

**HAPPEN 4U COMMUNITY RESEARCH SERVICE**

**on behalf of Halton Partnership**

**RESEARCH STUDY INTO YOUNG CARERS IN HALTON**

**2007**

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# **YOUNG CARERS RESEARCH PROJECT**

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## 1. Introduction

Happen 4U Community Research Service was commissioned by HITS on behalf of Halton Partnership to undertake a local study to assist with future service development and delivery for young carers in the Borough of Halton. Halton Children and Young People's Plan (2005) includes the following target:

*All young carers who are identified receive support and the numbers known to support services increases by 50% by 2009.*

The current estimate of the number young carers in Halton is of 474 (2001 census). HITS knows of around 200 of these and approximately 55-60 young carers access services on a regular basis. Setting this data against the Children and Young People's Plan target generated the research questions:

1. What is the nature of the data behind the figure of 474?
2. Why have less than 45% of the estimated number of young carers been identified?
3. Why do only 30% of the known young carers access services?

In relation to the second and third questions, existing research suggests that lack of awareness is a significant factor: young carers and families lacking awareness of their entitlements, others' lacking awareness of issues facing young carers, and both groups lacking awareness of services for young carers. In addition to seeking answers to the research questions, the Report itself seeks to contribute to the awareness raising: hence, the inclusion of material on the nature of the caring task.

## 2. Methodology and Limitations

### 2.1 The process

The research work was originally contracted out to Happen 4U, a trading subsidiary of HITS jointly owned with 3 other voluntary organisations. When Happen 4U ceased to employ staff from 31<sup>st</sup> March 2007, the remaining research work and completion of the Report was undertaken by HITS.

#### Stage 1

- Establishment of research team
- Completion of research brief
- Commence literature survey and site visits
- Design referrer survey tool and identify respondents
- Identify individual young carers to be contacted (arrange parental consent)

#### Stage 2

- Complete literature survey and site visits
- Complete referrer survey and interviews with individual young carers
- Complete report with recommendations

### 2.2 Methodology

Due to the nature of the research questions, the perceptions of young people and of their families, and their descriptions of the caring task, provide the primary data. A

qualitative approach was, therefore, the principal means of data gathering and analysis. The research team aimed to validate this primary field data with larger scale information through a literature review and comparative data from other local authority areas. The posing of research questions in numerical terms demanded that quantitative data was also included. The reliability of such data is limited by the validity of the concepts underpinning it: concepts such as ‘young carer’ and ‘in receipt of services’ are not necessarily applied consistently from time to time and place to place.

### **Interviews/focus groups – with current young carers (Appendix 2)**

The research team developed a series of questions for young carers to be conducted either as interviews or focus groups depending on the take-up and/or availability of current young carers to participate. The questions sought to gain an insight into their perceptions of being a young carer, their description of the caring task, how they became involved with HITS and their subsequent experiences. Staff at HITS assisted with interview/focus groups, which were conducted in the HITS accommodation, familiar surroundings for the young people.

### **Interview/focus groups – with former young carers (Appendix 3)**

It was recognised that the numbers in receipt of services is a product of the numbers of young people commencing, and ceasing to receive, the service. It was appropriate, therefore, to seek information from those formerly in receipt of services as a young carer, about the factors that precipitated their leaving the service. Here, the research team was particularly interested in participants reflecting on their experiences of being a young carer and to what extent had being supported through HITS had an impact on their lives.

In practice, whilst those currently in receipt of service were generally willing to take part in the survey, it proved very difficult to access former young carers. It is possible to infer from the age profile of those in service (Figure ) that the HITS service was less attractive to young people as they entered older adolescence, but it is not possible to validate this inference with the accounts of young people.

The data provided by young people was supplemented by data gathered from parents, through interviews conducted in their own homes. The primary focus of these interviews was parents’ perception of the HITS service, and their understanding of the caring role undertaken by their child.

### **Interviews – local organizations who are potential referrers of young carers (Appendix 4)**

The final research tool developed was a semi-structured interview to be used with organizations and agencies that have a remit and/or involvement with young carers to discuss key issues around:

- Identification & assessment
- Referral processes
- Access to and take-up of support services

## **Limitations**

The focus of interviews on individuals who were current service users at HITS, and absence of data from young people who had left the service, or who had chosen not to receive it, means that the researchers were unlikely to hear from young people whose needs were not being met by the service as currently provided. This made it difficult to have a view on whether the quality of the existing service was a factor in the level of take up by young people. Following inconclusive attempts by Research staff to interview current and former young carers, the majority of the interviews with young people were conducted by a HITS' employee. Although this was a new member of staff, and one not engaged in direct service to young carers, it is very likely that the status of the interviewer had an impact on the dynamics of the interaction with the young people.

## **3. Literature Review**

### **Defining Young Carers**

Young carers are children and young people under the age of 18 years who provide care to another family member who has a physical illness / disability; mental ill health; sensory disability or has a problematic use of drugs or alcohol.

The level of care they provide would usually be undertaken by an adult and as a result of this has a significant impact on their normal childhood.

### **Underpinning guidance;**

- The child or young person does not have to live with the person they care for.
- The term does not refer to young people under the age of 18 years who are caring for their own children.
- The term does not refer to young people under the age of 18 years who accept an age appropriate role in taking increasing responsibility for household tasks in homes with a disabled, sick or mentally ill parent.
- The impact of caring on a young person varies and it is important to assess needs on an individual basis.

*(Service for young carers; a framework. 2002)*

### **Prioritizing Research into Young Carers**

Whilst there is a considerable amount of academic literature on adult carers, there is still little in comparison that examines in any depth the experiences and needs of young carers. *(Fallon 1990)*. A possible reason for this is offered by Becker et al *(1995)* who states that young carers have been traditionally excluded from official data collection procedures and analyses and subsequent wider policy debates. This situation improved with the introduction in the 2001 Census of a question devoted to the provision of unpaid care. However, it is still then necessary to undertake secondary analysis to extrapolate specific data on young people (under 18) providing varying degrees of care.

### **Understanding the scale of Young Carers in the UK**

Official estimates suggest there are around 175,000 children and young people in the UK providing unpaid care for a sick or disabled member of the family *(UK 2001-*

*Census of Population*). Barnardo's (2006) however, express concerns that many carers in the UK are not captured in official statistics and as such remain "hidden" in service planning and delivery.

In a recent survey of young carers Barnardo's conducted they found that although the young carers surveyed were currently receiving support from a Barnardo's project, many admitted it had been years before their problem was spotted and acted on. On average each young carer had spent 4 years looking after a relative or parent before they received any support Barnardo's (2006).

### **Why do so many children and young people care in secret?**

The Barnardo's study suggested a number of factors that contribute towards young carers caring in secret and therefore remaining "hidden" from official statistics and support agencies:-

- A culture of secrecy, often based on fear and suspicion of intervention by statutory authorities.
- Lack of awareness within families about the support that exists for young carers.
- Lack of knowledge amongst teachers about issues facing young carers and about external services.
- Teaching staff being unaware of procedures that exist in their school and inadequate procedures.

Social Care Institute for Excellence (*SCIE, 2005:1*) suggest that only small numbers of young carers are currently being identified or assessed for support, identifying the following reasons:-

- Blurred boundaries of responsibility between adults and children's services
- A lack of awareness among many professional groups of young carers' needs and concerns
- Young carers' lack of awareness of their entitlements, and their reluctance to seek formal help.

#### 4. Young Carers in Halton

There is no absolute figure for the number of young carers in the county or the UK. Young carers are only known to agencies when they or their families chose to identify themselves. Therefore, the true extent of caring by children and young people is 'hidden'. The 2001 Census identified 175,000 young carers aged under 18 in the United Kingdom, 474 of whom are in Halton.

**Table 1 Provision of Unpaid Care**

| 00ET<br>Halton<br>UA            | Total   | Provides<br>no care | Provides<br>care:1 to<br>19 hrs | Provides<br>care: 20 to<br>49 hrs | Provides<br>care: 50<br>or more<br>hrs | Total          |
|---------------------------------|---------|---------------------|---------------------------------|-----------------------------------|--|----------------|
| <b>All<br/>people</b>           | 117,209 | 103,678             | 7,944                           | 1,891                             | 3,696                                  |                |
| <b>0 to 4</b>                   | 7,160   | 7,160               | -                               | -                                 | -                                      |                |
| <b>5 to 7</b>                   | 4,495   | 4,477               | 15                              | 3                                 | -                                      | 18 (0.4 %)     |
| <b>8 to 9</b>                   | 3,398   | 3,372               | 20                              | -                                 | 6                                      | 26<br>(0.77%)  |
| <b>10 to 11</b>                 | 3,471   | 3,431               | 34                              | 3                                 | 3                                      | 40<br>(1.15%)  |
| <b>12 to 14</b>                 | 5,302   | 5,163               | 120                             | 9                                 | 10                                     | 139<br>(2.62%) |
| <b>15</b>                       | 1,815   | 1,752               | 57                              | 3                                 | 3                                      | 63<br>(3.47%)  |
| <b>16 to 17</b>                 | 3,526   | 3,338               | 143                             | 28                                | 17                                     | 188<br>(5.33%) |
| <b>Mean<br/>total<br/>hours</b> |         |                     | 3890                            | 1380                              | 1560                                   | 6830           |

- figures in blue indicate numbers of young carers

**Total = 474**

**Source - (UK 2001 – Census of Population)**

It is notable that the numbers declaring a caring role increases with age, and that the numerical dip at age 15 is accounted for by a sharp dip in the total population.

The Mott MacDonald (2006) research carried out in Halton stated 24508 of young people between the ages of 5 and 19 years live in Halton in 2004. Research carried out by Saul Becker et al (1995) suggests that 2.1% of the population of young people are young carers. Based on this projection, an estimated 515 young carers live in Halton. The difference of 41 between the estimated figure and the self declared figure (8% of the total) may be said to represent the 'hidden' young carers in Halton.

Some of the research undertaken by Chris Dearden and Saul Becker at Loughborough University in 2004 of 6,178 young carers supported by specialist young carers' projects across the United Kingdom is highlighted in the table below and compared to local information taken from the referrals received in Halton

| <b>National</b>  | <b>Halton</b>  |
|--|--|
| 56% of the sample are girls                                | 55% of the sample are girls                                |
| 44 % of the sample are boys                                | 45% of the sample are boys                                 |
| 52% of people with care needs are mothers                  | 67%of people with care needs are mothers                   |
| 29% of people have care needs due to mental health issues  | 37% of people have care needs due to mental health issues  |
| 63% of siblings with care needs have learning difficulties | 50% of siblings with care needs have learning difficulties |

### **Current provision and support for Young Carers in Halton**

There is a history of local provision since 1996 and HITS has been involved in work with young carers since 1998. A young carers worker has been in post in the organisation since September 1998 and in 2000 a qualified social worker was appointed to lead the project.

Halton's Children's Services commission the Halton Young Carers Project at HITS through their mainstream budgets and additional funding is provided from Carers Grant for support, activities and short breaks for Young Carers. Adult Services provides Carers Grant funding for young people in the age range 16-17, while Children's Services funds services for those aged between 5 and 15. Consequently, the remit for young carers, who cover the full age range is split between two service areas, leading to a lack of continuity of provision across the age range. The funding from Children's Services is supplemented by time limited grant funding through the Children's Fund, Positive Activities for Young People, Neighbourhood Renewal Fund, and the Carers Grant.

The primary function of the Carers Grant of £503k, administered by the council, is to fund breaks for carers, and it is distributed to voluntary organisations via an application process. According to the Service Development Officer for Carers, the fund is under-utilised, particularly by the HITS Young Carers' Project. The results of this research may inform ways in which the Young Carers' Project could better utilise these funds in the future.

Young carers' needs cut across the responsibilities of many agencies, including Children's Services, Health and Adult/Children's Services and Voluntary Agencies. Whilst HITS is the only agency in the Borough providing a dedicated service for young carers, it is not the only agency providing services for young carers. In common with other services working on the Every Child Matters agenda, a key priority is to achieve better integration of services for young carers provided by different agencies.

## 5. The Field Research

The focus of the field research was to provide explanations for the deficits of 'known' young carers, and of the numbers of known young carers accessing services.

### 5.1 The views of referrers

The organisations selected were Halton Autistic Families Support (HAFS); The Butterfly Project, an organization set up by NCH to provide support to families of children with life-limiting conditions; Crossroads Caring for Carers, an organization mainly supporting adult carers; and the Carer Involvement Officer Halton and St Helens Primary Care Trust. The member of staff selected for interview from the Primary Care Trust declined to take part in the interview, stating ethical concerns.

The interviews were conducted face-to-face, following a semi-structured format. The aim was to gain a perspective representative of the whole organization with reference to their perceptions of, and attitudes to, young carer issues. The questions covered the following areas:

**Definition of a young carer:** There were some discrepancies here, Butterfly Project giving a definition of a young carer as a sibling of a child with a life limiting condition, and HAFS defining the term as applicable to anyone under the age of 18 who cares for a parent or sibling. This discrepancy probably arises from the difference in focus of the services provided by the organizations.

**Awareness of the existence and needs of young carers among service users:** Two of the organizations involved work with families, so awareness is high. The third organization, Crossroads, deals specifically with adult carers, and only sees young carers in a secondary role, providing assistance to their adult counterparts. The Butterfly Project, which no longer operates in Halton owing to funding difficulties, previously supported 20 Halton families, and within these families, at least 5 children could have been classed as young carers. HAFS questioned the accuracy of the figure for young carers in Halton, due to a perception that most organizations would not consider sibling carers to fit the definition.

**Awareness of service provision for young carers:** All the participating organizations were aware of the HITS young carers project, and have referred young people to it. The Butterfly Project has a high regard for the project, citing the value for the young people of the opportunity for social interaction with peers, something that is often very difficult for them to achieve without outside help. HAFS also acknowledged the value of HITS' project, but went on to describe the ways in which their own service provides activities that involve the whole family, without segregating by age or ability. Although the group does not cater specifically for young carers, respite time for adults is built into the activities.

**Barriers to accessing services:** This question elicited some interesting and varied comments. The main perceived barrier was the concern among adults and young people alike that "interference" from people in authority could result in the break-up of the family unit. Other issues centred around self-esteem and confidence, with some young people, especially in the younger age range, finding the prospect of socializing

with strangers, out of their family environment, just too daunting. Time, location and accessibility of sessions are also an issue, with particular relevance in Halton, given the inbuilt disinclination for many people to cross the bridge between Widnes and Runcorn!

A further negative aspect brought up concerned a prevailing attitude towards HITS as being an organization that deals with “difficult” young people, based on it being the lead provider of services for young offenders in Halton up until the formation of the Youth Offending Team in 1999. Although HITS’ remit has evolved over time since this was the case, many local people, especially those of the generation who are now parents, still subscribe to this point of view.

## **5.2 The Views of Young Carers and of Families**

There were a total of 20 interviews conducted with young carers, the majority of which were with current young carers accessing the support services offered by HITS. From this sample, 12 interviews came directly from interviews with young carers (ages 9 to 15 years) and the remaining 8 (aged 13 to 18 years) through family interviews.

The interviews conducted revealed that on average each young carer had spent nearly 4 years performing a caring role before they had received or accessed support. This finding is consistent with the recent Barnardo’s study that also revealed a similar time-period before support was accessed (*Barnardo’s 2006*). One of the main contributing factors identified in that study as to why young carers ‘care in secret’ was the notion of there being a “culture of secrecy” amongst families, often based on fear and suspicion of intervention by statutory authorities.

This was also reflected in this study through the interviews with staff from local organizations, who, when commenting on potential barriers to accessing services, suggested that families could perceive potential “interference” from people in authority as possibly resulting in the break-up of the family unit - therefore influencing their decisions on accessing the appropriate support.

A further issue was a lack of awareness within families around the support that exists for young carers (as highlighted in the Barnardo’s study). This is reflected in the comments of one of the young carers who had until recently only started to access the support services offered by HITS but had been performing a caring role amongst her family for over 5 years;

“Although I have been a carer for all this time I did not realize this until just before Christmas when I was talking to another young carer. I then contacted HITS. Before I started HITS I did not know what the proper meaning of a young carer was and I didn’t really think much of my caring role”.

This lack of self-defining in terms of their caring role may account for the lack of awareness as it appears to be consistent amongst many young carers who have almost inherited the role from an early age. It is probably safe to say that not one single factor alone can explain why only small numbers of young carers are currently being identified or assessed for support but more a combination of issues.

The interviewees (young carers and parents) expressed very high levels of satisfaction with the current service provided by HITS, and all the parents noted the importance of a break from the caring role for their child and the value of the personal support that s/he received. It is not possible to infer from these positive views that there is not a relationship between service satisfaction and young people going out of service in their later teenage years. A perspective from those who had already left is required here. Such negative comments there were focused on the timing and frequency of activities – there were several requests for more of the same, and suggestions that start and finish times were later. The provision of transport (mainly through volunteers) was much appreciated.

## **6. The Caring Task (as described by young carers)**

The total sample was 20 but the aggregated replies do not always equal that figure: not every question was answered and in a few cases there were multiple dimensions to the caring role. .

### **Length of time as a young carer (sample: 16)**

The number of years spent in the caring role ranged from 1 to 14, with an average of just over 5 years. This is not completely reliable because some respondents dated the commencement of the role as coinciding with the onset of the cared for person's condition, and in a few cases this put them at an age too young (under 5 years) to fulfill the usual definition of a 'young carer'.

### **Amount of time (hours) per week in the caring task (sample: 12)**

The number of hours spent in the caring role ranged from a very modest 20 minutes a week to 25 hours, with an average of just over 11 hours. This is rather less than a figure of 14.4 hours derived from the census statistics (Figure 1 p 6)<sup>1</sup>. Once again, the young people's accounts are not wholly reliable. There is not necessarily a clear division between being 'on' and 'off' duty as a young carer, and between those duties which might ordinarily be expected as part of a young person's contribution to family life and those which are additional requirements to meet the cared for person's needs. The contexts ranged from 'emotional support' (which could be said to be continuous) to a very specific 'look after the young ones while Mum is in the shower'.

### **Nature of the caring task (sample: 18)**

The predominant tasks involved caring for people (8) or practical work (7). The people cared for included younger and older members of the family as well as for the person whose additional needs are the basis of the caring role. Practical tasks included the familiar routines of shopping, cooking, cleaning and washing up. In two cases, the young people described their contribution in terms of positive mental health, as 'emotional support' and 'try and stable (stabilize) situations'. Only one young person specifically referred to the giving of medication. Overall, the caring task was more likely to be indirect (i.e. doing things the cared-for person would do if they were well – 13 cases) than direct (caring for that person – 7 cases).

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<sup>1</sup> The figure was based on the mean of the three time bands, i.e. 10, 30, and 40 hours. These means were multiplied by the number of individuals in each time band (column) and then the aggregated hours divided by the total number of young carers (474).

The testimonies of individual young people provide the richest picture of life as a young carer and their experience of HITS (Appendix).

## **7. Conclusion and Recommendations**

### **The data behind the census figure of 474**

This figure, as highlighted earlier in the study, derives from the 2001 census of population. It identifies 16-17 year olds (188) as containing the highest numbers of young carers by age group, followed by 12-14 year olds (139).

Although these official statistics could provide an indication of “ball-park” figures – a certain caution has to be applied: some leading organizations (such as Barnardo’s) believe many carers are not captured in official statistics and therefore remain ‘hidden’ from those responsible for service planning and delivery. The decision by the Halton Young Carers Steering Group to adopt the Saul Becker et al formula of 2.1% of the population of 5 to 18 year olds being young carers gives a figure of 515 young carers living in Halton. This figure has been incorporated into the Halton Strategy, and makes the ‘known of’ and ‘in service’ targets still more challenging.

A further issue is that there is considerable gap from one census to the next (10 years) in terms of being able to accurately quantify the numbers of young carers in a particular area. There is also the potential threat of the question surrounding the provision of unpaid care being removed from the 2011 census.

### **Why less than 45% of the estimated number of young carers been identified. Why only 30% of the known young carers access services.**

The inference behind these questions is that the needs of many of Halton’s young carers may not be being met, because those needs are not known due to the young people remaining ‘hidden’, or because known young carers are not receiving services. The data available from other Local Authorities is too limited for comparisons to be made, but Halton seems to be doing at least as well as any of its neighbours in being interested in the number of young carers in the Borough and knowing how many are known to services as young carers, and how many access services.

This Report makes two contributions.

Firstly, it provides information that helps to explain the figures. The local testimonies confirm the findings of other research rather than add new explanations. Lack of awareness, fear of official interference and misunderstandings about the roles of individual agencies all have part to play. The central issue may be said to be about ‘awareness’ in that people (parents, young people, referrers) and lack of good information upon which to base decisions: information about different agencies and the services they provide, and how to access those services.

Secondly, the Report – its production and dissemination - is itself part of a process that changes the subject of the research. There has been a significant increase in referrals of young carers to HITS, but this will not change the ‘percentage’ problem because the

adoption of the 2.1% of the 5 to 18 population criteria raises the bar in terms of the assumed population of young carers.

## **Recommendations**

The recommendations that flow from this Report are already being pursued by the Halton Young Carers Steering Group and incorporated into a Strategy for the Borough. This is because the emerging findings from the research process, along with an element of ‘action research’ being part of the role of a Young Carers development worker, have informed the thinking of the Steering Group.

### **1. Develop a common understanding of the definition of young carers.**

### **2. Gain a greater understanding of other agencies and their roles in terms of young carers support.**

(5.1 The views of referrers)

Although it is recognised that other projects support the needs of young carers in Halton, this contributes to the confusion of what the term ‘young carers’ is defined as. To minimise confusion and ensure young carers have the maximum opportunity to receive support, a common understanding of the definition of young carers and roles of individual agencies needs to be more widely developed.

### **3. Develop and support a wider range of activities across agencies that meet the individual needs of young carers.**

### **4. Develop consistent ways of providing information to those young carers who do not access support services.**

(5.1 Barriers to accessing services)

There are a number of issues that seem to prevent young people from accessing young carers support that may be minimised by developing support services in a wider range of community based projects. Raising awareness of the support available increases opportunities for young people to

### **5. Sustain the role of the development worker to establish links between children’s and Adults services; identify other areas of support and maintain increasing levels of identification.**

### **6. Sustain multi agency steering group and links to the North West Young Carers Forum**

The young carers support service has the potential to be developed across all agencies to ensure the maximum number of young carers are identified and supported as appropriate. HITS has both the experience and ability to take this forward becoming a coordinator as well as provider of services. If this is to be done effectively it will be necessary to sustain a development worker capacity

**Appendix 1: Comparative statistics, North West authorities.**

| <b>Local Authority Area</b>                                | <b>Salford</b> |
|--|----------------|
| Total population aged 5 to 18 years (2001 Census)          | 43,226         |
| Estimated number of young carers (2.1% of 5-18 population) | 907            |
| Numbers of young carers known to services                  | 684            |
| Numbers of young carers currently receiving services       | 100            |

| <b>Local Authority Area</b>                                | <b>Liverpool</b> |
|--|------------------|
| Total population aged 5 to 18 years (2001 Census)          | 91,103           |
| Estimated number of young carers (2.1% of 5-18 population) | 1,932            |
| Numbers of young carers known to services                  | 160              |
| Numbers of young carers currently receiving services       | 80               |

| <b>Local Authority Area</b>                                | <b>Halton</b> |
|--|---------------|
| Total population aged 5 - 18 years (2001 Census)           | 23618         |
| Estimated number of young carers (2.1% of 5-18 population) | 496           |
| Numbers of young carers known to services                  | 197           |
| Numbers of young carers currently receiving services       | 49            |

| <b>Local Authority Area</b>                                 | <b>Knowsley</b> |
|---|-----------------|
| Total population aged 5 to 18 years (2001 Census)           | 33,672          |
| Estimated number of young carers (2.1% of 5- 18 population) | 707             |
| Numbers of young carers known to services                   | 75              |
| Numbers of young carers currently receiving services        | 75              |

**Appendix 2: age profile of young carers engaged by HITS, 2006-07**

|     | Age engaged | Age disengaged | Yrs engaged |
|-----|-------------|----------------|-------------|
| 1.  | 8           | 11             | 3           |
| 2.  | 9           | 11             | 2           |
| 3.  | 9           | 11             | 2           |
| 4.  | 10          | ongoing        | -           |
| 5.  | 10          | 12             | 1.5         |
| 6.  | 9           | ongoing        | -           |
| 7.  | 11          | ongoing        | -           |
| 8.  | 6           | 12             | 6           |
| 9.  | 11          | 16             | 4           |
| 10. | 13          | 15             | 2           |
| 11. | 10          | 15             | 5           |
| 12. | 15          | 16             | 1           |
| 13. | 9           | 13             | 4           |
| 14. | 13          | 14             | 1           |
| 15. | 11          | ongoing        | -           |
| 16. | 12          | ongoing        | -           |
| 17. | 11          | 14             | 3           |
| 18. | 14          | 14             | 0.25        |
| 19. | 17          | 17             | 0.25        |
| 20. | 15          | 15             | 0.25        |
| 21. | 10          | 12             | 2           |
| 22. | 13          | ongoing        | -           |
| 23. | 15          | 16             | 2           |
| 24. | 13          | ongoing        | -           |
| 25. | 9           | 14             | 1           |
| 26. | 13          | ongoing        | -           |
| 27. | 13          | ongoing        | -           |
| 28. | 5           | ongoing        | -           |
| 29. | 7           | 11             | 4           |
| 30. | 7           | ongoing        | -           |
| 31. | 5           | ongoing        | -           |
| 32. | 6           | ongoing        | -           |
| 33. | 5           | ongoing        | -           |
| 34. | 9           | ongoing        | -           |
| 35. | 9           | ongoing        | -           |
| 36. | 7           | 8              | 0.5         |
| 37. | 8           | 9              | 1           |
| 38. | 7           | 9              | 2           |
| 39. | 8           | ongoing        | -           |
| 40. | 9           | ongoing        | -           |
| 41. | 6           | ongoing        | -           |
| 42. | 9           | 10             | 1           |
| 43. | 15          | 18             | 3           |
| 44. | 15          | 18             | 3           |

## **Sample of young carers engaged in project, April 2006 – March 2007**

Average age when engaged = 9.5 yrs

Average age on disengagement = 13.25 yrs

Those still engaged at end of year = 43%

Of those engaged, average length of time engaged = 2.25 yrs

### **Appendix 3: Interview schedules**

#### **1. Interviews/focus groups – current young carers**

What jobs do you do at home that makes you a young carer?

How many hours per week do you help out at home?

How long have you been a young carer?

How long were you in a caring role before your family got any help from other people such as HITS?

How did you hear about HITS?

What would help you and your family more?

#### **2. Interviews/focus groups – former young carers**

Allow ½ hour for meeting and greeting and refreshments.

*Confidentiality* – emphasize no-one will be identified, and comments will remain confidential within the room, unless there is concern that there is a risk of harm.

Ice breaker quiz - £10 voucher for winner, £5 for taking part.

##### *Before*

How many of you considered yourselves to be carers, before you were identified as such by someone else?

Can you remember who first identified you as a “young carer?”

What worries did you have about what might happen next?

How did you find out about the HITS project, and what did you expect it to be like?

Opportunity to ask if they know of others who didn't come to sessions, and why they think that might be.

What worries/concerns did you have about coming to HITS?

Are they happy to discuss?

##### *During*

What did you most enjoy about coming to HITS?

Facilitator to log comments on flip.

What was most helpful about the sessions?

As above.

What could have been better?

What were your reasons for deciding not to attend any longer

*Now*

In what ways has coming to the YC Project continued to help you?

With school/college

With your personal life

With tackling your problems

Is there anything else you would like to say about your time with the Young Carers Project?

### **3. Interviews – local organizations**

What do you understand to be the definition of a young carer?

Are you aware of any young carers among your service users/members?

How do you identify them?

If so, do you know whether any of them access services for young carers?

Is your organization aware of the fact that there are services out there, and of who provides them?

What, if any effort does your group/service make to signpost young carers in the direction of support services?

If young people or families have not wanted to be signposted, what reasons have they given?

What barriers do you think might exist that could stop young carers from deciding to access services?

### **Appendix 4: testimony from young people**

1. I'm SH; I'm 15 and live at home with my mum, dad and 12 year old brother. I am a young carer because my brother has ADHD and my Nan has Parkinson's disease. I an average week I do jobs such as;

- See my brother out to school
- Take my Nan shopping
- Take my Nan to the local Parkinson's group
- Take my Nan out when she needs to get out
- Make sure my brother takes his medication
- Generally support my Nan, brother and mum
- And sometimes I have to look after my niece or brother when my mum has to visit / look after my Nan

I have been a young carer for a while now as we found out my brother had ADHD at the age of 5 and my Nan has had Parkinson's ever since I can remember. Although I have been for all this time I did not realise this until just before Christmas when I was talking to another young carer. I then contacted HITS. I went to my first Time-out session once every week and really enjoyed it. Before I started HITS I did not know what the proper meaning of a young carer was and I didn't really think much of my caring role. I think going to the Time-out group and being made part of HYCC at HITS has really helped me because it gets me out of the house and helps me meet other young carers in the same position as me. I love being at HITS because the environment makes me feel relaxed and in a calm and safe place. The staff are very calm and relaxed this makes it easier to talk to them. I think HITS has changed my life quite a lot for example;

- Understand what a young carer is
- Have timeout
- Meet other young carers
- Meet other people
- People to talk to

Since I have joined HITS I think I have become a little more confident. I couldn't thank HITS enough for all the help this year and can't wait to meet more great people and do more fun things with HITS in the future.

2. I'm DC: Before I became a young carer, I thought the rest of my life was going to be chaos it was. My life in them days were crap! Mum was an alcoholic for year's, I got bullied in school, I thought my life wasn't worth living, I was only young; I didn't know what to do.

I had a mentor in school on behalf of mum being like she was every day. My mentor mentioned HITS to me which I first thought was a counselling organisation. Going to HITS made me realise that I was a young carer which made sense to me in the end.

I found going to HITS very helpful, but I would worry about mum a lot Mum has now been of drink for 3 years now but has Rheumatoid Arthritis so I help her round the house an awful lot, clean mostly as mum is a clean freak!

I find HITS very mind easing for when you are always at home. Staff are great to talk to, funny and caring all in one. I have been involved in plenty of things with HITS such as: HYCC, HYA, Duke of Edinburgh, Bridging Generations, Scrapbook and many more! Yes, it has changed me as a person. I am a lot more confident! I'm older and wiser now.

HITS has always been there for me. HITS do meet existing needs. I provide care everyday for mum, after college and weekends

## 8. References

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