

**THE ISLE OF WIGHT YOUNG
CARERS PROJECT**

EVALUATION REPORT

November 2006

**Written by
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1. INTRODUCTION

This document will report on evaluation of the Isle of Wight Young Carers Project (IOWYCP), from 2001 and leading up to the present (2006). It will provide both an historical context (targets met against original goal statements), as well as a contemporary snapshot of the project in its present context (2006). Furthermore, it will offer practise and policy guidelines and recommendations that could inform future planning and service delivery. This report will provide both formative and summative evaluation of the IOWYCP, and provide evidence in support of its progression throughout the last five years. This body of evidence will be drawn from multiple perspectives and sources, for example:

- Perspectives from the project workers
- Perspectives from the young carers in all three age categories (5 – 11 yrs, 12 – 15 yrs., 16 – 18 yrs)
- Perspectives from the parents of the young carers
- Project evaluation data sets
- Assessment and referral data

It is important, at the outset of this report, to contextualise the IOWYCP in terms of a historical overview, management structure, funding streams, and project aims.

1.1 *Historical overview*

The Isle of Wight Young Carers Project was formed in 2001, by Spurgeon's Child Care (in partnership with the Isle of Wight Children's Services Directorate).

1.2 *Management structure*

In 2001, the IOW Council commissioned Spurgeon's Child Care (and independent and not-for-profit charitable organisation), as part of a competitive tendering process to take on the management of the IOWYCP. The Project intends to support children and young people under the age of 18; who look after or help to look after a relative who has an illness or a disability.

Spurgeon's Child Care is one of the UK's largest Christian charities working with children, young people and families. With over 100 projects in the UK and overseas, they are committed to professional social work as a practical expression of their Christian faith. Their work relies upon the support of individuals and churches, and the partnership of local authorities, trusts and companies. Spurgeon's has been working in the UK since 1867. They have projects from St Andrews (Scotland) to Newport (Isle of Wight), working with children, young people and families. "We are committed to working in partnership with local authorities, local churches and other groups. As a result, each of our projects in the UK and overseas is unique. Each project responds to the needs of its local community."

(<http://www.spurgeonschildcare.org/>)

The Children's Services Directorate is part of the Isle of Wight Council, and was formed in September 2004 when the Education Directorate was combined with the sections of Social Services that deal with children and families. However, it is important to note that the IOWYCP has received funding from IW Social Services since 2001.

The IOWYCP aims to support children and young people under the age of 18 whose lives are in some way restricted because of the need to take responsibility for the care of a parent or relative who may be affected by: chronic illness, a learning difficulty or a serious disability, periods of mental ill health or substance misuse.

The tasks the young carer undertakes could include:

- Domestic chores (ironing, cooking, cleaning)
- Intimate personal care (showering, toileting)
- Child care (looking after siblings)
- Emotional Support (coping with unusual behaviour)

The Project aims to -

- Ensure young people with significant caring responsibilities have access to the service
- Work with the young people, their families and other agencies
- Recruit/train potential volunteers to work with the young people
- Put young carers in touch with others in similar circumstances
- Develop self-help support groups
- Enable young carers, if they wish, to access services currently available within their locality
- Facilitate opportunities for young carers to have time for themselves away from caring responsibilities
- Obtain the views of the young people on how best the project can support them and develop the project accordingly
- Provide additional support to statutory service provision
- Provide support to the young person at 'assessment of need' meetings, if the young person wishes

1.3 Aims of the project

The following aims were identified for the project. The achievement of these aims and objectives will be assessed and evaluated throughout this report.

- Assess the needs of young people with caring responsibilities on the Island
- Develop the Project to meet the assessed needs of young people with caring responsibilities within their own Community
- Promote the rights and welfare of young people with caring responsibilities
- Raise Island wide awareness and knowledge of young people with caring responsibilities
- Record the unmet need and report this to the Steering Group
(*Service Objectives – Schedule One – Contract 2003 – 2006*)

1.4 Policies and National Framework

The last decade has seen a significant increase in the amount of research and project evaluation in the young carers field. This commitment to scientific investigation has slowly begun to move the needs and experiences of young carers from “invisibility” to a point where their needs are recognised through legislation, as well as their daily caring roles and responsibilities being discussed as part of the national carers agenda. Numerous pieces of research have served as a catalyst in this paradigm shift, for example, Aldridge and Becker (1998, 1999), Becker *et al* (1998, 2001), Dearden and Becker (1998, 2000), Becker (2000), Dearden and Becker (2004), Frank *et al* (1999), Frank (2002), Underdown (2002), Eley (2004), Olsen (1996), and Banks *et al* (2001), amongst others. In spite of this increase in research output, Olsen (1996:49), in his critique of young carer research, argues that “practice has run ahead of knowledge in this area, and that in-depth, basic research, designed to enhance our knowledge of who young carers are, what they do, and how they do it, is urgently required.” This need for a more in-depth observation and analysis of young carers lives served as an impetus for this report.

Research estimates suggested that there are between 20,000 and 50,000 young carers in Britain. The Social Services Inspectorate report, “*Something to Think About*” (November 1999), revealed some of the effects that children and young people experience when they have been providing care: Isolation and social exclusion, stigmatisation; problems at school, including bullying; lack of time for play or leisure activities; lack of self-esteem; lack of recognition, praise or respect for their contribution and difficulties moving into adulthood, especially finding work, a career, further study and establishing relationships. This evaluation report will endeavour to provide evidence with regards the work with young carers in a uniquely geographical context: a young carer’s project off the mainland of the United Kingdom – in the Isle of Wight. Furthermore, this body of evidence could add to the knowledge base regarding young carers in the UK, and serve to share models of good practice with other young carer’s projects. Butler and Astbury (2004) found that young carers in Cornwall experienced similar effects to those mentioned above, with regard to their caring roles.

Thus, it was concluded that while Cornwall was relatively unique in terms of its rural context and population size, it shared many characteristics with other young carers around the United Kingdom. A recent survey (2004) commissioned by the Princess Royal Trust for Carers has found that a much higher proportion of young people are carers than reported by the census. The survey of over 1300 young people found that 12 percent of 7 to 19 year olds were looking after and caring for someone with an illness, disability or health problem. This would correspond to over a million people aged up to 19 in the UK, which is dramatically higher than the census which found that around 225 000 people up to 19 were performing caring responsibilities for a family member

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

The 1988 Griffiths report reviewed the way in which public funds were used to support community care policy, and to advise on options that would improve the use of these funds as a contribution to more effective community care (Young, 2000). The NHS and Community Care Act 1990 adopted many of the Griffith recommendations, and established the legislative framework for supporting vulnerable people requiring residential, nursing home or home-based care in the community. Since the inception of this Act, guidance now confirms that carers should be fully involved in the assessment process of their disabled relatives, and that they are entitled to ask for an assessment of their own needs (Becker, Aldridge & Dearden, 1998). Two further pieces of legislation and a national assessment strategy also had an impact upon the way practice and policy has sought to address the specific needs of young carers, namely The Children Act (1989), The Carers (Recognition and Services) Act of 1995, and the National Services Framework for the

Assessment of Children in Need and their Families (DOH, 2000). The Children Act 1989 and the Carers (Recognition and Services) Act 1995 state that young carers can receive support from local and health authorities. Furthermore, with Section 17 of the Children Act, Social Services Departments can assist young carers, by considering whether their welfare or development might suffer if support is not provided. Young carers are also entitled to request a comprehensive assessment of their needs. A significant finding from this evaluation has been that young carers on the Isle of Wight have been at the very centre of assessing their own needs. There are numerous examples of good practice re: the child/young person centeredness approach adopted by the IOWYCP (which will be illustrated throughout this report).

In 2003, the Government published a green paper called Every Child Matters. This was published alongside the formal response to the report into the death of Victoria Climbié, the young girl who was horrifically abused and tortured, and eventually killed by her great aunt and the man with whom they lived. The green paper built on existing plans to strengthen preventative services by focusing on four key themes:

- Increasing the focus on supporting families and carers - the most critical influence on children's lives
- Ensuring necessary intervention takes place before children reach crisis point and protecting children from falling through the net
- Addressing the underlying problems identified in the report into the death of Victoria Climbié - weak accountability and poor integration
- Ensuring that the people working with children are valued, rewarded and trained

The green paper prompted an unprecedented debate about services for children, young people and families. There was a wide consultation with people working in children's services, and with parents, children and young people. Following the consultation, the Government published Every Child Matters: the Next Steps, and passed the Children Act 2004, providing the

legislative spine for developing more effective and accessible services focused around the needs of children, young people and families.

Every Child Matters: Change for Children, is a new approach to the well-being of children and young people from birth to age 19. The Government's aim is for every child, whatever their background or their circumstances, to have the support they need to:

- Be healthy
- Stay safe
- Enjoy and achieve
- Make a positive contribution
- Achieve economic well-being

This means that the organisations involved with providing services to children - from hospitals and schools, to police and voluntary groups - will be teaming up in new ways, sharing information and working together, to protect children and young people from harm and help them achieve what they want in life. Children and young people will have far more say about issues that affect them as individuals and collectively.

<http://www.everychildmatters.gov.uk/aims>).

It is encouraging to note how effectively the IOWYCP has integrated and applied the primary tenants of Every Child Matters to their planning and service delivery. This national framework has informed many aspects of their work, and examples of the project working within this framework are illustrated in this report. (see section 5.6)

2. PROJECT IN CONTEXT/ LOCALITY

In order to fully understand the unique nature of the IOWYCP and its contribution to meeting the diverse needs of its young carers, it is important to contextualise its programme in terms of its geographical locality and various health indicators. The 2001 Census gave the population of the Isle of Wight as 132,731. This represents a change of 5.2% since 1991. This is a much higher rate of increase than the figure for England, which was 2.6%. Children (15 and under) formed 18% of the population.

http://www.statistics.gov.uk/census2001/pop2001/isle_of_wight_ua.asp

Therefore, the number of young carers on the Island could be significantly higher than the 80 that have already been identified. This is merely the “tip of the iceberg” for young carers on the Island. The 1991 Census gave the total white British population of the Island as 99.3%. This figure has decreased by 2.53% to 96.77 in 2001. Table 1 (below) presents an analysis of the various ethnic groups on the Isle of Wight (from the 2001 national census).

Table 1: Isle of Wight Ethnic Groups (2001 census)

Ethnic Groups	IW Nos.
White	130,982
Mixed White & Black Caribbean	270
Mixed White & Black African	65
Mixed White & Asian	243
Other Mixed	141
Asian or Asian British – Indian	189
Asian or Asian British – Pakistani	88
Asian or Asian British – Bangladeshi	89
Asian or Asian British – Other Asian	66
Black or Black British – Caribbean	160
Black or Black British – African	109
Black or Black British – Other Black	35
Chinese	123
Other ethnic group	171

Table 2 (below) demonstrates the ethnicity demographics of the young carers project. It is important to note that the IOWYCP has a higher

number of people from an ethnic minority background (5.5%), as opposed to the Island's average (as evidenced in Table 1).

Table 2: IOWYCP Ethnicity

White British	70
Black African	2
Asian	1
Other mixed blacks	1
Caribbean	1
Unknown	5

(IOWYCP Quarterly report January 06 to March 06)

Health Indicators

The 2001 Census asked questions about limiting long-term illness and provision of unpaid health care. The first detailed results on health, disability and the provision of care from the 2001 Census show that in England and Wales there are 5.2 million people providing unpaid care, one in ten of the population. For the Island, the equivalent figure is 14364, which equates to approximately 1 in 9 of the population. Carers are people looking after or giving help or support to family members, friends, neighbours or others, because of long-term physical or mental ill-health or disability, or problems related to old age. (<http://www.wightchyps.org.uk>).

The main findings for the Isle of Wight are:

10.8% of the population provides unpaid care. This is a similar percentage that those regions with the highest proportion, such as the North East, with 11%. 21.96% of the population has limiting long-term illness, while the figure for the South East and London is 15.5%, the lowest of the English regions. Over 90% of the population stated that their health was either good, or fairly good, with approximately 10% stating that the health was not good. 22.81% of people on the Island are providing unpaid care for more than 50 hours p/w. (<http://www.wightchyps.org.uk>).

This has relevance to the evaluation, and the issue of caring on the Isle of Wight, in general.

Households with Long Term Limiting Illness (LTLI) %

% Households: No adults in employment, with children 4.34

% Households: No adults in employment, no children 39.21

% Households with dependent children (all ages) 26.01

% Households with dependent children, 0-4 9.08

% Households with 1 or more persons with LLTI 38.1

(http://www.statistics.gov.uk/census2001/pop2001/isle_of_wight_ua.asp)

Again, this is a very high percentage of households with disability – which relates specifically to young carers on the Island.

It is interesting to note that there is no specific category of evidence in this census regarding young carers. This is so often a forgotten population of children and youth. This only serves to increase their invisibility and reduces the significance of their daily caring tasks and responsibilities. In so many ways, this denies young carers recognition of their role. This reflects that caring statistics and census are still very adult oriented – little reflection of young carers' realities. An analysis of the English Health Improvement Programme (Corlyon, 2001) also drew attention to the virtual invisibility of young carers (Underdown, 2002).

3. SCOPE OF THE REPORT/ EVALUATION AIMS

The aims of this evaluation are:

- To involve as many young carers as possible, from various age groups, in the research/evaluation process
- To provide a literature base re: experiences of young carers, from which the evaluations programme and direct practise guidelines can emanate.
- To engage with young cares from the IOWYCP, in gaining an understanding of their experiences and the implications for support services.
- Provide evidence re: effectiveness of the IOWYCP in responding to and meeting the needs of its young carers

Research Question

The grand tour question was:

What are the realities, experiences and specifics of young people (and their families) as they engage in their roles as young carers?

Research design, methods and analysis

The approach to the evaluation of the IOWYCP was action-oriented. The chance to influence the development of the project was of great importance within this evaluation design. Realistic evaluation (Pawson and Tilley, 1997) was the guiding principle for this approach. In this respect the evaluator aimed to establish what the key policy are, and delivery issues in practice and set up measures to assess, in as rigorous a manner as possible, not just what happens but also process information about how it happens. This provided valuable information for the transferability and sustainability of both processes and outcomes.

In gathering viewpoints and personal perspectives from the young carers themselves, the evaluator endeavoured to establish valuable evidence around which support for each aspect of the project's development can be built, as

well as providing summative evidence of the effectiveness of the project as a whole. This could also (depending on funding) bring the evaluation evidence forward into debates on policy and decisions about delivery methods within the IOWYCP.

As the evaluation was conducted in the local community (Isle of Wight), a participatory action research model was adopted. Shurink (1998) defines this as a research process where people involved in the situation become “actively involved in collective efforts to address and solve their own social problems” (p. 408). This approach is typically guided by the following principles:

- self-development,
- shared and collective reflection,
- mobilisation of internal group resources,
- stakeholder involvement in decision-making,
- mutual trust between researchers and stakeholders,
- community empowerment and participant ownership,
- equal partnership in the research process,
- inclusive and multi-disciplinary approach.

(Whyte, 1991; Lammerink, 1994; Rahman, 1993).

This required the evaluator to adopt a stance of researcher-practitioner (facilitator, co-learner and team builder) (Shurink, 1998). Because the evaluation of the IOWYCP initiative was conducted in parallel with service delivery, active service user participation and involvement was critical. A further premise of this evaluation was the need to engage young carers in the evaluation process. It is easier to engage young people in an evaluation process if they are involved from the outset and encouraged to express their thoughts, ideas and perceptions (Curtis, Roberts, Copperman, Downie, and Liabo, 2004). It is important that we did not assume that just because a young person actively uses the support provided by IOWYCP that they would automatically want to be a part of the research/evaluation process. This required an innovative strategy to ensure that a cross-spectrum of young carers are involved. To this end, the project coordinator extended an invitation

to all young carers who were actively engaged with the project, to participate in the evaluation.

The research methodology sought to examine the changes brought about by the IOWYCP i.e. project effectiveness, the process by which change took place, and understanding the specificities of adopting a young caring role. It therefore gathered different kinds of data in order to validate findings through triangulation. Quantitative data was collected through detailed analysis of the projects reports on statistics and associated data. Qualitative data was collected through focus groups and structured interviews. This will be elaborated upon in the methodology discussion (section 4). Furthermore, this paper will report on the findings of a five-year evaluation (2001 - 2006) of the IOWYCP, and contextualise these local findings with national trends relevant to the experiences of young carers. More specifically, comparative references will be made to the findings from Dearden and Becker's national 2004 survey report, in which 87 young carers projects were evaluated (and a total of 6,178 young carers).

4. METHODOLOGY

The approach adopted in this evaluation strategy was triangulative, in that a variety of data capturing and analysis methods were utilised. Methodologies utilised were predominantly qualitative, however quantitative work was undertaken when considering categorical responses to questionnaires and considering the changes and growth in demographic distributions between 2001 and 2006.

4.1 Demographic distribution

Data collection and analysis

Throughout the evaluation process it became evident that the IOWYCP had kept detailed and systematic information relating to their client group. This evidence was critical in assisting the evaluation strategy (and subsequent analysis) as it fed meaningfully into the phased evaluation of the IOWYCP. Details of newly identified young carers (including age, gender, location and extent of caring role, referral sources and geographical distributions) were compiled and provided to the evaluator for analysis.

4.2 Secondary Data Analysis: Reviewing project evaluation and monitoring instruments

At the outset of the evaluation process, it became apparent that the project had conducted a significant amount of data capturing and primary evaluation. This information was a critical body of evidence and as such it was important to incorporate this data into the overall evaluation of the IOWYCP. Thus, various aspects of data recording from the project was integrated and subsequently analysed, for example:

- Quarterly reports
- Assessment forms
- Referral forms (see Appendix 4)
- Activity lists
- Various excel spreadsheets (demonstrating respite session breakdowns)
- Demographics data

- Service user involvement, feedback and consultation
- Perspectives from parents of the young carers
- Young carers evaluation of activities/action plans etc
- Termly newsletters

The evaluator will highlight those sections of the report that were assessed and evaluated via secondary data analysis. For example, Section 5.4 focused on the perspectives of the parents of young carers engaged in the project.

The evaluator did not conduct one-to-one interviews with these parents.

However, the evaluator compiled the written commentaries (from the parents) provided by the project coordinator, into meaningful thematic categories. The evaluator would like to acknowledge the information/charts/tables provided by the IOWYCP project coordinator. This data provided a valuable snapshot with regards the growth and development of the project.

4.3 Focus groups with young carers

Sampling procedures/criteria for inclusion

Focus groups were conducted with three groups of young carers (from various age categories), namely:

- 7 to 11 yrs
- 12 to 15 yrs
- 16 to 18 yrs

Purposive and convenience sampling was used. Every child/young person actively involved in the Project was invited to take part in the evaluation.

Participation was voluntary. As a result 23 young carers (from the three age categories) requested to participate in the focus groups. Of the participants, 7 were female and 16 were male, and their ages ranged from 8 to 18. (Please see 5.2 for full focus group demographic breakdown). The criteria for inclusion included: young carers had to have been involved with the project for at least one year, and voluntarily agreed to participate (see Appendix 1 – informed consent form).

Data collection and analysis

An interview schedule was used to guide the facilitated focus group interview (see Appendix 2). Permission was sought from each young carer participating

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

4.4 Structured interviews with project workers

Sampling procedures/criteria for inclusion

The project coordinator and the development worker were interviewed. The project coordinator has been with IOWYCP since 2001, and hence could provide an in-depth and longitudinal focus of enquiry. The development worker, having joined the team in November 2005, could provide significant data pertaining to the more recent fieldwork aspect of the project.

Data collection and analysis

A structured interview schedule was used to guide these interviews (see Appendix 3). However, the primary focus of the interview pertained to the project's programme cycle from 2001 until 2006. The interviews covered topics such as service provision, gaps and barriers to provision, partnership

working, assessment of young carers needs and various referral systems, outcomes and target achievements, goal setting, carer identification, amongst other issues. Interviews were audio-taped and subsequently thematically analysed by the evaluator. Themes were then sorted into meaningful categories.

5. RESULTS AND DISCUSSION

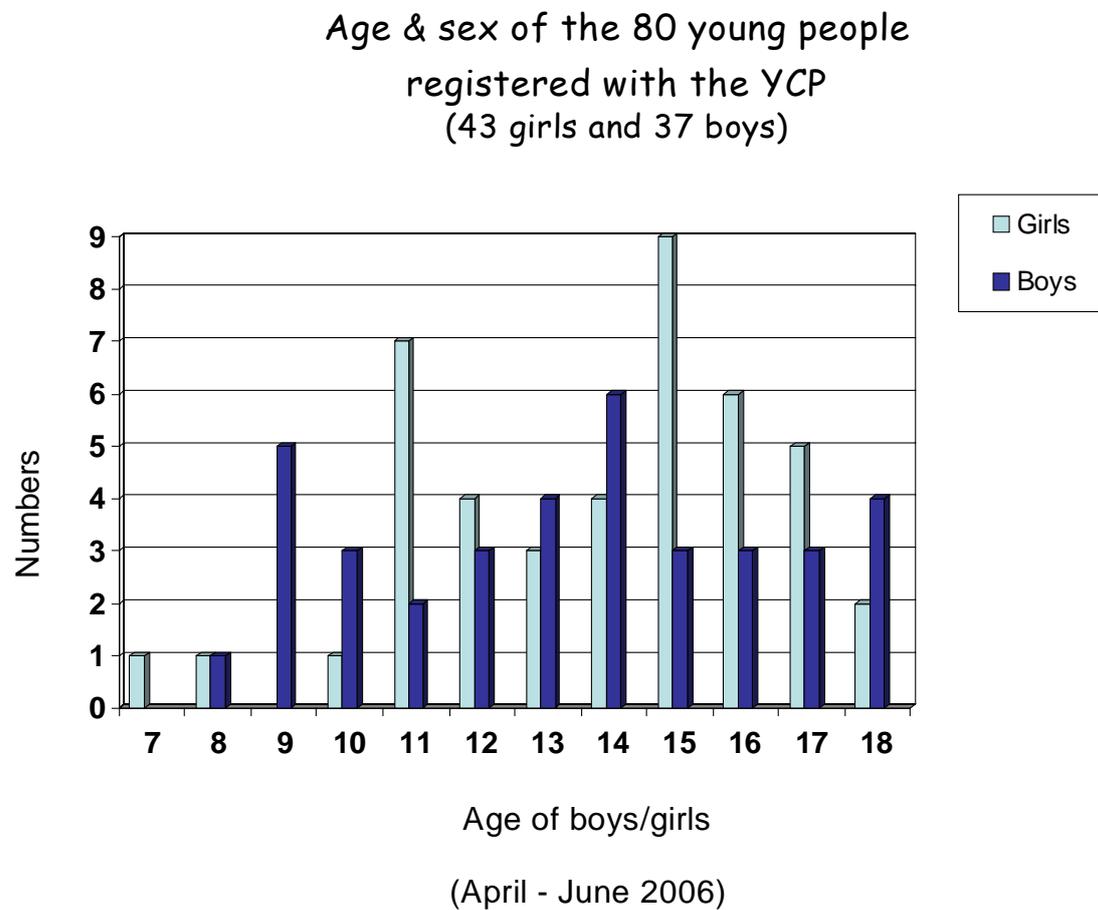
5.1 Demographic data/ young carer profiles

5.1.1 Age

The age distribution of identified young carers in the IOWYCP is displayed in Figure 1. Identified young carers fell predominantly into the 11-15 year age range (56%, n=45). This statistic is in line with Becker and Dearden's (1998) survey, which showed that 32% of young carers supported by projects were in this same age range. The identified young carers in the 16 – 18 year category are 29% (n=23). 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.

Equally significant is that 15% (n=12) of identified young carers fall into the 6-10 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 6 – 10 years of age, may require more extensive home assistance than would be required by an older age group. The Princess Royal Trust for Carers (2005) web page references the effects of being a carer at an early age. They refer to the stress and worry young carers experience and that young carers often experience traumatic life changes such as bereavement, family break up or seeing the effects of an illness or addiction affecting their loved ones.

Figure 1: Age and Gender



5.1.2 Gender

The gender distribution of identified young carers in the IOWYCP, at the point of review, is relatively equally distributed. Of the 80 young carers involved in the project 54% (n=43) are females and 46% (n=37) are males (see Figure 1 above). It is important to note that in this instance the even gender distribution demonstrates that the project is able to meet the needs of both genders. Prior assumptions in the young carers field hypothesised that the majority of tasks associated with “being a young carer” would be carried out by girls (and young women). The gender findings from this projects work is indicative of the fact that the lives of young carers so often dispel the myth that “only girls do chores in the home”, and that increasingly, more and more boys (and young men) are taking on young carer roles in the home. Dearden and Becker’s 2004 national study paralleled the findings of the IOWYCP in terms of gender

distribution. Their sample found that 56% of the young carers were females and 44% were males.

5.1.3 Geographical locality

As stated in Section 2, this project should be viewed within its unique geographical location. Figure 2 (below) provides a map of the Island, which will offer the reader a better sense of the main towns on the Island. For a more detailed analysis of the IW Ward Boundaries please see Appendix 6.

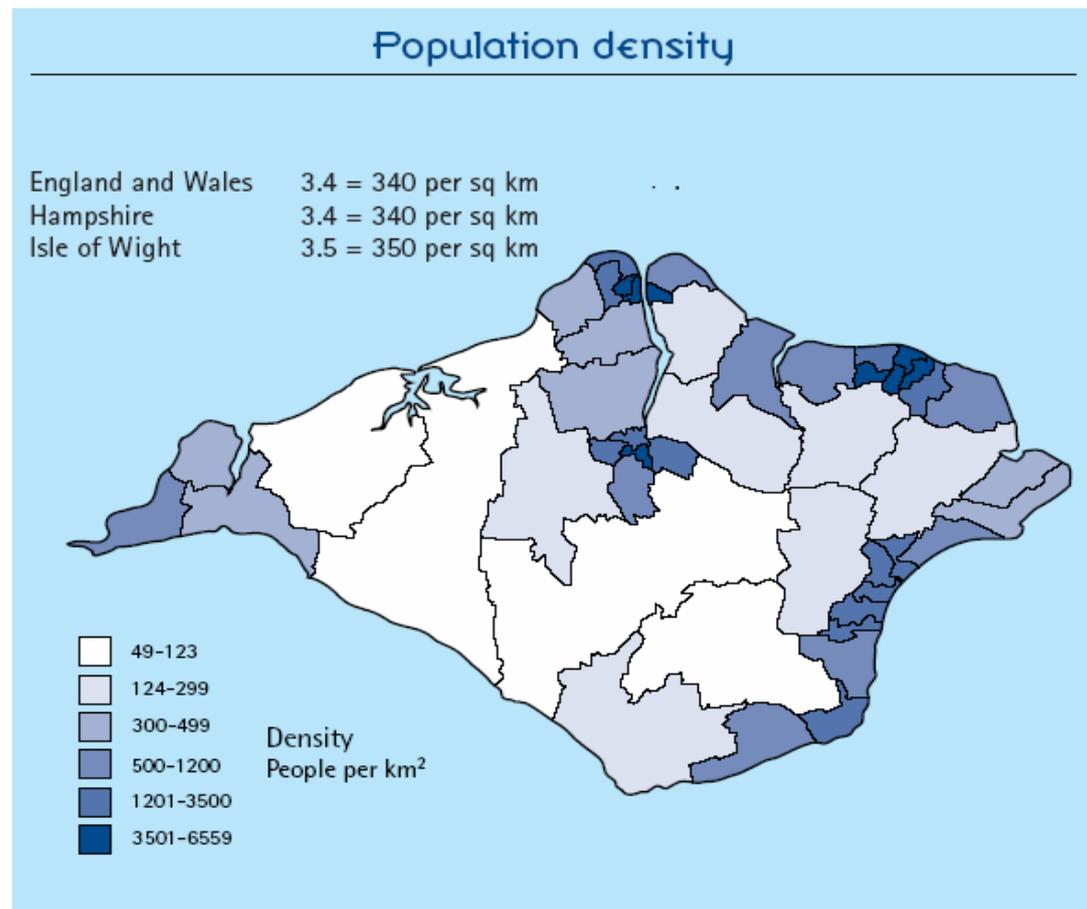
Figure 2: Map of the Isle of Wight



http://www.iwight.com/living_here/stats/censusatlas.pdf

In order to understand the distribution of young carers on the Island and the urban and rural centres of the Island, the map (below) shows the population density on the Island. As you will notice, the majority of people are located in the towns of Newport, Ryde, Cowes and East Cowes, and also in the Eastern coastal areas. Shalfleet and Yarmouth, Brighstone and Calbourne, as well as Wroxall and Godshill wards have the lowest population density.

Figure 3: Population density



http://www.iwight.com/living_here/stats/censusatlas.pdf

Table 3 (below) indicates that the majority of the **identified** young carers live in the urban centres of the Island. The highest population of the young carers reside in Newport and Ryde (51%, n=40). To a lesser extent the young carers associated with the project live in Cowes, East Cowes, Sandown, Ventnor and Shanklin (33% (n=26). It is worth noting that there are very few young carers who have been identified who live in the more rural and isolated areas of the island (16%, n=13). This is not to say that young carers do not exist in these rural communities. More significantly, it may relate to the inability of the IOWYCP to proactively endeavour to identify young carers in such isolated areas, to a lack of resources. This is an issue that will be addressed throughout this evaluation report. It is worth considering how best to identify and access young carers who live in the more rural and isolated

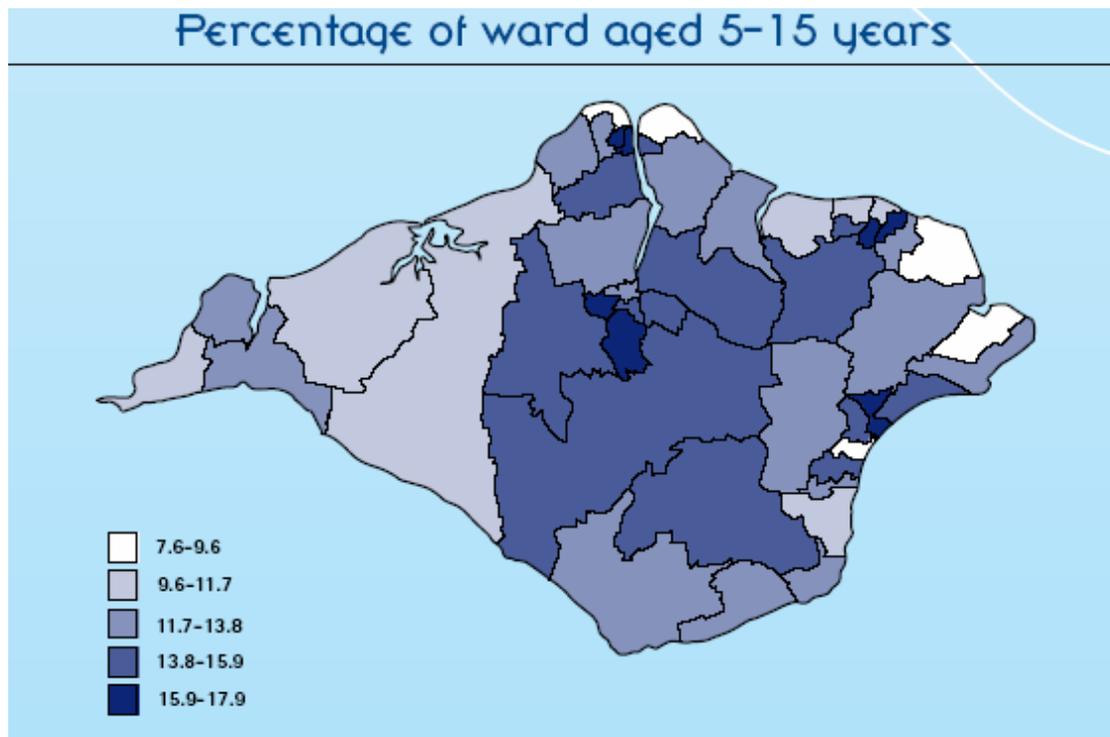
towns/villages on the Island. One option is to look at the impact a community outreach worker (part time or full time) may have on identifying new young carers in these areas. This persons job remit would need to be a dedicated post, focussed primarily on outreach and identification.

Table 3: Town of residence of each of the 80 young people registered with the Young Carers Project (includes siblings)

Town	Number of Young Carers
Ryde	22 (28%)
Newport	18 (23%)
Sandown	7 (9%)
Cowes	6 (8%)
East Cowes	5 (6%)
Shanklin	4 (5%)
Ventnor	4 (5%)
Totland	2 (3%)
Freshwater	2 (3%)
Wootton	2 (3%)
Bembridge	2 (3%)
Chale	1 (0,8%)
Wroxall	1 (0,8%)
Godshill	1 (0,8%)
Brading	1 (0,8%)
Apse Heath	1 (0,8%)

Figure 4 (below) provides further contextual analysis in terms of age, population distribution and rural versus urban settings. The demographic distribution of the young carers who have been identified and engage with the IOWYCP, fall within similar population distribution trends for the Island's general 5 to 15 year old population.

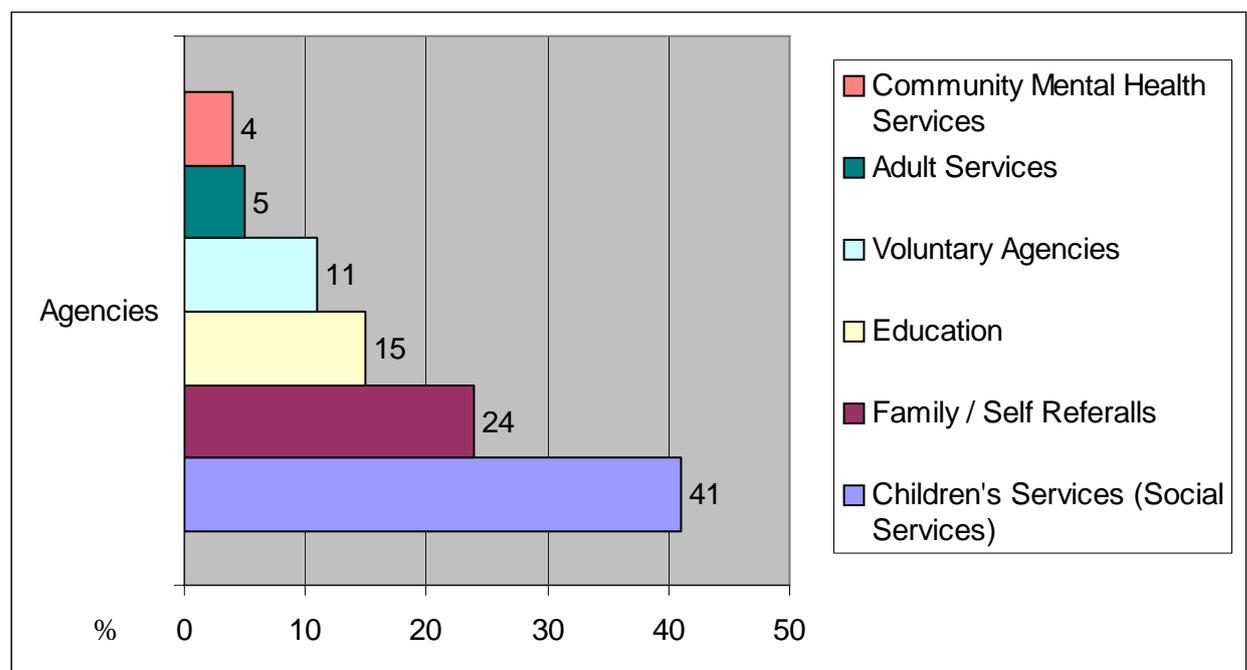
Figure 4: Percentage of ward ages (5 – 15 years)



(http://www.iwight.com/living_here/stats/censusatlas.pdf)

5.1.4 Referral systems

Figure 5: Referral systems



The IOWYCP relies on referrals from agencies and community resources that come across children and young people with caring responsibilities, through offering varying services in the community. The breakdown of referrals is presented in Figure 5 (above). With regards referral systems, it is important that this figure be viewed in terms of the broad categories of carers currently registered with the project. This information has been categorised in terms of statutory services, voluntary agency sector, and family/self referrals. Furthermore, as explained by the project coordinator, many more referrals and subsequent discharges have been made over the last 5 years. While there are 80 young carers registered on the project, there have been approximately 140 referrals made to the project since the IOWYCP started in 2001. In reviewing the data it is clear that specific referral trends have emerged.

Children's Services emerged as the primary source of service provider referrals to the IOWYCP, with 41% (n=33) of young carer referrals. It is encouraging to note that the second highest referral base came from family and self-referrals (24%, n=19). While it is difficult to ascertain precisely how these referrals evolved, it can be assumed that a significant majority emerged as a result of 'word of mouth', siblings of young carers registered with the project, and the school and community work carried out over the last 5 years. This speaks volumes to the fact that not only is the IOWYCP receiving recognition for its work but also perhaps more importantly, it is serving as a recipient of service signposting.

A further finding was that 15% (n=12) of the referrals came from the Local Education Authority. These referrals came from school nurses, school EWO's and Head Teachers. Young carers report considerable difficulties in the school environment (including: poor academic achievement, not turning in homework on time or not at all, school absences due to having to care for ill parents, and some teachers not understanding their roles as young carers). Young carers express embarrassment at being 'below standard' in their school environment and this impacts on their sense of well being and stress levels. It is therefore essential that young carers should be identified within

the school environment and referred to the IOWYCP for appropriate support. As a result of this, the project coordinator identified the need to raise awareness in schools regarding both the identification of young carers, and referral to the project. For example, a lot of work has taken place in the various schools over the last five years i.e. each year the project has run 2-day workshops where most Middle and High schools have had staff representation, in addition to staff from children and adult services.

An area of concern emerging from the data was the non-existent referral rate from GP practices. Given that so many of the young carers mentioned their direct involvement in the pharmacological aspects of their parents/siblings illness (see focus groups), it would be anticipated that general practise surgeries would be referring young people to the IOWYCP. This matter was taken up by the PC with the PCT (about 4 years ago). They responded by saying that they would always make the referral to Children's Services, who would carry out the assessment and possibly refer on to the IOWYCP. A strategy for increasing referrals from GP's is requesting GP's to document and monitor those young people who they believe to be young carers; and to feed this information back to the IOWYCP. A final observation is the encouraging level and amount of referrals received from various youth agencies in the Isle of Wight. Agencies such as CAMHS, YISP, YOT, and Youth Trust play a critical role in the lives of young people, and as such their referrals to the project is a critical link in their role as partner service providers.

5.1.5 Condition of Cared for Person

Figure 6 (below) represents the complexity and diversity of illness that the young carers in this project encounter, on a daily basis. The most significant illness is physical disability (42%, n=34), followed by a sibling and/or parent with a learning disability (34%, n=27). As articulated throughout the focus group interviews (see section 5.2), the young carers spoke about the various levels of mental health issues that they cope with as part of their parents/siblings care needs. This is reflected in the fact that 18% (n=14) of their caring roles revolve around mental illness. Furthermore, 6% (n=5) of

young carers parents/siblings have a sensory impairment. These figures are similar to those found in Dearden and Becker's national study (2004:3). They found that "people with care needs have a range of illnesses or physical or mental problems. Half of the conditions are of a physical health nature, 29% are mental health problems, 17% are learning difficulties, and 3% are sensory impairments." It is important to note that in many instances young carers have to engage with their parents and/or siblings who have a dual illness/diagnosis, e.g. many of those they care for may have a physical as well as a mental health illness. Again, it is important that this figure is viewed as a 'snapshot' of the primary health condition experienced by the cared for parent and/or sibling. Thus, it does not represent the entire complexity of a cared for person's physical and mental health issues. Furthermore, the project coordinator stated: *"at the moment in time captured in the graph there were no issues related to drug and alcohol misuse. However, throughout the life of the project there has been – though the numbers have been quite low. This is one area where specific awareness raising could be increased, if resources allowed."*

Figure 6: Condition of Cared for Person

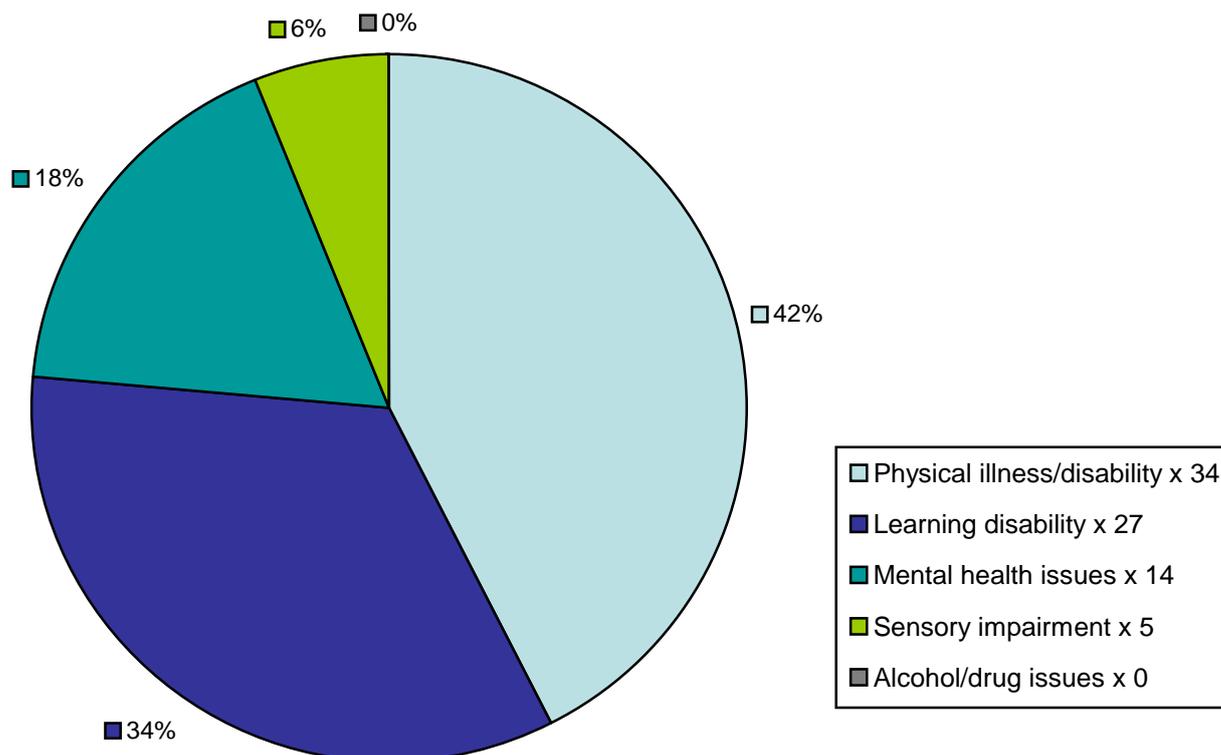
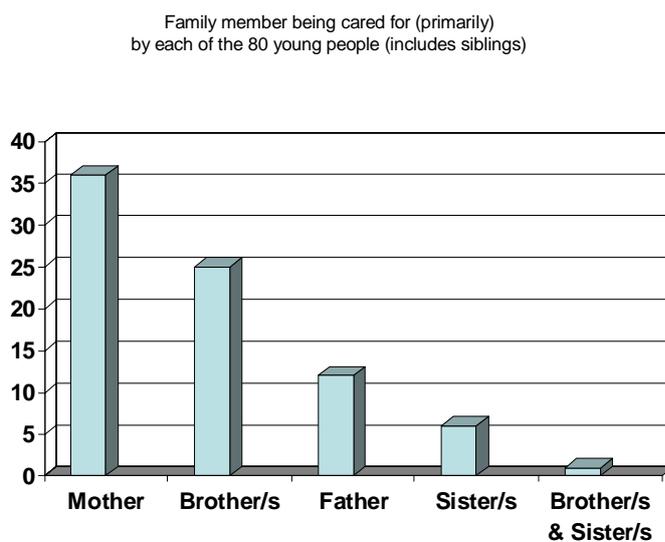


Figure 7 (below) emphasises the fact that young carers in the IOWYCP provide care for all members of their families. The majority of caring responsibility is focused on providing care and support for their parents. 45% (n=36) is focused on their mothers, and 16% (n=13) is focused on supporting their fathers. A significant part of their caring tasks are also focused on providing support for their siblings. In the majority of instances, young carers are supporting their brothers (31%, n=25), and to a lesser extent they also care for their sisters (8%, n=6).

The stress of caring is exacerbated when caring for more than one person simultaneously. This is an important consideration in the light of the number of young carers in the project reporting caring for more than one person (additional adult and/or siblings). Similarly, Dearden and Becker (2004:3) found that the majority of people with care needs are mothers. "This is essentially true in lone parent families where mothers account for 70% of people needing care. In two parent families almost half (46%) of people receiving care are siblings."

Figure 7: Caring Responsibility



(April - June 2006)

5.1.6 Length of registration with the project

The following diagram (figure 8) outlines the length of time each of the current 80 young people with caring responsibilities has been registered with the IOWYCP. It is worth noting that a significant number of young people have been with the project for over three years, and in many cases, for four years or more. This bears testimony to the commitment that the IOWYCP has made to the young people it serves, as well as a commentary on the continuity of care it provides. This is borne out by the fact that 19% of young carers have been involved in the project for 4 years or more, 22% have been involved for at least 3 years, and 20% have been involved for at least 2 years. It is also interesting to note that the project is continuing to receive more referrals and, as a result of this, have registered 39% of young people who have been registered between one and two years. Dearden and Becker (2004) found that caring can be a long-term commitment for many children, and can start at an early age. One third of their national sample of young carers (36%) had been caring for 2 years or less; 44% for 3 to 5 years; 18% for 6 to 10 years; and 3% for over 10 years.

Figure 8: Length of registration with the project

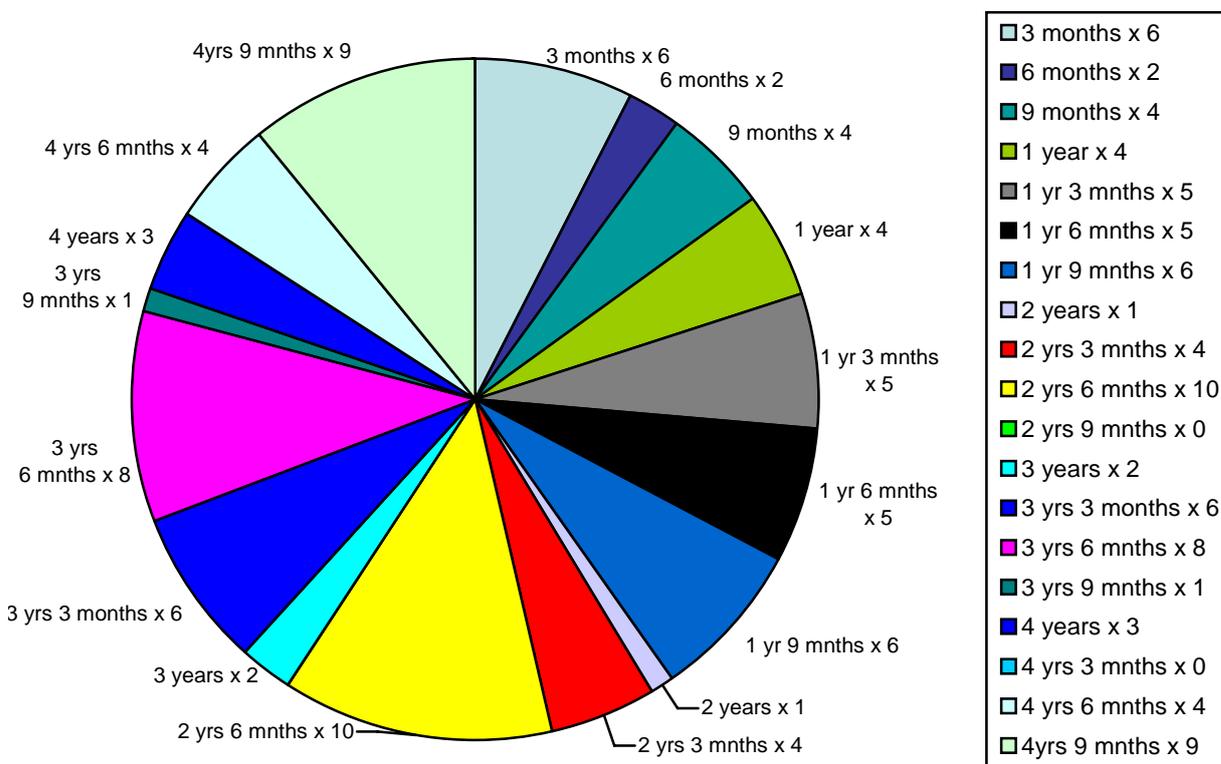


Table 4: Discharge reasons

A total of 38 young carers have been registered and subsequently discharged throughout the life of the Project. The reasons young people have left the project are:

Young person now 18	12
Did not fully engage and chose to leave	9
Cared for person died	4
Left IOW	4
Cared for person now in residential care	3
Health of cared for person improved	3
Young person now in residential unit	1
Parent withdrew child following child protection issues being raised	1

5.2 Focus groups with young carers

The following discussion will provide an analysis of the three focus groups conducted with the various young carer age groups. At the beginning of each focus group the evaluator asked the young carers to provide a written response to key questions, for example: their age, gender, no of siblings, the primary person (s) that they care for, and how long they have been involved with the IOWYCP. For each focus group/age category I have provided a table to capture this information. The numbers of primary caring responsibility may, in some cases, exceed the number of participants in each focus group. This is due to the fact that the young people may be caring for more than one parent (s) and/or sibling (s).

5.2.1 Focus group 1 (7 – 11 yrs)

Table 5: 7 to 11 year demographics

FOCUS GROUP 1 (7 – 11 YRS)	
No of participants	5
Mean age	10 yrs
Gender	Male (4) Female (1)
No of siblings	Brother (3) Sister (4)
Primary caring responsibility	Mother (4) Father (1) Sibling (2)
Average yrs involved in IOWYCP	3 yrs

Complex nature of caring

The evaluator was struck by the complex and varied nature of the caring tasks carried out by this group of young carers. It is even more remarkable when considering that this focus group drew from a sample of 7 to 11 year olds.

This level of daily caring responsibilities is supported by Dearden and Becker's third national survey (2004). Dearden and Becker (2004) found that two thirds of young carers provided domestic help in the home, 82% provided emotional support and supervision, and 18% provided intimate personal care for their parent(s). The following remarks echo the complexity of their daily lives, in spite of their very young age.

"Because you are looking after someone else you can not have so much fun."

"It is like taking over two bodies."

"It is like you are caring for yourself and somebody else and you being two things."

These young carers also shared their experiences with regards to the family member they care for, and the familial illness/disability that they cope with. These range from epilepsy, degenerative illness, to a brother with downs syndrome.

“My mum has epilepsy and asthma. She has had asthma since she was 17 yrs old and she has had epilepsy all her life.”

“I care for my mum as she has a bad disc in her back and it is disappearing. She gets injections in her hand and it always swells up.”

“I care for my brother as he has downs syndrome. He has the mind of someone much younger than me, and I also help with my older brother.”

Caring responsibilities

At the outset of the focus group the young carers were asked to identify the main responsibilities that were inherent to their daily lives as a young carer. In response, they mentioned tasks such as housework, medication management and administration (for ill parent), caring for siblings (both younger and older), dressing and feeding parent(s), shopping, advocacy on behalf of their parents needs, amongst others. The following comments attest to the range and diversity of their caring responsibilities, most often on a daily basis.

One young carer spoke about pharmacological management as part of his caring responsibility. This is a daunting responsibility when considering this young carer is only 9 years old. Traditional parent/child relationships would argue that the parent would be responsible for managing their child's medications during a bout of illness. This role reversal in parent child relationships and dynamics permeates throughout this focus group interview. According to Aldridge and Becker: “the way forward for young carers is to acknowledge, value and respect the reciprocal and interdependent nature of caring within their families and to support and nurture these relationships through a range of policies, services and procedures (1999, p. 317).”

“I do mum’s tablets every night and every morning. I also get her drinks of water and wash her face and her hands.”

“She sits on the sofa because she cannot go up the stairs.”

One young carer referred to the fact that caring for his mother is not his only responsibility. He also cares for his siblings.

"I do a lot of stuff for my mum that she cannot do. I get her water and help her up and down the stairs and carry things for her, and I also have to look after my brother and sister."

"I care for my mum as she has a bad back. She cannot bend over."

Likes and dislikes of being a young carer

When asking this group of young carers about their likes and dislikes of their caring roles, it is interesting to report that none of the participants referred to any dislikes in their role and tasks. Perhaps one conclusion, which could be drawn from this evidence, is that this group of young carers, who are at the youngest end of the age continuum, regard their daily routine as a normative expectation of their childhood.

One young person alluded to the fact that being a young carer could have a positive impact upon his future: *"It is good to be a young carer. I like it because you get something back from it. You get some pocket money for helping. And you get things that will help you in the future when you are older."*

Personal, emotional and mental health

In addition to parental illness, some young carers have health issues (physical and mental) of their own to contend with. Coping with their own struggles and the numerous responsibilities within the family context is difficult for young carers. The Princess Royal Trust for Carers (2005) further reinforces the young carers school experience in stating that some young carers protect their vulnerable parents from their negative feelings at home, but cannot "keep their feelings in" at school. 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 find it hard to care for someone else because you have to go the extra mile to help someone. It is hard because your school work, you go to do it and at the same time care for your mother and your brother.”

“If I get sick then there is not someone to care for me.”

Another young person spoke about the difficulty in articulating their own exhaustion: *“We all get tired sometimes it is hard to tell people. Sometimes it is only easy to tell your mum and your dad.”*

Even when young carers receive support from their extended family they are still expected to continue with their daily caring tasks and routine. *“Sometimes my nan helps me when I am sick. She will take care of my brother so I can go to the shops and buy some food.”*

The aforementioned comments attest to the need for these young people to demonstrate a high level of competence in the “art of multi-tasking.” – a skill more often associated with adulthood.

School environment

National findings indicate that 20% of young carers miss school (Franks, 2002). One of the reasons for this is that stigmatisation and social exclusion are experienced within the school context. The perceptions of authority figures within school contexts were problematic to young carers. The perceived lack of interest regarding their plight contributed to stress regarding home responsibilities. As voiced by IOWYCP young carers:

“I do not like the teachers to know that I am a carer”

“At school it is intimidating and they all just take the micky”

“I do not know how the teachers will respond if they know about me caring for my mum. I don’t think my teachers will care about my situation. They will just say ‘get on with it.’”

These observations reinforce the silence moratorium that many young carers maintain regarding their lives as carers. Their fear of 'being found out' often inhibits self disclosure about their caring responsibilities, and in so doing prevents them from receiving the necessary support from their schools.

One young carer expressed some positive comments regarding teachers' perceptions: *"I like my teacher. She tries to make you happy and to make you do good at your homework."*

The national young carers' message to education authorities was a request for improved communication, a desire to be listened to, believed and understood; and to be recognised and valued. Young carers expressed that they required practical facilities while at school, for example, access to telephones and one-to-one mentoring support (Franks, 2002).

Relationship with family and friends

The young carers 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. The isolation experienced by young carers is broader than merely geographic constraints. Societal perception and stigmatisation have a compounding effect for these young people. The impact of caring on the well being and development of carers needs to be considered (Franks, 2002).

"Our lives are different to our friends. They can do more fun things and they do not understand what we do for our parents to help them and care for them."

"Their parents are okay and they do things for them. So they can go and enjoy themselves."

"They do not know what it is like to do things for other people who need you."

This misunderstanding and cruelty was illustrated by a young carer as follows:

“We have got different lives to our friends. We do different things. They call my mum names and I don’t like it. So I don’t play with them too much.”

Role of the IOWYCP

Young carers in this age group voiced numerous benefits of being involved in the IOWYCP. These benefits seemed to revolve around being away from the home context in an enjoyable environment. The following observations from this group of young carers provide clear evidence re: the important role the project plays in their lives.

“The project gives me a lot of time out and it is so enjoyable”

“I like doing things with the project like horse riding, bowling, swimming, and laser shooting.”

They also mentioned the importance of respite care opportunities provided by the IOWYCP, and the positive impact it has on their own personal stress reduction.

“The project is good as it helps me with my stress. I help mum with lots of things and it is good to come to the project to do things I want to do and get my mind off it.”

“The project gives me a break from mum and I get time out.”

“We like the club nights the most because we all come together.”

The young carers were also requested to provide one word that describes the way in which they perceive the IOWYCP. Their words eloquently summarise the positive relationship they have with the project:

“Fun”

“Loving”

“Great”

“Exciting”

“Helpful”

Recommendations for future service provision

When asked what they would change in future involvement with the IOWYCP, participants made the following suggestions. Their recommendations centred around issues of more time with the project, and fun recreational activities.

“I would like to have more time with the project.”

“I would like the project in the future to take us to St Johns ambulance, the hospital and paint balling.”

5.2.2 Focus group 2 (12 – 15 yrs)

Table 6: 12 to 15 year demographics

FOCUS GROUP 1 (12 – 15 YRS)	
No of participants	11
Mean age	13
Gender	Male (7) Female (4)
No of siblings	Brother (10) Sister (16) + brothers
Primary caring responsibility	Mother (4) Father (4) Sibling (6)
Average yrs involved in IOWYCP	3 and a half yrs

Complex nature of caring

As with the 7 to 11 year old focus group, the young carers in this focus group provided evidence with regards the complex nature of their caring roles and responsibilities. Some of these included caring for a brother with epilepsy, a sister in a wheelchair and a sister with a cognitive disability.

"It is difficult looking after someone else."

"I care for my sister. She is in a wheelchair. She has like a 'head disease.' She cannot walk properly. She has been like that all her life."

"My sister is my age but she has a mental age of 6 yrs."

Furthermore one young carer spoke about his complexity by stating that: *"I care for my brother. He has epilepsy and he is younger than me."*

Caring responsibilities

The evaluator asked the young carers in this focus group to describe an average day in their life, with specific reference to their caring roles and responsibilities. An interesting feature of this commentary is the systematic recitation of a typical day. It was evident that this was a well-rehearsed set of events. Each component of the young carers day is carefully allocated to ensuring that other people's needs are met, allowing little opportunity for spontaneity, self-expression or self-care. On a poignant note, even walking the dog (a chore that teenagers often grumble about) caters predominantly for the needs of his pet – although this is expressed as his one enjoyable activity of the day because it allows him to escape. The following comments relay the variety of roles fulfilled by this cohort of young carers:

"I help my dad do things around the house."

"For my mum and dad I do the washing, clean the house all the time, and take the dog for a walk."

"I have to help my half sister with everything."

"Being a young carer is quite difficult when you've got a disabled brother who always gets into mischief. He is always going out the front door."

Personal, emotional and mental health

This young person speaks about the isolation he feels, and the lack of opportunity to share his feelings with others: *“Sometimes there is no one to talk to about what I feel”*

The following three quotations illustrate the coping strategies which these young carers adopt when they get sick – which reflect the fact they feel they have no ‘entitlement’ to being sick themselves.

“If I am sick I do not tell my friends.”

“I just get on with it, no matter how I feel.”

“It is very stressful. I get sick all the time.”

Young carers referred to the impact their caring roles had on their sleep patterns. Lack of sufficient time to rest will exacerbate the exhaustion (physical and mental) that many of these young people experience on a daily basis.

“I cannot sleep at night. I can sleep for 4 hours a night sometimes.”

“It all depends how much pain my mum is in. If she is having a bad night then I only get about 3 hours sleep.”

Various features emerge from the young carers comments about their typical day. Their mature sense of responsibility and concern for their family member’s well being is reported as a sense of exhaustion - but having to carry on regardless. This is evidenced through their litany of chores and caring responsibilities. There is also a sense of each distinct area of responsibility having to synchronise into a carefully planned routine. Eley (2004:69) refers to the complex nature of young carers tasks in that “caring does have connected to it, responsibilities that frequently override other activities. Compromises need to be made and respite tends to come in the form of a few hours here and there.” Eley (2004) further expands upon the complex balancing act that

young carers have to juggle, especially between school attendance, doing their homework and carrying out the various caring responsibilities that are part of their everyday lives.

Relationship with family and friends

Young carers in this 12 to 15 year old cohort proved insights into the relationships they have with their family and friends.

The following three quotations refer to the envy and lost opportunity they feel in comparison to the lives of their peer group and friendship networks: *“They [other friends] go away on holiday with their parents and do stuff like that.”* *“I have to work for my parents. My other friends get pocket money for doing nothing.”* *“My friends parents’ have jobs.”*

A young carer spoke about how his caring role influences his relationship with his friends by saying: *“You can not go out with your friends. It is difficult looking after someone else.”*

High levels of caring can have an adverse impact on young carers, resulting in friendship difficulties, limited time for social and leisure activities, limited time for school work and homework, and can limit opportunities and make transitions into adulthood more problematic (Dearden and Becker, 2004, Aldridge and Becker, 1993, Dearden and Becker, 2000, Frank et al., 1999

School environment

Given that all young people spend a significant part of their day in school, it is hoped that schools would provide this cohort of young carers with a supportive and nurturing environment. It is disappointing that so many of these young carers reported on the lack of understanding which they experienced in their schools. The “Too much to take on” study of young carers’ experiences found that one third of the 240 young carers studied believed that their teachers were not aware they were carers (Crabtree and Warner, 1999, in Eley, 2004). Eley (2004: 70) further contends, “teachers were reported as being insensitive at times and that young carers felt that

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

"My teacher does not understand anything. They never listen to you."

"Teachers talk to you and then just leave you. When you tell them what is wrong they say it is not their problem and to just get on with it."

"If you tell a teacher you are feeling tired she just says go back to your lesson."

"They say if it is still bad in ten minutes then you can leave the class. They ask if I can stick it out until lunch."

On an encouraging note, one young carer spoke about the positive regard she has for her teacher by saying that: *"My teacher gives me a hug in class."*

Service provision (external to IOWYCP)

It is important to emphasise the fact that young carers have a diverse range of individual and collective needs, and as such, will rely on a myriad of health and social care service providers in response to these needs. Given this backdrop, it is of great concern when young carers provide examples of negative and non-supportive accounts with regards direct engagement with service providers. The following illustrates this lack of professional understanding about their roles as young carers:

"My doctor is a cow. She is an arse to my mother. She ignores what my mother says."

“My doctor says there is nothing wrong with me.”

“There are no other people who support young carers [except the IOWYCP project].”

On a more positive note a young carer mentioned the important role that youth workers play in his school: *“We have youth workers in our school who help us.”*

Role of the IOWYCP

The number of comments these young carers provided speaks volumes to the positive regard they have for the IOWYCP. They spoke about the break and respite the project provides. Underdown’s (2002:60) national analysis of 1200 young carers experiences found that “the young carers praised their voluntary support groups which offered emotional, social and personal support, understanding and fun.” Dearden and Becker’s (1998:11) evaluation of the Sheffield Young Carers project bore similar findings, in that “for many of the young people the Project offers the only opportunity for them to engage in social and leisure activities and to experience holidays.”

“It gives me time to relax and get time out.”

A young person mentioned the fact that they feel more energised since they joined the project: *“The project is helpful. I now have more life as I don’t feel so sleepy anymore.”*

“The project is helpful and gives all of us a good break. All the staff make you feel welcome and safe and they are so nice and supportive. They listen if I have a problem.”

Other observations about the significant role the project plays in the lives include:

“The project gives you a chance to meet other young carers in your situation, and to make new friends.”

“Coming to the project cheers me up. It gives me something to look forward to.”

“The project helps me to look after my parents better”

“Coming here helps me do well at school.”

“I know my mum could not take me on all of these trips because she has a bad back. I am so lucky.”

Furthermore, young carers in this focus group offered the following words in describing the ways in which they valued the IOWYCP

“Good experience.”

“Alive”

“Time out”

“Excitement”

“New start”

Recommendations for future service provision

Young carers in this focus group suggested varied and sometimes longer respite opportunities:

“I would like more holidays and to go to different places. Like the mainland”

“We could have smaller day trips and then we can build up towards bigger trips, then we could have something to look forward to.”

Young carers suggested different activities which they want to be involved in, for example, they said: *“I would like the project to continue with the activities which we can all do together, like the Fairthorne weekends, and lots of sleepovers because they are fun.” “I think we should have more quizzes because I enjoy them.”*

5.2.3 Focus group 3 (16 –18yrs)

Table 7: 16 to 18 year demographics

FOCUS GROUP 1 (16 - 18 YRS)	
No of participants	6
Mean age	17
Gender	Male (5) Female (1)
No of siblings	Brother (6) Sister (1)
Primary caring responsibility	Mother (5) Father (2) Sibling (4)
Average yrs involved in IOWYCP	5 yrs

Complex nature of caring

The following comments clearly illustrate the complex nature of caring responsibilities that this group of 16 to 18 year old young carers engage in. In many instances, a young person is providing primary care for more than one family member. The types of illness/disability, which they encounter on a daily basis, are: epilepsy, diabetes, spinal injuries, visual impairment, and MS, amongst others.

One young carer provides care for three members of the family (mother, brother and sister). It is difficult to fully appreciate not only the complexity of these responsibilities, but also the level of dedication and full time commitment it takes in caring for an entire family – whilst attempting to cope with your own life as a teenager: *“My brother has epilepsy and my sister has cerebral palsy, and my mother has spinal degenerative disease.”*

“My brother and mother are both disabled. At first I did not know what the hell it was all about.”

A participant mentioned the fear of his mother’s possible death as weighing heavily on his caring tasks and duties: *“My mother has epilepsy and diabetes. I know she could die at any time from a brain aneurysm.”* The complexity of caring for these young people often includes their parents’ complete dependence on them in fulfilling their daily living tasks: *“My parents are both visually impaired. When I was younger they were dependant on me for everything.”*

“My mother has MS and my dad has a slipped disc”

A young person spoke about the insidious nature of their caring role. His parent’s needs and safety were uppermost in his mind, irrespective of where he is or what he is doing: *“I think about my parents all the time and whether or not they are safe.”* This complexity could provide a young carer with a juxtaposed position – and resultant conflict. In this instance a young person mentioned that: *“Everyday I wonder if my dad’s in pain or if mum is down. Having just received my GCSE results everyone is celebrating but unfortunately I am focusing on my parents. The volunteers try as much as they can to help and they do it very well.”*

Caring responsibilities

As evidenced throughout all of the focus group interviews, the young carers encompass a significant range of caring responsibilities. Young people in the 16 to 18 year age range provided the following insights into their daily routines.

A participant commented on the cyclical and repetitive nature of their caring role by saying that: *“I get dad up in the morning. Plan the day with him and see that he is okay. I come straight home from school and take him for a walk. And then I wake up the next day and do it all over again.”* The following two observations speak to the length of day and time commitment which young

carers invest in these roles. *“My caring goes from 6.30 am to 11 pm every single day.” “Because my mother and brother are disabled for the last 6 years I wake up at 5.30am – get my brother ready and my mum settled in her wheelchair before I go to school. Then I collect my brother after school as dad works all the time.”*

A young carer commented on the impact that negative social perceptions have on his caring for his mother. A lack of social understanding and negative stereotyping exacerbates the functions he has to perform: *“When walking down the road I have to take a chair for my mother. People stare and laugh at us. The worst thing is people don’t understand my mum will not be getting any better.”*

“There is still stuff I have to do for my parents, like the shopping and cleaning.”

Young carers also have to deal with family members who, at times, refuse to co-operate with their child’s caring role. This young person commented on the vigilance that she needs to adopt in order to ensure her mother’s safety: *“I often have to rescue mum from falling down the stairs and she refuses to use the chair lift.”* The following observations provide supportive evidence re: the quasi-professional roles that some young carers fulfil as part of their responsibilities. In these two instances young carers are required to conduct physiotherapy sessions as well as using a hoist to support their parents. *“I have to do physio with my disabled sister. Now that she is a teenager it is a challenge. I have to do physio with my mum as well.” “I do all the cleaning around the house. I also have to use the hoist to get mum in and out of bed.”*

One young carer spoke about the duality of caring for both of their parents as well as trying to hold down a part time job. *“Living with my parents disability is quite hard sometimes. I have to do the washing up, washing all the clothes, dusting, hoovering and doing the dinners. This is why I hold down a part time job as well.”*

This reflection is in stark contrast to many other teenagers in the UK, who would invariably prefer being at home and engaging freely with their friends, than being at school all day. This further demonstrates both the magnitude of caring role and variant socialisation processes that these young carers endure. Their daily reality prescribes that attending school on a full time basis is coupled with the full time household responsibilities that are usually the domain of parents. Invariably, their adolescent peers do not share this 'double reality' (Butler and Astbury, 2005).

Pharmacological management

As evidenced throughout the first two focus groups (7 to 11 and 12 to 15 yrs), the young carers in the 16 to 18 year category also reported on the extensive pharmacological management role they fulfil in the administration and supervision of the disabled family members medication.

As one young carer commented: *"I do the housework and the dinner and get my mother her tablets. I do it every morning before I go to College. I come home and do the same again. It becomes the same thing."* A young person mentioned that he had the primary responsibility of giving his mother her daily injections. This is not a normative role one would usually associate with adolescent psychosocial development. This level of responsibility would add enormous stress to a child's life: *"When I was younger I used to organise all of mum's medicines for her. I have to do the injections for my mum as well. When I was younger I hated doing the injections"*

The young carers also mentioned the fear inherent in this burdensome responsibility. This young carer was constantly concerned with not confusing his parents medication – a role usually fulfilled by a health care professional: *"I had to work out all of mum's tablets and also which ones dad takes. I did not want to confuse them. Now I have one of those Monday to Friday tablets gadgets which really helps."* Another participant spoke about the pride he felt in his pharmacological management skills as a young carer: *"My mum was on pain killers for 6 years. It made her lose her short-term memory. And she is epileptic. I have always helped her with her pills. I learnt the names of all the*

tablets when I was younger. I am quite proud of myself.” Other observations were: “I was 10 years old when I started giving medication to mum and dad.” “I did my brothers diazepam because he had a heart attack at age of 10 and he had very bad seizures.”

Young carers provided numerous illustrations that demonstrate their frustration and disappointment with the way they and their family members were treated by their medical GP’s. They commented on the general apathy and lack of concern in GP’s attitude, especially in relationship to managing and co-coordinating medication. As one participant said: *“The doctor told my mum ‘take these pills and those pills.’ No help at all. He did not explain to my mum or me. Some are for pain and some are for depression. It was so confusing to us.”*

A major concern is the lack of education and relevant information sharing regarding pharmacological management provided by the GP’s. This young carer demonstrated an “adult” appreciation of the consequences inherent in the inaccurate administration of his parents medication by saying: *“We got taught to do it when we were given some leaflets to read. It was so boring. But at the end of the day if you did not read it you were putting your parents lives at risk.”* Other comments included: *“Some doctors just give you the pills and do not care.” “All the diabetic pills my dad needed my friend helped me with. The doctor did not care. He gave me the pills for my dad and it was like he told me to get lost and did not care.”* One young carer said how easy (and perhaps unauthorised) it was to collect and gain access to his parents medication: *“You can just take a prescription in and no one asks anything. Even if you a child.”*

Acceptance of normalisation

This finding re: acceptance of normalisation expands upon the fact that these young people, who are transitioning through adolescence, have very little decision making power or influence over their caring responsibilities – and as such seem to be accepted as their everyday reality. The following comments

and observations from this cohort of young carers expand upon this normalisation process:

“Now that I am 18 I don’t feel like a young carer anymore. I just get on with it. It is just part of my everyday life.”

“Now it is just like normal. I just do it.”

“I have been doing it, for so long it is just part of me now.”

“It feels like you have not got a normal family situation.”

“It is hard for us. It is normal for us. It is our life.”

Likes and dislikes of being a young carer

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

In terms of what they appreciated about being a young carer, numerous responses focused on the transition from adolescence to young adulthood. Olsen (1996) supports the young carers insights by offering a commentary with regard to the potentially positive aspects of caring. Olsen (1996: 45) states that “the inference repeatedly made is that young carers have lost their childhood (Dearden et al., 1994), or have been prevented from participating fully in childhood (Aldridge and Becker, 1993), or have been excluded in some sense (Aldridge and Becker, 1993). Anecdotal evidence points to some of the positive (as opposed to compensatory) benefits of caring, in terms of personal development, sensitivity, and self-esteem (Kornblum and Anderson; Segal and Simkins, 1993). A young carer shared the following perspective on their likes and dislikes pertaining to their caring roles and responsibilities:

“I think I gained a lot from being a young carer. You learn to do things for yourself like cooking, washing and you can take care of a household.”

This young person eloquently comments on the way in which his attitudes have changed towards people with a disability, as a result of the fact that his mother is disabled and he has to care for her: *“If my life had not changed I would not be here now. I used to take the piss out of people and then my mum became disabled. Since then I have grown up. I now work with disabled people seeing the way they are showing them the little things cheers me up. It is quite amazing you know when you do something.”*

Young carers felt that there is a positive impact which caring had on their personal development as young adults, as the following quotes illustrate: *“I think I have become the person I am because I am a young carer.” “I have grown a lot quicker being a young carer.”* This young carer expressed his anger at the impact which public ignorance and lack of sensitivity had on his caring role: *“What pisses me off about being young carer is people with cars who park in disabled parking. The police do not care about it. My mum one night had an epileptic fit. She nearly died because of the van in the way.”*

Personal, emotional and mental health (isolation)

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

The young carers responded by describing their own physical illnesses and how they coped with this. Their responses spoke of an inability to focus adequately on their own needs, resulting in them feeling run-down and exhausted.

Expressions of ongoing feelings of being down or depressed were unanimous in this group of participants. A lack of entitlement to authentically acknowledge and express this in their family environments could potentially have a significant impact on the overall well being of this cohort of adolescents. The aforementioned insularity and lack of emotional expression is compounded by the fact many of the young carers reported 'hiding' or 'minimising' their true feelings, as a means of protecting and caring for their parents:

"If I am ill I still got to get up and do things. You just have to get on with it. If I get pissed off it will take a lot before I told someone about it and how I feel inside"

"Caring for my brother has restricted me. I could not even go to my mates house over the road. It is a pain in the ass sometimes."

This young person commented on the significant impact the project has had on her self-confidence, and reducing her sense of isolation: *"When I first joined the young carers project I was nervous and shy. I did not know what to expect and what people would be there. But when I stayed I made new friends and everyone was so nice. This gave me a lot of self-confidence, as I knew there were people who cared about me."*

"My mum went into hospital from a stroke. They said they did not want to scare me. But I said 'I have already seen a dead person. My granddad died and I saw him dead.'" This young person's story provides evidence in support of the mental health stressors caring responsibilities can engender and the impact it has on their young lives. The pressure and stress involved in performing a myriad of caring roles and responsibilities can result in a young person self harming. The following quote attests to this: "I already lost it three times in my life and it sent me off the rails and I went nutty, throwing things around and self harming. "

Accessibility

Access to transport was a primary concern for the participants. Due to their family responsibilities, they perceived transport to be important in fulfilling their caring roles. Focus group members referred to distinct lack in terms of transport available within the family context, as well as having to use public transport covering large distances. Young carers do not get sufficient access to disabled access transportation on the Island. This only serves to render the task of caring even more onerous. The rurality of the Island, and lack of effective transportation, further imbed feelings of isolation as unanimously articulated throughout the focus group. Banks and others (2001, p.797) support this in their observation that “the dominant paradigm at present is that of young carers being socially and physically isolated.” 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 have to wait until they are the legal age before being licensed to drive.

“Disabled buses on the Island are useless. I have to wait for a disabled bus for my mum forever to get a disabled access bus. That is why I was forced to buy a car.”

“I feel bad as my disabled sister is stuck at home all day. There is no support or transport access for her. I tried to take her to the park by myself but it was almost impossible.”

Relationship with family and friends

Young carers provided observations about their friendships, and how their friends lack of appreciation for their caring role had on their lives. The following quotes expand upon this: *“Being a young carer is one of the hardest tasks to deal with. Most of my friends do not understand that I have very little free time.”* *“When I try and talk to my friends about how I feel and what I have to cope with they don’t know how to react or what to say.”* *“It gets harder as you get older as your friends think you are skiving off.”*

A young person mentioned the difficulty he has in trying to explain his caring situation to his friend, and the fear of potential humiliation if he decided to disclose his role: *"I find it difficult explaining to my friends that I cannot go to their home or go out with them for a night. And that they could not come to my house because of my mother. They would take the piss out of me."* Another young carer recalled a physical assault by a group of 'friends' as a result of disclosing his caring status as a full time job: *"My mates wanted to come for a sleep over at mine. I told them no and they put me through a bus window because they did not like what I do as a carer. Some people say I wish your mum was dead and that really hurts."*

There is also a sense of 'differentness' in relationship to friends, as one participant explains: *"When I was a young carer at first I was very young and I could not have friends around. I knew I was different."* A young person spoke about the positive impact a caring and understanding friend can have on their lives, and the way in which their caring role is perceived by the outside world: *"The only person who understands me is my best mate. He is possibly the best mate I have ever had. He really knows what is going on. If we do go out for a night out and I disappear he makes an excuse for me. He is great and none of my other friends understands me like he does."*

Young carers provided examples of the frustration and anger they feel, at times, toward the family member(s) they are caring for. This frustration is an expected and anticipated consequence of the enormity and sometimes overwhelming responsibility that is placed on their very young shoulders.

"Sometimes I am tempted to leave my mother there [on the stairs] because I get so frustrated."

"Sometimes I want to say bugger off and do it yourself."

School environment

Dearden and Becker (1998:10), in their Sheffield evaluation, found that "bullying in school can compound educational difficulties and seems to be a

particular problem for young carers. One of the reasons she kept her caring role a secret from friends in school was fear that bullying would be worse if people knew she had a parent with mental health problems. Any child perceived as being 'different' runs the risk of victimisation and this seems to be one of the reasons young carers do not openly discuss their family situations. In a sense they suffer stigma by association." The "Too much to take on" study of young carers' experiences found that one third of the 240 young carers studied believed that their teachers were not aware they were carers (Crabtree and Warner, 1999, in Eley, 2004). Underdown's (2002:58) study supports these IOWYCP young carers self perception in their school context, by saying that "few of the young carers felt that schools had sufficient understanding of their situation and many felt stigmatised and isolated. Children said they often felt stigmatised at school and labelled as 'problem children' if they were unable to complete homework due to caring commitments."

"You go to school and get picked on because they know what you do [caring]."

"My mum was taken into hospital. My teacher told me that was not an excuse to miss school. When she met my mum she looked at her like she was contagious. They think they will get something from my mum. It is disgusting."

"You have to repeat yourself over and over again. And some teachers pity you. At the end of the day I had to deal with it. Nothing will ever change."

"With my mobile being on I have to tell my teacher I have to keep it on in case my mum needs me. If she does not like it I must get up and walk out of the class."

"When I was younger I would not walk out of class because of the shit you get when you get back into the room. The teacher really scared me. As you get older you do not care. You know more about your situation. I just want a good career and my mum to get better."

“Teachers can be made to listen to you and try and understand you so they can know how caring affects you and how difficult it is being a young carer.”

“I asked my teacher if I could miss a lesson to go shopping for my mum. I had to explain it to her but she was good about it.”

Service provision (external to IOWYCP)

Young carers in this focus group provided examples of positive support they received from various service providers (external to the help they received from the IOWYCP). These ranged from support with transport, alarm systems, and the provision of respite care. *“Some people are good. The Charity Two Counties takes me to the shops because we cannot afford a taxi.”*

“Wightcare is good thing. It is a button like a panic button. If you fall out of your wheelchair they will come and help you.”

“There are respite carers to take my sister out over the weekend which gives me and my mother a break. The respite carers are very good to us.”

The young carers singled out Social Services for discussion. The comments made by the young carers are provided below. It should be noted that these are the perceptions of the young carers themselves. 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. 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.

“When my sister was adopted she was not supposed to be because she was disabled. Her father injured her. She is back in contact with him now. Now the

social worker comes to our house to check to make sure we are doing things right. They ask me silly questions and I do not like them.”

“When I spoke to the social workers they do not understand. They say that my mum cannot care for us and that they will put us in care. And put my mum in a hospital”

“They [social worker] said to me [as his dad had been incarcerated] that your mum cannot cope on her own and I had to go into care. I was so scared for us to split up from her and my brother. I said to the social worker ‘no way.’ That is not going to happen to me and my brother. Not in my life. If I have not got my brother then what is there for me?”

Role of the IOWYCP

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

They spoke about the opportunity it gives them for personal growth, and to feel supported in the knowledge that other young people are in similar situations as themselves:

“Time to get to know yourself and to see friends and to get out.”

“The young carers project has helped me to look after my family and how to also have a great time. Sitting down in a group listening to other young carers and how they care for their families makes me realise I am not alone.”

“I like going on the activities and meeting other new people.”

Young carers also valued the time out and break away from their everyday roles and tasks as young carers. The following observations illustrate the value they place on these opportunities for respite:

“From time to time every carer needs a break because being a carer is very stressful. The project gets you away from it all. They do what they can to make it fun and try to take our minds off of our problems.”

“Young carers project gives me a break from home and you know people will go and help you. You know your mum is safe because someone will go to be with her at home.”

The young carers in this age group placed significant importance on the value of the project staff and the volunteers (past and present), as they provide them with support and confidential counsel.

“I want to say how much the project has helped me. Not just the activities that we do but all the volunteers are there if we need to talk to them. So I say from the bottom of my heart a big thank you.”

The evaluator again asked the participants in this focus group to identify one word which encapsulates the way they feel about the IOWYCP. They offered the following observations:

“Friendly”

“Helpful”

“Freedom”

“Trustworthy”

These words clearly articulate the valuable resource and support which the IOWYCP provides these young people as they not only fulfil their role as carers, but also as they begin to embark on the complex roles inherent in their young adulthood status.

Recommendations for future service provision

Young carers provided recommendations for future service provision. Some of these suggestions centred on extended respite opportunities and additional one to one contact with the project workers.

“I would like more group trips and perhaps a week away so that you really get a chance to help or talk with each other.”

“It would be great if there more people to talk to – not just over the phone.”

One young carer spoke about the importance of older young carers, upon turning 18 and graduating from the project, to return to IOWYCP and serve as mentors for the younger carers. *“I would like to be a mentor for young carers. I would like to come to the project and show them what to do from what I did.”*

One of the major gaps and concerns in service provision is the lack of services afforded young carers who turn 18, and are deemed by the government as having achieved independent status. The project coordinator has noted this as a point of concern, and is aware that an adequate response is required. The project coordinator explained *“the children and young people with caring responsibilities can go on to the Adult Carers IW branch though many members are very much older there. Attempts have previously been made by the IOWYCP and adult carers to introduce an 18 – 25 year old group”*.

This may require procuring additional specialist funding to address the needs of this population of young carers. It is important to consider that the needs of this cohort may be greater when considering that their lives have transitioned from secondary education to more independent living, e.g. full time employment, attending college etc. The social isolation and restricted

emotional expression experienced by many young carers restricts normative socialisation, psychosexual development and both intra- and interpersonal development. Young carers participating in this evaluation have voiced conflicting feelings surrounding needing to have ownership of their lives balanced against ongoing family needs. Their need for support, respite care and one to one mentorship could be critical as they cross the threshold into young adulthood (Butler and Astbury, 2005). Furthermore, Dearden and Becker (2000) concluded that children and young people who adopt inappropriate caring responsibilities can be affected not only during childhood, but also as they become adults. The absence of family focussed, positive and supportive interventions by professionals, combined with inadequate income, hold negative long-term psycho-social effects for young people and their parents. As some of the young carers stated:

“I am going to be working and I want to know there is going to be help for me and my family.”

“I want more support – forever.”

“Someone to talk to that you know that are there for you if you need them”

Dearden and Becker’s (2004:14) third national study concluded with a reference to this lifelong caring commitment in saying that “many children care for several years and some will be committed to caring for many years.” In relationship to this cohort of 18+ young carers’ future aspirations as a young adult, Olsen (1996) expands upon the impact that the unpredictability of a parents illness can have on a young careers aspirations. Olsen (1996:46) explains, “a young carer of a mentally ill parent is likely to have particular problems in terms of the reliability and predictability of the condition, and the disruption and inability to plan and have a degree of control that this means.” (Parker, 1993, Mapp, 1994).

5.3 Structured interviews with project workers

5.3.1 Interview with the Project Coordinator

The Project Coordinator (PC) identified her main tasks as:

- To be responsible for the effective daily management of the IOWYCP
- To locate, assess, support and review young people with caring responsibilities in the locality
- To ensure that service users are involved in the design, delivery and evaluation of the service
- To organise respite sessions for the young carers
- To recruit, train and support volunteers to provide support to the young people with caring responsibilities
- To be involved in contract negotiations and ensure acceptable levels of service provision
- To provide statistical information and reports for Spurgeon's Child Care and the IW Council, as needed
- To be responsible for controlling the budget
- To secure ongoing funding
- To create and introduce new developments and local working procedures
- To continuously develop the project, ensuring the needs of young carers are met.

The structured interview with the Project Coordinator (PC) aimed to elucidate information regarding the various aspects of the IOWYCP. The following discussion will provide an analysis of the various cycles of the project, and focus specifically on: the projects conception; goals and objectives; funding streams; partnership and multi-agency collaboration; professional-user interface; management structures; staffing and resources; project achievements; barriers to service delivery; frustrations and difficulties; types and nature of service delivery; service user involvement and consultation; parental and family involvement; awareness raising and identification strategies; and future plans and project priorities.

Project conception

With regards to the inception and context of the IOWYCP the PC stated that: *“Prior to the Spurgeon’s Child Care YCP started by myself in 2001 there had been a YCP on the Island for 2 years managed by NCH. I understand that there had been a pilot prior to this but I was not provided with any information when I started up the new Project.”* This commentary serves to reinforce the fact that the project was given a ‘clean slate’ as a *modus operandi*, and was thus able to work towards the aims and objectives at the outset of the project in 2001 (see below).

Goals, aims and objectives of the IOWYCP

The PC stated that: *“It was specified in the initial Contract 2001 – 2003 between the IW Council Children’s Services and Spurgeon’s Child Care that the aims & objectives were to:”*

- Assess the needs of children and young people with caring responsibilities on the Island
- Develop the Project to meet the assessed needs of children young people with caring responsibilities within their own community
- Promote the rights and welfare of children and young people with caring responsibilities
- Raise Island wide awareness and knowledge of children and young people with caring responsibilities
- Record the unmet need

Furthermore, *“the service will be provided in partnership with the full range of social, health and community services on the Isle of Wight.”* The PC also made mention of the fact that *“these service objectives remained the same in the 2003 – 2006 contract. However, many new initiatives have been introduced by the coordinator as time has gone by.”* This subsequent evaluative analysis will assess the projects efforts towards achieving these identified goals and objectives.

Funding streams/cycles

The Project has been funded with monies from Children's Services of the Isle of Wight Council. Initially this included:

- Project Co-ordinator for 30 hours per week
- Admin Assistant for 15 hours per week.
- Allocation from the Carers Grant to provide 'respite' to the young people (to include volunteer expenses)
- General running costs (office, stationery, phones etc.)

It was also important to ascertain if, and how, the funding streams had changed over the course of the project (2001 to 2006). In this regard a full-time Development Worker (which was initially a per time post but with funding from Children's Services was increased to a full time position) and part-time 'casual' workers (i.e. Schools Worker and Youth Group Worker) were employed in 2005 to meet the needs of the IOWYCP as it grew in size. Over the 5 years the project has also received funding from the Children's Fund and Connexions. Donations have also been made to the project (information provided by the PC).

Partnership and multi-agency collaboration

The evaluator was interested in identifying which partner agencies (statutory and voluntary) signed up to work in partnership with the IOWYCP project. The PC provided the following examples of joint working with other agencies on the Island.

- Children's Services (IW Council): Project Partner, access to training, staff attendance at IOWYCP training, referrals, access to initial accommodation, advice and joint working re: individual young people
- Adult Services: Staff attendance at IOWYCP training, joint working re: individual young people
- IW Youth Service: Steering Group, Access to free training for staff and volunteers, free youth club facilities, Staff attendance at IOWYCP training, minibus hire
- Steering Group: advice and local support to IOWYCP i.e. quarterly meetings
- Youth Trust: accommodation, referrals
- Soroptimists: Steering Group, fundraising
- Rural Community Council access: to training, advice re: fundraising

- CAMHS: referrals; joint working re: individual young people
- Education Welfare Service: Steering Group/Referrals, IOWYCP Training, joint working re: individual young people
- Children's Fund: Funding for Schools Work
- Carers IW Branch: Information sharing, joint events, referrals
- Big Day Out - a free fun day out for families incorporating advertisement of local services and consultation with children and young people about the services available to them on the Island
- Healthy Schools Network – awareness raising of IOWYCP Connexions – Funding, staff attendance at IOWYCP training
- Hampshire Constabulary – IOWYCP provided a community placement for a student police office
- Schools: Training staff attendance at IOWYCP, young carer awareness, visiting directly within schools of young carers

In this regard the PC stated: *“other than the unstable funding issues; relations between the IOWYCP, Spurgeon’s Child Care and Children’s Services have been very positive. Multi agency collaboration has also been very good.”* The IOWYCP aims to access all young carers within the Isle of Wight region. A key facet of providing services is the identification of young carers and ensuring that they are aware of services offered by the IOWYCP. The IOWYCP relies considerably on partnership working across a cross spectrum of agencies, so that an efficient referral system can be constructed.

A variety of methods were used for building partnerships. These included meetings with individuals and groups, presentations at team meetings, conference attendance and presentations, participation in various forums, information sharing and dissemination of updated service provision. Training regarding what it means to be a young carer, and raising awareness of the difficulties encountered by young carers, plays an important role in partnership building and multi-agency collaboration. Evidence gleaned through this evaluation indicates that young carers value the project and the range of services that it has been able to deliver over the last five years. They have expressed that they have been listened to, consulted with, responded to

and supported in their daily lives as young carers. This has provided an example of good and innovative practise with this marginalised group of young people on the Isle of Wight.

Unfortunately, this has not been the case when considering the entire service delivery system for young carers on the Island. The premise of all agencies working together, and in the same direction, has in the view of young carers, been lacking in support from various statutory agencies. The young carers expressed strong views regarding Social Services. National research regarding young carers has revealed that Health and Social Care Services need to improve with regard to communication, resources, and support for young carers, and response to crises.

Management Structure

A contract review meeting between Spurgeon's Child Care, Children's Services and the Project Coordinator is held each quarter. In addition, an annual Review meeting is held which includes a member of the IW Council's Contract Department. The Project Coordinator presents a report at each of these meetings and targets are reviewed and discussed.

The evaluator has reviewed a number of these quarterly reports (including June 2006, as the most recent report). They provide an excellent tool of data capturing as well as tracking progress towards key targets and identified milestones. I am particularly impressed with the level and breadth of data, which is captured, and subsequently analysed. It is apparent that these quarterly reports play a significant role in reformulating plans and ultimately to influence service delivery to the Island's young carers. I can see that these quarterly reviews have also enabled the project coordinator and other stakeholders to identify new programmes, based on feedback from the young carers themselves. Furthermore, it has provided important evidence re: partnership working and multi-agency collaboration, and how these relationships can be fostered in the future. It has also captured relevant demographic data, which has enabled the project to formulate a clear profile of the young carers cohort whom they serve. Finally, the strength and quality of these

quarterly reports has resulted in the project conducting ongoing project monitoring and evaluation.

In addition, the Steering Group meets quarterly which aims to provide a framework to enable the work of the IOWYCP to maintain stability without reliance on one individual. The purpose of this group is

- To support the IOWYCP in meeting its purpose, aims and objectives
- To ensure networks are established to facilitate communication and information sharing
- To be kept informed of the progress of the IOWYCP
- To review the role, implementation and operation of the IOWYCP and make any recommendations for change
- To take an interest in the development of the different components of the IOWYCP
- To support response to messages, guidance and initiatives from central government whilst relating all work of the IOWYCP to local conditions
- To encourage the participation of young carers in shaping service delivery and developments

As an evaluator I can see clear evidence as to the effectiveness of this tripartite management structure and relationship. The projects relationship with Spurgeon's and Children's Services has provided the IOWYCP with a clear and well operationalised management structure, as well as proving accountability and ongoing support to the project. Furthermore, it has served to increase the quality assurance component of the projects cycles, and provided a vision towards future planning and service delivery. This relationship has been a significant catalyst in the projects ability to meet its intended targets and outcomes.

Staffing Structure

The PC spoke about the staffing structure and human resources by stating that:
"With the 2003/06 Contract the hours for my post was increased to 37 pw plus 16 hours pw administrative support. The team of volunteers continue to provide the

respite. The employment of additional staff allowed the Project Coordinator to hand over some areas of work that became unmanageable as the Project grew in size”.

Evaluating the achievements of the IOWYCP targets/aims/objectives

The IOWYCP has to meet the targets set out in the Service Level Agreement. This includes ensuring that minimum ‘respite’ session targets are met. The following data provides supportive evidence as to how the number of young carers receiving respite opportunities (one of the projects main aims) has increased throughout the five-year cycle of the IOWYCP.

Table 8: Respite sessions

Year/cycle	Target	Actual
2001/02	30 YCs x 3 respite sessions each = 90 pa	158 (only 6 months)
2002/03	40 YCs x 3 respite sessions each = 120 pa	584
2003/04	66 YCs x 5 respite sessions each = 330 pa	523
2004/05	73 YCs x 5 respite sessions each = 365 pa	539
2005/06	84 YCs x 5 respite sessions each = 420 pa	635

It is worth noting that as the number of young carers entering the project has increased (from 30 to 84) in this five-year period; the actual number of respite opportunities has also increased (from 158 to 635). It is encouraging that a total number 2439 respite care sessions have been provided to young carers during this time period. This figure exceeds the target number of respite opportunities by almost 100%. Given the limited number of staffing resources available to the project, this is a significant achievement. Furthermore, the project has demonstrated steady and incremental growth in identification of new young carers and their engagement in the project. Thus, identification strategies can be deemed to be successful in recruiting new young carers on the Island.

A further finding is the significant increase in identification and respite care sessions offered in the first three years of the project (2001/02 to 2003/04). The number of young carers increased by 54% (from 30 to 66), and the number of

respite sessions increased dramatically from 158 to 523. It can be deduced from this information that in the first three years the Project was responding to a significant gap in service provision for this cohort of young people. The subsequent two years showed a slower yet gradual increase in the number of young carers registered with the project. The evaluator would argue that this is only the “tip of the iceberg” in terms of the numbers of potential young carers on the Island. However, given the projects financial staffing constraints, they have reached their capacity threshold.

The PC reported that: *“the IOWYCP has always exceeded its targets with respect to the respite sessions provided every quarter/year throughout the life of the Project. This has been in the form of many trips and outings and has been enabled by a wonderful team of volunteers, both past and present.”* Furthermore, the PC identified the following areas of success/achievement:

- Newsletter: This includes Project updates (staffing ‘who is who’, funding, what we’ve been doing, new members, leavers), Recent Events (articles written by the children and young people with caring responsibilities about things we have done, places we have been), comments from family members, Introduction to a Volunteer, thanks to volunteers for recent trips, useful contacts for support and activities (i.e. Princes Trust, Duke of Edinburgh, youth serve initiatives, consultation events, local counselling services, Childline etc.), Brainteasers & Quiz.
- Volunteer Training: A comprehensive volunteer training file was developed when the project started. This has been amended and updated as required and is used at volunteer training sessions, before the volunteer takes it home for reference.
- Young Carers Festival: A group of young people with caring responsibilities has attended the national YCF for the last 5 years.
- Schools Work; Awareness raising through IW schools about children and young people with caring responsibilities. These have taken place intermittently over the last five years.

- Club sessions: Weekly meetings for different age groups to get together with a focus on the 5 outcomes of Every Child Matters i.e. first aid, health eating, yoga etc. were introduced in September 2005
- Training workshops: 2 day multi-agency training events have taken place each year for professionals who may come into contact with children and young people with caring responsibilities throughout the course of their work
- Independent Breaks Fund: In 2006, families were able to apply for funding to enable them to take 'a break' independent of the YCP.
- Recruitment, training, assessment, and supervision of sufficient suitable volunteers
- Partnership working with young carers and parents/carers
- User involvement in the development of services
- Group from IW to the National Young Carers Festival
- Training/publicity to increase awareness of the needs of young carers to other services – e.g. schools, Youth Service, voluntary agencies
- Publicity in places where young people will see it
- Sign-posting and/or referral to mainstream services
- Annual events for young people with caring responsibilities, families, volunteers and supporters

In reviewing the project coordinators observations and comments re: the projects achievements, it is also evident that the IOWYCP has provided valuable support and respite care from the home environment. This is especially important in the light of many young carers' rural isolation and current restricted mobility. It is evident that the IOWYCP has made significant progress towards achieving all of its original aims and goals, and has exceeded a number of its targets. The continuous assessment of young carers' needs has also been a significant cornerstone of the overall success of the project. It is encouraging to note that this process has been conducted with constant service user feedback and consultation. The young carers are the major stakeholders and their input has been valued at every stage of the project's development.

The project has been able to respond to the needs of young carers by providing one to one sessions during difficult times, as well as range of respite and educational opportunities. It is clear from feedback received in this evaluation that the IOWYCP provides a critical and valued service to a vulnerable group of young people. This has served to both empower young carers and encouraged confidence in their abilities to advocate on behalf of their own needs and rights. Furthermore, the project has placed a great deal of their work around holistic family care and support. No longer are the young carers viewed in isolation, but their needs are seen by IOWYCP within the context of their families. (Butler and Astbury, 2005).

Barriers to service delivery

The PC identified unstable funding as a key barrier to service delivery.

Her comments reflect this issue:

“Difficulties in recruiting/retaining staff (partly due to insecure funding).”

“Difficulties in finding long-term office accommodation.”

“Difficulties in making plans for the future.”

The PC felt that the source of many of the frustrations centred on funding. It has been clear from this evaluation that the five-year funding from the Children’s Services (Isle of Wight) has had a positive impact on service delivery. However, procuring funding in one, two or three year cycles impedes the ability of the project to consider long term planning.

Furthermore, the PC also mentioned the rural context of the Island as having a significant impact on service delivery. *“The Island being a rural area and hence transportation of the children/young people to ensure they can attend activities can be time consuming for staff and volunteers and expensive if taxis are required.”* 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.

The issue of volunteers leading outings was also raised: *“The wonderful commitment of the volunteer team (past, present and future) has enabled 2439 episodes of respite to take place throughout the life of the Project. However, it is sometimes difficult to get volunteers who are willing and/or able to take the lead on a group outing.”* This puts pressure on project staff to lead trips – which are usually carried out voluntarily.

The evaluator also asked the PC what she found most frustrating/ difficult in terms of service delivery.

“Since September 2001 the YCP has moved offices 5 times! This is generally disruptive and time consuming.”

“Trying to find enough hours in the day to meet the various demands of the Project!”

“Finding enough time to meet with the young people on a 1:1 basis.”

“Too much paper work.”

Rewarding aspects of service delivery

The evaluator asked the PC what she found most rewarding in terms of service delivery. She provided numerous aspects of the job which she found rewarding, namely: benefits to the young carers, role of the volunteers, working relationship with the local authorities, Spurgeons and funders; as well as the network aspects of partnership working and multi-agency collaboration, to name a few.

“When you hear that a young person genuinely finds the Project beneficial and supportive of their own particular needs.”

“When you can see that the Project has really improved the quality of life for a child/young person.”

“The commitment of the volunteers who enable the respite to take place.”

“The support and good working relationships with Spurgeon’s Child Care.”

“Good relations with the funders/Children’s Services”.

“The support of the IOWYCP Steering Group etc, and other organisations, and individuals too numerous to mention.”

Types and nature of services for the young carers

- Ensure young people with significant caring responsibilities have access to the service
- Work with the young people, their families and other agencies
- Put young carers in touch with others in similar circumstances
- Develop self help support groups
- Enable young carers, if they wish, to access services currently available within their locality
- Facilitate opportunities for young carers to have time for themselves away from caring responsibilities
- Obtain the views of the young people on how best the project can support them and develop the project accordingly

The Project mainly provides support to families and ‘respite’ for the children/young people in the form of leisure and recreational opportunities. Due to the nature and extent of their caring responsibilities, young carers are frequently deprived of opportunities for relaxation outside of the home environment. A large component of the services offered to young carers by IOWYCP therefore involves creating respite times away from the caring environment. These are opportunities for young carers to relax and socialise with other young people. The project has successfully provided the following respite opportunities:

- Time out from caring
- Individual support (i.e. 1:1 meetings, talking to schools, social workers on the young person’s behalf)

- Signposting (counselling, careers, Connexions PAs)
- Birthday card and cinema voucher
- Advice to professionals about the needs of children and young people with caring responsibilities

As Spurgeon's YCP nears the end of its 5th year of operation, there are 83 young people (aged 7-18) currently registered with the IOWYCP. A total of 635 respite sessions were been provided to the young people in the year April 2005 – March 2006. A waiting list has been required as referrals continue to come in from health, education and children's and adult social services, as well as direct referrals from families.

Service user involvement and consultation

The evaluator was interested in exploring the projects strategies for user/carer involvement and consultation i.e. how were the young carers involved in the planning and delivery of services? The evidence from this evaluation suggests that consultation with the young carers regarding service provision has been the cornerstone of the project's development. Numerous strategies have been adopted in terms of consultation. The PC also mentioned that *"when Spurgeon's Child Care Young Carers Project was set up in 2001 a self-assessment 'Your Shout' form was devised, piloted and adjusted as necessary."* This form seeks to gain from the children and young people with caring responsibilities:

- who they are caring for and why
- whether they are the main carer
- whether they are happy to carry on as they are
- what things they do to help the person they care for (a check list of practical and emotional responsibilities).
- how they feel about caring for the person that they care for
- what hobbies or interests they have
- what things they may feel they miss out on
- whether the young person feels their schooling is affected by their caring role

- whether the young person would like some support from the Young Carers Project
- what kind of support the young person would like from the Project

The PC offered the following comments attesting to the role of young carers in the life of the project:

“The termly YCP Newsletter keeps families updated about any developments that are being considered or have taken place (funding, staffing etc).”

“Views of children and young people are also sought through the Newsletter and informally whenever we meet with them.”

“An evaluation in the form of a questionnaire to both children/young people and parents was carried out by myself in 2003.”

“Questions in the Annual Review’s include asking families what they think of the Project i.e. best things, any recommendations for future development etc.”

“A young person from the Project has been part of staff interview panels.”

“Young carers have been involved in all aspects of the independent evaluation of the project (2006)”

The Project’s main focus continues to be providing ‘respite’ in the form of trips, outings and activity clubs for the young carers. As the PC explained:
“They have the opportunity to confide in trusted adults if they wish to. This continues to be in keeping with what the children and young people say they want from the project at the point of assessment. “

Other examples of service user involvement include:

“A young person from the IOWYCP was on the interview panel for the Development Worker post.”

“Young carers have been willing to be interviewed by the Joint Area Review Team, the Local Authority auditors and the local paper.”

Inclusion of parents/families in care planning of service delivery

Section 5.4 will provide a more in-depth analysis of parents' perspectives regarding the IOWYCP. Suffice to say at this juncture; that the parents regard the impact the project has had on their children's lives as being positive and supportive. The evaluator was therefore interested in assessing the role that parents play in the overall project, and their involvement in care planning for their children. The PC provided the following illustrations re: parental involvement in the project:

“Assessment and Reviews attempt to identify needs of all family members (i.e. liaising with social services about respite; housing issues; and signposting onto counselling services etc.).

“Some families were interviewed as part of the IW Councils Audit of the IOWYCP.”

“The project has a Family Day each year where staff, volunteers, young people with caring responsibilities and their parents and siblings can all get together in an informal setting.”

“On some occasions the project has included parents in activities.”

“Recently, the project has introduced the Individual Breaks Initiative. This may allow for the child to apply for allocated funding on a family day/event, if they so choose.”

“Both parents and the children/ young people with caring responsibilities were included in the projects' informal evaluation in 2003.”

Awareness raising and young carer identification strategies

As stated in the previous 'types of service delivery' discussion, awareness raising and the identification of new young carers are critical to the ongoing growth and success of the IOWYCP. The PC identified the following

strategies that the project has developed re: awareness raising with other service providers on the Island.

- Awareness raising within schools (PSHE and Assemblies)
- Promotion of IOWYCP to groups of professionals at team meetings (i.e. Children's Services, Adult Services, Mental Health Teams, Healthy Schools Network etc.)
- Training Workshops (2 day) covering identification and support strategies for professionals who may come into contact with young people with caring responsibilities, throughout the course of their work, have been run each year
- Training Workshop for Connexions staff

Future planning/priorities

The PC provided a commentary as to the "way forward." This discussion focused on the main priorities of the IOWYCP (structure, management, services, partnership working, funding etc)

- Secure funding for staff posts, respite and office accommodation, etc.
- To develop the project in accordance with the children and young people's wishes
- To have the resources to develop and have a longer term view
- Be more proactive in reaching out to support individual children and young people with caring responsibilities, who are going through a particularly difficult time

It is also important to note that the projects plans are linked and matched with the Department of Health's (DOH) Every Child Matters document. "Every Child Matters: Change for Children" is a new approach to the well-being of children and young people from birth to age 19. The Government's aim is for every child, whatever their background or their circumstances, to have the support they need to:

- Be healthy

- Stay safe
- Enjoy and achieve
- Make a positive contribution
- Achieve economic well-being

This means that the organisations involved with providing services to children - from hospitals and schools, to police and voluntary groups - will be teaming up in new ways, sharing information and working together, to protect children and young people from harm and help them achieve what they want in life. Children and young people will have far more say about issues that affect them as individuals and collectively. Over the next few years, every local authority will be working with its partners, through Children's Trusts; to find out what works best for children and young people in its area and act on it. They will need to involve children and young people in this process, and when inspectors assess how local areas are doing, they will listen especially to the views of children and young people themselves.

<http://www.everychildmatters.gov.uk/aims>

Please see Section 5.6 for specific evidence regarding the IOWYCP working within the Every Child Matters national framework.

5.3.2 Interview with Development Worker

The Development worker (DW) identified his main tasks as:

- Recruit, train and support the volunteers so as to provide respite for the young carers in the form of trips and outings.
- Run the weekly Club Nights so as to provide the young carers with regular contact with the project, and to meet the requirements of the ECM agenda.

Volunteers

When discussing the volunteers the DW stated: *“Our volunteers are adults who are interested and committed to working with children and young people. While working on the project we hope they will develop good communication*

and listening skills which will allow them to develop relationships with the children and young people.” There are now 17 volunteers on the project. Some have been with the project since its inception; others have recently joined the project and are in the process of being integrated into their volunteering role.

He explained that before a volunteer can become fully enrolled with the project and start attending activities, they need to have completed:

- Informal interviews with the Project Coordinator and DW
- A Satisfactory CRB check and two satisfactory references.
- Training (Individual session and group training)

The first couple of trips a volunteer attends are all supervised by either the PC or DW and is part of the assessment process. Only if it is decided that they are suited to the volunteering role will they be allowed out with the children accompanied by a “senior volunteer”. A “Ladder of Responsibility” clearly highlights the volunteer’s individual progression from a Volunteer Assistant to a Senior Volunteer capable of leading the diverse activities offered by the IOWYCP.

“With 80 young carers now registered with the Project it is impossible to guarantee that the same volunteers will be able to work with the same children on a regular basis. We have to work around the volunteer’s free time that they generously give up for the IOWYCP. Naturally developing relationships with the children is harder when you are only getting to work with them on an irregular basis.” The number of volunteers has grown to facilitate the growing numbers of young carers.

The PC and the DW maintain regular contact with the volunteers. A volunteer planning meeting takes place every quarter where past and present activities are discussed. Any issues or concerns can be raised at these meetings or in a 1:1 situation. One key point of contact with the volunteer is after a trip has taken place. This swift feedback forms the basis for the reports that are written on each child attending each trip. These reports alert the project to any

possible child protection issues and are also a way of maintaining a record of the young carer's character, likes and dislikes and general behaviour. The volunteers also feedback how successful the trip was and what could be done to improve similar trips in the future.

Activities and Clubs

The DW explained that the project aims to provide activities and respite opportunities that are cultural, physical, educational and, "*most importantly enjoyable*". Examples of the activities offered by the IOWYCP are as follows: Activity centres (both Island and Mainland based), trips to wildlife centres, theatre trips, horse riding, sleepovers and even simple short trips such as bowling and the cinema.

The project has always sought the young people's views when looking to book trips and their ideas are discussed with the volunteers at the planning meeting. The project offers a range of activities during the school holidays, evenings and at weekends. The young people are invited to choose which of the many activities they would like to attend. In September 2005 the IOWYCP started weekly clubs in a response to some of the young carers requesting that they have the opportunity to meet on a more regular basis (please see section 5.6). The new clubs also helped the project fully embrace the tenets of the Every Child Matters Agenda (ECMA) whereas previously the project had been mainly dealing with the 'Enjoy & Achieve' section of the ECMA with its trips and activities. The project also hired two Youth Group Workers to help the DW run the clubs.

The young carers were divided into three age groups: 12 and under, 13+ and 16+. Each five weeks during term time the two younger groups would have two club nights and the 16+ group would meet once. The activities aimed at the younger groups were First Aid, Arts and Crafts, Yoga, a visit from the Healthy Living Chef, a Dance workshop, Karate and a DJ workshop for the 13+ group. The general consensus of the 16+ group was that they wanted to

meet for a meal out and this idea was incorporated as the basis for their club night.

Looking back over the last year since the club nights began the DW was able to comment on the success of the venture. He noted that the 12 and under club had been consistently well attended and felt that the children had enjoyed themselves (please see Section 5.6). He also noted that this regular meeting allowed him to get feedback from the young carers concerning their recent trips and what sort of activities they wanted to see on offer in the future.

He noted that unfortunately the 13+ group had failed to attract the numbers needed to effectively run the club for their age group. Ultimately, this age group preferred to continue with the outings/activities that the IOWYCP already provided. He stated that all efforts were made to try to accommodate the young people's wishes and expectations, including running a DJ workshop at considerable expense, however, numbers remained unacceptably low. Therefore, the 13+ club was discontinued in late Spring.

While the 16+ club was well attended and received good feedback from the young carers, it was felt that the meal out concept had problems. Firstly, it was not conducive to working within the ECMA. Secondly it was an outing that could be run by volunteers sparing the project the expense of having paid workers run it. The project has now shifted the emphasis of the clubs to focus on the younger group. Ways of accommodating the older groups are being looked at.

Barriers to service delivery

While the DW noted that the volunteers on the project are committed and very generous with their time he did note that there are understandable problems in working with voluntary staff:

“Having to work around other people’s free time can be awkward and at times quite frustrating. We are not always able to organise the trips the children want because sometimes we are unable to get the volunteers to run the trip. An example of this is that many young carers request the opportunity to have sleepovers as they have in the past. This is an exceedingly difficult trip to organise because it would mean multiple volunteers giving up an entire weekend or even longer to run the trip. This sort of devotion to the project can be hard for the volunteers when they have their own working and family commitments to contend with. However, it should be noted volunteers have enabled a group of young people to attend the national Young Carers Festival for the past 5 years. I have even had a volunteer ask me about when he should book his holiday from work so that he could do some volunteering. This sort of commitment to the project is outstanding, but it cannot be relied upon on too regular a basis. The Volunteers are entitled to a life too!”

5.4 Parents perspectives

The evaluator did not conduct one-to-one interviews with these parents. However, the evaluator compiled the written commentaries (from the parents) provided by the PC, into meaningful thematic categories. This evaluative feedback from the parents was gathered by the PC in 2003, and was received in the form of written observations and commentaries. It was felt that inclusion of the parents’ perspectives in this evaluation report would provide a more holistic family perspective of the work that has been carried out by the IOWYCP over the last five years. Parents of young carers involved in IOWYCP offered their comments and perspectives regarding their life experiences, the roles and responsibilities of their children in their caring role, and the value of IOWYCP in supporting their family systems. Aldridge and Becker (1999, p.316) expand upon this by arguing that “young carers and their families require, in practice, recognition of two sets of needs and rights – those of young carers and those of the disabled parent(s).” This further reinforces the project's commitment to being user lead and driven, both in terms of assessing and responding to needs. The IOWYCP has ensured that all its young carers have the right to be consulted in decisions that affect their lives, and ensure that the service is “child-centred.”

Impact of caring role on young carers (2003)

Parents were acutely aware of the pressures placed on their children in their role as young carers, and the impact of this role on their daily lives and socialisation processes. They recognised that their children's social activities were restricted:

“She really deserves this support group as she works so hard at home and at school in between trips and meetings. I don’t know what I would do without her – but I do know life would be much harder, bless her, I love her to bits.”

They also expressed concern about the impact of the young carer role on their children's self-esteem and sense of self: *“My daughter has been a young carer since the age of 2. Incredible isn’t it and hard to believe. But when I was left by my husband with 3 kids [name of son] who was 5 and hadn’t been diagnosed as autistic yet, [name of young carer] who was 2, and an 8 week old baby, [name of young carer] used to help with baby’s feeds, nappy changing, and dressing and now she helps with everything from helping her brothers to helping me with my spinal injury. She never moans but I know she looks forward to the young carers trips and activities, a chance to be a child, to have fun and forget about everything.”*

Perspectives regarding IOWYCP (2003)

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

- As part of the IOWYCP these children have been given the opportunity to mix with children who have similar life experiences (2003).

“The trips my daughter has gone on have been a great help to her. It’s given her some time on her own with children of her own age. Her brother who is 8 is quite demanding wishing her to play with him all the time. As I don’t get too much time with the children as caring for my wife who has a disability takes up all my time, the project has been really valuable for my daughter to be involved in.”

*"In my position I cannot give [name of child] all the things that I would like to give him. The young carers project has helped him experience things and make new friends without me having to worry about his safety. The project is a wholesome and worthwhile project led by dedicated people."
(2003)*

- Parents felt that their children's confidence had been enhanced through involvement with CYCP:

"I hope you will be able to get more funding for the project as it has been a worthwhile experience for [name of son] over the last few years. You can tell the gentleman from the boy now. He has benefited in that he has met new people and other grown ups and you have given him the experiences he would not have had because of our circumstances"

- It was felt that children were given the opportunity to relax and be themselves:

"The project is excellent. It gives my son time out he would not otherwise get as we can't go away on holidays anymore."

- Parents appreciated the mentoring, advocacy and volunteer aspects of the project :

"I want to thank [name of project coordinator] and her team of volunteers who work so hard to give enjoyment to all of them."

"My thanks go to [project coordinator] and all the volunteers. Without them the young carers may not get this great experience which they all need so badly."

"[name of husband] and I would like to thank you and everyone of the volunteers that have looked after [name of son] and for all of your kindness, help and advise that you have given him over these years."

- Knowing that their children are being given support in their role of young carers has helped to alleviate parental pressure:

“[name of child] has a real buzz from joining in with the activities provided by Young Carers. She has particularly enjoyed the Young Carers Festival 4 weekend and evenings out are good as well. She enjoys the company of others who have similar challenges and looks forward to each new activity. Thanks to all those involved. This is a real benefit to her as an individual and to us as a family.”

“My son was very happy after his trip. He bought me a lovely crystal. He did not stop talking all evening, and went to bed without a moan as you’d tired him out. It was nice to know he was enjoying himself. I had a nice relaxing time while he was out so we both benefited from the break – so it’s not just the carers who benefit. He had nothing but praise for the volunteers and loved his McDonald’s and made many new friends. He knows now that he’s not the only one with parents who need help, and he can call other people to talk to.”

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

Suggestions for the future development of IOWYCP

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

- Their comments predominantly focussed on group activities and individual support

“[name of child] has fully enjoyed her time out which you have enabled her to enjoy. She looks forward to the outings and really seems to enjoy them. She especially enjoyed the Young Cares Festival which she went to this year. I think on the whole the things they do are fantastic and the fact that people volunteer their time to help is amazing. Some positive publicity for

your cause may bring forward more volunteers and enable more kids to attend events which this last six months have been oversubscribed. “

- They felt that more opportunities should be provided for outings
“My son could possibly benefit from more frequent contact with the young carers project. My son is very young with adult responsibilities on his shoulders. I am a bit worried about how much he is taking on now my health is deteriorating. Is there any more support available to him?”
- Parents also commented on the current upper age limit for involvement in the IOWYCP, expressing that they felt the project should be open to older young carers, as well as the need for ongoing funding:
“The only problem I have with the project at present, is that there are a lot of new children on the lists, the trips could be half and half, some for the younger ones and some for the older children. I know that must be difficult to find ideas for everyone – especially when trying to find trips and outings to suit all and finding the funding for it. Our son has enjoyed the High Wycombe flying trip – he was full of it, and the London Eye, the Science Museum, bowling at Ryde, horse riding (which he would love to do again), and the Speedway.”

“I would like to thank Spurgeon’s Child Care and Social Services for funding all the trips and would hope that more funds could be found to keep such a great idea of a project going on for the children.”

The views offered by these parents have emphasised how much they depend on the support of their children in coping with their daily lives. They have demonstrated insight into the pressures experienced by their children in their role of young carers. The support of the IOWYCP to their children has assisted them in providing this support, thus maintaining family cohesion and contributing to the well-being of both parents and young carers alike. For some parents, IOWYCP support is currently the only support they are receiving; whereas for others this support contributes to an holistic support

network. The unanimously positive views expressed regarding the importance and value of IOWYCP, to both parents and young carers, is encouraging as it demonstrates that the project workers are succeeding in meeting practical and emotional support needs to family systems.

5.5 Good practice: Response to service user feedback

As evidenced throughout the evaluation service user feedback and consultation has been a key feature of the IOWYCP. The PC, project workers and volunteers have made this a priority and an integral part of their work. It is important to note the critical role, which the volunteers have made regarding consulting with the young carers and feeding this information back into the project planning, and service delivery. The following quotations speak volumes to the appreciation that the young carers feel towards the project volunteers [note: these observations were captured during the 2003 internal project evaluation].

“I really like the project. There’s fun activities and the volunteers are great.”

“I would like to thank all the volunteers for all their help”

“It is a great project. It couldn’t get any better. Thank you [name of project coordinator] and the volunteers for all the trips and the newsletters. I really, really, really like the project and the things it does.”

“I know I can always call [name of project coordinator] if I need to talk to someone.”

“I think the young carers project is like an educated fun place. This weekend I achieved canoeing, then the burma bridge and also abseiling. “

“My parents and I read the young carers newsletter. It says what happened, future activities and general fun. It is always a pleasure to read. The project has helped me understand just how much support I have around me and I am grateful for the support all the volunteers and [name of project coordinator]

have given me. Both my parents and me are amazingly happy with the services and are tremendously grateful with the project. You all helped me and I can't say how much my family and I appreciate it."

"I think the project is great. It gives me a break from being a carer. I have really enjoyed myself every time I've come out with the project. I want to thank all of you and the volunteers because we couldn't get a break without you."

The IOWYCP has responded to recommendations presented by the young carers (and their parents), which has resulted in new and innovative activities being developed and implemented. This section will present a few illustrations of good practice, which demonstrate how service user feedback and consultation has served to modify the IOWYCP programme.

- Summer Outings

One of the key suggestions proposed by young carers (during the 2003 internal project evaluation) was the need for an increase in the number of outings during their summer holidays. As young carers stated:

"A few activities during the 6 week summer break would be nice."

"It would be nice if we had more outings during the summer holidays."

In response to this consultation and feedback every effort has been made by the workers and volunteers to ensure more trips took place throughout the summer holidays, in spite of the volunteers having day jobs. For example, 120 sessions of respite were provided this summer (6 weeks), and 199 sessions were provided in July to September 2005.

- Club Nights

Another suggestion that the young carers proposed (in 2003) was the need to have their own space to meet. Because of societal perceptions and extensive responsibilities at home, some young carers felt that they wanted a place that they could “escape to” when they felt that they could not cope. They felt that this facility should be made available to young carers and other young people. As young carers said:

“It would be great if we could have a room at KJ’s to pop in and have a cup of tea with other young carers in the future.”

“It would be really cool if we could have a chillout evening when we could all go to a place, hangout, listen to music, and play games.”

The project responded to this request by starting up weekly club nights for different age groups. However, in responses to subsequent and ongoing feedback from the young carers, some of the groups have now been disbanded. This is an excellent illustration of how the IOWYCP has responded to the needs identified by young carers themselves, over the last five years.

- Good practice: service user feedback strategy

The PC and the DW spoke about the projects service user consultation strategy and how the IOWYCP gains constant feedback from the young carers. Numerous strategies have been adopted towards this goal, namely:

- Weekly club nights
- Speaking to each young carer individually, at least once a week, when they attend the club nights
- Call to the newsletter – in which they can offer ideas and suggestions for future activities
- Write a report on each child’s activities and respite opportunities, and evaluate their enjoyment of the activity.

The DW offered the following observations in this regard.

“I run a few clubs for the young carers. It is a great way to keep up to date with these things and to consult with them regarding what they want to do. I like talking to the young people about what they are doing and what they would like to do in the future.”

“I make a point of seeing the kids on a regular basis and getting their feedback.”

The PC added: *“Individual young carers have attended group meetings with me...with the purpose of recruiting volunteers. This is really important as the young carer can talk and articulate directly to the volunteer what they think makes a really good volunteer with the Project.”*

5.6 Links to Every Child Matters (ECM)

This discussion will analyse the work of the IOWYCP within the contextual framework of Every Child Matters (ECM) – (DOH 2004). Evidence will be provided in support of the numerous ways the project has linked with the ECM; as well as providing examples illustrating how the PC has linked the project’s planned services and activities to the five tenets of the ECM.

Be healthy

The three focus groups (with the young carers) have identified numerous ways in which the project has provided mental health support services. For example, young carers in the 7 to 11 year old focus groups spoke about the fact that the project helped them with their stress levels, and takes their mind off their caring responsibilities. Young people in the 11 to 15 year old focus group said that the project helped them look after their parents better, as well as giving them a new start. The young carers in the 16 to 18 year old focus group mentioned that being part of the IOWYCP has helped to increase their self confidence, as well as reducing their stress levels.

This report has provided evidence regarding the critical role volunteers have played in the projects ability to deliver its services and planned activities.

Thus, the role of the volunteers is significant in achieving the 'be healthy' objectives as set out by ECM. The volunteers have responded to the young carers health needs, both mentally (support, one to one interaction, confidential counsel, advice and guidance), and physically (recreation, sports, physical activities etc). The project strives to build a relationship of trust with the children and young people so that they may discuss any problems they are experiencing with staff/volunteers whereby reducing stress and supporting mental health. Furthermore, the IOWYCP has developed Club Nights and activities which focus on encouraging young people to think about healthy living. Examples are: healthy eating programmes, inviting a healthy living chef to a club night, and yoga sessions.

As part of the projects commitment to assessment, they continue to assess young carers against YCP criteria. For example, is a child or young person within the home caring or helping to care for a family member affected by: physical illness/disability, a learning disability, mental ill health, sensory impairment or misuses drugs and/or alcohol? Does that young person require support? Also, at the point of assessment the project refers to additional services that will relieve stress on the young carer (i.e. Adult Services, Counselling etc.). One of the many strengths of the project is its commitment to considering the needs of the whole family. This informs them with referral/signposting to other agencies, as appropriate.

Other examples of the project coordinators planned activities with regards 'being healthy' are:

- Promote healthy lifestyles within contact sessions (healthy diet, exercise, alcohol etc)
- Discuss the hazards of risk taking behaviour (smoking, drinking alcohol etc.) during contact sessions
- Provide fruit as a healthy option at activities
- Organise regular indoor/outdoor activities to promote physical well being
- Promote healthy eating options within the Newsletter's Healthy Living page

- Operate a no-smoking policy
- Provide specialist training Workshops to professionals who work with children and young people so that these professionals may be better able to support the needs of children and young people with caring responsibilities throughout the course of their work

Stay safe

In terms of 'staying safe' the young carers (in the three focus groups) have spoken about the fact that the IOWYCP provides them with a safe place/space to be themselves; where they can simply be a child or young person; where they know they are understood and supported; and where they can find peer support.

Young people in the 11 to 15 year old focus group felt that the projects staff and volunteers listened to them and truly understood their caring responsibilities. Young carers in the 16 to 18 year old focus group spoke about the importance of safety in that they think about their parents all the time, and whether their parents are safe. They also mentioned how important it is just knowing there are people who care for them [the project]. Furthermore, the fact that they find the project to be trustworthy speaks volumes to the safe environment which the IOWYCP provides for the Island's young carers. Parents (from the 2003 evaluation conducted by the project coordinator) say that are happy that their children are safe at the project.

In response to issues of safety, the project has also provided a First Aid course, as well as trips to the Fire Station. The IOWYCP provides a safe & secure environment for children and young people to meet via YCP groups/activities. Club Night activities have also included, for example, karate (fun and safety).

In addition to the reports that are written on each young person after a trip, more confidential records are also kept. This will raise issues of child protection, where appropriate. Referrals are made by the project to Children & Family Services, where neglect or abuse is suspected. The project also

advocates on behalf of children and young people for additional support from statutory agencies where inappropriately high levels of caring are being taken on. All IOWYCP staff/volunteers have to have an Enhanced Criminal Record clearance, and all IOWYCP staff/volunteers have to attend Child Protection training.

Other examples included in the projects planning re: 'staying safe' were:

- Ongoing guidance and training be provided to staff/volunteers on how to recognise and raise child protection concerns
- Risk Assessments be performed for all outings/activities, to avoid unforeseen incidents
- Sufficient child: adult ratios are observed at all times.

Enjoy and achieve

The young carers in the project have articulated the enjoyment they receive from their involvement in the IOWYCP. Some of the 7 to 11 year olds have singled out the enjoyment as the project provides 'time out', the activities are enjoyable and fun and in some cases their 'best times', enjoyment of activities such as bowling and swimming, and club activities, amongst others. The 12 to 15 year old group mentioned activities as being a good break, time to relax and have time out. The older group (16 to 18 year olds) emphasised that the project made them realise that they are not alone, and a sense of freedom, as being particularly enjoyable aspects of the project.

In response to this tenet of the ECM the IOWYCP has provided 2439 respite sessions (between 2001 and 2006). Furthermore the projects activities are diverse in nature, ranging from cultural, to educational and recreational activities. In response to consultation with the young carers Club Nights were introduced. Some of the Club Night activities included arts and crafts, and DJ workshops. The project has also introduced the Independent Breaks Scheme which can be used by young carers (and possibly other family members) on an activity of their own choosing.

Furthermore, the project coordinator has identified the following areas as ways to support young carers' enjoyment and achieving their potentials:

- Address low self-esteem issues by encouraging children and young people to take part in activities that will increase their confidence
- Reduce feelings of isolation for children and young people with caring responsibilities by offering a range of activities to the children and young people where they may socialise with other children and young people experiencing similar circumstances
- Support and encourage children and young people who are socially restricted by providing 1:1 and group activities
- Offer safe, fun and enjoyable activities so that the children and young people may have freedom from the caring role and time away from their normal environment and stressors
- Provide opportunities for social interaction with both peers and adults via IOWYCP clubs and activities
- Liaise with EWOs, SENCO's, Connexions etc and advocate for additional support when it is known caring responsibilities are affecting the schooling of children and young people.
- Provide transport for children and young people to ensure they are able to take part in activities
- Support children and young people at key transition points in their lives (i.e. before discharge from the IOWYCP)

Make a positive contribution

The evidence in this evaluation has demonstrated that parents and children have both grown as a result of their links to the project, and as such not only has it been a positive experience for the child or young person, but equally positive for the parents as well. One example which has supported this ECM tenet is the projects involvement with the Isle of Wight's 'Big Day Out' initiative (with parents/family). Other illustrations of making a positive contribution are the young carers willingness to be interviewed about the service, and being on interview panels.

The project coordinator has identified the following areas as ways to support young carers in 'making a positive contribution':

- Offer opportunities for children and young people to express their feelings and suggest how they could best be supported in their caring role at the point of assessment
- Actively consult with children and young people re: the development, management and evaluation of IOWYCP activities
- Include children and young people on interview panels
- Encourage children and young people to develop social networks via the IOWYCP
- Promote interaction between peers and staff/volunteers
- Publish articles written by children and young people with caring responsibilities and their parents in IOWYCP Newsletter
- Promote volunteering opportunities for young people aged 18+

Achieve economic well-being

The project has spent a great deal of time and energy trying to enable the 18 plus (even those young people are 16 or 17 years old) to think about and plan for their own economic well-being. The IOWYCP has recognised that this is a transition period in their lives and that issues of financial independence, getting jobs, and going to college etc, are taking on more critical importance.

The PC has identified the following areas as ways to support young carers in 'achieving economic well-being':

- Discuss benefits & services to ensure family are receiving what they are due
- Identify educational needs and refer on as required
- Actively seek other organisations to support children and young people gain access to training and employment where appropriate

6. PROGRESS AGAINST IDENTIFIED AIMS AND OBJECTIVES

The following discussion will evaluate and provide evidence of the IOWYCP's progress towards achieving its originally formulated aims and objectives (as presented in Section 1.3)

Assess the needs of young people with caring responsibilities on the Island

- **Formal and Informal Assessment**

The PC developed the Shout Self assessment tool in 2001. This assessment instrument has served to capture crucial information about the young carers experiences and their needs in terms of their caring responsibilities. More importantly, the PC has modified this assessment tool at different times throughout the last five years. This has been done in response to service user feedback, and to ensure that the tool captures the evolving and changing nature of young carers needs. Furthermore, assessment has also been conducted at an informal level. The project coordinator, the project workers and the volunteers (both past and present) have used their one to one (and group) interactions with the children and young people as a strategy of assessing the young carers needs.

- **Continuous Assessment**

Leading on from the formal and informal assessment strategies, it is important to document that the IOWYCP has a strong commitment to ongoing assessment. Once the young carer completes the Shout Tool as part of their initial assessment, this is not then viewed as a 'once off' piece of work re: needs assessment. The assessment process is viewed by the project as a cyclical process, with constant review and reassessment. This is linked to the reports which the project writes in terms of each young carers engagement with the IOWYCP, and it's working towards meeting their identified needs. Furthermore, evidence supports the fact that the young carers are at centre of their assessing their own needs. Their feedback is not only actively sought

and valued, but more importantly used to assess whether or not their needs are being met by the IOWYCP.

- Data Capturing

The Projects needs assessment strategy is well supported by its data capturing methodologies. The IOWYCP has been able to obtain an evidence-based profile of young carers needs by capturing ongoing categorical data at individual and collective levels. This has both linked and informed the services and activities which they have developed and implemented over the last five years.

- Monitoring and Evaluation

One of the strengths of the IOWYCP has been its commitment and implementation of monitoring and evaluation strategies. Two specific examples can be provided in support of this, namely:

1. The internal evaluation that was conducted by the project coordinator in 2003. This comprehensive evaluation enabled the project to think reflectively at the work they had completed (since its inception in 2001), and use this data to inform their future planning re: policy and service delivery. Even more significant is the fact that this evaluation incorporates the perspectives and experiences of young carer parents', thus offering an holistic family systems approach to their work.
2. This externally funded evaluation (conducted in 2006) will be linked to the IOWYCP's programme modification and reformulation (where appropriate), and to the continuation of the work presently being delivered (where appropriate).

These monitoring and evaluation strategies have enabled the project to deliver their services that are child/young person centred, with the needs of the young carers at the centre of the IOWYCP's work.

Develop the Project to meet the assessed needs of young people with caring responsibilities within their own Community

- Statutory and Voluntary sectors

In developing the project to meet the assessed needs of young people on the Island with caring responsibilities, the IOWYCP has continuously linked its service provision to work done within both the statutory and voluntary sector. This approach has been successful in enabling its young carers to receive a diverse range of appropriate services (within and external to those provided by the project itself).

- Signposting

Furthermore, the projects successful signposting strategies have been an important and effective way of linking young carers with community services. Examples of signposting are links and referrals to: Counselling, Careers and Connexions.

- Good referral base

As discussed and evidenced in Section 5.1.4, the project has developed a strong and rigorous referral base (both to the project and referrals to outside partners on the Island). This has enabled the project to develop its services and programmes in response to a wider and varied range of identified young carers needs.

- Response to isolation

When considering all of the evidence that has been provided in this evaluation (in conjunction with the evaluation conducted in 2003), one of the most salient illustrations of the project meeting the young carers identified needs is the way in which the IOWYCP has reduced the sense of isolation which so many young carers reported in the focus group interviews. As the young carers expressed, in many cases 'the project was their only means of support'. In addition, the project developed its programmes with the explicit philosophy that by meeting other young carers, they could draw on the strength and support of their peers.

- Every Child Matters

As discussed in Section 5.6, the project has linked exceptionally well with the Department of Health's (2004) Every Child Matters initiative. Evidence has been provided illustrating how the project coordinator has linked the project's planned services and activities to the five tenets of the ECM (be healthy, stay safe, enjoy and achieve, make a positive contribution, and achieve economic well-being). This provides support of the fact that not only was the project developing its work within locally defined needs and parameters, but that it was also doing so within national drivers and strategies.

- Respite sessions

The project has met (and exceeded) this aim by the number of respite opportunities it has been able to provide for their young carers. The initial target for provision of respite sessions over the last five years was 1325. However, the project has been able to provide 2439 respite sessions during this time period. (exceeding its original target by 1114 sessions). The level, quality and quantity of respite sessions provided by the IOWYCP clearly illustrates just how much it has developed in terms of the young carers identified needs.

- Club Nights

In response to feedback and consultation with the young carers, the IOWYCP introduced the Club Night activities. This provides evidence in support of the way in which the project has developed and responded to changes in young carers needs and expectations.

- National Young Carers conference

The fact that the IOWYCP has been able to take their young carers to the annual national young carers conference is yet another example of the project developing its service provision from, 2001 to 2006. This national event provided the project workers and the young carers with an opportunity to feel that their work was being carried out within a broader, national context.

- Volunteer recruitment and ongoing training

One of the reasons the IOWYCP has been able to develop the project is due to the strength and commitment of its volunteers. It is important to look at the range and length of experiences that the volunteers have brought to the project. The volunteer group includes the IOWYCP Project coordinator, IOWYCP Development Worker, Student, Support Worker, Trainee Teacher, Health Visitor, Staff Nurse, Paediatric Nurse, Retired Teacher, Retired Naval Architect, Learning Support Assistant, Council Administrator, Chief Engineer – Ferry Company, Assistant Chef, Admin Assistant and Soroptimist, amongst others. The investment from the project towards its volunteers (in terms of recruitment, training, continuous professional development, and support), and the volunteer's time commitment to the project have been invaluable sources for project development and growth.

- Diverse service provision

As presented and discussed throughout this evaluation, the project has not only provided respite service for their young carers. On the contrary, it has provided an eclectic and diverse range of services, namely: one to one, support, respite and recreational, educational and cultural, amongst others.

Promote the rights and welfare of young people with caring responsibilities

Given that so many young carers reported difficulties they had encountered in their schools (from all three age groups), the project coordinators training in schools (and with other professionals) has (and will continue) to help to promote the young carers welfare and rights on the Island.

Raise Island wide awareness and knowledge of young people with caring responsibilities

- Collaborative multi-agency links

Since its inception in 2001 the project has made significant strides re: raising Island wide awareness and knowledge of young people with caring responsibilities. More significantly, the IOWYCP awareness raising strategy

has been conducted in collaboration with a full range of health, social, educational and community services on the Island.

- Young carers training

The project coordinators annual 2-day multi-agency training workshops have been a significant contributory factor in raising awareness about young carers experiences and their needs, as well as raising the profile of the IOWYCP. As stated previously in the report, some examples of the agencies engaged in this training are: Children's Services, Adult Services, Youth Services, Voluntary Services, Education Services, and Schools.

- Newsletter

The projects regular newsletter has been an effective method of raising awareness. Given that young carers are encouraged to make their own submission in the newsletter, it has also provided them with an opportunity to 'tell their story.' This is another illustration of how the young carers themselves form a critical part of their own awareness raising. Furthermore, the young carers parents are also entitled to make their own submissions, which add to the dissemination of information and experiences from all members of the family.

- Publicity events

The project coordinator has also raised awareness via publicity events, where other young people are located. This has been a very important strategy, especially when young carers in the three focus groups reported that so many of their peers and friends lacked an understanding and appreciation for their caring roles and responsibilities.

Record the unmet need and report this to the Steering Group

- Record reasons for discharge

Section 5.1.6 presented a tabular summary of some of the reasons why young carers have been discharged from the IOWYCP. This data collection strategy has enabled the project to record information/reasons why some

children and young people have left the project, and to evaluate whether any of these were due to needs of the children and young people not being met. This strategy also supports the project with its future planning.

- Data Collection

One of the strategies that have been adopted in order to achieve this aim re: recording unmet needs is significant levels of data collection and analysis. This has allowed the IOWYCP to capture information regarding both met and unmet needs. It has also given the project a method of assessing gaps in services, and how these can be addressed in the future. Section 5.1 included illustrations of the ways in which the project coordinator has collected and presented information with a view to providing an important 'snapshot' of various categories/variables of needs and services. The project coordinators data collection methodologies have provided the IOWYCP with critical baseline information from which targets, goals and objectives can be tracked and monitored.

- Report writing and reviews with stakeholders and funders

There are numerous illustrations regarding how the project coordinator has been able to record and report unmet needs. Examples of this include: Quarterly report to Steering group, Contract review quarterly with Spurgeons Child Care and IW Children's Services, and Annual review meeting.

- Good quality assurance/accountability

Recording and reporting of both met and unmet needs have played a crucial role in the projects quality assurance functions and its accountability to its service users and stakeholders.

7. PROJECT ACHIEVEMENTS AND COMMON THEMES

Steady Growth

One of the projects most salient achievements is the way in which it has grown and developed throughout the last five years being externally evaluated (2001 to 2006). The IOWYCP has increased its number of registered young carers with the project from 30 in 2001/2002, to 80 in 2005/2006. Given the rural and geographical context of the Isle of Wight this has been an outstanding success. Furthermore, the project has not only demonstrated clear evidence of steady and incremental growth, but it has also been able to modify and adapt its programme to cater for this increase in the numbers of young people joining the project.

Volunteers

Another achievement has been the projects ability to recruit, train and maintain volunteers. Volunteers are a key component to the overall success of a project of this size and nature. The IOWYCP has been able to recruit and maintain 16 volunteers on their books. Furthermore, the commitment, dedication and work of the volunteers have played a significant role in enabling the project to provide a diverse range of respite opportunities for the Isle of Wight young carers. It is also important to provide a commentary with regards the training packages offered to the projects volunteers. The project has demonstrated its commitment to the volunteers' continuous professional development - and in turn the provision of quality care for its young carers – by providing a range of internal project based volunteers training programmes. Furthermore, the project identifies training needs for their volunteers external to the IOWYCP, and signposts them to the relevant training providers. In addition the PC stated that: *“all YCP volunteers are required to undertake formal Child Protection training. The IW Council and the Youth Service have been supportive to the IOWYCP by allowing staff and volunteers to access their training locally without charge to the project. Volunteers are also able to access training provided by Spurgeon’s Child Care”*.

Respite sessions

The IOWYCP has provided a diverse and eclectic range of respite sessions and activity based programmes for their young carers. Another achievement is the projects ability to provide these opportunities for all three young carer age categories (5 to 11, 12 to 15, and 16 to 18). This is not an easy task; thus its achievement is even more impressive. The project has remained cognisant of the importance of avoiding the ‘trap’ of “all young carers have the same needs and life experiences.” They have constantly provided packages of care and respite activities that are age appropriate/specific, as well as varied in its content (educational, cultural and recreational).

Responding to massive unmet need

The work of the IOWYCP has responded to the myriad of needs of a cohort of young people (age 6 to 18 yrs). The achievements and goal attainment of the project provides support for the fact that there are many young carers on the Island, and that this is a group of young people who have very unique and specific needs. The project has increased the profile on the Isle of Wight re: the plight and life experiences of its carers.

Working within constraints

The project coordinator, its workers and volunteers have to be commended for reaching their targets and intended outcomes; while working within the confines of significant organisational constraints. This is one of those intangible and non-measurable achievements, which is difficult to quantify or hypothesis test. It refers to the project staffs’ resilience, patience and dedication to the work at hand – providing extensive, quality, user-centred services to the Islands young carers. They have achieved significant project success; in spite of staff shortages, numerous office space relocations, and a lack of long term funding, to name a few. These organisational and macro-level limitations have not deterred the IOWYCP in its programme plans, nor has it impeded it in carrying out and implanting its policies and services. However, it is important to acknowledge that the project has now reached a plateau in service provision and a capacity threshold in terms of identifying

additional young carers. This will be elaborated upon in the final section of this report: recommendations for service provision.

Service user consultation

A common theme throughout this evaluation is the fact that the project has been child centred and service user lead. In recent years service use and carer involvement and consultation has been a key target in health and social care service provision. At times, however, the concept of service user and care consultation has been tokenistic at best – a tick box exercise in response to reaching intended targets as outcomes. On an encouraging note, there is no such tokenism about the way in that the IOWYCP consults with its young carers. The needs and wishes of their client group are constantly at the very centre of all aspects of the projects work – in planning, policy formulation, decision-making, activity proposals, staff selection, service provision, quarterly monitoring, needs identification, and programme evaluation. Therefore, a critical achievement is the reflective and authentic approach that the project adopts in relationship to its service user and carer consultation and involvement.

Impact and benefits on young carers' lives

The evidence from all of the three focus group interviews with the young carers clearly demonstrated the impact the project has had on their lives and the enormous benefit they have gained from their involvement in the IOWYCP. The benefits ranged from support and respite, time out, getting a break, making new friends and feeling understood by their peer group, to being understood and heard by adults (often times for the first time), feeling they could talk in confidence with the project staff and volunteers and they would be 'listened to', increase in confidence and sense of self, true value for the caring they provide their parents and siblings. Similar benefits were echoed in the responses from the parents of the young carers. The fact that the IOWYCP has been able to achieve dualistic benefits for both the young carers and their parents is a significant achievement. This is based upon the evaluation conducted by the project coordinator with parents of young carers (in 2003), in conjunction with this externally funded evaluation report.

Monitoring and evaluation

The IOWYCP understands and appreciates the importance of scientifically lead and well-monitored data sets. This has been critical to the overall success of the project. They have been able to provide well evidence based information and baseline data, from which their progress and goal attainment could be managed and assessed. Their work has been an excellent model of evidence based practise as all the data which they have accrued over the last five years has informed their policy formulation as well as informing their practise models and service provision. Two significant examples of achieving this have been the Quarterly reports and the Your Shout form. These monitoring tools and instruments have enabled the project to remain flexible in its approach, and adapt its programmes and activities as and when required to do so. It is important to mention that that the young people have been involved in the informal project evaluations that have previously taken place.

National Policy framework

The IOWYCP has demonstrated a knowledge and understanding of the importance of national frameworks, and the way in which these frameworks and policy initiatives impact upon their work with young carers, on the Isle of Wight. They have constantly linked these national initiatives and government drives to their own aims and intended targets. This has presented evidence of not working in a vacuum, but within a wider children and families context of policy makers and service provider networks. I have been particularly impressed by the way in which the project has, for example, responded to the Every Child Matters DOH document and standards for practise. This has permeated all aspects of their more recent work delivered by the IOWYCP, as well as forming a critical part of this evaluation strategy.

Multi-agency collaboration

An extension from national frameworks discussion (above) has been the successful way in which the project has identified, built, and nurtured positive and effective working relationships with other service providers on the Island. This significant achievement has been the multi-agency collaboration and partnership working the project has developed with statutory and voluntary

agencies. The IOWYCP also embraces the fact that partners are critical to the sustainability and growth of the project.

8. RECOMMENDATIONS FOR POLICY AND PRACTISE

It is important that this discussion is viewed in two distinct, yet interlinked ways, namely:

- Recommendations which are provided as new suggestions for future planning and development, and
- Recommendations that build and expand upon the work that is currently being implemented by the project. These recommendations are provided as a validation of the success of various existing programmes and activities, and the proposed intention is to maintain and sustain these areas of work as the projects priorities.

Thus, based on the findings from this evaluation study, the evaluator proposes the following recommendations for the development of service provision and policy formulation for this population of young carers on the Isle of Wight.

Mentoring

The IOWYCP presently offers young carers a befriending service, if required. Young carers identify on the Shout form if they would prefer a befriending service or a group activity. The majority of young people opt for the group activities. This recommendation refers specifically to the “value added” service of a mentor (which could be provided as an additional service of befriending). Presently there are no mentoring services for young people aged 7 – 11. This is an increasing problem area because there are an increasing number of young carers who fall within the age range 7 – 11. At present Youth Service and Connexions only provide a mentor for young people who are 13 years or older.

Action steps: (a) the project could find alternative providers for mentoring services, for example: the NCH Action for Children or the Children’s Society; b) the project could build in financial resources dedicated specifically to facilitating a mentoring system for the 7 to 11 year old age range; (c) the Early Years Partnership, whose specific remit is to target children and young people under the age of 12, could be approached in offering mentoring service to the IOWYCP (d) young carers who have left the project, as they have turned

eighteen, may be willing to serve as mentor for a young carer who has recently joined the project.

Schools

Given that significant progress has been made by the IOWYCP in terms of multi-agency partnership working with Children's (Social) Services and a variety of other agencies, it is important that the project also continues with its priority on achieving the same results within schools and the local education authorities. The project coordinator expressed how supportive the Healthy Schools Project has been of the IOWYCP, and the fact that the project coordinator is invited to their meetings. The PC has also commented on the fact that almost every Middle School and High School on the Island has allowed a member of their staff to attend the IOWYCP 2-day training workshops. While the project has received referrals from schools, the comments provided by many of the young carers in the focus groups suggest that there is still work to be done in terms of raising teachers awareness and understanding of their roles as young carers. School referrals could play a key role in young carer identification; when considering that young carers spend a significant part of the day within the school context. Raising teacher awareness and placing the needs and experiences of young carers on the Island's educational agenda could be a step towards addressing this issue.

Action steps: (a) to continue to access as many schools as possible within the Isle of Wight, 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 could continue to recognise and promote the value of young carers work in all of its schools; (c) an initial awareness/knowledge base questionnaire (to assess baseline understanding of young carers responsibilities), as well as a follow-up questionnaire could be distributed to all the schools in order to ascertain the impact that the awareness raising strategies has had in various school settings.

Social Services Assessment Form

This refers to the 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 forms, 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. In this regard, the PC explained that they are now moving toward the JAF form to be used alongside Your Shout.

GP referrals

Throughout the last five years of the project there have been very low referral rates from GPs and community nurses. Urgent attention needs to be given to ensuring that GPs are adequately informed about young carer identification and how to refer to the IOWYCP.

Action step: the project workers could continue to embark upon comprehensive awareness raising campaigns within these settings, as well as developing a monitoring and recording system for GPs, community nurses and the PCT's.

Partners and Volunteers

Partner voluntary organisations have played a significant role in the project. However, it is important to maintain the momentum of procuring additional partners and volunteers. There is an ongoing need for the project to capitalise on the role of volunteers. Thus far, volunteers have proven to be a significant factor in the positive experience that young carers have had with the project. Strategies need to be put in place that addresses both the recruitment and training of volunteers. This issue becomes even more critical when considering the significant increase in young carer referrals to the project over the last five years. For health and safety reasons it is essential that an adequate adult/child ratio is maintained on fieldtrips and residential outings.

Action step: to continue to raise awareness about the IOWYCP among the voluntary sector on the Isle of Wight, with a view to increasing the partnerships and a broader volunteer base.

Mental Health Support

There is a significant need among these young people in terms of accessing information and knowledge around living with parents who have a mental illness or have issues around substance misuse. While it is not expected that the project provide this service, it is necessary to link with specialist organisations in the Isle of Wight, who can provide this level of expert information for the young carers. In this regard the IOWYCP has always had strong links with CAMHS and the Youth Trust. However, the evaluator offers other alternatives that may be explored in order to address mental health support issues for the projects young carers.

Action step: visit all the District Mental Health Teams around the Island 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. This may also serve to continue raising awareness in the mental health/community services sector on the Island.

Increasing communication

Increasing communication regarding the project as well as increasing access to services could be addressed in future planning.

Action steps: (a) continue with the newsletter and send 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.

One to one Contact

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 groups, they understand that it is impossible for the project coordinator 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 (s).

Action step: the project needs to be granted more resources (human and financial), for example: the appointment of youth workers, outreach 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.

Awareness Raising

In spite of all the work that the project coordinator has conducted, there still appears to be a lack of understanding amongst some professionals working with young people in the Isle of Wight regarding “**What is a young carer?**” While this has been one of the projects priorities since its inception, it is important that this works continues. It would appear from this evaluation that there are still pockets of professionals and agencies who are not aware, or who have not made the effort to raise their awareness regarding the needs and everyday life experiences of young carers.

Action steps: (a) for the project coordinator to attend professional conferences in order to raise the profile of the IOWYCP; (b) to continue to raise awareness regarding the role of young carers.

Organisational Constraints

In reviewing the project status over the last five years, it appears that there have been certain organisational restraints and constraints placed on the project. This report has provided evidence regarding the difference an additional support/development worker makes in the planning and delivery of the project’s services e.g. in recruiting and training volunteers, consultation with young carers, record keeping, etc. The appointment of a community/outreach worker may enable the IOWYCP to grow and meet the needs of young carers living in geographically isolated areas of the county. It would be worthwhile assessing the impact that just one additional staff member can make in a project of this nature. It is recommended that the project be financially able to procure and appoint at least two additional staff, in the subsequent funding cycle. Given the office constraints placed on the Project in its present locality, it would perhaps be more advisable to look at appointing part-time workers (or job share alternatives). Without this increase in staff to young carer ratio, these recommendations will be impossible to implement. Over the last five years, this project has demonstrated a

significant increase in referrals and thus an increase in demand for service provision to meet the needs of these young people. Lack of additional staff would result in a reduction in one to one contact with the young carers, as well as jeopardising the project's ability of meeting its intended outcomes and targets.

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

Action step: a) develop a rigorous financial/income generation strategy in the future. (in conjunction with the financial/management commitment from Spurgeon's and IW Children's Services - which has been a significant component of the project success over her last five years) (b) research accessing a broader base of funding opportunities (locally, nationally and internationally)

Training

Young carers, the project workers, and partner organisations could benefit from ongoing training in issues (e.g. legal issues, mental health issues, abuse and child protection, sign language, etc.) pertinent to service planning and delivery to young carers.

Action step: future-funding proposals could include specialised funding for existing and ongoing training requirements.

Monitoring and Evaluation

Monitoring and evaluation has been one of the most significant strengths and achievements of the project over the last five years. The monitoring and evaluation strategy should continually be adapted to include changes and new variables as the project grows and develops.

Action steps: a) Continue capturing data as reflected in Section 5.1 of this report (age, gender, geographical location, referral base, parental illness, length of registration), amongst many other variables which are critically important to the project b) Conduct in-depth critical case study research with a young person from each of the three age categories c) Survey studies re: KAS (knowledge, attitude and skills about young carers) of other professionals/disciplines/service sectors working with young people d) As stated previously plan for another rigorous internal evaluation in 2008/09 e) Assess and identify new baseline data for all aspects of the project i.e. adopt a monitoring strategy as the IOWYCP embarks on a new five year cycle

Reformulate project goals and aims

Given that the project has completed a full five-year cycle, and undergone a rigorous internal evaluation (2002/03) as well as an external evaluation (2006), this may well be an ideal opportunity to revisit the project goals and aims. The evaluator supports the decision to place identification of young carers and the assessment of their needs, and providing respite in response to these needs, as being the appropriate starting point for the project. It is now recommended that these aims be reformulated, reassessed and reprioritised. For example, it is clear from the evidence in this report that the initial goals of identification, referrals and assessment of need have been met, and in fact, exceeded in many instances.

Some possible ideas are:

- Volunteer recruitment
- Links to national young carers initiatives and strategies i.e. roll out the good practise which the IOWYCP has delivered over the last five years

- Twinning with another young carers project (sharing ideas, plans, and outcomes, knowledge transfer, support, good practice models, joint working etc)
- Plans for the next internal evaluation (perhaps in 2008)
- Work with 18+ young carers
- Work in identifying young carers in the more isolated areas of the Island as a priority aim

Please note that these are only provided as illustrative examples. The project coordinator, in consultation with the young carers and the project steering group, would need to make their own decisions about reformulating and reprioritising their goals and aims

Holistic work with parents

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

Dualistic care (parents and/or siblings)

As noted throughout this evaluation report, these young people engage in caring roles which are both complex and multi-layered. For example, they may be providing primary care for an ill parent, and as a result of their parent's illness will also need to provide additional care for a younger sibling. An alternative scenario may be the fact that a young carer is providing support

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

Service provision to age 18+

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

Additional respite and social activities

While the young carers on the Island have reported very positively about the respite care that is provided by the IOWYCP. It is important to look at other

ways of providing this level of support. Attending residential weekends, on an average of four or five times a year, could prove beneficial to the lives of the young carers. The evaluator appreciates that this needs to be balanced against funding constraints. While appreciation for the more coordinated activities and events is unanimously voiced in this evaluation, it seems that young carers would also appreciate the opportunity to just “hang out” with other young carers. Furthermore, numerous young carers, during the life of the project, have grown into young adulthood, and it is possible that some of them may wish to become involved in the IOWYCP as volunteers. Their experiences and insights could considerably enhance the ongoing development of the IOWYCP.

10. CONCLUSION

In reviewing the anticipated target outcomes which were established by the IOWYCP 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 80 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 the Isle of Wight.

This evaluation identified numerous project achievements. One of the projects most salient achievements is the way in which it has grown and developed throughout the last five years being evaluated (2001 to 2006). Another achievement has been the projects ability to recruit, train and maintain volunteers. Volunteers are a key component to the overall success of a project of this size and nature. The IOWYCP has been able to recruit and currently maintains 16 volunteers. In addition, the IOWYCP has provided a diverse and eclectic range of respite sessions and activity based programmes for their young carers. Another achievement is the projects ability to provide these opportunities for all three young carer age categories (6 to 11, 12 to 15, and 16 to 18).

They have achieved significant project success; in spite of staff shortages, numerous office space relocations, and a lack of long term funding, to name a few. These organisational and macro-level limitations have not deterred the IOWYCP in its programme plans, nor has it impeded it in carrying out and implementing its policies and services. The needs and wishes of their client group are constantly at the very centre of all aspects of the projects work – in planning, policy formulation, decision-making, activity proposals, staff selection, service provision, quarterly monitoring, needs identification, and programme evaluation. The fact that the IOWYCP has been able to achieve

dualistic benefits for both the young carers and their parents is a significant achievement. I have been particularly impressed by the way in which the project has, for example, responded to the Every Child Matters DOH document and standards for practise. This has permeated all aspects of their work delivered by the IOWYCP, as well as forming a critical part of this evaluation strategy. Furthermore, the project has successfully identified, built, and nurtured positive and effective working relationships with other service providers on the Island.

While the majority of referrals have come through Social Services and self/family referrals, there is evidence to suggest that the referral system may be widening. With awareness raising continuing to be at the top of the projects agenda in the years ahead, it could be anticipated that there would be an increase in referrals from existing partner agencies. Furthermore, it is hoped that there will also be an increase in identification of young carers and subsequent referrals to the IOWYCP from new partners in the statutory and voluntary sectors.

In consulting with the young carers themselves, evidence suggested that this project (with its array of services and programmes) has addressed the unique needs of a previously “invisible” population of young people in the Isle of Wight. The IOWYCP is committed to allowing the voices of young carers to be heard. 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.

It is encouraging to report that the IOWYCP has given these young people numerous opportunities to ‘escape’ their assumed adult roles and to recapture a part of their childhood. The isolation experienced by these young carers outside of their IOWYCP involvement is far reaching. This encompasses their social, educational and family environments – all key contexts in the life of a young carer. It is, however, unfortunate that so many young carers do not feel adequately understood in their school context, to the extent of needing to

'hide' why they are unable to fulfil certain tasks. This evaluation concludes that the school environment could provide much needed support and encouragement to young carers on the Island.

These young people's aspirations are still firmly enmeshed within the ever-present needs of their families. At present they express very little sense of ever being separated from these demands and caring responsibilities. They will need ongoing support in order to fully develop a sense of their own right: both as a developing adolescent and eventually as a young adult functioning in separation from the demands of his nuclear family. It is encouraging to note that the amount of time and resources invested by the IOWYCP in needs assessment has resulted in three significant outcomes: a) the project has been user and needs led, b) the project has been able to develop a clearer picture/profile of the range and diversity of needs of young carers, and c) through the process of identifying young carers, the project has been able to obtain a demographic overview of this population – in terms of gender, age, geographical locality, and referrals from partner agencies. These achievements will further contribute towards future planning and service delivery being formulated within a more informed picture of the needs as identified and articulated by the young carers.

While significant strides have been made by the IOWYCP since its inception in 2001, there are a few areas for consideration as it begins to plan for the future, namely: volunteer recruitment and training; funding and organisational constraints; increasing staff resources, work around sibling and family/holistic care, support for age 18+ young carers, increased mentorship (particularly for the young age range), increased awareness raising campaigns in schools, GP practises and other statutory and voluntary agencies, increase its referral base, mental support for the young carers, increased one to one contact, reformulation of the IOWYCP's goals and aims, increase multi-agency collaboration; and finally to increase respite care and informal social contact opportunities for their young carers.

This evaluation report concludes that the Isle of Wight Young Carers Project has made significant progress towards achieving all of its original aims and goals, and has exceeded a number of its targets. The continuous assessment of young carers' needs has also been a significant cornerstone of the overall success of the project. It is encouraging to note that this process has been conducted with constant service user feedback and consultation. The young carers are the major stakeholders and their input has been valued at every stage of the project's development. The project has been able to respond to the needs of young carers by providing one to one support services, as well as range of respite and educational opportunities. It is clear from feedback received in this evaluation that the IOWYCP provides a critical and valued service to a vulnerable group of young people. Not only has the project increased its profile in the Isle of Wight, but also perhaps more importantly, the young carers have been granted opportunities to present their experiences and insights to various audiences. This has served to both empower young carers and encouraged confidence in their abilities to advocate on behalf of their own needs and rights.

The IOWYCP is a critical and valuable service in the field of children and young people on the Isle of Wight. With long-term funding it is anticipated that the project will grow from strength to strength, and continue to meet the needs of young carers as they engage in their daily caring roles and responsibilities.

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11. BIBLIOGRAPHY

Aldridge, J. & Becker, S. (1993). Children as Carers. *Archives of Disease in Childhood*, 69, 459-462.

Aldridge, J. & Becker, S. (1988). *The National Handbook of Young Carers Projects*, Carers National Association, London.

Aldridge, J., & Becker, S. (1999). Children as carers: the impact of parental illness and disability on children's caring roles. The Association for Family Practice. *Journal of Family Therapy*, 21, 303-320.

Banks P, Cogan N, Deeley SW, Hill M, Riddell S, Tisdall, K, (2001). Seeing the Invisible Children and Young People Affected by Disability. *Disability and Society* 16(6): 797-814.

Becker S, Aldridge J, Dearden C. (1998). *Young carers and their families*. Oxford: Blackwell Science.

Becker S, Dearden C. (1998). Unknown quantity. *Community care* 7(May): 16-17.

Becker, S. (2000). Carers and Indicators of Social Exclusion, *Benefits*, 28, April/May: 1- 4.

Becker, S., Dearden, C., & Aldridge, J. (2001). Young carers in the UK: research, policy and practice. *Research, Policy and practice*.

Butler, A.H. & Astbury, G. (2004). The Caring Child: an Evaluative case study of the Cornwall Young Carers Project. *Children and Society*. Volume 19 no 5.

Butler, A.H. & Astbury, G. (2005). *A five-year evaluation of the Cornwall Young Carers Project*. Commissioned report by the Cornwall Rural Community Council.

Carers (Recognition and Services) Act of 1995 (c.12). London: The Stationery Office.

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

Caring about Carers (National Strategy for Carers). 1999. London: Department of Health.

Children Act of 1989 (c.41). London: The Stationery Office.

Children and Young People's Unit (undated). *Involving Children and Young People*. London, CYPU.

Corlyon J. (2001). *Improving Children's Health 2: An analysis of Health Improvement Programmes 2000/3*, NSPCC: London

Crabtrees, H. & Warner, L. (1999). *Too much to take on: a report on young carers and bullying*. London. Princess Royal Trust for Carers.

Curtis, K., Roberts, H., Copperman, J., Downie, A., and Liabo, K. (2004). 'How come I don't get asked no questions?' Researching 'hard to reach' children and teenagers. *Child and Family Social Work*, 9, pp 167-175.

Dearden, C., & Becker, S. (1998). *Young carers in the UK: A Profile*. Carers National Association: London

Dearden, C. & Becker, S. (1998). *Sheffield Young Carers Project: The Evaluation*. Young Carers Research Group. September 1998.

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

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

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

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

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

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

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

Edwards, L. and Hatch, B. (2003). *'Passing Time: A Report About Young People and Communities'*, Institute for Public Policy Research, London.

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

Every Child Matters: DOH (2005). Can be found at: <http://www.everychildmatters.gov.uk/aims>

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

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

Isle of Wight Statistics (2003). Can be found at: <http://www.wightchyps.org.uk>

Kirby, P. et al (undated) *Building a Culture of Participation: Research Report*, London, Department for Education and Skills.

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

Lammerink, M.P. (1994). '*People's participation and action research in community development: Experiences from Nicaragua*'. *Community Development Journal*, 29(4), 362-368.

Marshall, F. et al. (2003). '*Research Report 20: Young People in NDC Areas: Findings from Six Case Studies. New Deal For Communities: National Evaluation Main Phase*'. Neighbourhood Renewal Unit, Office of the Deputy Prime Minister.

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

Nash, V. and Christie, I. (2003). '*Making Sense of Community*'. London, Institute for Public Policy Research.

National Strategy for Neighbourhood Renewal. (2000). '*Report of Policy Action Team 12: Young People*'. The Stationary Office, London.

Office of National Statistics. (2003). Can be found at: http://www.statistics.gov.uk/census2001/pop2001/isle_of_wight_ua.asp

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

Pawson, R. and Tilley, N. (1997). *'Realistic evaluation'*. Newbury Park, Sage.

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

Rahman, A. (1993). *'People's self-development: Perspectives on participatory action research'*. London, Zed

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

Shurink, E.M. (1998). *'Participatory action research as a tool for sustainable social development and reconstruction'*, in A.S. de Vos (Ed.), *Research at grass roots* (pp. 405 –418). Pretoria, van Schaik

Spurgeons Child Care. Charitable organisation (2006). Can be found at: <http://www.spurgeonschildcare.org>

Tesch, R. (1990). *'Qualitative Research Analysis Types and Software Tools'*. Falmer Press, London.

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

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

Whyte, W.F. (1991). *'Participatory action research'*. Newbury Park, Sage

APPENDIX 1: Consent Form**ISLE OF WIGHT YOUNG CARERS PROJECT EVALUATION**

July 2006

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

The report will be used to tell people about the IOWYCP.

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

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

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

I (name)
agree to take part in the IOWYCP evaluation.

Signed:

Witnessed by (Project coordinator and loco parentis):

Signed:

I agree for my photograph to be included in the report or at conference

presentations. I understand that my name will not be included.

Signed:

Witnessed by (Project coordinator and loco parentis):

Signed:

APPENDIX 2: Focus group with Isle of Wight Young Carers

Explain about anonymity and how what they say will be reported

Demographic info:

- (a) 1st names (nicknames)
- (b) Ages
- (c) Do they live inner city or are they rurally isolated?
- (d) Siblings (and ages of siblings)
- (e) Who is/are the person/persons they care for?
- (f) How long have they been young carers (from what age)?

Understanding of their role:

- (a) Can you tell me, in your own words, what a young carer is / does?
- (b) Can you explain to me how you became a young carer?
- (c) Please give me an idea of your responsibilities on an average school day?

Compounding variables:

- (a) Can you tell me about anything you find easy about being a young carer?
- (b) What do you find difficult about being a young carer (lack of support, finances, travel, loss of childhood)?
- (c) Is there anything you hate about being a young carer? If so, what do you hate?
- (d) If you could change anything in your world right now, what things would you change?
- (e) If you compare yourself to other children the same age as you, what would you say is the same?

- (f) If you compare yourself to other children the same age as you, what would you say if different?
- (g) What would you like to say to your friends and the other children at school?
- (h) Gently explore around what happens when the young carers themselves get sick or feel down. Have any of them felt unwell for a long time, or not felt happy for a long time? Who supports them during that time? Are any of them needing support at the moment?
- (i) Do you sometimes wish that you could say something to the person or people you care for? What would you like to say (explore anger issues)?

Experience of statutory support systems:

- (a) Can you tell me about any people who give you support?
- (b) Are there any people who are supposed to support you that do not give you the support that you need?
- (c) What would you like to say to the people who are supposed to give you support?

Experience of IOWYCP:

- (a) Tell me, in your own words, what the Young Carers Project is, and what it means to you?
- (b) How did you get involved with IOWYCP?
- (c) What do you enjoy about IOWYCP?
- (d) Is there anything you would like to change about IOWYCP?

(e) What was your life like before you joined IOWYCP? Has anything changed for you since you joined IOWYCP?

Affirmation:

- Spend some time thinking about the strength that these children show in their daily lives – e.g., get them to shout out the amazing things they do that other children may not do. Have a shout spot: I AM AMAZING BECAUSE
-
- Ask them to share their aspirations for the future.
-
- Have them draw a picture of themselves:
- “What I would like people to see when they look at me”

End with cutting a big celebration cake. Each person gets to cut their own piece and as they cut their piece, they make a wish for their lives. Or we could have individual cakes with candles on. As each person blows out their candle they make a wish.

Dr Allister Butler

July 2006

Evaluation Consultant

APPENDIX 3: Interview with Project Coordinator and Development worker

The Beginning

1. What were the original goals, aims and objectives of the IOWYCP?
2. What was the original project based upon? i.e. research findings etc
3. How was the project originally funded?
4. Which partners agencies (statutory and voluntary) signed up to work in partnership with the project?
5. What was the management structure?
6. What was the staffing structure?

Project Cycle

1. Have the aims and goals of the project changed/ modified?
2. How would you evaluate the achievement of your targets/aims/objectives?
3. What are the significant achievements/ successes?
4. What are the barriers to service delivery?
5. Could you discuss the types/levels/strength and weaknesses of multi-agency collaboration and partnership working?
6. What did you, as the project coordinator, find most frustrating/ difficult?

7. What did you, as the project coordinator, find most rewarding?
8. How has the project funding changed?
9. Has your staffing structure changed? If so, how?
10. Has your management structure changed? If so, how?
11. What types of services do you provide (for the young carers)?
12. Could you explain your strategies for user/carers involvement and consultation i.e. how were the young carers involved in the planning and delivery of services?
13. Does your work only focus on the young carers, or were you able to include the parents/families of young carers?
14. Could you discuss your awareness raising and young carer identification strategies?
15. As you look ahead, what do you regard as the main priorities of the IOWYCP (structure, management, services, partnership working, funding etc)?

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APPENDIX 4: Agency Referral Form

A Young Carer is anyone under the age of 18 whose life is in some way restricted because of the need to take responsibility for the care of a person who has a long term illness, disability, mental illness or who is affected by substance use. This definition includes the emotional responsibilities taken on by some children, such as being concerned or worried about an ill/disabled person. **HOWEVER, FILLING IN THIS FORM DOES NOT GUARANTEE A SERVICE.** An assessment will be completed by the Young Carers Co-ordinator that will take into account the needs of the individual. This form should be completed with the consent of the young person and the young person's parent/carer. This referral information may be shared with the family.

Please complete in BLOCK CAPITALS and ensure ALL sections are completed
Section 1: Personal Details

Name of Young Carer: _____	Male/Female (please circle)
Address _____ _____	
Post code: _____	
Telephone No.: _____	Date of birth: _____
Ethnic origin: _____	Religion: (if applicable) _____
Name of GP: _____	
Does the child/young person give their consent to this referral?	<input type="checkbox"/> Yes No <input type="checkbox"/>
Is the child/young person currently on the child protection register?	<input type="checkbox"/> Yes No <input type="checkbox"/>

Section 2: Background details

Name of Parent/Guardian(s):	
Name of person cared for:	
Relationship to young carer:	
Nature of illness/condition/disability:	
Is there a caring responsibility for siblings also?	
Does the parent/carer give their consent to this referral?	<input type="checkbox"/> Yes No <input type="checkbox"/>

APPENDIX 5: Ward boundaries (2001 Census)

