

Cornwall and Isles of Scilly Health Action Zone



CORNWALL YOUNG CARERS PROJECT: A CHAZ EVALUATION CASE STUDY

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1. INTRODUCTION

The Young Carers Project (CYCP) works with Young Carers and their families, and puts them in touch with the most suitable organisations to provide help and support for their individual circumstances.

The guiding principle is the development 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.
- Increasing and facilitating partnership building, which includes raising awareness, understanding and knowledge base among various agencies. It has been evident from the current Young Carers project, that children are often only referred to it once a crisis has reached. Many of the children are known to the Child and Family Service and /or Child Protection Teams. It is hoped that this identification project will 'get in early to solve problems'.

In 1996, Social Services, Youth Service and the Cornwall Rural Community Council worker 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. The group met once a month and was attended by about 10 Young Carers. Procuring long term funding for a Young Carers project had always been problematic. The Youth Service funded a sessional worker for 8 hours per month and latterly Social Services funded an assistant for about 5 hours per month. However, with the funding which HAZ provided the project became fully operational in the middle of 2000

Research estimates suggest that there are between 20,000 and 50,000 young carers in Britain. The Social Services Inspectorate report "*Something to Think About*" (November '95) 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

Inferring from this national data set, it was anticipated that there could be as many as 400 Young Carers in Cornwall. The research also validated that, in other areas of the country, work with Young Carers was successful and fulfilled a need for this population.

A multi-agency approach was felt to be essential in this project. In light of this a Cornwall Young Carers Strategic Partnership was established.

The objectives of this Strategic Partnership were outlined as follows:

- To ensure a strategic approach/direction in relation to the health improvement and other development programmes.

- To respond positively and collectively to the national strategy for carers by action in Cornwall.
- To ensure co-ordinated planning of services in terms of geography, methodology and issues.
- To maximise the effective use of resources across the range of services for young people.
- To involve young people in developing and evaluating strategy.

In terms of the operational status of the project, the project worker encourages young carers to identify their own needs. Having identified these needs, the worker endeavours to meet those needs in creative and innovative ways. It is recognised that traditional, sometimes narrow answers to problems do not always best meet the situations these young people face. However, where possible and appropriate, young carers are also supported to integrate into existing networks/projects drawing on existing knowledge and expertise. Networks are also encouraged to work effectively and efficiently with and on behalf of young carers. It is important to note at the outset of this cases study report that young carers are involved throughout the consultation process in the planning and delivery of the project's services.

2. CONTEXT

Within many Government-led reports on children and young people's mental health is a clear recognition of the importance of early identification and intervention. There is a large body of evidence that clearly identifies the risk factors within children, their families and in the environment that predispose the development of mental health problems. Using this evidence would indicate that children and young people who meet the criteria of being a "young carer" are at risk of developing mental health difficulties, as noted in the report *Young Carers, Something to talk about* (National Social Services Inspectorate, 1999).

In the national strategy document "*Caring About Carers*" (National Strategy for Carers, HM Government, March 1999), there is a specific chapter devoted to the subject of young carers. In it is acknowledged the work young carers do for members of their immediate family. 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. In families where alcohol or drug abuse is a problem, children can be faced with a caring role which can create even more significant anxiety or stress.

Legislation

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.

Youth Service

"Bridging the Gap" (New Opportunities for 16 – 18 year olds: Not in education, employment or training, HMSO, July 1999) from the Social Exclusion Unit and *"Learning to Succeed"* (A new framework for post 16 learning, HMSO, June 1999) from the white Paper from the Department for Education and Employment, identify the extent and complexity of issues surrounding the nature of social exclusion and under achievement amongst young people in Britain. Young carers are identified by research as a priority group for whom effective multi-agency support is vital. *Bridging the Gap* outlined the key role for a new youth support service in this area and highlights the important contribution that the Youth Service must make to such developments.

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.

Social Services

“Caring About Carers – A National Strategy for Carers” (National Strategy for Carers, HM Government, March 1999) 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 impacts upon the lives of young carers..

Child and Adolescent Mental Health Service (CAHMS)

Within the national development framework for CAHMS there are no specific policies relating directly to young carers. The strategies for planning and delivering CAHMS currently being adopted across Cornwall are aimed at providing a comprehensive service that incorporates early identification and intervention through to treatment of complex mental disorders. These differing levels of intervention are expressed in “tiers”. Nationally the principles underpinning CAHMS are joint commissioning by statutory agencies, comprehensive service delivery across a range of providers including the voluntary sector, and strong links to strategic planning groups e.g. Children’s Service Plans, Youth Offending Teams, Area Child Protection Committees, Drug Action Teams etc. The following two reports: *“Together we Stand – thematic review of Child and Adolescent Mental Health Services”* (NHS Advisory Service Report, 1995); and *“Bright Futures: Promoting Children’s and Young People’s Mental Health”* (Mental Health Foundation Report, 1999), will hopefully underpin the work with Young Carers in Cornwall in the future.

In Cornwall these factors are in place and there is now a need for further development to ensure the needs of all vulnerable groups, including young carers, are met in a robust and systematic way.

British Red Cross (voluntary sector)

The British Red Cross in Cornwall have recognised the need for young carers to have time away from their responsibilities. Specially trained Red Cross young people have been able to befriend and work with. Red Cross young volunteers have played a valuable role in this project as they have been able to: support young carers; help to enhance their social and personal well-being, offer practical information, support, and time to listen, as well as identifying gaps in service provision for Young Carers.

Cornwall Young Carers Strategic Partnership

As stated in the introduction Cornwall Young Carers Strategic Partnership was established.

The membership of this partnership will be open to those organisations and agencies whose remit aligns them with the National Carers Strategy. The lead partners are:

Cornwall Youth Service
 Social Services
 Children and Family Services
 Cornwall Rural Community Council – Carers Co-ordinator
 Education – Schools
 British Red Cross
 Health Promotion

The project has identified the following activities which will guide this strategic partnership, namely:

- Actively linking with Primary Care Groups and strategic plans (e.g. Health Improvement Programme) and ensuring that this strategy is incorporated into the health improvement programmes of Primary Care Groups.
- Focusing on the needs of young carers in particular towns and areas (e.g. HAZ areas).
- Sharing information and plans at regular meetings and disseminating information to other appropriate organisations when necessary
- Using data from workers identifying young carers
- Identifying gaps in needs/services
- Generating joint bids/responses to unmet need
- Planning shared use of resources and facilities
- Promoting the work of the partnership
- Advocating on behalf of young carers in Cornwall
- Generating joint responses to consultation or related issues

3 EVALUATION STRATEGY

3.1 Building Evaluation Capacity

In attempting to increase evaluative capacity, the University of Plymouth Evaluation Team have translated the Theory of Change Model into a series of ordered questions, which would guide the process of developing a rigorous and robust evaluation strategy. Proponents of this approach stress that a Theory of Change should be plausible, doable and testable. To facilitate building evaluation capacity, the project lead was asked to undertake the following:

- Explore the **assumptions** that underlie the work
- Identify the **aims** of the project
- Ensure that the **activities** planned are likely to contribute to these aims
- Think about the **questions** they need to ask if they are to establish the success of the project and
- Look at the kind of data they need to collect in order to establish baseline **indicators**.

The remainder of this paper draws upon the case study analysis of the CYCP, outlining how this evaluation and monitoring model has enabled the project lead to make an objective assessment of their strategy and to devise operational plans that are not only capable of evaluation by the stakeholders, but also likely to translate into effective practice.

3.2 Evaluation Plan/Strategy

The project identified the following assumptions at the outset of the project.

Assumptions

- That there are Young Carers in the county who are not yet known to CYCP (as statutory agencies) and who are therefore not receiving help and support in their caring role.
- That by assisting Young Carers we can reduce the impact of caring on their emotional and physical development, thereby reducing future mental health and family problems.

In review, after the project had been operational for one year, it was found that these assumptions were accurate. Therefore it is important to acknowledge that the CYCP had not been guided by false assumptions.

The following project aims were identified in conjunction with specific activities which were implemented in meeting each of these aims.

Aims

1. To develop quality services and provision to support Young Carers .
2. To maximise opportunities for the social, educational and personal development of Young Carers.
3. Increasing and facilitating partnership building, which includes raising awareness, understanding and knowledge base among various agencies.

Activities

1. To assess the needs of Young Carers and ensure they receive the support they need.

- By identification of Young Carers.
- Enable Young Carers to identify own needs - this could be achieved by 1:1 or fun days away - weekends.
- Provision of services through funds from Carers Grant and other agencies that can provide a service.
- Sustain contact with young people and families in partnership with other agencies.
- Encourage other agencies to assess the needs of Young Carers and ensure they receive the support they need.

2. To research and identify the needs of Young Carers across Cornwall.

- Enable Young Carers to identify own needs - this could be achieved by 1:1 or fun days away - weekends.
- Through partnerships with other agencies.
- Sustain contact with young people and families in partnership with other agencies.

- Website, guest book and e-mail.
- 3. To research and map services available to meet the needs of Young Carers in Cornwall.**
- Project Worker will compile database of services available.
 - Website, guest book and e-mail.
- 4. To identify gaps in current services which create barriers to opportunities for Young Carers.**
- Enable Young Carers to identify own needs - this could be achieved by 1:1 or fun days away - weekends.
 - Discussion with other agencies e.g. Careers, Health Professionals.
- 5. To support the development of new provision and services to address the barriers experienced.**
- By helping networks work efficiently for Young Carers .
 - Raising awareness and encouraging agencies etc to incorporate Young Carers and their needs into policy, practice and strategy.
 - Website.
- 6. To raise awareness of the needs and expectations of Young Carers in schools and other organisations.**
- By using - Theatre in Education group in assemblies and PHSE classes, video also being produced.
 - Presentations by project Worker to various organisations etc.
 - Training with Teachers, EWOs, Nurses, Health Professionals etc.
- 7. To support, advise and encourage organisations and agencies to develop provision and services. which are readily accessible by and available to Young Carers.**
- Presentations to and communications with other organisations and agencies etc,
 - Encouraging flexibility and imagination in service provision.
- 8. To create a voice for CYCP in policy and decision-making processes across the sectors.**
- Enable Young Carers to identify own needs - this could be achieved by 1:1 or fun days away - weekends.
 - Through linking into district Youth Forums.
 - Membership of Council for Voluntary Youth Services.
 - Have a Young Carer as a member of the strategic partnership group.
 - Page in Carers Newslink or own Newsletter.

9. To support organisations and agencies in developing procedures and protocols which take account of, record and respond to the needs of Young Carers identified by that organisation.

- Developing record card to be placed in Young Carers notes of school, SSD, GP, Careers and any others.
- Raising awareness in schools etc. with Cascade etc. in assemblies, videos in PHSE classes.

Evaluation Questions

The project lead proposed the following questions to guide the evaluation process.

- To ascertain where services are to support Young Carers (mapping) and ensure young people get the help available.
- To evaluate how effective the services are in maximising opportunities for Young Carers and develop new services and supports where there are gaps.

Baseline Indicators

The final component in developing the evaluation strategy, was the establishment of baseline indicators as they relate to each to the project aims. These indicators then became a critical part of assessing the progress of the project against identified targets and outcomes. It was decided to focus on the following categories of baseline data:

- Number of new Young Carers contacted.
- Number of enquiries re: CYCP.
- Number of referrals and referrals from whom.
- Young Carers recorded in notes of schools and GP practices.
- Number of ongoing Young Carers contacted.

4. DATA COLLECTION STRATEGIES

The approach adopted in this evaluation strategy was triangulation in that a variety of data capturing and analysis methods were utilised. The following data collection methodologies were adopted.

4.1 National Statistics

National statistics were analysed with a view of contextualising and comparing the data recorded in the CYCP with those of national standards. Research by Saul Becker and Chris Dearden of Loughborough University suggested that there are between 20,000 and 50,000 Young Carers in Britain. The Social Services Inspectorate report Young Carers, Something to Think About (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 in moving into adulthood, especially finding work, a career, further study and establishing relationships

4.2 Local Pilot Study

As early as 1993, Social Services and the Youth Service recognised the unique position of Young Carers and their needs, and organised a weekend workshop in Liskeard for them to get together, explore their situation and discuss the sort of support they would find helpful. The outcome of the workshop was that these young people wanted to put together a newsletter that would link Young Carers in Cornwall, and keep them informed about local and national carers issues. Unfortunately, this plan did not come to fruition due to lack of resources. In the same year, the Carers Co-ordinator convened a multi-agency meeting and all those present agreed that the issue of Young Carers should be addressed in Cornwall. However, it was clear that one particular agency needed to take the lead, and in April 1996 Social Services organised a meeting with the County Youth Service and the Carers Co-ordinator. As a result of this meeting, it was agreed to go ahead with the pilot project for one year, albeit with no specific funding.

The aim of the project was to set up a Young Carers support group to help Young Carers both practically and emotionally. The idea was the group would be able to have fun and time out from caring, find mutual support from other young people sharing similar experiences and find out relevant information about caring. The group was run at Redruth Youth Centre and demonstrated a fully multi-agency approach.

4.3 Assessing and Establishing Baseline information

In order to establish the baseline information, it was essential to obtain the figures of Young Carers already known to the statutory services i.e. Social Services, Attendance Workers and Education Welfare Officers. In addition figures were obtained from Carers Support Workers and the original pilot in gathering this baseline information we established the source of the figures, the gender of the Young Carers and their age group; 5 – 10 years, 11 – 14 and 15+

4.4 Identification of Young Carers

This is probably the most important objective. Without identifying Young Carers we are unable to meet many of our other objectives. Identification has primarily been achieved through referrals from Social Services, Carers Support Workers, Health Visitors, District Nurses, relatives and with others coming from a School Nurse, Head Teacher and Assertive Outreach Worker.

4.5 Developing a Monitoring Evaluation Instrument (Appendix 1)

The HAZ evaluator and the Young Carers project worker developed a monitoring evaluation instrument. This instrument was established to track the progress of the project on the monthly basis.

4.6 Monitoring Project by Quarterly Reportage

As this project fell within the domain of the CHAZ programme the project worker was also required to monitor the progress and outcomes of the project with the use of a quarterly monitoring report structure.

4.7 Focus Groups with Young Carers

The researcher was exposed to 20 young people at a residential weekend for Young Carers in Cornwall. From these, a sample of 7 was selected for participation in a Focus Group. The sample consisted of 3 boys and 4 girls. Although the ages ranged from 11 – 18 years, the group was found to be homogenous in terms of shared experience and ability and willingness to articulate their life stories. The interview schedule can be viewed in Appendix 2.

5. FINDINGS

5.1 Themes from the focus group with Young Carers

The following discussion relates to themes and categories emerging from the focus group held with Young Carers from the CYCP. The discussion is illustrated by direct quotes from the Young Carers who participated in the focus group. In order to differentiate direct quotes from the body text, quotes are presented in Italics.

5.1.1 How did you learn about the CYCP project?

Respondents offered the following as examples of how they first learned about the CYCP.

- Notification from the project by mail
- Social Services (The Social Worker told us “we need a reward for the work we did with our mum”.)
- Anger management classes

None of the respondents had been involved in any kind of project focussing specifically on the needs of Young Carers.

5.1.2 Difficulties in accessing services

Transport emerged as the over-riding theme from this discussion. Two facets were discussed, namely lack of transport options and reimbursement for travel expenses.

5.1.2.1 Lack of transport options

Access to transport was a primary concern for the respondents. Due to their family responsibilities, they perceived transport to be important in fulfilling their caring roles. Focus group members referred to distinct lacks in terms of transport available within the family context, as well as having to use public transport covering large distances.

(a) Private or family transport

A variety of concerns were voiced regarding lack of transport within the family context. Issues ranged from not having a car, to parents not being able to drive due to health difficulties.

“We don’t have a car.”

“We have a car, but mum can’t drive. Well she can drive, but she can’t cope.”

“My mum is not allowed to drive for 2 years.”

(b) Public transport

Respondents expressed that they use various transport modes, for example bus, bike and walking. One respondent said that he had to travel far distances by bus [*“I have to go 7 miles on a bus to get to Newquay”*].

A recurring theme in discussing the difficulties in accessing transport services, was the need for Young Carers to be more self-sufficient. Frustrations emerged regarding lack of self-sufficiency related to transport. These are

compounded by the fact that these young people are forced by circumstances to play adult roles within their families, yet they are legally constrained from being licensed to drive. In relation to this, one 11 year old respondent commented that his role as a carer would be made easier if “I could have a monkey bike” so that he could run errands for his mother.

5.1.2.2 Reimbursement for travel expenses

Although some project related activities have transport provided (e.g., residential weekends), respondents felt that they needed more financial support for day to day transport requirements – both for family related activities as well as project related activities. As one respondent stated, *“I get no reimbursement for transport, and it costs me £8 on a bus”*. Suggestions for change included receiving money for taxis and bus fares. Another suggestion was that the project lead arranges transport when required by a Young Carer (*“I would like to phone [name of project lead] and say I need a lift, and she will organise it”*).

One respondent did however state that the CYCP was supporting his taxi fares in order to enable him to gain access to work experience related to his college course.

5.1.2.3 Rurality

Rurality and transport difficulties are linked in terms of accessing services. Living in a rural context means that there are limited facilities available ‘on site’ for young people. When considering the multitude of responsibilities associated with the role of a young carer, issues of rurality are more salient. As commented by a respondent: “I wish I had a house in Newquay” [this family lives 7 miles from Newquay]. Rurality also impinges on the ability of young people to have a social life. Young Carers, like any other young people, need opportunities to socialise with their peers. For Young Carers, their role restricts opportunities to socialise and results in carers having to ‘steal’ an hour here or there for social activities. Rurality linked with transportation difficulties means that young people need more than an hour in order to travel to social activities. As one respondent said: *“There are only a few shops around where I live”*. Rurality and transportation further imbed feelings of isolation as unanimously articulated throughout the focus group.

5.1.3 Benefits of being involved in the CYCP

Respondents voiced numerous benefits of being involved in the CYCP. These benefits seemed to revolve around being away from the home context in an enjoyable environment.

- Getting away
- Good companionship
- Getting to meet other people
- Having fun
- New ideas
- Having free time was crucial to Young Carers (*“At home all we do is jobs”*). As articulated by one 11-year-old respondent: *“I only have 4 days off a month”*. His days off are linked to home help services (*“When the home help comes to help my mum with her shopping and the cleaning”*).

Respondents clarified what their home responsibilities were with regard to parental illnesses. Illnesses included:

“The big fat hairy bastard syndrome” (the young carer was referring to her father when offering this comment. It was supported by another respondent who exclaimed: *“That is my father exactly.”*)

“My mother has everything ... epilepsy, cancer, bad legs, bad eyes.”

“ME and rheumatoid arthritis.”

“Rheumatoid arthritis. My mum can only walk down to the end of the drive.”

“Sore legs, sore back, reproduction organs, bad birth experience and she is disabled and uses crutches.”

In addition to parental illness, some Young Carers have health issues (physical and mental) of their own to contend with:

“My mother has clinical depression and so do I.”

“Arthritis”

“I suffer from ME”.

Coping with their own struggles and the numerous responsibilities within the family context is difficult for Young Carers. Within the focus group they voiced strong feelings of being burned out. When this was clarified, in terms of how they cope during these “burned out” times, they offered the following as coping strategies:

“I sometimes want to run away and hide. I go into my room, curl up into a little ball and listen to music.”

“I go down to the tennis club.”

“I just bite my lip and get on with it.”

The respondents expressed that the best part of the CYCP was the residential weekends and day outings:

“I like the stuff we do when we are here.”

“You get to do stuff you would never normally do” [this was in reference to surfing]

“I enjoyed going to [name of local theme park]. It is the ultimate theme park in Cornwall.”

“I enjoyed the day trips.”

5.1.4 Recommended changes to existing services offered by the CYCP Project

When asked what they would change in future involvement with the CYCP, respondents were vociferous in their suggestions. Responses centred around issues of extended away periods, increased contact and better communication, as well as improving societal perceptions of Young Carers and their charges.

5.1.4.1 More residential weekends.

Residential weekends were felt to be a welcome break from home responsibilities. Young Carers offered the following comments:

“At present we have these weekends once every two months, but we would like them once a month.”

Another respondent also expressed the need for more day outings.

“During half-term we should go away for a whole week.” [they realised that schools would not give them time off, and so expressed that such activities should take place during school vacations]

5.1.4.2 More contact with the project lead

Some respondents expressed dissatisfaction regarding limited contact between themselves and the project lead:

“She used to come to our house often to see how we are, but not so much anymore.”

“I want her to come more often.”

“I want her to talk to us by phone more often” [this respondent clarified this by saying: “[name of project lead] never phones me up – I don’t think she likes me.”

These critiques speak to the need for more youth workers to be available to Young Carers. The Young Carers expressed that they were aware that the project lead was very busy and could not be available to them all the time:

“She can’t be everywhere at once.”

“She does a lot already.”

5.1.4.3 Increasing access to other Young Carers

One respondent commented that setting up a web site would help “so we can all keep in touch”. He went on to say that he felt there were a lot of other Young Carers in Cornwall who were either unaware of the CYCP or unable to access services offered by this project. A positive way of improving access, which is already in process, is the setting up of a CYCP web site.

Respondents also commented on the importance of raising awareness of the CYCP, so that other Young Carers could access this project’s services.

5.1.4.4 Changing teachers’ perceptions

The perceptions of authority figures within school contexts, regarding Young Carers, were problematic to respondents. Perceived lack of interest regarding their plight contributed to stress regarding home responsibilities.

“Teachers don’t know about Young Carers.”

“Teachers don’t care.”

Respondents expressed some positive comments regarding teachers’ perceptions:

“Primary school was best because teachers listened to you.” (linked to this was the negative perception that secondary school has been the opposite experience, in that they “are expected to be adult” and not complain about their responsibilities as Young Carers)

“My form teacher understands me.”

“College tutors have been good.”

5.1.4.5 Changing peer and societal perceptions

Respondents felt that oftentimes their friends and peers do not understand what it means to be a young carer. Furthermore, friends are sometimes cruel in expressing comments regarding the ill parents of Young Carers.

“Friends don’t understand what it means to be a young carer. They think we go on holidays for free”. This respondent went on to say: “We don’t have holidays for free ... we earn it!” [emphasis by respondent]

“Some of my friends understand, but it is a problem when they want me to go out with them.”

“I don’t think my friends understand.”

“My friends tease my mum. It is horrible when they call my mum dirty names, like she is fat.”

One respondent felt that her friends and peers did not understand her health condition (this young carer suffers from clinical depression). As a result of her condition, she struggles with concentration, and offered the following insight: *“My friends give me a hard time for not listening. I can’t listen as well because of the depression”*.

Societal perceptions are also hurtful to Young Carers (*“Because it is a long term illness, people don’t want to know ... they don’t want to care.”*).

5.1.5 Recommended changes to existing statutory agency services

The Young Carers within the focus group had experience a lack of support from various statutory agencies which were designed to assist them and their ill parents. The agencies mentioned by respondents were Social Services and Health Services.

5.1.5.1 Perspectives regarding Social Services

The Young Carers singled out Social Services for discussion. The comments made by the respondents are provided below. It should be noted that these are the perceptions of the respondents. At times their frustrations were expressed through the use of expletives. The accuracy of their comments could possibly be debated, however their feelings are the key issue here. The comments are presented without censorship, in order to both allow them to voice their concerns in their own words, and to demonstrate the extent of their frustration.

“Social Services make promises but don’t deliver.”

“That lady at Social Services, I don’t know what her name is but she is a bitch.”

“They (Social Services) don’t care about nothing.”

A 13-year-old respondent commented: *“Social Services told me it would be cheaper to put us into foster homes. They want to split us up and my baby brother is only 2 years old.”*

Regarding concerns about being placed into foster care with strangers, one respondent (11 years old) drew an analogy with the story of Romulus and Remus (*“It is like that story where babies were put into baskets and left in the river to be brought up by wolves.”*). Young Carers expressed a considerable amount of anxiety at the possibility of being placed with strangers, and

expressed feelings of their needs and fears being ignored in order to serve agency cost-effectiveness.

Respondents were angry regarding a lack of home help provided for their ill mothers. Of the 7 participants in the focus group, only 2 of the families received home help every day. The remainder received help once or twice a week, for a few hours. The Young Carers offered the following comments in this regard:

“The problem is they are cutting down on home help.”

“When my mum was in hospital she was promised home help, but it was cancelled.”

“We only get 3 hours a day provided.”

“It’s tough after a hard day at school. We need more home help, after school until 9pm.”

Young Carers offered both positive and negative perceptions regarding home care assistants. Some perceived these helpers to be cold and clinical (*“My home help is so unsociable. They come in, bath my mum, and go back out. They never ask me how my day was.”*). On a positive note, one participant spoke of the support he receives from a home care assistant by commenting: *“My home help is really kind and everything. She brings big bags of sweets.”*

When asked whether they had discussed the need for more home support with their Social Workers, respondents were very negative. Two of the comments offered were:

“Social Workers never listen.”

“I can’t get hold of my Social Worker.”

5.1.5.2 Perspectives regarding Health Services

The Young Carers themselves singled out health Services for commentary. Once again, it is the perceptions and frustrations of Young Carers which are presented. This should not be considered as a factual critique of Health Services, but rather an expression of Young Carers’ feelings in this regard.

Respondents were disappointed regarding perceived slowness of diagnoses for parents, as well as financial difficulties in accessing needed medical care.

“My mum’s partner told Health for 4 years that she was ill, and they didn’t do anything.”

“Health services charged my mum £10 for the car to get medical help.”

Numerous Young Carers are responsible, not only for their parent’s wellbeing, but also for looking after young siblings. Considering the youth of many Young Carers, this is a daunting task. In summing up a perceived lack of support from agencies, Young Carers felt that they were dependent on the goodwill of older siblings (*“My 16 year old brother doesn’t help. He makes things worse.”* – a comment by an 11 year old respondent) and their mother’s friends to help out in the home environment. This was not ideal (*“My mom relies on her friend ‘L’. Now ‘L’ has moved and I don’t know what I am going to do.”*).

5.1.5.3 Inadequate financial support

Young Carers keenly felt the strain of having to contribute to the family's finances and, in some cases, be responsible for paying the mortgage and household bills. These bills were a constant worry for the respondents (*"We have to switch off all the lights, otherwise we can't afford the electricity"*). There was a perception that carers should receive financial reward for their role within the family (*"We are fulltime carers. They should pay us something for being carers, even if it is only £5 or £10 a week."*). They further experienced that existing financial support for parents was inadequate, resulting in continual worry regarding the family finances (*"The grant is not enough to cover mortgage and food."*; *"We need more money, around £50 extra per week."*). As a suggestion, one respondent commented that perhaps her family could be placed into a *"cheaper house"* as their *"rent is £600 a month"*.

5.1.6 Consultation with Young Carers

Respondents were unanimous in the view that the project lead for CYCP consults with them regarding potential activities. The process is that the project lead tells the group what she has in mind, and the group then has the opportunity to give feedback and good ideas (*"[name of project lead] will listen to us if we have a good idea."*).

5.1.7 Other areas of concern

There were numerous factors that exacerbated the difficulties encountered by Young Carers. These included inadequate support from parents, and the need for a safe environment for them to *"escape to"* when things become unmanageable.

5.1.7.1 Perceived inadequate support from parents

All of the respondents who participated in the focus group came from broken homes. Respondents expressed feelings of abandonment as estranged fathers could not be relied upon to contribute to the family upkeep. In one poignant moment, a young respondent (aged 11) disclosed that he was glad that his birthday was coming up because he would be able to *"beg"* his father for £25 as a birthday gift, which he could then put towards paying the rent. Only one respondent had some positive experiences with his absent father (*"My dad helps out quite a lot, even though he has a new life."*). Extensive anger was displayed by the group towards absent fathers:

"I wouldn't let my dad through the door."

"My dad doesn't help out anymore. When I was 18 months old he beat my mom up and broke her nose."

"My dad has a new family now. He can afford to do up their house, but he pays no maintenance to my mum."

"I wish I could keep my dad's money and make him disappear."

"I want my dad to die."

"I'd like my dad to care and send money – even if it's just a tenner."

"I was quite lucky with my dad, but he has a new girlfriend. She gets all the money I used to get, and he takes her to the places he used to take me."

"There is something about men, they are all ignorant pigs."

A 15 year old respondent summed up the group's feelings toward their absent fathers by exclaiming: *"I have noticed that we all have a connection about our fathers – they are all stupid cunts"*.

The bad feelings between Young Carers' mothers and estranged fathers have impacted on relationships with paternal grandparents:

"The family disowns you. They expect everything to be fine. They offer, and then they don't do anything about it."

"My grandparents don't care since my dad walked out. They blame my mom for him walking out."

Another respondent, aged 15, held down a part time job earning £30 a week. This was all put into the *"family money pot"* to be split up in order to try and cover family expenses.

5.1.7.2 The need for a safe house

Because of societal perceptions and extensive responsibilities at home, respondents felt that they wanted a place that they could *"escape to"* when they felt that they could not cope. Some suggestions were a *"safe house"* (*"...only for Young Carers"*) or a *"holiday chalet"* (*"buy a hotel that Young Carers can stay there whenever we like"*). Respondents were very clear that this facility should only be made available to Young Carers and not be accessed by other young people (*"... they would think we are a bunch of weirdos"*).

Although Young Carers were quite negative regarding support received from other agencies, they were very appreciative of support offered by the CYCP. Perhaps this is best summed up in the words of an 11 year old who approached the evaluation team at the conclusion of the focus group: *"There is something I want to say, and I want to go up to [the project lead] and tell her this too. I am always certain that the trips we go on are always going to be fun."*

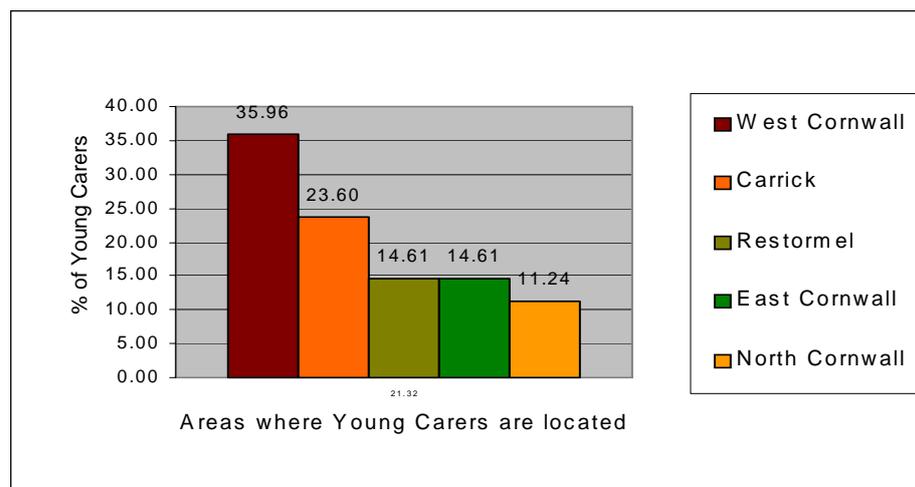
5.2 Themes and outcomes from the project and programme (strategic) level

5.2.1 Identification of, and initiating contact with, Young Carers

5.2.1.1 Number of Young Carers identified

During the months under review (November 1999 – September 2001), 202 new Young Carers have been identified by the CYCP. The distribution across the action area is presented in Figure 1.

Figure 1: Geographic distribution of new contacts

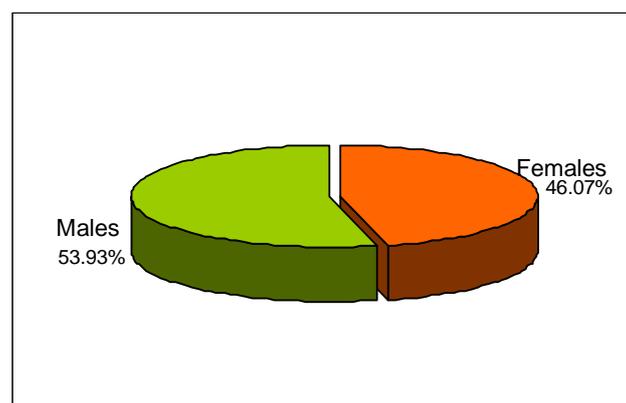


As depicted in Figure 1, the majority of new contacts are located in West Cornwall (35.95%, $n=32$), with the minority located in North Cornwall (11.24%, $n=10$). Frequencies relating to the other areas contained in the action area are: Carrick (26.30%, $n=21$), Restormel (14.61%, $n=13$), and East Cornwall (14.61%, $n=13$).

5.2.1.2 Gender distribution of new Young Carers identified in Cornwall

The gender distribution of new contacts identified during the period of review is relatively equally distributed – females (46.07%, $n=41$) and males (53.93%, $n=48$) (see Figure 2).

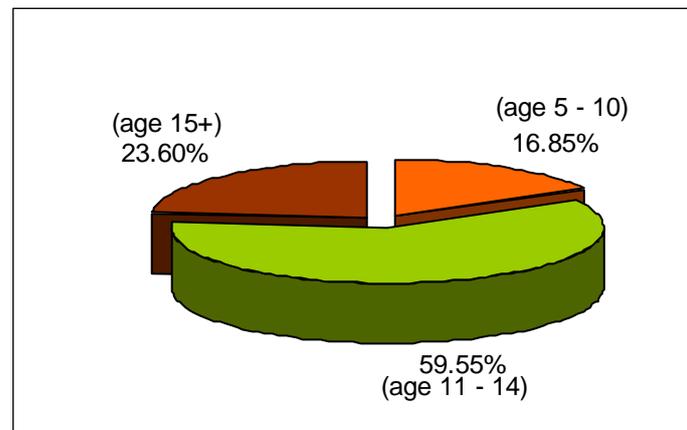
Figure 2: Gender distribution of new contacts



5.2.1.3 Age distribution of new Young Carers identified in Cornwall

The age distribution of newly identified Young Carers is displayed in Figure 3. Newly identified Young Carers fell predominantly into the 11-14 year age range (59.55%, $n=53$). Although a prior expectation of the project lead was that Young Carers would predominantly be 15 years and older, this can be seen as not the case (23.60%, $n=15$). The implications of these findings are that the majority of Young Carers known to support agencies in Cornwall fall on the threshold of adolescence. Given the extensive responsibilities faced by Young Carers, this developmental phase could exacerbate stress and the feelings of alienation and depression voiced by Young Carers. These findings speak to the type and extent of support needed by this vulnerable age group.

Figure 3: Age distribution of new contacts



Equally disconcerting is that 16.85% ($n=21$) of newly identified Young Carers fall into the 5-10 year age group. Children of this young age would normally not be left to fend for themselves, and yet they find themselves in a context of having to assume the primary caregiver role within the family. Young Carers who fall between 5 – 10 years of age, may require more extensive home assistance than would be required by an older age group.

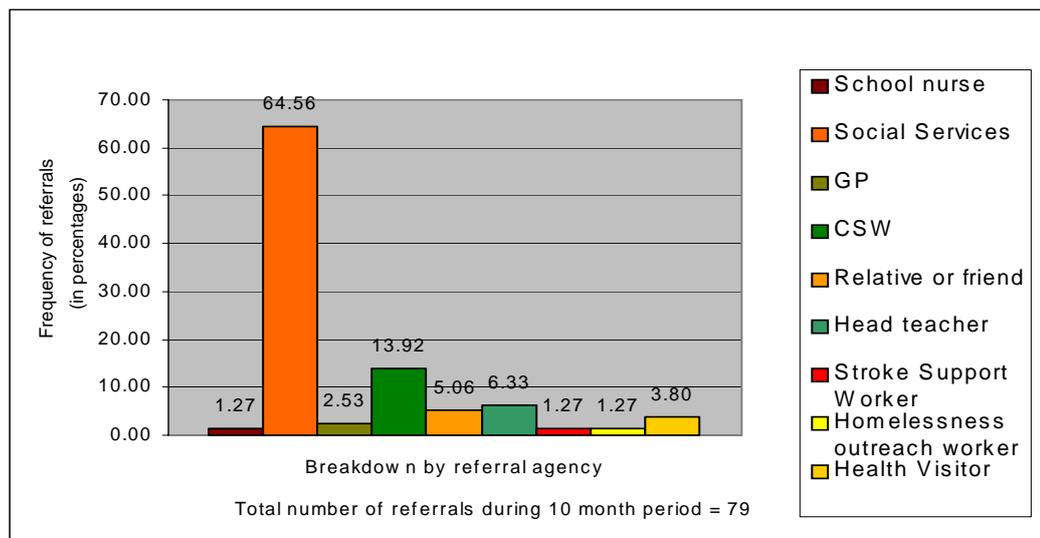
5.2.1.4 Referrals to CYCP by partner agencies and community resources

The CYCP relies heavily on referrals from agencies and community resources who come across CYCP through offering varying services in the community. The breakdown of referrals is presented in Figure 4. In total, the CYCP Project received 79 referrals during the 10 month period presented in this report, which is encouraging. However, in reviewing the data it is clear that Social Services emerges as the primary source of referrals to the CYCP, with 64.56% ($n=51$) of referrals, followed by Care Support Workers (13.92%, $n=11$).

A disappointing finding was that the referral rate from schools was markedly low, with only 1 referral from a school nurse and 5 referrals from Head Teachers. The project expected that there would be a much higher number of referrals from schools around the county. As a result of this low referral rate, the project lead has identified the need to raise awareness in schools

regarding both the identification of Young Carers, and referral to the project. In order to raise awareness the project produced and circulated the video plus an accompanying training manual to all secondary schools (N = 32), as well as primary school cluster groups (N = 70) in Cornwall. Furthermore the video and training booklet were also disseminated to the Youth Service, youth clubs, youth organisations, the Health Promotion Unit, as well as the three statutory agencies. The total number 214 videos and training manuals were disseminated.

Figure 4: Distribution of referrals from partner agencies



Another area of concern emerging from the data was the low referral rate from GP practices (only 2 referrals were made during the 10 period under review). In response to this, the project lead has identified this as a priority focus and has begun to visit numerous GP practices around the country with a view to increasing referral rates in the future. This awareness raising strategy has been complemented by the development of a leaflet, which is currently available for distribution in GP practices around the county. A further strategy in increasing referrals from GPs is requesting GPs to document and monitor those young people who they believe to be Young Carers, and to feed this information back to the CYCP lead.

5.2.2 Services provided to Young Carers by CYCP

The CYCP offers a diverse range of services to Young Carers in the region, including: respite, transport, education and training, mentoring and support

5.2.2.1 Provision of respite for Young Carers

Due to the nature and extent of their caring responsibilities, Young Carers are frequently deprived of opportunities for relaxation outside of the home environment. This is compounded by economic deprivation resulting from parents being unable to sustain employment. A large component of the services offered to Young Carers by CYCP therefore involves creating respite times away from the caring environment. These are opportunities for Young Carers to relax and socialise with other Young Carers. Stated succinctly, they are opportunities for Young Carers to simply be young people.

Respite opportunities take various forms:

- Day outings
 - Make a difference day
 - One day of respite to dry ski slope
 - Respite day out
- Evening outings
 - Tenpin bowling
 - Disco
- Day and a half outings
 - Trip to a theme park
- Residential weekends
- A week of respite
 - Attendance at a holiday play scheme
- Week outings
 - Trip to a Young Carers Festival
- Respite holidays
 - Provision of holiday opportunities
 - Provision of finances towards a holiday

Financial support in providing respite opportunities, provided through Young Carers Grants, ranged between £15 and £101 per Young Carer, depending on the nature and duration the activity, and the geographic location of the Young Carer.

5.2.2.2 Provision of transport for Young Carers

Due to the age, family circumstances and frequently the geographic location of Young Carers, transport to respite opportunities as well as other daily activities is problematic. A large proportion of the CYCP budget is allocated to the provision of transport. Types of transport support offered to Young Carers include:

- School transport
 - Finances are sometimes required as a once off for emergency transport to school. Other Young Carers require school transport assistance on an ongoing basis.
- Transport to support ongoing education

The CYCP has been involved with providing ongoing transport assistance so that older Young Carers can receive work based training (block placement) necessary for their college course.

- Transport to respite opportunities
It stands to reason that it is pointless organising respite activities if the Young Carers do not have transport in order to attend. Transport to respite opportunities is an expensive and ongoing form of support offered to CYCP.
- Transport related to hobbies
Young Carers who need assistance in order to be able to attend a hobby or sport activity (for example, transport to surf lifesaving) sometimes approach the CYCP. Such activities are important in trying to maintain a healthy balance in Young Carer's lives.

Financial support in providing transport for Young Carers, ranged between £8 and £96 per Young Carer, depending on the nature and duration of the activity, and the geographic location of the Young Carer.

5.2.2.3 Support for education and training

Numerous requests are received from Young Carers who require assistance with education and training requirements. Examples of support offered during the period under review include:

- Course fees for attending a 10 week course in Woodwork
- Provision of wood for Woodwork course
- College placement
- Drama lessons
- Driving lessons
- Educational support - home study
- Replacement computer to help with homework

Financial support in providing education and training opportunities for Young Carers, ranged between £10 and £400 per Young Carer, depending on the nature and duration of the activity, and the geographic location of the Young Carer.

5.2.2.4 Emotional support and mentoring

The role of Young Carers is not an easy one, and Young Carers report needing additional support and mentoring to enable them to cope and discuss their frustrations. In collaboration with the Youth Service, the CYCP is able to link Young Carers (age 15 and older) with suitable mentors. The need for suitable mentors, who can work with the younger aged Young Carers, is discussed under "Gaps in Service Provision".

An additional form of support that is extended to Young Carers, is access to Anger Management.

5.2.2.5 Agencies utilised during service provision

It stands to reason that the CYCP relies heavily on partner agencies in providing suitable services to Young Carers. Other agencies are utilised both

in the realisation of an initial request from a Young Carer, as well as on a referral basis for ongoing support. Examples of partner agencies who assist with service provision include:

- Social Services
- Cornwall Youth Services
- Contract through local firm
- Cornwall Centre for Volunteers
- Local companies
- Health Services

5.2.3 Gaps in service provision

Through the process of continually monitoring services, CYCP has identified gaps in service provision. Some of these gaps have been resolved during the duration of this review, whereas other gaps need further consideration and planning to resolve them in order to improved services to Young Carers. The gaps identified and extent of resolution are detailed in Table 1.

Table 1: Gaps in service provision and extent of resolution obtained

GAP IN SERVICE PROVISION IDENTIFIED	RESOLUTION OBTAINED
CRISIS MANAGEMENT	
<ul style="list-style-type: none"> • It is recommended that more prevention work be done, in terms of statutory systems benefiting Young Carers, in order to prevent issues from reaching crisis level (identified January 2001). 	No resolution to date.
DIFFICULTIES IN ACCESSING YOUNG CARERS GRANTS	
<p>Access to, and use of, Young Carer grants:</p> <ul style="list-style-type: none"> • Clarification required regarding who is eligible for YC grants (identified in February 2001) • Clarification required regarding how the YC grant system operates. • Difficulties in accessing money limits provision to Young Carers (identified in September 2000). • The time taken for the process of accessing funds is too lengthy, and limits service provision to Young Carers (identified in October 2000). 	<ul style="list-style-type: none"> ✓ Social Services addressed regarding issues of accessing funding (September 2000). ✓ Meeting arranged between Social Services and CYCP to discuss issues (September 2000). ✓ Meeting with Care Managers to clarify issues of access (November 2000). ✓ Decision made by Social Services regarding petty cash provision to assist with trips and transport (April 2001) ✓ Petty cash float made available in Truro (May 2001).
CLARIFICATION OF ACCESS TO CYCP SERVICES	
<p>Issues of access and eligibility:</p> <ul style="list-style-type: none"> • Clarification required regarding: whether YC have to be registered with Social Services in order to access CYCP services (identified in September 2000); who is eligible for 	No resolution obtained to date.

<p>CYCP services (identified in February 2001); and who has the final say regarding eligibility for CYCP services (identified in February 2001).</p> <p>Factors hindering service provision:</p> <ul style="list-style-type: none"> • There are time delays in active steps to helping Young Carers to accessing CYCP services (January 2001). 	No resolution obtained to date.
ACCESSING SERVICES OFFERED BY STATUTORY AGENCIES	
<ul style="list-style-type: none"> • Social Workers are busy and therefore difficult to contact (identified October 2000) 	No resolution to date.
ADDITIONAL SUPPORT WORKERS REQUIRED	
<p>More support required:</p> <ul style="list-style-type: none"> • In order to enable greater support for Young Carers, additional support workers are required (identified November 2000). • Support groups of volunteers needed to enable greater support for Young Carers <p>Greater support needed for younger age groups</p> <ul style="list-style-type: none"> • Services needed for Young Carers aged 5-12 – similar to Youth Service mentoring scheme (identified February 2001, March 2001, April 2001, July 2001) 	<p>No resolution to date.</p> <p>No resolution to date.</p> <ul style="list-style-type: none"> ✓ The Children's Fund will be looking at issues concerning their work with young people aged 5 – 12 (May 2001). ✓ To date no resolution of mentoring services required for this age group.
TRANSPORT DIFFICULTIES	
<ul style="list-style-type: none"> • It is difficult to provide transport for Young Carers (July 2001). 	No resolution to date.
RURALITY	
<ul style="list-style-type: none"> • Additional transport required by Young Carers isolated by rurality (identified July 2001). 	No resolution to date.
INFORMATION PROVISION	
<ul style="list-style-type: none"> • A new information form for Young Carers is recommended (identified November 2000). 	No resolution to date.

5.2.4 Partnership working

The CYCP aims to access all Young Carers within the Cornwall region. A key facet of providing services, is the identification of Young Carers and ensuring that they are aware of services offered by the CYCP. The CYCP relies considerably on partnership working across a cross spectrum of agencies, so that an efficient referral system can be constructed. In order to ensure the sustainability of the project, the project worker has also been in touch with academics / researchers and potential funders. The partnerships which are being cultivated are listed below:

A variety of methods were used for building partnerships. These included meetings with individuals and groups, presentations to meetings, conference attendance and presentations, participation in forum and support groups, collaborative case studies and review, information sharing and distribution of leaflets and a video regarding the work of the CYCP. Training regarding what it means to be a Young Carer, and raising awareness of the difficulties encountered by Young Carers, have played an important role in partnership building. The partnerships that are being cultivated are listed below:

- **Voluntary agencies**

ADHD Support Group Meeting
 Cornwall Council for Voluntary Youth Services
 Homestart
 Millenium Volunteers
 Music group in Penwith
 Pehhaligons Friends
 Senior Citizens Luncheon Club
 Various voluntary organisations within Kerrier District
 Voluntary Sector Forum
 YMCA Housing team
 British Red Cross

- **Statutory agencies**

Primary Care Groups
 Care Managers
 Social Services
 Young Carer Workers
 Youth Service
 Connexions
 Disability related meetings

- **Education authorities**

Schools /Governors
 Headteachers
 PHSE teachers
 PSME teachers

- **Funders**

Health Action Zone
 Social Services

- **Academic / research**

The University of Plymouth

- **Health**

GP practices
 Practice managers
 Community nurses
 NHS

Heath Action Zone
Local Health Authority

- **Training provision**

Carers Support Workers induction
Launch of CYCP Video
Multi-agency training

- **Case conferences and reviews**

Care managers
Health visitors
Social Services
Families

5.2.5 Referrals resulting from service provision

As already discussed, the CYCP relies on partnership working with various agencies throughout Cornwall in order to provide the best services possible. Agencies to which Young Carers were referred as a result of service delivery are detailed below:

- Youth Service / Mentoring Service
- Case co-ordinator
- SSD
- Social Services
- Care Manager

5.2.6 Training needs identified

Numerous training needs were identified as a result of ongoing interaction with Young Carers and the broader helping community. These training needs are delineated in Table 2.

Table 2: Training needs identified

TRAINING NEEDS IDENTIFIED		
Training required by	Identified training needs	
CYCP worker	Assessment training	
	Legal implications	
	BSL sign language	
	Child abuse training	
	Knowledge of illnesses and processes	
	Mental Health issues	
	I.T. training (database construction and use)	
Workers from other organisations	Heightened awareness required:	In schools
		In GP practices
		In health practices
	Information sharing required:	Regarding the work of CYCP
		Regarding the role of YOUNG CARERS within the home
Regarding how CYCP can benefit young people		
More inter-agency communication		
Young Carers	Anger management	
	Knowledge of illnesses and processes	
	Assertiveness training	
	Awareness of the rights of YOUNG CARERS	

(a) Training needs required by the CYCP worker

The role of the CYCP worker is diverse, requiring a broad spectrum of skills. An area of concern is that the CYCP worker, although not a qualified Social Worker, is required by Social Services to complete a formal assessment (using a generic Social Services assessment form) of each new Young Carer identified. This practice is far from ideal, and serious consideration should be given to providing urgent and appropriate training to enable the CYCP worker to complete these assessments satisfactorily and in an ethical manner. Another suggestion is the development of an assessment protocol, which captures the specific and unique needs and requirements of Young Carers. This would hopefully result in a more appropriate care plan being developed for Young Carers. The project worker also specified requiring in-depth training on the legal implications implicit in working with Young Carers.

Other specialised training is also required by the CYCP worker to enable her to more adequately understand Young Carers and address their concerns. These specialised training areas include: sign language, child protection, mental health issues, and knowledge of illnesses and illness processes.

As monitoring and evaluation are ongoing components of the CYCP, it is essential that the project worker be equipped to capture data accrued, and meaningfully analyse the results. These results are essential to inform practice and improve ongoing services. Towards this end, I.T. training is required, with specific reference to database construction and usage.

During the ten months under review, the CYCP worker has received some training in two fields: 'Child abuse multi-agency training' and attendance of a 'Y. C. Research / Good Practice and Law Training Day'.

(b) Training needs required by workers from other agencies

Two key components of training, required by workers from other agencies, were identified. Firstly, to ensure ongoing referral of Young Carers to the CYCP, heightened awareness regarding the project is required by GPs, community nurses, health practices and schools. Linking with this is the need for agencies to understand the mandate of the CYCP, services offered to Young Carers, and a deeper understanding of the role of the Young Carer in the family environment (including concomitant stressors).

In order to realise these training needs, improved communication between agencies should be encouraged and cultivated.

(c) Training needs required by Young Carers

The training required by Young Carers is associated with self-empowerment, both within the family and broader social contexts. Within the family context, Young Carers are daily faced with extensive responsibilities, frustrations and stressors. This can result in Young Carers feeling overwhelmed, which sometimes erupts in potentially inappropriate anger. The CYCP worker has encountered cases where bottling of anger has resulted in the Young Carer becoming abusive towards the parent they are caring for. As a preventative

stance, in assisting Young Carers with coping in this difficult environment, it is essential for them to receive training in anger management and assertiveness. An additional training component, which would greatly enhance their caring role, is gaining an understanding of illnesses and illness processes.

Within the broader social context, Young Carers would benefit from training regarding their rights as Young Carers.

RECOMMENDATIONS

- **Difficulties in accessing Young Carers Grants**
Action steps: (a) provide a weekly petty cash system which is managed by the Project Manager; (b) Make money for Young Carers outings (e.g., day trips) more easily and quickly accessible; (c) Centralise the Young Carers Grants within the project. There could be a better understanding between Social Services and Care Managers.
- Presently there are **no mentoring services** for young people aged 5 – 12. This is an increasing problem area because there is an increasing number of young carers who fall within the age range 5 – 12. At present Youth Service and Connexions only provide a mentor for young people who are 13 years or older.
Action steps: (a) the project needs to find alternative providers for mentoring services, for example: NCH action for children or the Children's Society; (b) the project needs to build in financial resources dedicated specifically to facilitating a mentoring system for the age range 5 – 12; (c) the Early Years Partnership, whose specific remit is to target children and young people under the age of 12, should be approached in offering mentoring service to the Young Carers project.
- **Schools**
 The project worker has experienced difficulty in gaining access to Head Teachers and school governors as well as difficulty in schools recognising the importance and the role of young carers.
Action steps: (a) to access as many school as possible within Cornwall in terms of encouraging schools to both identify young carers as well as understanding their roles both within schools as well as in the family; (b) the LEA should recognise and promote the value of Young Carers work in all of its schools; (c) a follow-up questionnaire is being planned to distribute to all the schools in order to ascertain the impact that the video and training manual has had in various school settings.
- **Social Services Assessment Form**
 This is a standard form adopted by Social Services, which does not adequately reflect the unique and specific needs of Young Carers
Action step: Social Services need to be more flexible and ensure that their assessment form, and any forms relating to young carers, are not just generic forms but they are sensitive to the needs of young carers. Ideally revisiting this form should be completed in consultation with the Project Worker and the Young Carers themselves.
- Throughout the last year of the project there have been very **low referral rates from GPs, community nurses, and schools.**
Action step: the project worker should embark upon comprehensive awareness raising campaigns within these settings, as well as developing a monitoring and recording system for GPs (of young carers) in particular.

- Partner **voluntary organisations** have played a significant role in the project thus far, however it is important to maintain the momentum of procuring additional partners and volunteers.
Action step: to continue to raise awareness about the CYCP among the voluntary sector in Cornwall.
- The complexity of potential **mental health problems** (exhibited both by parents and young carers) is often overlooked in planning and delivering services for this population.
Action step: visit all the District Mental Health Teams around the county in order to ensure that the mental health needs of young carers are prioritised and granted the appropriate resources in order to deliver these specialised services.
- Oftentimes the **rights of young carers**, as both young people and young carers, are disregarded. The Young Carers, during the focus group made this point on various occasions with the evaluator.
Action step: to raise awareness among professionals working with populations of young people, and specifically young carers themselves, of the rights of young people as specified in the UN charter for children – more specifically:
Article 15: *“You have the right to meet, make friends with and make clubs with other people, unless it breaks the rights of others.”*;
article 27: *“You have the right to a good enough standard of living. This means that parents have the responsibility to make sure you have food, clothes, a place to eat, etc. If parents cannot afford this, the government should assist.”*;
and Article 31, which simply states: *“You have the right to play.”*
- **Increasing communication** regarding the project as well as increasing access to services needs to be addressed in future planning.
Action steps: (a) a monthly newsletter to be drafted and sent to all identified young carers, making them aware of different services and community resources, for example: youth forums, day trips, residential weekends, young carers grants, and their rights; (b) to enable young carers who have not yet been identified by the project to gain access to the services through, for example, the construction of a web page.
- There needs to be an increase in the amount of **1:1 contact** between professionals and young carers. As stated by the young carers in the focus group, they understand that it is impossible for the project worker herself to individually meet all the young carers on an ongoing basis. This task would become even more difficult, considering the projected increase of young carers throughout the next year.
Action step: the project needs to be granted more resources (human and financial), for example: the appointment of youth workers and support staff, who would be able to provide 1:1 support to existing young carers as well as increasing the profile of the project and in so doing identifying more young carers in their communities.

- There appears to be a lack of understanding amongst professionals working with young people in Cornwall, regarding “**What is a young carer?**”
Action steps: (a) for the project manager to attend professional conferences in order to raise the profile of the CYCP; (b) to continue to raise awareness regarding the role of Young Carers.
- Young Carers have often referenced the fact that they feel **isolated**, most often by their peers.
Action step: Perhaps the various district youth forums could include adopting young carers as part of their planning for the future. Furthermore the youth forum members could make a concerted effort to facilitate greater access and involvement of young carers in the various youth forums.
- In reviewing the project status over the last year, it appears that there have been certain **organisational restraints and constraints** placed on the project by statutory agencies.
Action step: it would seem logical and viable that the Young Carers Project attains an independent status once the joint funding between Social Services and the HAZ draws to an end in March 2002. This independence could facilitate: (a) Gaining non-profit status would facilitate access to a broader base of funding opportunities (locally, nationally and internationally); (b) this could also facilitate the constraints of bureaucracy which are inherent in all statutory agencies, for example this would be able to circumvent issues of accessing funds for young carers; (c) Being independent would enable the project to develop more innovative and creative services and in so doing expand the gamut of services which it could potentially provide in the future.
- Young Carers, the CYCP worker and partner organisations need ongoing **training** in issues (e.g., legal issues, mental health issues, abuse and child protection, sign language, the role of home help etc.) pertinent to service planning and delivery to Young Carers.
Action step: future-funding proposals should include specialised funding for existing and ongoing training requirements.
- **The monitoring and evaluation strategy** should continually be adapted to include changes and new variables as the project grows and develops.
Action steps: In collaboration with project manager, the evaluator should revisit monitoring and evaluation instruments and ensure that they capture relevant data in a user-friendly manner.
- Professionals need to be trained as regarding **consultation with Young Carers** in the planning and delivering of services which are targeted towards meeting their specific needs.
Action step: the Young Carers themselves should be involved in designing and delivering various training modules to professionals working in this field in Cornwall (this could be modelled upon the Youth Participation and Advocacy Project).

CONCLUSION

In reviewing the anticipated target outcomes which were established by the Young Carers project at the outset of its service delivery, the project has made significant progress in not only meeting these targets, but in many instances, exceeding these initial expectations and targets. The fact that the project has been able to identify 202 new young carers is a key milestone in demonstrating the critical need for such a service, but it also speaks to the fact that this is perhaps only the “tip of the iceberg” in identifying significantly more young carers in Cornwall.

While the majority of referrals have come through Social Services, there is evidence to suggest that the referral system is widening. Given that the project lead has identified information sharing, monitoring and recording young carers by GP’s and related professionals, and developing a more coherent and thorough referral base for young carers in Cornwall, the number of identified young carers will more than likely be significantly higher in the months ahead. In consulting with the young carers themselves, evidence suggested that this project (with its array of services and programmes) has begun to address the unique needs of a previously “invisible” population of young people in Cornwall. While the young carers have expressed significantly high levels of user satisfaction with the project, they have also raised numerous issues regarding the role of statutory services in relationship to providing more effective services for themselves and their families. Many of these suggestions have been captured in the recommendations outlined in this report.

It is recommended that the Young Carers project be viewed as a critical and valuable service in the specialised carer’s arena in Cornwall. Furthermore, the evidence from this case study strongly suggests that the project should either be mainstreamed or granted the support to obtain funding from external sources so as to continue its work, beyond the termination of HAZ funding (March 2002).