

# THE CORNWALL YOUNG CARERS PROJECT: PHASE TWO EVALUATION

*Young Carers are also very COOL!*

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# INTRODUCTION

- Report on a three-year (2002 – 2004) evaluation of the CYCP (phase 2)
- Comparative references will be made to phase 1 of the project's evaluation cycle (June 1999 to December 2001)
- 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.
- National context: policy, practice and legislation

*1. Caring About Carers (National Strategy for Carers, HM Government, March 1999),*

*2. The NHS and Community Care Act 1990*

*3. The Children Act (1989),*

*4. The Carers (Recognition and Services) Act of 1995,*

*5. NSF for Assessment of Children and their Families in Need (DOH, 2000)*

# METHODOLOGY

- Demographic profile of young carers (comparative analysis)
- Focus group with young carers
- Critical case studies
- Semi-structured interviews with young carers' parents
- Semi-structured interviews with project workers
- Service providers survey questionnaire



# DEMOGRAPHIC DISTRIBUTION

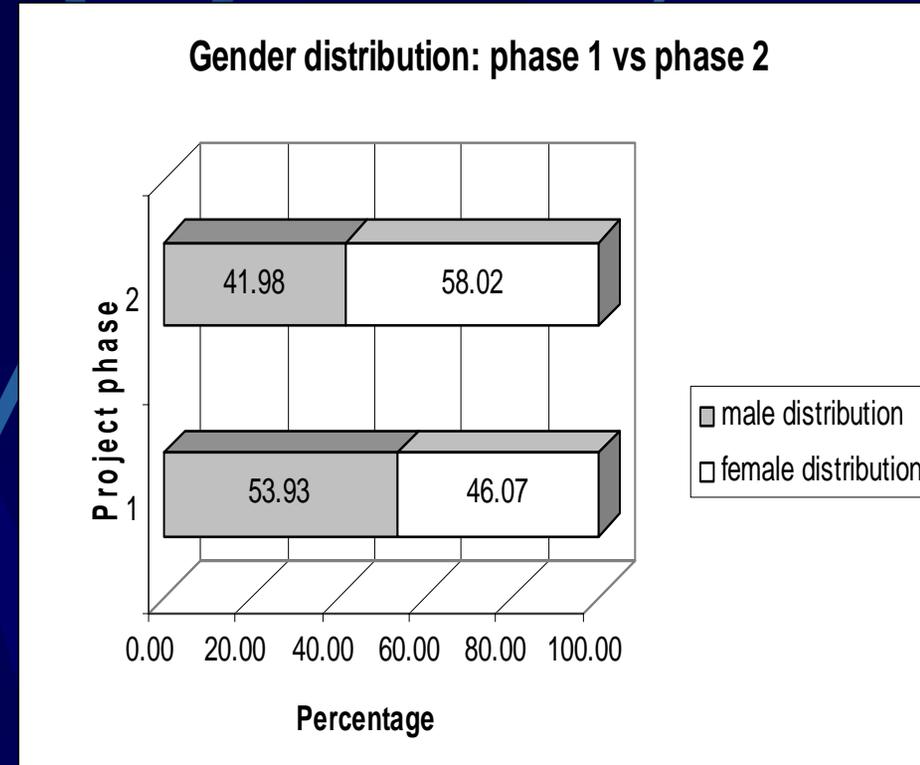
- Young carer identification

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

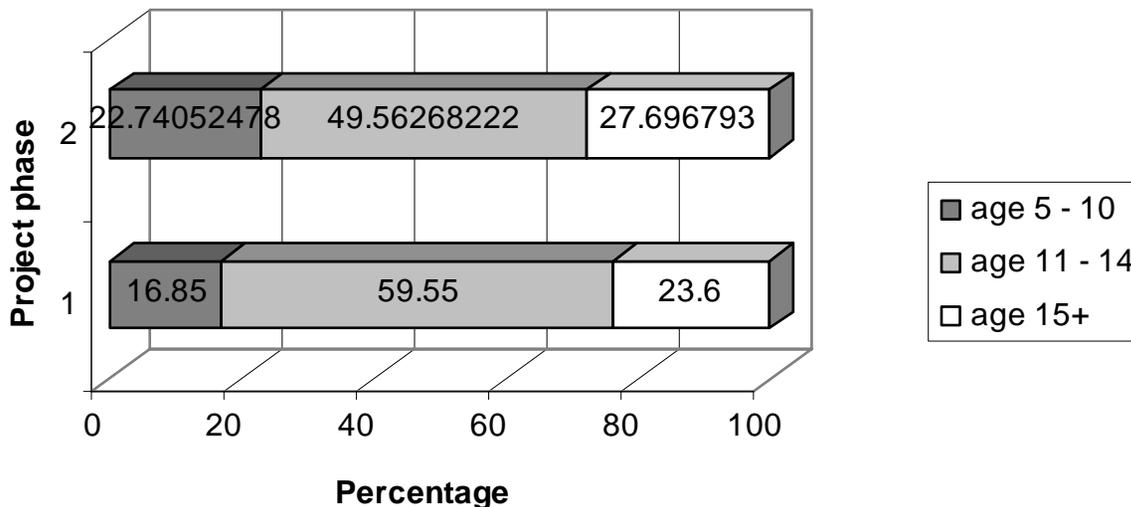
- Some differences were noted regarding the gender distribution of the client base. In phase 1, identified young carers were predominantly male ( $n = 48$ , 53.93%). Whereas in phase 2 the identified young carers are predominantly female (58.02%,  $n = 199$ ) compared to males (41.98%,  $n = 144$ )



# AGE DISTRIBUTION

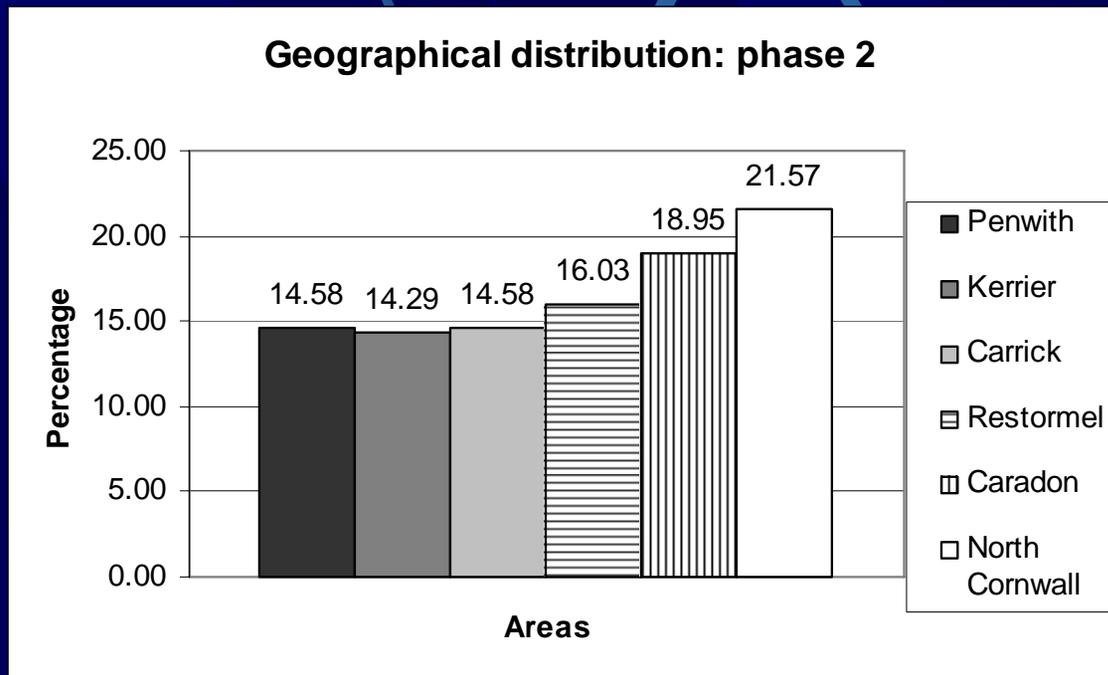
Some interesting shifts have occurred regarding age distribution (see Figure 2). While the 11- 14 year age group is still the most commonly identified group of young carers (49.56%,  $n = 170$ ), there have been increases in the identification of young carers in both the 5- 10 year range and those aged 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.

Age distribution: phase 1 vs phase 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.



# REFERRALS

- 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.
- 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

# 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).

# YOUNG CARERS' PERSPECTIVES

- Caring responsibilities

*“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.”*

- Likes and dislikes of being a young carer

*“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.”*

*“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”.*

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.”*

# YOUNG CARERS' PERSPECTIVES

- Personal emotional and mental health

*“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.”.*

*“I cannot tell people how I really feel.”*

- Relationships with siblings and friends

– *“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.”*

# YOUNG CARERS' PERSPECTIVES

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

*“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.”*

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.”*

# YOUNG CARERS' PERSPECTIVES

## ● Services provided by the CYCP

*“Enjoyable”; “Amazing”; “Helpful”; “Life changing”; “Great”; “Exciting”;  
“Love it”; “Spectacular”.*

*“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' PERSPECTIVES

## ● Services provided by the CYCP

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”*

*“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”*

*“Getting involved in the web site would be cool.”*

# PROJECT LEAD AND FIELD WORKER'S PERSPECTIVES

## THE EARLY YEARS (1996 TO 1999)

- Aims
- Funding and pilot study
- Partners
- Management structure/staffing



# PHASE 1 – THE DEVELOPMENTAL YEARS (1999 TO 2001)

- Aims and operational status
- Job description
- Project achievements
- Multi-agency partnership working
- Frustrations and service barriers



# PHASE 2 – THE OPERATIONAL YEARS (2002 TO 2004)

- Aims and goals
- Funding and staffing
- Redefining job descriptions
- Young Carers Forum
- Management structure
- Service Provision
- Gaps in service provision/multi-agency collaboration
- Project achievements and frustrations

# SERVICE PROVIDER'S PERSPECTIVES

- Knowledge regarding young carers and CYCP

*“The cases I have come across suggest I have no idea of the level of young people in caring roles.”*

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.”*



# SERVICE PROVIDER'S PERSPECTIVES

- Service provision to young carers
- Perspectives on the referral system

*"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."*

- Inter-agency collaboration and partnership working

*"Allowing the young carers themselves to talk about their experiences. They are the best ambassadors for young carers."*

*"Set projects up together.";*

*"Continue to look at ways to work together as Carers Projects to all sectors."*

- Future development of CYCP

*"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.";*

*"Let the CYCP continue to raise the profile of young carers, support them and advocate on their behalf."*

*"Vital to reassure parents that involvement with young carers is to support and avoid fear of children being 'take away'."*

# PERSPECTIVES OF PARENTS

- Medical condition
- Impact of medical condition on daily functioning

*“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”]*

*“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*

- Support offered by young carers
- Length of young carer involvement in CYCP
- Impact of caring role on young carers

- Perspectives regarding CYCP

*”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.”*

- *“It has helped their confidence.”;*

*“Has thrown a massive lifeline to a struggling teenager. Has completely boosted her confidence and self esteem.”.*

- Additional support received by parents

- Suggestions for the future development of CYCP

# CRITICAL CASE STUDIES

- Daily caring tasks
- Sibling care
- Role of the project
- Self-care and self-perception
- Future aspirations
- *Concluding comments*



# COMMONALITY OF EXPERIENCE

- **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**

# COMMONALITY OF EXPERIENCE

- **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**

# RECOMMENDATIONS

- **Increasing identification and referral from service providers**
- **Mentorship**
- **Volunteers**
- **Awareness raising**
- **Funding and staff resources**
- **Reformulate project goals and aims**
- **Holistic work with parents**

# RECOMMENDATIONS

- **Sibling care**
- **Education around mental health and substance misuse**
- **Service provision to age 18+**
- **Multi-agency collaboration and partnership working**
- **Additional respite and social activities**

# CONCLUSION

Significant progress towards achieving all of its original aims and goals, and has exceeded a number of its targets.

Identification and referral process has resulted in the number of young carers increasing dramatically from phase one of the project.

Holistic family work

CYCP provides a critical and valued service to a vulnerable group of young people

Substantial progress re: to multi agency collaboration and partnership working

The young carers have been granted opportunities to present their experiences to local and national audiences - empower them and to advocate on behalf of their own needs and rights

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Constant service user feedback and consultation

# ACKNOWLEDGEMENTS

- The evaluators would like to thank the young carers for being so willing to share their life stories with us. Your courage and resilience is testimony to the extraordinary young people you have become, and it has been an enormous privilege to have the opportunity to be part of this evaluation process, and to share in your experiences.
- To the project lead, Dawn Madden and the project field worker Millie, for your commitment to the evaluation process and for ensuring that it was a positive experience for everyone concerned. You are the very heart of this project, and your love and commitment have emerged from all the young carers' stories.
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