bbc.co.uk/1/hi/health/3614918.stm>).

## **2. NATIONAL CONTEXT: POLICY, PRACTICE AND LEGISLATION**

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.

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.

Furthermore, the new Connexions service has been established to ensure the 'best start in life for every young person' by providing personal support, guidance and advice for all young people aged 13 to 19 years. Young carers are recognised as a priority group for multi-agency support, to address their specific opportunities in education, employment and community life. The Youth Service plays a central role in Connexions work, and can support vulnerable and at risk young people in a variety of ways, including mentoring, counselling, advice and information, and personal development activities in youth centres, and projects around the county.

Another important consideration is the recommendations resulting from "Caring About Carers – A National Strategy for Carers" (March 1999), which encourages Social Services Departments to work with other agencies in order to support young carers better, particularly in the areas of:

- Schools: whose role it is to liaise with and refer young carers to relevant organisations within the community; education about young carers is included in PSE lessons (Personal and Social Education), heightening awareness of pupils and staff.
- Improving awareness training for GPs, primary health care teams, social workers and teachers.
- Increasing community support for carers, and promoting their independence.

Following the *"Framework for the Assessment of Children in Need and their Families"* (DOH, 2000), it is intended for Social Services to continue working with other agencies in a shared and more focussed assessment process. This is also a requirement of the *Quality Protects Special Grant for Children's Services* – all of which impact upon the lives of young carers.

This paper will report on the findings of a three-year evaluation (2000 - 2004) of the CYCP, and contextualise these local findings with national trends relevant to the experiences of young carers. More specifically, comparative references will be made to the findings from Deardon and Becker's national 2004 survey report, in which 87 young carers projects were evaluated (and a total of 6,178 young carers).

### **3. METHODOLOGY**

The approach adopted in this evaluation strategy 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.

#### **3.1 Demographic distribution**

##### Data collection and analysis

Following the phase 1 evaluation it became evident that the CYCP would need to keep more detailed and systematic information relating to their client group. This was felt essential in order to assist need based project evaluation and to feed meaningfully into the phase 2 evaluation. Details of newly identified young carers (including age, gender, location and extent of caring role), referral sources and distribution were compiled and provided to the evaluators for analysis. These were examined descriptively, where possible, in terms of shifts from phase 1 to phase 2. Details of service provision were also evaluated, in terms of types of service provision, frequency and collaborative working.

#### **3.2 Focus group with young carers**

##### Sampling procedures/criteria for inclusion

Purposive and convenience sampling was used. The CYCP project lead chose those young carers whom she felt could make the most significant contribution to the evaluation process. Participation was voluntary. As a result 9 young carers were invited to a residential weekend with the specific aim of evaluating the project. Of the 9 participants, 5 were female and 4 were male, and their ages ranged from 13 to 18. The criteria for inclusion included: young carers had to have been involved with the project for at least one year,

and voluntarily agreed to participate (see appendix 1 – informed consent form).

### Data collection and analysis

An interview schedule was used to guide the co-facilitated focus group interview. Permission was sought from each young carer participating (see consent form in Appendix 1). The evaluation process and their rights of anonymity within that process were explained at the outset of the focus group. Young carers were given permission to withdraw at any point. It was explained that should any area be addressed that they were not comfortable discussing in a group context, they had the right not to respond. It was also explained that should any participant say anything during the focus group which they later felt they would prefer not to be included, they had the right to tell the evaluators and this would not be included in the report. While not in the interview context, the project lead was available within close proximity should any young carer become distressed during the focus group. Signed consent forms were countersigned by the project lead, as *loco parentis* within the evaluation process. Interview schedules were submitted to the CYCP workers prior to the evaluation taking place, to ensure suitability for use with young carers. The main focus areas included: demographic information, understanding of their young carer roles and responsibilities, compounding variables, experience of statutory and voluntary support systems, experience of the CYCP project, coping strategies and their sense of self. The focus group was audio taped, and subsequently thematically analysed by both researchers. Emergent themes were sorted into meaningful categories.

### **3.3 Critical case studies**

#### 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, and subsequently thematically analysed by both evaluators. Resultant themes were sorted into meaningful categories.

### **3.4 Semi-structured interviews with young carers' parents**

#### Sampling procedures/criteria for inclusion

A convenience sampling strategy was adopted, as the potential pool of parents was limited. The criteria for inclusion were: voluntary participation, a willingness and ability (given their physical and mental health impairment) to participate in the evaluation, and their child could have been associated with the CYCP for any given period of time (i.e. only recently joined the project as well as being involved from the inception of the project).

#### Data collection and analysis

An interview schedule was used to guide the semi-structured interviews with the parents. The interview covered topics such as their illnesses, how their child was referred to CYCP, roles and responsibilities of their child as a young carer, perception of the worth and quality of the project to themselves and their child, and service provision from other agencies. Seven parents

participated in interviews, which were administered by CYCP project workers. All participants were female. Their ages ranged from 38 – 55. Participants were drawn from the Penwith, Saltash, Caradon, Restormel and Launceton areas. Responses were transcribed verbatim and thematically analysed by both evaluators. Resultant themes were sorted into meaningful categories.

### **3.5 Semi-structured interviews with project workers**

#### Sampling procedures/criteria for inclusion

The project lead and the project field worker were interviewed. The project lead has been with CYCP since 1999, and hence could also provide an in-depth and longitudinal focus of enquiry. The field worker, having joined the team in phase 2, could provide significant data pertaining to the fieldwork aspect of the project.

#### Data collection and analysis

A structured interview schedule was used to guide these interviews. Initially, the interview focused on events leading to the creation of the CYCP, as well as phase one (1999 – 2001). However, the primary focus of the interview pertained to the project's programme cycle from 2002 until December 2004. The interviews covered topics such as service provision, gaps and barriers to provision, partnership working, assessment of young carers needs and various referral systems, outcomes and target achievements, goal setting, carer identification, amongst other issues. Interviews were audio taped and subsequently thematically analysed by both evaluators. Themes were sorted into meaningful categories.

### **3.6 Service providers survey questionnaire**

#### Sampling procedures/criteria for inclusion

All possible agencies (both voluntary and statutory), which are involved or connected to the CYCP, were considered. The only criterion for inclusion was direct involvement in any aspect of the daily operations and implementation of the CYCP services.

### Data collection and analysis

Questionnaires were distributed by mail to 15 service providers. A response rate of 7 was obtained. Questionnaires comprised a number of closed and open-ended questions, focussing on:

- area of operation
- agency represented and job title
- length of time in post
- gender
- how long the participant had known about the CYCP (i.e., from its inception [1999], through the middle stages of the project [circa 2002], to the latter stages of the project [circa 2004])
- how the participant had first heard about CYCP
- whether the participant could have defined the term “young carer” when the CYCP first began, and where their understanding currently stood
- whether their agency had direct contact with young carers and reasons for that contact or lack of contact
- whether their agency had direct contact with family members of young carers and reasons for that contact or lack of contact
- an exploration of the referral process, examining how referral rates could be improved and any difficulties encountered
- an exploration of how multi-agency collaboration and partnership working could be enhanced to provide holistic support to young carers
- an exploration of how service delivery could be enhanced to meet the growing and diverse needs of young carers both locally and countywide

Responses were analysed according to emerging themes and categories.

## 4. RESULTS AND DISCUSSION

When presenting results, the evaluators have used direct quotes from the pool of participants in order to substantiate the emergent themes. In these quotes CYCP is sometimes referred to as YCP (Young Carers Project).

### 4.1 Demographic distribution

This section of the evaluation report focuses on changes and developments from phase 1 to phase 2 of the CYCP. This will be examined in terms of the demographic profile of young carers (numbers identified, gender, age, location and referral source), types of activities undertaken, additional forms of support provided, medical conditions of parents and extent of caring role.

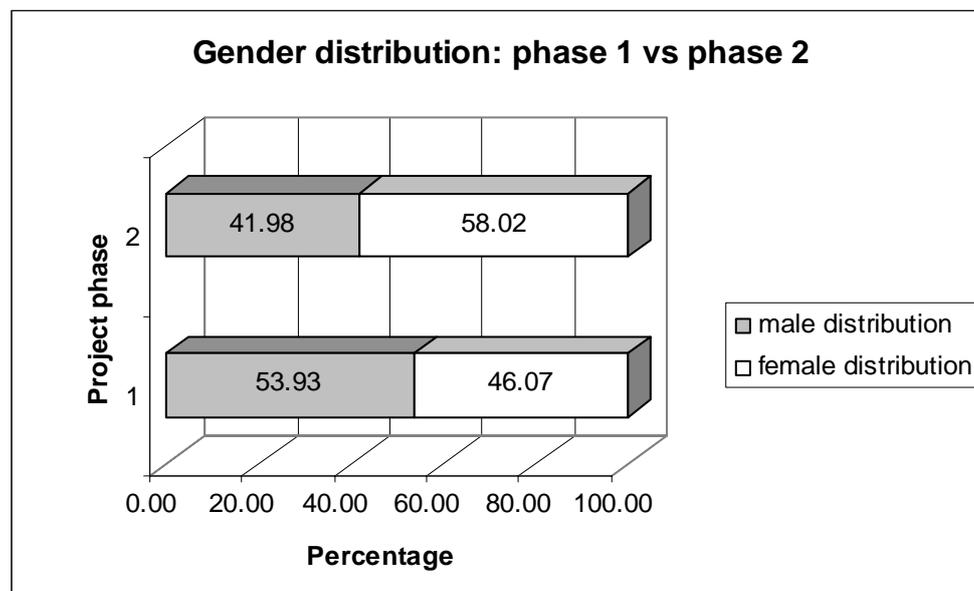
#### Young carer identification

In phase 2 of the project 343 young carers were identified. This is a significant increase in the number of referrals when compared to phase 1 of the project ( $N = 202$ ).

#### Gender distribution

Some differences were noted regarding the gender distribution of the client base. In phase 1, identified young carers were predominantly male ( $n = 48$ , 53.93%). Whereas in phase 2 the identified young carers are predominantly female (58.02%,  $n = 199$ ) compared to males (41.98%,  $n = 144$ ) (as noted in Figure 1).

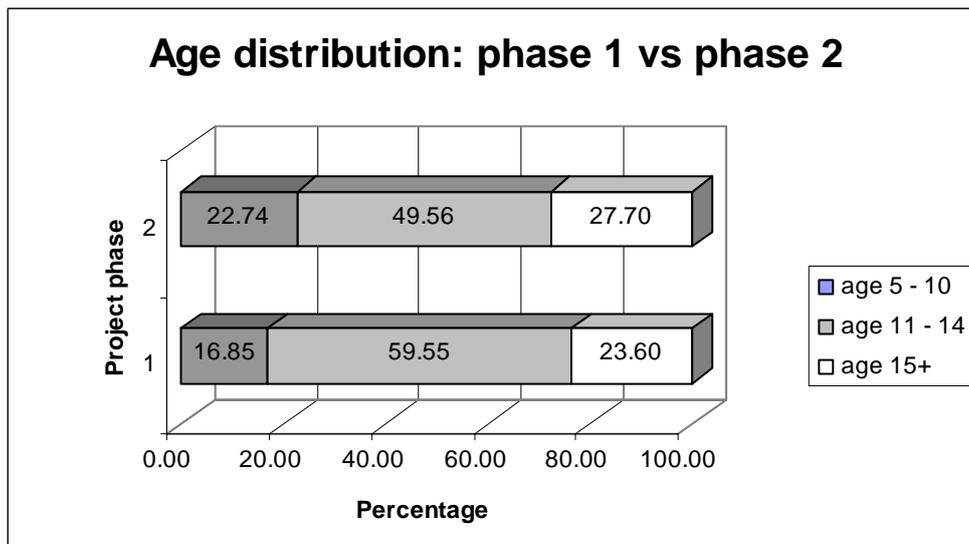
Figure 1



### Age distribution

Some interesting shifts have occurred regarding age distribution (see Figure 2). While the 11- 14 year age group is still the most commonly identified group of young carers (49.56%,  $n = 170$ ), there have been increases in the identification of young carers in both the 5- 10 year range and those aged 15 years plus. Whereas in phase 1 the age 5 – 10 group comprised only 16.85% ( $n = 21$ ); in phase 2, 22.74% ( $n = 78$ ) fall into this category. This is reassuring as it implies that those in the most vulnerable age range are being identified earlier. However it also speaks to the increasing need for mentoring to be provided for the younger age range. Similarly those in the age 15+ age group are also being more readily referred to the project (23.6% [ $n = 15$ ] in phase 1, compared to 27.7% [ $n = 95$ ] in phase 2). Again this is reassuring as it means that support is being provided to those who are entering the transition into young adulthood and making life choices with serious implications for their future.

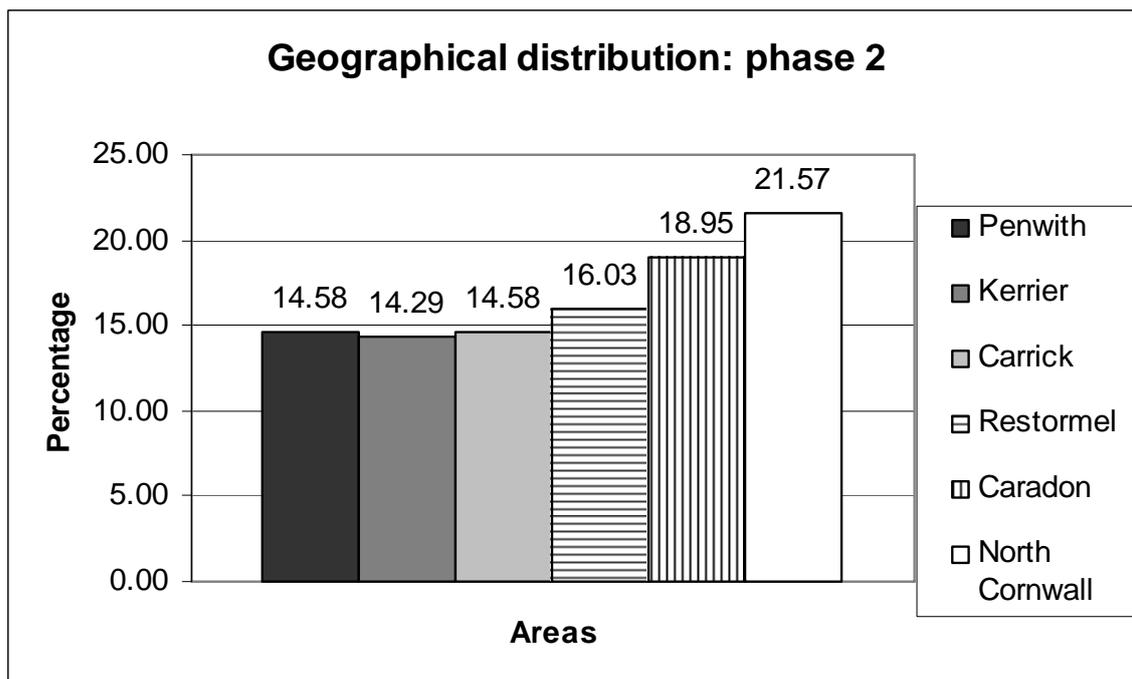
Figure 2



Geographical distribution

A relatively even distribution of young carer identification has occurred across the six areas covered by CYCP. The difference in real terms between Penwith (currently emerging as the lowest serviced area) and North Cornwall (currently emerging as the most serviced area) translates into only 24 young carers. This can be seen in Figure 3.

Figure 3



Due to changes in local authorities, it is difficult to provide a point of comparison with the 5 areas covered in phase 1. However, these findings can be found in Butler and Astbury (2004). It suffices to say that with the provision of an additional worker in phase 2, the work is more equitably spread across all target areas – whereas in phase 1, work tended to centre predominantly on West Cornwall and Carrick. There has also been a noticeable increase in service provision to North Cornwall (11.24% [ $n = 10$ ] in phase 1, compared to 21.57% [ $n = 74$ ] in phase 2.

The issue of rural isolation was raised in phase 1, as it was felt to impede young carers from attending services and also impacted on their caring role (e.g., doing shopping and transport). In the current phase, it was noted that approximately one third of identified young carers lived in rural areas.

As can be seen by the increase in client referrals, the referral system has grown exponentially during phase 2 of the CYCP. This is encouraging as the CYCP workers have made concerted efforts to network and distribute information about the project. Some notable differences are worth mentioning. Social services still emerge as the predominant source of referrals; however whereas in phase 1 only 51 referrals were forthcoming, in phase 2 this has increased to 133 referrals. The referral rate from MHCSWs and CSWs has also slightly increased from 11 in phase 1 to 20 in phase 2. It is also exciting that self-referrals are starting to occur (at present only 6) as this indicates that information about CYCP is becoming more widely spread in the community. The scope of referral sources has increased dramatically.

During phase 2 referrals were received from:

- Self referrals
- Social services
- School nurse
- GPs
- CPNs
- Schools
- MHCSWs/CSWs

- Health visitors
- EWOs
- Child and family services
- Connexions
- Surestart
- Stroke association
- Youth service
- RATS
- Police

Unfortunately, there are also some alarming similarities with phase 1, in that what should undoubtedly be primary sources of referral are simply not forthcoming as such. In phase 1, school nurses had only referred 1 young carer and in phase 2 they have referred 2 young carers. This is a disappointing referral rate. Schools have lessened their referral rate, having referred 5 young carers in phase 1 and only 4 in phase 2. Young carers report considerable difficulties in the school environment (including: poor academic achievement, not turning in homework on time or not at all, school absences due to having to care for ill parents, and difficulty in keeping school uniforms clean and in good repair). Young carers express embarrassment at being 'below standard' in their school environment and this impacts on their sense of well being and stress levels. Low academic standard also has the capacity to impact on future career options in a detrimental way. It is therefore essential that young carers should be identified within the school environment and referred for appropriate support from CYCP. Equally disappointing is the continuing low referral rate from GPs (2 referrals in phase 1, and 2 referrals in phase 2).

While the numbers of referrals and referral sources have increased in phase 2, it remains a matter of concern that some primary referral sources are not referring adequately. This needs to be a priority issue in phase 3 of the project. The need for mentoring in the 5 – 10 year age group remains a

matter of concern and should be given increased attention as the CYCP develops.

### Service provision

CYCP project workers provided detailed information pertaining to activities undertaken with young carers, including:

- type of activity
- number of young carers attending
- month of delivery
- age group of those attending
- whether the activity was a day trip or residential
- the aim of the activity
- transport provision

A comprehensive list of activities and events can be seen in Tables 1, 2 and 3. Some activities are age delimited due to health and safety reasons, suitability for age group and availability of funding. Letters are sent to all eligible young carers within these criteria and activities are based on a first come first serve basis. However, some activities are open to all young carers (e.g., ice skating and swimming).

Whereas in 2002, activities were only offered over the summer months and focussed exclusively on respite, over 2003/4 an effort has been to offer a range of activities (including educational and respite). It is also noted that activities now take place over the course of the year.

**Table 1: Activities provided in 2002**

Activity	Number of Y.C. attending	Month	Age group (in years)	Day trip or residential	Aim	Transport provision
Alton Towers	30	July	10+	2 day trip	Respite	CCfV and coach
Ice skating and swimming	35	Aug	10+	Day trip	Respite	CCfV and coach
Snowboarding and skiing	30	Sept	12+	Day trip	Respite	CCfV and coach
Disneyland Paris	35	Oct	7+	Residential	Respite	CCfV , coach and Euroshuttle

CCfV = Cornwall Centre for Volunteers; Y.C. = young carers

**Table 2: Activities provided in 2003**

Activity	Number of Y.C. attending	Month	Age group (in years)	Day trip or residential	Aim	Transport provision
Pantomime	30	Jan	8 – 18	Day trip	Respite	CCfV and coach
Consultation day	8	Mar	11 - 18	Day trip	Educational and respite	CCfV
Horse riding	20	Apr	12+	Day trip	Educational and respite	CCfV and hire car
Snowboarding and skiing	42	Jun	9+	Day trip	Respite	CCfV and coach
Consultation day	13	Jun	12+	Day trip	Educational and respite	CCfV
Alton Towers	32	Jun	11+	Residential	Respite	CCfV
Young Carers Festival	26	Jun	11+	Residential	Educational and respite	CCfV and coach
Flambards	6	Jul	7 - 11	Day trip	Respite	CCfV and hire car
Theatre ("Joseph")	25	Aug	11+	Day trip	Respite	CCfV and coach
Meeting with MPs	6	Sept	12+	Day trip	Educational	CCfV
Activities weekend	13	Oct	12+	Residential	Educational and respite	CCfV
Disneyland Paris	12	Dec	10+	Residential	Respite	CCfV

Table 3: Activities provided in 2004

Activity	Number of Y.C. attending	Month	Age group (in years)	Day trip or residential	Aim	Transport provision
Young Carers Forum	15	Jan	12+	Day trip	Educational	CCfV
Activity fun day	10	Feb	<10	Day trip	Respite	CCfV
London weekend trip	5	Feb	13 - 16	Residential	Educational and respite	Hire car
Ice skating and swimming	45	Apr	7 - 18	Day trip	Respite	CCfV and coach
Theatre ("Grease")	13	May	11 - 17	Day trip	Respite	CCfV and coach
Crealy Adventure Park	10	Jun	<11	Day trip	Respite	CCfV
Young Carers Festival	27	Jun	11 - 18	Residential	Educational and respite	CCfV and coach
Willow workshop	11	Jun	10 - 16	Day trip	Educational and respite	CCfV
Residential weekend	15	Jul/Aug	11 - 17	Residential	Educational and respite	CCfV and hire car
Quad biking and go-karting	30	Aug	11 - 16	Day trip	Respite	CCfV
Youth achievement awards	12	Sept	11 - 17	Day trip	Educational and respite	CCfV
Paintballing	25	Oct	12+	Day trip	Respite	CCfV, minibus and hire car
Evaluation weekend	9	Nov	11 - 17	Residential	Educational and respite	CCfV
Eden Project	11	Nov	14+	Day trip	Educational and respite	CCfV
Swimming	4	Nov	12+	Day trip	Respite	CCfV
Ten Pin bowling and quasers	17	Dec	5 - 12	Day trip	Respite	CCfV, minibus and hire car
Theatre ("Fame")	17	Dec	11 - 16	Day trip	Respite	CCfV and coach
Christmas party	35	Dec	10+	Day trip	Respite	CCfV

A variety of agencies and individuals were involved in the provision of activities:

- Youth achievement awards (Cornwall Youth Service)
- Consultation events (Health visitors, Cornwall Youth Forums, Connexions, Absolute Sports Adventure, Nicky Chambers – willow workshop)
- Volunteers (to ensure adequate child/adult ratio)

In addition to providing a variety of respite and educational opportunities, CYCP also provides one-to-one support for young carers. This is borne out by comments by the young carers and their parents in which they attest to the value of having CYCP workers available to listen to and support young carers (discussed later in this report).

### Signposting and advocacy

Another primary role of the project is that of signposting to suitable agencies.

During phase 2, young carers had been signposted to:

- Cornwall Youth Service (mentoring / counselling scheme)
- Connexions
- Tic Tac Office
- Chicks Holidays for the Disadvantaged
- Penhaligon Friends
- Disability Living Allowance
- Housing

The CYCP workers in collaboration with other agencies have provided advocacy on behalf of young carers and their families where needed.

### Grant provision

In order to explicate the demand placed upon funding by requests for grants from young carers, CYCP workers provided details on the number of grants allocated, as well as the types of grant requests received during phase 2. An astonishing 330 young carers have received grants during phase 2. Grant funding is required for attendance of events and activities as well as allowing for specialist provision and personal/financial needs. Types of grants allocated include:

- Trips and activities
- Horse riding
- Driving lessons
- Computers
- Mobile phones and top up cards

- Dance/drama lessons
- Clothes
- Drumming lessons
- Tae Kwondo
- Transport to discos
- Bicycles and helmets
- Skateboards
- Dentist
- Visits to parents in hospital
- Football and transport to football games
- Swimming lessons
- After school clubs
- Youth achievement awards
- Fishing lessons

In reading this list it is evident that all of these expenditures are the types of funding typically provided for young people by their parents or guardians. However in their current context, without this assistance, young carers would not have access to daily activities and personal expenses which most young people take for granted. While it is evident that CYCP is itself limited by funding and therefore cannot provide every young carers' expenses, this provision demonstrates that a concerted effort is being made to provide a sense of normalcy to these young people.

#### Medical conditions (of parents) and extent of caring role

The types of medical conditions experienced by parents as well as the extent of the caring role have been monitored during phase 2 of the CYCP. In terms of type of disability/illness experienced by parents, mental health is the most prevalent ( $n = 182$ ), physical disability ( $n = 83$ ) and chronic illness ( $n = 79$ ) are comparable in frequency, and substance misuse ( $n = 13$ ) is the least prevalent. It is difficult to provide a percentage breakdown for this information, as more than one young carer may have commented on the same parent, plus parents may present with more than one condition.

In terms of the extent of their caring role, 81 young carers reported caring for 1 adult, 50 reported caring for more than 1 adult, 75 reported caring for both adults and siblings, and 137 reported co-caring with siblings. The stress of caring is exacerbated when caring for more than one person simultaneously. This is an important consideration in the light of 212 young carers reporting caring for more than one person (additional adult and/or siblings).

## 4.2 Young carers' perspectives

The following themes arose from the focus group conducted with 9 young carers from the CYCP project.

### Caring responsibilities

At the outset of the focus group the participants were asked to identify the main responsibilities that were inherent to their daily lives as a young carer. In response, they mentioned tasks such as housework, medication management and administration (for ill parent), caring for siblings (both younger and older), dressing and feeding parent(s), co-ordinating meetings with service providers, managing the household finances, shopping and budgeting, advocacy on behalf of their parents needs, amongst others. Rather poignantly two young carers summarised their caring responsibilities as: *“All the stuff that mum would normally do, I have to do.”*; *“It feels like being a responsible parent all the time... like all the paperwork and making sure that the bills are paid on time.”*

Young carers also stated that their responsibilities and daily tasks were in no way reduced over the weekend. In fact, many of the participants felt that their 'workload' increased over the weekend. As one participant said: *“Sometimes on the weekend it is worse because I have to take care of the backlog of work I could not do in the week as I was in school.”* Other young carers spoke about the mental and physical fatigue they experience at the weekend: *“On the weekends I am so tired that I don't want to get up on Saturday morning.”* One of the ironies is reflected by one young carer who felt that it was far better being at school all week: *“because at least when I am at school, no one*

*asks me to take care of my mum at home all day.*” This reflection is in stark contrast to many other teenagers in the UK, who would invariably prefer being at home and engaging freely with their friends, than being at school all day. This further demonstrates both the magnitude of caring role and variant socialisation processes that these young carers endure. Their daily reality prescribes that attending school on a full time basis is coupled with the full time household responsibilities that are usually the domain of parents. Invariably, their adolescent peers do not share this ‘double reality’.

#### Likes and dislikes of being a young carer

The evaluators thought it important to avoid adopting the assumption that being a young carer was necessarily a negative experience. Thus, the young carers were granted the opportunity to reflect upon both their likes and dislikes of being a carer, as well as providing examples of what they would like to change in these roles and responsibilities.

In terms of what they appreciated about being a young carer, numerous responses focused on the transition from adolescence to young adulthood. In one instance, a participant said: *“Being a young carer will prepare me for when I am an adult.....not like my friends who complain and get annoyed if they have to wash the pots once a week.”* It is worth noting that this young carer is only 14 years old and is already anticipating and preparing for his adulthood’s roles – when still only a young adolescent. Participants also spoke about the positive impact it has on their family relationships: *“This makes me spend more time with my family and makes us closer.”*; *“It will make me always protect my family...it tears me apart if anything bad happens to them, like if my mum got worse.”* One participant framed the positive aspects in relationship to his future career path by saying that: *“I am better off than all my friends as I already know what I want to do.... I want to get a job and care for other people...maybe like I am doing now.”*

In terms of the difficulties of their multiple roles and responsibilities, young carers spoke a great deal about their coping mechanisms and emotional exhaustion: *“I just get so frustrated and feel helpless. I don’t know what to do*

*sometimes.*”; *“Trying to cope is very difficult. I don’t tell anyone about it”*. Feelings of being trapped within their young carer role were also evident: *“I did not choose this.”*; *“But for me I have no choice. I just have to accept it and get on with it.”* These comments and reflections reinforce the sense of isolation and frustration that young carers articulated in the phase 1 evaluation of the CYCP project (See Butler & Astbury, 2004). It also expands upon the fact that these young people, who are transitioning through adolescence, have very little decision making power or influence over their caring responsibilities – and as such seem to be accepted as their everyday reality.

Other young carers framed their dislikes at their caring role in terms of the complexity of their parents’ illnesses: *“I hate it when my mum gets ill.”*; *I had to go with to hospital to take care of my sister, as well as taking care of my mum. It was too much.*” In this case, the young carer (male, aged 13 years) was simultaneously caring for his sick mother and visiting his seriously ill sister in hospital. This dual role continued when his sister returned home, as he was providing 24-hour care for a parent and a sibling. This level and complexity of care, if provided by a parent, would be enormous. Thus, the pressure and burden placed on this thirteen year old is difficult to comprehend. However, this was his reality and in his own words, *“I just got on with it.”* It is worth noting however that this young carer has left school as a result of being overwhelmed.

Parent /child role reversal was another area of difficulty identified by young carers: *“Myself and my sister find it hard being the mum all the time.”*; *“I don’t want to be the parent.”* The constant struggle and dissonance contained in being a child but also a parent figure impacts on the mental health of these young people. At school they are expected to be children, to do all of their homework and fit into their peer networks; but during school lunchtimes and outside of school hours they are juggling adult roles.

The young carers offered examples of what they would like to change about their caring roles. Central themes included a need for more understanding

and a shift in attitudes: *“If people would understand more and change their attitudes about being a carer.. just knowing me better.”*; *“I want others to go through what I go through.”* One young carer offered a poignant wish, based on his own enforced maturity: *“I wish my sister was younger because I like younger people better. They are more responsible. Like me, I am only fourteen and I take responsibility for my whole family even though I am the youngest.”*

### Personal emotional and mental health

The evaluators thought it was important that the participants did not feel that we were only interested in speaking about their parents/siblings illnesses, but that we wanted to know more about their own personal journeys as a carer. Thus, they were asked to reflect upon their own internal processes, coping mechanisms, and to think about who provides care for their physical and emotional needs.

The young carers responded by describing their own physical illnesses and how they coped with this. Their responses spoke of an inability to focus adequately on their own needs, resulting in them feeling run-down and exhausted: *“If I get ill there is not enough time to recover and get better so I always feel really run down.”*; *“I am tired....always.”*. For one young carer this had meant that their illness (a stomach complaint) kept recurring and did not seem to improve: *“I was off sick for three months. I could not get better.”* Another young carer expressed this feeling of not having time to focus on getting better simply as: *“I was so ill I felt like I was breaking.”*

Furthermore, they presented a picture of insularity and isolation in their response to emotion or mental ill health: *“I just take care of myself”*; *“I go and stay in my room.”* One young carer referenced the fact that they were not ‘entitled’ to feel upset by saying: *“I cannot get depressed. I know that.”* Expressions of ongoing feelings of being down or depressed were unanimous in this group of participants. A lack of entitlement to authentically acknowledge and express this in their family environments could potentially

have a significant impact on the overall well being of this cohort of adolescents.

The aforementioned insularity and lack of emotional expression is compounded by the fact many of the young carers reported 'hiding' or 'minimising' their true feelings, as a means of protecting and caring for their parents:

*"I wouldn't tell my mum I was feeling down because it would make her feel worse.*

*"In my family we have a rule that we don't talk about our problems."*

*"I don't like crying in front of my dad. It just makes it worse."*

*"I cannot tell people how I really feel."*

There were examples, however, of support being provided to young carers, for example: *"My gran sometimes listens to me."*; *"My sister takes care of me"*, *"My aunty sometimes comes over and takes me out for a few hours."*

#### Relationships with siblings and friends

All of the young carers in the focus group reported providing care for at least one sibling (younger and older). In one case, a young person was providing primary care for a parent, two older siblings and one younger sibling. In some instances, the level of care provided to a sibling was more complex and stressful than caring for their parent who was ill.

Further examples exemplify the difficult task of sibling care. One carer said:

*"My younger brother used to live with us. He had cerebral palsy. My mum could not cope with him so I had to take care of him. He is dead now. He died two years ago."* Another carer shared his experiences of living with and caring for his sister who is profoundly deaf: *"At first I did not understand that she was deaf. No one told me. But I got to learn sign language which was a good thing."*

The participants were also asked to explore and express the types of relationships they have with their friends. Many of the carers referenced the

fact that they often had to lie to their friends in order to 'keep their secret' of being a young carer: *"I just say that I have something to do. I don't tell them what."* This isolation and protectionism is further linked to a comment by a carer who spoke about his mother's reaction to his friends, *"I was so embarrassed because when my mother was very sick she shouted at my friends. I don't invite them anymore."*

Some participants reflected upon the frustration they felt when considering the lives of their friends in comparison with their own reality:

*"My friends just don't understand."*

*"They have so much free time and I don't have any."*

*"Eventually, after a while, they stop inviting me out. They don't like all of my excuses."*

#### Service provision (external from the CYCP project)

The participants provided examples of services that they (or their parents) had received, and reflected upon the effectiveness of these services. Overall, the comments and observations were constructive and positive. This is in stark contrast to the first CYCP evaluation report (see Butler and Astbury, 2004), in which the young carers were extremely critical of social services, the local health authority and the local education authority. This transition is perhaps, partly due, to the significant impact the CYCP project has had on shaping and influencing the level and quality of service provision to young carers in Cornwall, via their networking, information provision, advocacy and signposting).

Many of the participants reported positively about the supportive role that mentors had played in their lives, which had enabled them to cope more effectively with their roles and responsibilities as a carer:

*"I have a mentor who is a great help."*

*"I have had a Connexions mentor for a year and I get on really well with him."*

*"My mentor really listens to me. I can talk for ages."*

However, one carer had a less positive experience and said: *"I felt like my mentor was interrogating me so I dropped him."*

Participants also mentioned the role of social workers in a positive light: *“The social worker told us about the young carers project which has really helped us.”*; *“The social worker comes to our house sometimes and she is helpful.”*

The young carers provided the following suggestions in response to being asked what changes they would make in terms of service provision:

- the need for more mentors (*“We need more mentors, for all young carers. So they can listen to us and we can chat and they can offer different views.”*)
- the need for young carers to receive mental health support (*“My parents have their own social workers and CPNs which is a good thing. But I think we should also have our own social workers.”*; *“I want more services just for me and my sisters”*; *“All the services are for my mum but none for me.”*)
- the need for consistent and ongoing support (*“My mum has had help but not very helpful...because she came one and never came back.”*; *“Sometimes a service just stops and I don’t know why.”*)

These observations and recommendations refer to the critical need for young carers to be recognised as needing support in addition to their parents, and the need to consult young carers around continuity of care. Providing, and then removing a service, without consulting young carers does them a disservice. It is easy to understand why service providers would feel uncomfortable consulting young carers about both their parents and their own needs. However, this is exactly what young carers are requesting. The fact that they are taking on adult roles and responsibilities (directly or indirectly) results in young carers wanting service providers to view them in that role. This would require a significant paradigm shift in the viewpoint of many professionals, but it is change that is necessary and vital in order to maintain open lines of communication between the professionals and the family.

### Services provided by the CYCP

Initially the participants were requested to provide one word that describes the way in which they perceive the CYCP. Their words eloquently and powerfully summarise the positive relationship they have with the project: *“Fantastic”*; *“Enjoyable”*; *“Amazing”*; *“Helpful”*; *“Life changing”*; *“Great”*; *“Exciting”*; *“Love it”*; *“Spectacular”*.

Furthermore, the young carers expanded upon specific examples of what they found supportive and helpful, as well providing recommendations for change. Young carers commented on the supportive role of CYCP, in that they could be themselves, be listened to, be one of the crowd, and not feel judged when attending CYCP events:

*“What I like about the project is no one asks me any questions. Everyone is on the same wavelength and you can just be yourself.”*

*“The only person I speak to about my problems is [name of project lead]. She always listens.”*

*“I can talk to [project lead and field worker] about what I want to be and they will help me.”*

*“These are my only friends.”*

*“I did not know there were so many people just like me.”*

*“I don’t feel so alone anymore.”*

Young carers also spoke positively about the activities and trips, commenting on the fun aspects, the respite provided and the opportunity to go to places that would otherwise elude them:

*“It is nice to just laugh a bit.”*

*“Going away on trips. Just getting away.”*

*“I love going paintballing”*

*“Going to Disney Paris was great...like a dream...if it was not for the project I could never have gone there.”*

For one young carer, an overwhelming burden of responsibility had been lifted by the CYCP worker ensuring that his mother received appropriate professional support. Thus, while he commented on the value of the fun and

support aspects for himself, he felt that the most rewarding component of being involved with CYCP was that: *“They helped my mum.”*

Young carers offered a variety of suggestions for the future development of CYCP:

- more respite activities: *“Loads of little trips so you can meet up with more people. Also helps you to meet different people each time.”*; *“More breaks away so you don’t have to wait for ages till the next one comes along.”*
- opportunities to socialise more with young carers: *“Get a chance to speak to other young people more often”*; *“I would like to get together outside the group, because I live in the sticks”*; *“Evening outings on the weekends”* [this included the need to keep in touch by phone: *“I would like to text and call my friends from the project more but it is too expensive.”*]
- the need for ongoing funding: *“Need more money for things”*
- becoming more involved in broader aspects of CYCP: *“Getting involved in the web site would be cool.”*

### **4.3 Project lead and field worker’s perspectives**

The following themes emerged from interviews with the CYCP project lead and the project field worker. These themes have been categorised around three sequential stages in the development of the project.

#### **4.3.1 The Early Years (1996 to 1999)**

##### Aims

Various organisations began to identify a need among young people in Cornwall who were caring for their parents. Thus, the initial aim was to provide respite care to these young people on an ad-hoc basis. There was a gradual movement towards identification. However, this process was hampered by the fact that Social Services did not, initially at least, see young carers as having specific needs.

### Funding and pilot study

A pilot study was conducted in 1996, which began to focus on the needs of this adolescent cohort. Only ad-hoc funding was provided for a youth worker to provide respite care for young carers and enable to have an occasional residential weekend away.

### Partners

During this stage of the project, four agencies (voluntary and statutory) were involved in planning and delivering services, namely: Social Services, Youth Services, British Red Cross and the Cornwall Rural Community Council. At this stage the local health authorities were not involved in the CYCP.

### Management structure/staffing

The Cornwall Rural Community Council (CRCC) served as the managing body from the outset of the project, and still serves in this capacity. As the project lead says: *“It is important that we are under the umbrella of CRCC because they are an independent body and the young carers see that....they see Social Services as a body that would possibly come and take them away from their families.”* During this phase of project development staffing was provided on an ad-hoc basis, as specific CYCP funding had not yet been procured.

## **4.3.2 Phase 1 – the developmental years (1999 to 2001)**

### Aims and operational status

The project became operational (on a part time basis) in 1999 when Health Action Zone funding was procured. Initially the funding paid for a part time worker (22 and half hours per week). In 2000 the project was able to employ a full time project lead.

According to the project lead the initially stated aims and goals did not change. However, the level of awareness significantly increased. *“With the full time lead in place there was more opportunity to raise awareness among services about young carers and to fight for the causes of young carers. It*

*was not possible before this because I was just plugging the holes.”* The levels of referrals also demonstrated a significant increase during this phase of the project cycle. The lead explains this as: *“On my first day I had twelve new referrals on my desk. It was overwhelming at first. The numbers, in less than a fortnight, had grown by up to a third. We knew then that there was a real need.”* She further explained, *“by the end of HAZ funding the project had identified over 240 new young carers. It was dramatic.”* It is important to note that HAZ funding for the CYCP terminated at the end of 2001.

### Job description

The project lead identified how the long term funding of her post on a full time basis enabled her to broaden her job description, *inter alia*:

- she could become the ‘face of the project’
- the carers could see her on a more consistent basis and more continuity of care could be provided
- more respite could be provided (as per young carers’ requests)
- the volunteer base could be built up (which is a critical part of the overall project service delivery)
- young carers could be linked to the national young carers’ initiative, by taking young carers to the national young carers festival.

### Project achievements

The project lead reflected upon the changes in terms of project achievement by saying: *“I could not do all I wanted to do before because of lack of time... I could not give quality time to the young people. It was like splitting myself in two, between the young carers’ needs and going out all over the county and raising awareness among the professionals.”* Another achievement during this phase was the significant increase in the extent and quality of one to one work with the young carers. The lead also felt that professionals and various service providers were gradually gaining more insight into *“what young carers had to put up with in their daily lives.”*

The lead also reflected upon the project's achievement via reference to the changes she has observed in the young carers. She offered the following examples to illustrate this point:

*"On their first trip there were thirty young people on the bus and there was complete silence. You could hear a pin drop. By the time they came back they were laughing, had made new friends, and were exchanging phone numbers. It was fantastic."*

*"Like today there are some young carers who were with the project from the very beginning. It is so encouraging to see them with a smile on their face."*

*"At first when I asked the young carers what they wanted to do they did not know what to say. Because they had never been given the opportunity to say 'I want to go swimming'. And that has changed now."*

The project lead explained that it was important to give these young people their childhood back, and a sense of pride in themselves. *"Initially the young carers I met were afraid to tell people what they did. So I wanted them not to feel embarrassed but to be proud of what they did for their ill parents."*

#### Multi-agency partnership working

The project lead was encouraged by the dramatic increase in referrals, but felt that there were still areas which needed development. The relationship with social services has increased and improved over the duration of the project cycle. One example has been the young carer grants provided by social services as *"this money was ring-fenced and used for trips for the young carers."* However, it has been a very different experience with the local health authorities. The project lead's perception is that health has never really *"come on board the project."* She further stated that: *"Like GP's, never really took it on board, while they are in a primary position to both identify and refer young people to the project."* She also referred to the poor response from schools. *"Schools didn't get it. They were very closed to it [needs of young carers]. I visited a number of schools but not much happened after I left."*

It is encouraging to note that various voluntary agencies played a supportive role in service provision to the CYCP project during phase one, namely:

ACHE, BRC, Millennium volunteers, and CCVYS, amongst others. One of the most significant achievements during this time period was the level of involvement the project had with the entire family unit: *“The family unit began to trust us and built up a relationship with the project. This was good as they have so much resentment and fear towards social services, as they feel their children will be removed if they told the truth about their situation.”*

#### Frustrations and service barriers

The project lead identified the following issues as being the most frustrating issues and barriers:

- Difficulty in accessing money and young carer grants.
- Insufficient time to conduct all aspects of the work, given that the project could only afford to employ one full time worker.
- No service provision for the 5 to 12 year old age group.
- Lack of administrative support impeded continuity of care and appropriate levels of follow up with young carers and their families.

#### **4.3.3 Phase 2 – the operational years (2002 to 2004)**

##### Aims and goals

Primarily, the aims and goals of the project remained the same, i.e. identification and referral, assessment of needs, direct service provision, respite care, and one to one support, amongst others.

##### Funding and staffing

When the HAZ funding was terminated at the end of 2001, the project was funded by community/lottery funding and Social Services. This funding was provided on a three-year basis. With this funding commitment the project was able to employ a full time field worker as well as a part time administrator (in 2002).

##### Redefining job descriptions

With these new appointments, significant changes occurred in terms of both job description and priorities of service delivery. The field worker was now able to focus her work specifically in the North of Cornwall (an area which had been neglected in the past due to its geographical locality). This enabled the project lead and the field worker to split their area of work across the county, thus reaching a far greater number of young carers and agencies. This resulted in further increase of referrals. The field worker explained that her post was made easier by the fact that *“I was an adult support carer before, and therefore had built up working relationships with many of the relevant service providers.”*

The project lead felt that the increase in staffing had a significant impact in redefining her job description. She identified numerous benefits that occurred as a result of this, namely:

*“It gave me more time to meet one on one with the young carers and provide them with the support which they needed.”*

*“Although the level of paperwork increased, I was now able to respond to requests and plans far more efficiently and effectively.”*

*“It was incredibly helpful to be able to talk to [name of field worker] and bounce ideas off of her. Before I felt like I was doing it all alone and no one to share my ideas with. It is such a supportive relationship now.”*

*“In working with [name of field worker] I realised that I did not have to be perfect at everything. I soon realised that both had lots of different skills to offer and we could use them at different times.”*

*“It also gave me the time I needed to go and meet with other agencies and do presentations in schools. This really raised people’s awareness so much more.”*

### Young Carers Forum

One of the most significant achievements during this time period was the establishment of the Young Carers Forum, as well as the many links that the young carers were able to develop at both county and national levels. The Young Carers Forum was set up mid 2004 with the view of *“giving young carers their own voice, increase their confidence, and to link with the*

*countywide youth district forums.*” At one of their meetings the group invited the Director of Social Services to address them (and visa versa) and according to the project lead: *“the young carers were really tough on her and asked her really difficult questions, which was excellent.”* Furthermore, they invited the Director of Education to address the issues of ‘why teachers and schools are so insensitive to their needs.’ He promised to ensure that the young carers could present their experiences at the next ‘secondary heads conference’. While this hasn’t happened yet, it is encouraging to note just how much more empowered the young carers feel in terms of advocating on behalf of their own needs. They have also spoken to MPs about the lack of resources in Cornwall. So, as the lead stated *“the forum is all about what they want to do and it is run by them.”*

In July 2004 the young carers were also granted the opportunity of speaking at the Child protection conference. As the project lead said: *“They were upfront and honest about their situations as young carers. They raised awareness more in that one day that I have done in four years.”* The lead further explained that the young carers were able to inform and influence policy, at a countywide level, and to ensure that the needs of young carers were placed firmly on the county agenda. Since then one of the young carers presented her experiences at “The impact of caring for someone with mental health problems and its effect on children” training day.

### Management structure

The CYCP is still managed by the CRCC. They provide numerous functions, i.e. line management, accounting and financial accountability, budgeting, support with funding proposals, support and supervision, and marketing the work of the project. Furthermore, the project has its own steering group, which consists of: CRCC, Social Services, Connexions, Health, CAHMS, and Youth Services. The project workers feel that Education needs to become more involved: *“There is a great need for Education to get more involved, but this has not happened yet.”* The field worker further explained, *“We just want teachers to be more sympathetic and show more understanding towards young carers. Not to assume the worse like they just come from dysfunctional*

*families and that is why they may look scruffy or not complete their homework on time.”*

### Service Provision

During this phase the project had set up a diverse range of services for the young carers (see Tables 1, 2 and 3 detailing provision from 2002 – 2004). Some of the activities included ballet lessons, tai kwondo, horse riding, one to one support, mobile top ups, as well as various respite opportunities. These respite programmes included residential weekends, day trips and weekly holidays. More recently the young carers have been linked with the educational division of the Eden project, and as such they have been asked to make recommendations and forward ideas regarding the development of the educational activities for young people. One of the highlights was the trip to Disneyland Paris. As the project lead explained: *“this was a once in a lifetime opportunity for the young carers and they had the time of their lives. I think it is something they will never forget.”*

A significant development in service provision is the work the project has done in conjunction with the families of the young carers. The field workers explained that this priority has *“enabled us to build up a trusting relationship with the parents and now they feel safe with us”*. Furthermore, consultation with the young carers regarding service provision has been the cornerstone of the project’s development. Numerous strategies have been adopted in terms of consultation, for example:

- Consultation days
- Newsletter and designing their own T-shirts
- Consultation residential weekends
- Recently the project employed external consultants to run a consultation weekend in Wales. This included a series of activities around how the young carers felt about the project and what they would do differently.
- Young carers have been involved in all aspects of the independent evaluation of the project.

### Gaps in service provision/multi-agency collaboration

The project lead and field worker have identified numerous gaps and barriers to service provision. The following points highlight these gaps, and in so doing begin to provide an overview of the way forward for the project as it enters its next developmental cycle.

- The significant increase in the number of young carers who are caring for their siblings has highlighted a significant gap in service provision. As the lead explains: *“We know that we need to do more work around sibling care but we do not have the resources.”*
- There is a need to further expand the work of the project to the most isolated and rural parts of the county.
- Given that there is no mentoring scheme for young people under the age of 12, this is still a significant gap for the 5-12 year category of young carers. The lead stated that: *“with another paid staff member we would be able to build up our volunteer base. They would be able to recruit and train potential volunteers who could provide much needed mentoring for this age group.”*
- The lead and field worker explained that they keep their mobile phones on 24 hours a day, 7 days a week, in case of emergencies with the young carers. While this level of commitment and dedication is commendable it is simply not practical, nor is it good practise. They felt that a paid worker, or volunteers, could manage a dedicated phone line in the evening and on the weekends.
- Special training for the young carers should be provided around two specific areas: living with parents with drug and alcohol problems, as well as living with parents with mental illness.
- There is still a dilemma when considering the over 18-year-old population of young carers. As the lead explains *“they have nowhere to go when they turn 18 and are ‘forced’ to leave the project.”* The field worker elaborated upon this by saying: *“they feel lost when we have to cut them off. They feel like they have just been dropped. This is not acceptable, especially as they have learned to building trusting relationships during their time with the*

*project.*” Efforts need to be made to look at transitional care and skills training for young carers who have turned 18.

- Another issue that the lead feels needs to be addressed is the lack of access to emergency money. This has been an issue since the inception of the project and continues to impede delivery in emergency situations.

The project lead explained that while multi-agency partnership working had improved during phase two of the project cycle, that there were still issues that impeded service delivery. The following examples attest to this observation:

*“Partnership working is sometimes a problem because it makes it more difficult to access funds. The reason is due to the fact that, for example, mental health services and social services do things differently.”*

*“If a case is closed [because the parents are deemed to be mentally or physically healthy] we cannot access funds for the young carers.”*

*“Young carers should be able to access funding from the local statutory authorities in their own right, and it should not always be linked or dependent on their parent’s condition.”*

#### Project achievements and frustrations

The project lead felt that the source of many of the frustrations centred on funding. It has been clear from this evaluation that the three-year funding from the community/lottery fund has had a positive impact on service delivery.

However, procuring funding in two year (Health Action Zone) and three year (community/lottery) cycles impedes the ability of the project to consider long term planning. For example, as expressed by the lead: *“it is frustrating not being able to plan ahead. Our funding ends in July 2005 but the young carers want us to plan activities until the end of the year. We obviously cannot plan ahead as we would like to.”* The lead further explained that one of the primary objectives of the project, given that it has been operational for five years, is to receive mainstream funding from one (or a partnership between all three) of the statutory agencies. *“I am so tired of always struggling, struggling, struggling for money, and always having to beg for it. I want to the project to be picked up by mainstream funding and also maintain our independence because this is so important to the young carers.”*

The lead and field worker referenced the projects main achievements in relationship to the significant growth they had observed in the young carers:  
*“Getting to know the young people and see them grow in confidence has been amazing.”*

*“Seeing the carers being able to now sit around a table and with ease, talk openly about their caring roles.”*

*“Just being able to see them grow is so rewarding.”*

*“They are so much more proud now. When they went to the festival they were all wearing their CYCP T-shirts and you could see that they were now proud to be a young carer.”*

References were also made to the educational/achievement strategies that this cohort of young people was actively involved in:

*“They are doing Youth Achievement Awards, which is great for their confidence as they get no recognition at all at school.”*

*“[name of young carer] did a power point presentation on her experiences as a young carer to over 200 professionals in county hall; when she before she was so quiet.”*

#### **4.4 Service provider’s perspectives**

Responses were obtained from 7 service providers, representing a range of service provision throughout Cornwall, including education, health, child and family work, adult carers, and youth work. These participants represented predominantly the statutory sector. Their roles ranged through management and coordination, support work, personal advisors and community-based practitioners. Length of time in post ranged from 3 days to 8 years. However, the participant who had been in her current post for 3 days had spent 2 years prior to that in a role as personal advisor. Some providers worked across more than one geographical area, with the result that each area covered by CYCP had at least 2 participating service providers providing responses to the questionnaire. One provider was male, four were female, and two neglected to indicate gender.

### Knowledge regarding young carers and CYCP

Participants had predominantly ( $n = 5$ ) only become aware of CYCP during the middle phase of the project (i.e., around 2002). One participant had known about CYCP from its inception and had been closely involved with the project. Whereas another participant had known about CYCP from 1999, but acknowledges that she knew very little about the project or young carers. Participants recognised the role of CYCP workers in increasing their awareness of young carers:

*“As a Senior Case Practitioner in Kerrier I initially found out about CYCP through referring a young person. In my current role I have involved them in training and presentations.”*

*“Multi-agency meetings attended by CYCP worker.”*

*“I know Dawn well ... Dawn [is a] speaker on H.S.W.C volunteer programme.”*

One participant had first learned about the project via a CYCP leaflet. Whereas others had increased their awareness via working with young carers, their parents or adult carers [*“I was the first CYCP worker, from November 1999 – July 2000.”*; *“Through visiting a parent cared for by her young son.”*; *“When I began work with the CRCC Carers project in 2001.”*].

When participants were queried regarding whether they would have been able to define what a young carer was five years ago, there were varied responses. Some participants felt that they had no idea [*“In a word – NO!”*; *“No”*], whereas others felt that they had only a vague idea [*“Five years ago I could not fully provide such a definition.”*; *“I had a vague idea of young carers 5 years ago.”*]. One participant had taken up a role in the CYCP and so had found her awareness and understanding increasing at a rapid rate: *“I only gained a clear understanding of the term “young carers” and an idea of what that means/involves when I took up post as the project worker. Through development of the project, over the last 5 years, my insight/understanding and awareness has increased dramatically and the level of need identified is far beyond my initial expectations.”*

Participants expressed the view that their knowledge and understanding of young carers had improved following their increased involvement with CYCP, either in a voluntary capacity or via inter-agency collaboration:

*“Volunteering for CYCP has given me great insight into needs of young carers. The effect on the school / home life and social life is very significant.”*

*“Since working alongside a young carer’s support worker I am much more aware of services provided for young carers.”*

*“Since 2001 my awareness of the level and needs of young carers has changed and grown due to colleagues in the YCP.”*

Another participant, whose job role entails working closely with children and families, had increased his/her awareness of young carers through using the assessment framework and through extra reading: *“As a social worker I have a very good concept of needs of children in role of a carer and have frequent contact with children in this group. This awareness has improved with wider reading and use of assessment framework.”*

Due to this increased awareness, participants expressed a deeper understanding of the range of needs and barriers confronting young carers, as well as more of an understanding of the numbers of young carers in Cornwall. Only one participant felt that he still did not fully comprehend the numbers of young carers: *“The cases I have come across suggest I have no idea of the level of young people in caring roles.”*

#### Service provision to young carers

Four of the participants worked in services which came into direct contact with young carers (ranging from occasional contact to ongoing and systematic contact), whereas the others only experienced indirect contact. Those who had only indirect contact were quick to point out that young carer work fell outside of the remit of their agencies (e.g., adult work) and furthermore that they did not have the staff to work with young carers due to funding stipulations. However, they made use of the referral system where appropriate.

When considering whether their agencies would be open to offering services to young carers, the same limitations of remit and funding applied to a few participants; whereas others felt that their agencies would do anything possible to support young carers – either directly or through inter-agency collaboration.

The same limitations held true when participants indicated whether they had involvement with family members of young carers. Those involved in adult service provision, or engaged in home visitation with children and families, had more likelihood of systematic work with family members. Whereas those involved in service provision outside of the home environment were less likely to have direct contact (or may not be aware that they have contact).

#### Perspectives on the referral system

Participants offered their opinions regarding the existing referral system. Some service providers felt that the referral system was operating effectively and that they had nothing to add in this regard: *“I feel the referral system is fine.”*; *“I do not have a problem with referral in itself.”*; *No problems with referral process.”*

Participants offered some points of critique and suggestions for improvement. Some critique centred around issues of staff shortages and over demands placed on existing staff: *“For me personally, no support workers are readily available and eager to work alongside the health visiting agency.”*; *“Takes time for feedback / action.”* Other critique focussed on suggested changes to service delivery as a method of enhancing the experience of referred young carers. One suggestion was the establishment of local groups to allow easier access: *“Trips are the main service offered and whilst this is brilliant, local groups would help.”* It was also suggested that young people caring for younger siblings with special needs would benefit from inclusion: *“Cannot support children who have a sibling with extra needs, even though this frequently places children in role of a ‘carer’.”*

The most prevalent suggestion focussed on increasing the number of referrals rather than the referral system itself. Participants recognised the need for raising awareness among service providers, via information distribution and training:

*“I can only suggest a raising of awareness which I believe our local coordinator attempts during her day to day duties anyway.”*

*“By raising awareness within training and giving the CYCP the opportunity to directly input into training whenever possible.”*

*“Send out referral forms to agencies with a letter explaining the process – contact names and the support that CYCP offers to young carers.”*

*“... increase the level of referrals by continuous updated information about the project and what is provided.”*

One participant recognised that it was not solely the responsibility of CYCP to raise awareness, but rather a shared responsibility with service providers:

*“We support the initiative to raise awareness of young carers and do all we can as a project to promote the YCP.”*

#### Inter-agency collaboration and partnership working

With regard to increasing inter-agency collaboration and partnership working, responses centred predominantly around raising awareness and information sharing: *“Raising awareness at every opportunity.”*; *“Raise the profile of young carers.”*; *“Continue to look at ways to raise awareness of young carers at all levels of work.”* Some useful suggestions were offered in this regard, including:

- Allowing young carers to be ambassadors [*“Allowing the young carers themselves to talk about their experiences. They are the best ambassadors for young carers.”*]
- Information sharing [*Talk to organisations. Conference, highlighting young carers. More publicity locally.”*; *“Talking to organisations – personal touch.”*; *“By sharing information and [keeping] abreast of new developments within the project through newsletter and networking.”*]
- Shared working on projects [*“Set projects up together.”*; *“Continue to look at ways to work together as Carers Projects to all sectors.”*]

One participant expressed frustration at this area of development, commenting simply: “?? If only I knew ...?!”

### Future development of CYCP

Participants offered suggestions on how current provision to young carers could be improved, both locally and county-wide. Numerous suggestions were offered:

- Some participants felt that service provision was already of an excellent level and that this should simply continue to develop [*“Continue the excellent work already being done. Strengthen links already made with and between various agencies.”*; *“I have no criticism of the way any cases I have referred have been dealt with.”*; *“Build on the excellent work they are already doing.”*; *“Let the CYCP continue to raise the profile of young carers, support them and advocate on their behalf.”*]
- There was a recognition of the need for ongoing, adequate funding to continue the work of CYCP [*“It is essential that the CYP is continued as the support workers involved grow in their knowledge and experience and are able to provide this unique service for young carers both in our own area and across the country.”*; *“If this service were to be abandoned it would be a great loss to the young carers and to the people they support in the community.”*; *“Continued, adequate funding – multi-agency care funding? Allowing for development and staff.”*]
- The need for information sharing and awareness raising was once again identified [*“Presentations in schools... in Health Centres.”*; *“Continue awareness raising – particularly with schools and others in direct / regular contact with young people and also those who may be able to identify them through providing services / support to the parent, e.g., health / social services.”*]
- The need to keep parents fully informed and involved was identified [*“Vital to reassure parents that involvement with young carers is to support and avoid fear of children being ‘taken away’.”*]
- The role of the young carers themselves was recognised, in terms of mentoring and profile raising [*“Opportunities for young carers to contact*

*each other directly. List of all carers and phone numbers (if people agree to it). Existing young carers agree to be a contact for new carers joining CYCP – sort of befriending scheme.”; “Involve the young carers directly.”; “Use young carers (as already) to ‘speak out’ and to improve services.”]*

- The importance of need assessment was identified [*“Ask young carers what they need. Ask referrers what they think carers need.”*]
- The need for ongoing consultation in order to provide holistic support was identified [*“Service providers (health, education, etc.) in consultation / initiatives and encourage holistic support to young carers, especially at transition stages.”*]

The service providers who participated were all very positive about the work of CYCP, expressing that it was of great benefit to young carers. The need for continued awareness raising and information sharing is a recurring theme through their responses. This would be most likely to improve with increased funding, so that additional CYCP staff resources could be provided. Similarly, frustrations with time delays and limited staff availability would be alleviated. At present, with limited staff, it is a delicate balancing act between direct service provision to young carers and networking with service providers. On an encouraging note, the suggestions offered are predominantly initiatives which are already underway, e.g., young carers as ambassadors; young carers offering support to each other; need assessment with young carers; involvement of parents; ongoing consultation; and distribution of information to schools and service providers. However, it is clear that there is scope for increased collaboration and holistic working in this area. This has increased from the inception of the project to its current stage. No doubt, this will continue to improve as the project develops and grows. The insight offered regarding the role of other service providers in raising awareness of CYCP is a valuable point and one which, if taken on board, could exponentially increase knowledge and understanding of the roles and needs of young carers and the support offered via CYCP.

## 4.5 Perspectives of parents

Parents of young carers involved in CYCP offered their comments and perspectives regarding their life experiences, the roles and responsibilities of their children in their caring role, and the value of CYCP in supporting their family systems.

### Medical condition

Parents were debilitated by a variety of chronic illnesses and disabilities, with most experiencing multiple conditions:

- MS
- Ankylosing Spondylitis
- Psoriasis
- Registered blind
- Learning disabilities
- Myalgic Encephalomyelitis
- Arthritis
- Fibromyalgia
- Clinical depression
- Postnatal depression
- Carpal Tunnel Syndrome

Duration of illness/disability ranged from 3.5 years to disability since birth. For some parents, medical conditions had been compounded by traumatic experiences such as grief and bereavement, marital breakdown and domestic violence.

### Impact of medical condition on daily functioning

All participants expressed that their medical conditions impacted significantly on their daily functioning:

- Difficulties with balance and coordination
- Memory problems, a sense of confusion and loss of previous skills (e.g., reading, writing, speaking)
- Restricted mobility and difficulty with using stairs

- Difficulties in doing household tasks ranging to finding it impossible to do household tasks
- Requires help for personal hygiene care
- Finds cooking very difficult ranging to finds it impossible to cook
- Has required help to eat
- Requires some supervision ranging to requires constant supervision
- Requires some emotional support ranging to requires constant emotional support
- Impact on ability to drive
- Debilitating fatigue
- Depression and mood swings
- Severe pain
- Sleep disturbance

#### Support offered by young carers

The roles of 12 young carers were reflected by this group of parents. The young carers ranged from age 7 – 19 years, with the majority clustered around ages 14 – 17. The youngest young carer (age 7) provided support in collaboration with an older sibling (age 16). Each parent expressed dependence on their children for a range of support on a daily basis. Types of support provided by young carers to this group of parents include:

- Caring for siblings (some of whom have debilitating medical conditions)
- Ensuring safety of parent
- Being responsible for household chores (e.g., cooking, cleaning, washing, making beds, doing the shopping)
- Fetching and carrying
- Dressing parent and assuming responsibility for personal hygiene (ranging from some support to total support)
- Being responsible for parent's medication (including obtaining prescriptions, obtaining medication, and administering medication to parents)

- Being responsible for household administration and finances (including reading the mail, ensuring that bills are paid, budgeting and assuming responsibility for parent's benefit book)
- Providing emotional support to parents

The parents reflected in this group were predominantly lone parents. One family was a two parent family, but in this instance the father was also off work with depression and the young carer was providing support to both parents.

#### Length of young carer involvement in CYCP

The young carers reflected in this sample had been involved with the CYCP for varying lengths of time. Three of the parents had young carers who had been involved from a few months to 2 years, while the remaining parents' young carers had been involved for 3 – 4 years. Some had children who had been involved in CYCP, but whose age now exceeded the cut-off point. A variety of referral resources had directed parents to the CYCP. These included:

- Word of mouth
- Social services
- School
- Education and Welfare Officer
- Adult Carers Support Project

#### Impact of caring role on young carers

Parents were acutely aware of the pressures placed on their children in their role as young carers, and the impact of this role on their daily lives and socialisation processes. Parents expressed that their children were different to their peers [*“He is very different to his friends.”; “They have a significant caring role – different to their peers.”; “He does a great deal more around the house than his peers”*]. They recognised that their children's social activities were restricted [*“Children are not able to go and visit places such as Flambards etc.”; “Will not leave the house to keep an eye on their mum”;* *His social life is also restricted.*]. They also expressed concern about the impact

of the young carer role on their children's self-esteem and sense of self [*"Don't consider their role as normal"; "My oldest child is probably more aware of caring role. Is aware that our family is quite different from others, particularly due to domestic violence situation."*]. One parent was particularly concerned about their child's education: *"Left school at 13 years due to pressure of caring role."*

### Perspectives regarding CYCP

Parents were unanimous in their positive views about CYCP as an important and beneficial project. They expressed that they felt their children's involvement with this project was important for a variety of reasons:

- As part of the CYCP these children have been given the opportunity to mix with children who have similar life experiences [*"I think it is very important for my daughters because they get to meet other children who are the same as them. They are able to talk to each other and even give support to one another."*; *"Very important. Gives them the chance to mix with people outside the home."*; *"... provided her with the opportunities to mix with her own age and also with people in similar situations."*].
- Parents felt that their children's confidence had been enhanced through involvement with CYCP [*"It has helped their confidence."*; *"Has thrown a massive lifeline to a struggling teenager. Has completely boosted her confidence and self esteem."*].
- It was felt that children were given the opportunity to relax and be themselves [*"It also helps them to wind down and get away from home and just be themselves."*; *"Very important. Brought a bit of normality to them."*; *"A break from the pressure at home."*].
- Parents appreciated the mentoring, educational and advocacy aspects of the project [*"YCP has helped in variety of ways. Given a contact for someone outside home situation."*; *"YCP was an advocate when [name of young carer] had problems with school."*; *"Youth achievement awards have been very beneficial."*].
- Knowing that their children are being given support in their role of young carers has helped to alleviate parental pressure [*"Brilliant. Very happy and*

*has been important to both of the children.”; “Given them an outlet. It has helped me knowing that. Takes some pressure off me.”; “Essential as it’s eased the pressure on the family as the young people are able to do more.”].*

- One parent acknowledged that her needs sometimes impinged on her children’s ability to be involved in YCP activities: *“At times I feel very run down and depressed and at times I have to let them down on outings etc.”*

It was the unanimous view of parents that their children felt the CYCP to be important in their lives. These parents spoke not only of the value of the support role of the project to their children, but also celebrated the fun aspects of the project:

*“My daughters love being involved with the YCP. They enjoy the day trips and meeting others who also have parents etc who need help. They are able to talk to each other and give support. It’s very important to them. I hope it gets the funding and can carry on supporting the children.”*

*“He thoroughly enjoys his time with YCP.”*

*“Very important for both of them. Adds to meeting other people, socialising with peer group. Nice to meet others in similar role.”*

*“My daughter has little contact outside family home due to leaving school. YCP gives her someone to talk to.”*

*“[name of young carer] can’t be involved enough and would not be the confident child she now is without it.”*

#### Additional support received by parents

In addition to the support provided by CYCP, the majority of parents were in receipt of support from a variety of agencies, including statutory, voluntary and community-based sectors. They expressed that they felt they were being supported holistically and spoke highly of the support provided [*“Social services is very helpful.”; “Excellent. No problems. Regular review meetings held, which has been very helpful.”; “Caring, understanding, helpful. Meets my needs practically.”*]. Only one parent reported a negative experience with home help. She had found the service to be “very good” at first, but commented: *“the service changed hands and the service was less reliable.*

*The new company did not provide the same service*". As a result she was no longer receiving home help. Two parents were not receiving support from any other source.

### Suggestions for the future development of CYCP

Parents offered their suggestions for ongoing CYCP service delivery and service expansion:

- Their comments predominantly focussed on group activities and individual support [*"The group activities and individual activities are very important and these have helped to build confidence."*; *"More time could be spent on one-to-one basis with young carers."*; *"More opportunities to mix socially with others from similar situations."*].
- They felt that more opportunities should be provided for outings [*"More outings and opportunity to meet other young people."*; *"More trips – a chance to meet up more often socially with other young carers."*].
- Parents also commented on the current upper age limit for involvement in CYCP, expressing that they felt the project should be open to older young carers [*"To extend age range of project, particularly to include those still in education."*; *"I think the only thing I regret is that [name of young carer]'s immediate sisters aren't included now. But I understand that funding is a problem and always will be."*].

The views offered by these parents have emphasised how much they depend on the support of their children in coping with their daily lives. They have demonstrated insight into the pressures experienced by their children in their role of young carers. The support of the CYCP to their children has assisted them in providing this support, thus maintaining family cohesion and contributing to the wellbeing of both parents and young carers alike. For some parents, CYCP support is currently the only support they are receiving; whereas for others this support contributes to an holistic support network. The unanimously positive views expressed regarding the importance and value of CYCP, to both parents and young carers, is encouraging as it

demonstrates that the project workers are succeeding in meeting practical and emotional support needs to family systems.

## 4.6 Critical case studies

### 4.6.1 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 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 to the evaluator 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 a bit 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.

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.

### 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 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.”*

#### 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 cognizance 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."*

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.

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 which 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.*"

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.

### Concluding comments

This young carer presents 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 (with developing psychosexual needs) 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.

#### **4.6.2 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. The 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."*

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."*

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. 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.”*

#### Concluding comments:

In conducting this critical case study the evaluator was faced by an attractive, eloquent young girl who had undergone numerous tragic life circumstances. 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.

#### **4.6.3 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

## **5. RECOMMENDATIONS**

Based on the findings from this evaluation study, the evaluators propose the following recommendations for the development of service provision for this population of young carers in Cornwall.

### **5.1 Increasing identification and referral from service providers**

Given that significant progress has been made by CYCP in terms of multi-agency partnership working with Social Services and a variety of other agencies, it is important that the project now focuses its priority on achieving the same results within schools, local education authorities and health/medical practitioners. School referrals could play a key role in young carer identification; when considering that young carers spend a significant part of the day within the school context. Raising teacher awareness and placing the needs and experiences of young carers on the countywide educational agenda would be a first step towards addressing this issue. Similarly, urgent attention needs to be given to ensuring that GPs are adequately informed about young carer identification and how to refer to the CYCP.

### **5.2 Mentorship**

While it is encouraging to report that many young carers have now been able to gain access to one-to-one mentoring, it is imperative that this work continues. Given that an increase has been noted in referrals from the 5 – 10 year category, it is recommended that mentorship schemes for the 5 to 12-year-old category be sought as a matter of urgency. This issue was raised in the phase 1 project evaluation, and is still presenting as a major gap in service provision.

### **5.3 Volunteers**

There is an ongoing need for the project to capitalise on the role of volunteers. Thus far, volunteers have proven to be a significant factor in the positive experience that young carers have had with the project. Strategies need to be put in place that address both the recruitment and training of volunteers. This issue becomes even more critical when considering the significant increase in

young carer referrals to the project over the last three years. For health and safety reasons it is essential that an adequate adult/child ratio is maintained on fieldtrips and residential outings. Male volunteers also play an important role in providing modelling, to compensate for often absent father figures. Volunteers could also assist greatly in manning a 24 hour emergency line for young carers, thus taking the pressure off the two existing project workers.

#### **5.4 Awareness raising**

While this has been one of the projects priorities since its inception, it is important that this works continues. It would appear from this evaluation that there are still pockets of professionals and agencies who are not aware, or who have not made the effort to raise their awareness regarding the needs and everyday life experiences of young carers. Awareness raising strategies with GPs, mental health workers and youth agencies, for example, need to be developed and targeted as a matter of priority.

#### **5.5 Funding and staff resources**

This report has provided evidence regarding the difference an additional support worker makes in the planning and delivery of the project's services. The appointment of the support field worker enabled the project to grow and meet the needs of young carers living in geographically isolated areas of the county. This is only one, of numerous examples, which illustrate the impact that just one additional staff member can make in a project of this nature. It is recommended that the project be financially able to procure and appoint at least two additional staff in the subsequent funding cycle. Without this increase in staffing to young carer ratio, these recommendations will be impossible to implement. Over the last five years, this project has demonstrated a significant increase in referrals and thus an increase in demand for service provision to meet the needs of these young people. Lack of additional staff would result in a reduction in one to one contact with the young carers, as well as jeopardise the project's ability of meeting its intended outcomes and targets.

In conjunction with the aforementioned staffing requirements, the issue of continued funding for the CYCP is vital. The successful procurement of funding over the last five years has been consistent with the needs and development of the project cycle. However, this report clearly indicates that the project is developing and refocusing priorities in order to meet expressed need. The funding status quo needs to be addressed in order to keep pace with this development. This project has demonstrated, with clear evidence based practise that it is not only able to meet its targets but that in many areas it has exceeded all expectations. It would now be appropriate to focus on long term funding, as opposed to shorter (two and three year) funding cycles. The evaluators recommend that consultation be initiated between the statutory agencies and the CYCP with a view of committing to long term funding. This discussion needs to be cognisant of the need for the project to retain its independent status, as reinforced by the project workers and the young carers themselves. This does not preclude the projects need to procure funding from voluntary and charitable funding agencies/bodies. These should be viewed as simultaneous funding strategies

### **5.6 Reformulate project goals and aims**

Given that the project has completed a full five-year cycle, and undergone two external evaluations, this may well be an ideal opportunity to revisit the project goals and aims. The evaluators support the decision to place identification of young carers and the assessment of their needs, and providing respite in response to these needs, as being the appropriate starting point for the project. It is now recommended that these aims be reformulated, reassessed and reprioritised. For example, it is clear from the evidence in this report that the initial goals of identification, referrals and assessment of need have been met, and in fact, exceeded in many instances. While pockets of priority partnership building still exist and require attention, it may be prudent to now focus and prioritise volunteer recruitment and training, sibling care, holistic family work and providing support for older young carers as the focal points and targets for the next phase of the project cycle. Please note that these are only provided as illustrative examples. The project lead, in consultation with

the young carers and the project steering group, would need to make their own decisions about reformulating and reprioritising their goals and aims.

### **5.7 Holistic work with parents**

A recommendation from the phase 1 evaluation was that parents needed to feel involved in their children being part of CYCP, and that support offered to parents in this regard could contribute towards holistic care. Similarly, young carers had expressed the need to be involved with decisions made about their parents' care. It is evident, from responses received in the current evaluation, that this is beginning to happen. The CYCP roles of signposting and advocacy are important, as they not only link families with valuable support but ensure that the voices of young carers are heard in this regard. It is encouraging that inter-professional collaboration including the role of young carers is beginning to enhance the well-being of family systems. It is therefore simply recommended that this priority work continue and be allowed to develop. It is self-evident that, with additional staff, more of this work could take place.

### **5.8 Sibling care**

At a national level, the issue of sibling care has been seriously neglected. All of the young carers in the focus group reported providing care for at least one sibling (younger and/or older than themselves). This finding was further supported by the project lead, which referenced the fact that many of the young carers in the project are caring for their sibling(s). It would therefore seem appropriate for sibling care to become one of the project's new priorities. It is important that the project provides information and additional support regarding sibling care, and to focus on the complexity and impact that this dual role of parent and sibling care has on young carers.

### **5.9 Education around mental health and substance misuse**

There is a significant need among these young people in terms of accessing information and knowledge around living with parents who have a mental illness or have issues around substance misuse. While it is not expected that the project provide this service, it is necessary to link with specialist

organisations in Cornwall who can provide this level of expert information for the young carers. The prevalence with which feelings of depression were reported by participating young carers during the evaluation, combined with their expressed need to keep this hidden, speaks to the urgency of enabling these young people to understand more about mental health issues. While only one young carer disclosed using drugs (cannabis) during the evaluation process, the potential dangers of exposure to substance misuse in the home environment cannot be underestimated – perhaps especially in the light of increasing referrals in the 5 – 10 age group.

### **5.10 Service provision to age 18+**

One of the major gaps and concerns in service provision is the lack of services afforded young carers who turn 18, and are deemed by the State as having achieved independent status. The project lead has already noted this as a point of concern, and is aware that an adequate response is required. This may require procuring additional specialist funding to address the needs of this population of young carers. It is important to consider that the needs of this cohort may be greater when considering that their lives have transitioned from secondary education to more independent living, e.g. full time employment, attending college etc. The social isolation and restricted emotional expression experienced by many young carers restricts normative socialisation, psychosexual development and both intra- and interpersonal development. The conflicting feelings surrounding needing to have ownership of their own lives balanced against ongoing family needs have been voiced by young carers participating in this evaluation. Their need for support, respite care and one to one mentorship could be critical as they cross the threshold into young adulthood.

### **5.11 Multi-agency collaboration and partnership working**

Participating service providers commented that their knowledge surrounding young carers had predominantly increased as a result of direct contact with the project lead. Given the existing staffing of CYCP, it is unlikely that this direct contact with agencies can increase at present. However, it is recommended that, should funding be procured for additional staff, the project

lead take a more focussed role in terms of liaising with partner agencies in an effort to increase collaboration and networking. A need has been expressed for more information to be circulated regarding CYCP. Again, this could be addressed with additional staff resources. An interesting point was raised during this evaluation that the responsibility of raising awareness of young carers could be shared with existing partner agencies. It is recommended that project workers encourage this stance.

### **5.12 Additional respite and social activities**

While the young carers have reported very positively about the respite care that is provided by the CYCP, it is important to look at other ways of providing this level of support. Attending residential weekends, on an average of four or five times a year, has proved very beneficial to the lives of these young people. The project is encouraged to create opportunities for these activities and 'get aways' to occur more frequently. The evaluators appreciate that this needs to be balanced against funding constraints. Young carers and service providers have noted that it would be beneficial to provide more regular social activities outside of the formal events, in locations spread across the service delivery areas. This would enable more young carers to participate and also allow for more frequent contact with their peers. Should the volunteer training and recruitment priority be activated, it is suggested that volunteers could play a key role in this regard. While appreciation for the more coordinated activities and events is unanimously voiced in this evaluation, it seems that young carers would also appreciate the opportunity to just 'hang out' with young carers in their areas occasionally. Numerous young carers have grown into young adulthood during the life of CYCP, and it is possible that some may wish to become involved as volunteers as they develop independence. Their experiences and insights could considerably enhance the ongoing development of the project.

## 6. CONCLUSION

The evaluators conclude 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. A concerted effort appears to have been made to build in recommendations from the previous evaluation. The identification of young carers and referral process has resulted in the number of young carers involved in CYCP increasing dramatically from phase one of the project. This is a remarkable achievement when considering that this has been achieved with only two full time project workers and a part time administrator. Despite staffing restrictions, service delivery appears equitable across all identified areas. A developing thrust towards ensuring holistic family work has been noted. 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. The young carers and their parents have spoken eloquently about the value they place on these services and the important role that the project has played in their lives. 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. Substantial progress has been made in phase 2 with regard to multi-agency collaboration and partnership working. Some ongoing gaps in this regard have been identified and need to be prioritised in the project's development. The awareness raising strategies and campaigns have proven successful, but again a need has been identified for this to continue and develop.

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.

While significant strides have been made by the CYCP since 2001, there are a few areas for consideration as it begins to plan for the future, namely: volunteer recruitment and training, roles of volunteers, mainstream funding, increasing staff resources, work around sibling care, support for age 18+ young carers, increased mentorship (particularly for the young age range), ongoing education in priority health issues, and additional respite care and informal social opportunities for young carers.

#### Limitations of the evaluation process

The evaluators are aware in offering these findings that, although efforts were made to include a range of providers and service users, the numbers participating are limited. A consideration for the ongoing evaluation of CYCP would be incorporating an 'action research' approach to service delivery. This would allow ongoing consultation to accumulate across a broader range of providers and service users, resulting in a broader frame of reference for evaluation. However, the evaluators are also aware that respite activities for young carers need to provide them with opportunities to 'just be children' and that clouding these experiences by ongoing formal evaluation may not be suitable. There is space however for more informal type of consultation to feed into ongoing evaluation.

The CYCP is committed to allowing the voices of young carers to be heard. It is therefore appropriate, in concluding this report, to reiterate the comments of a young carer regarding the future of CYCP:

*“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.”* [young carer, aged 17]

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## **APPENDIX ONE: INFORMED CONSENT FORM**

## CORNWALL YOUNG CARERS PROJECT EVALUATION

### 13 November 2004

This evaluation project aims to let young carers tell their stories about being a young carer, and their experiences of being part of the Cornwall Young Carers Project.

The report will be used to tell people about the Cornwall Young Carers Project.

By taking part in this evaluation, I understand that what I say will be written down and reported in the evaluation report and at conference presentations. I understand that my name will not be used.

Pictures that I have drawn and poems I have written may also be included in the report.

I do not have to take part if I do not want to. At any time during the day I can say that I do not want to be part of the evaluation, and I will be allowed to not take part.

I ..... (name)  
agree to take part in the Cornwall Young Carers Project evaluation.

Signed: .....

Witnessed by Dawn Maddern (Project Lead and loco parentis):

Signed: .....

I agree for my photograph to be included in the report or at conference presentations. I understand that my name will not be included.

Signed: .....

Witnessed by Dawn Maddern (Project Lead and loco parentis):

Signed: .....