

**THE ISLE OF WIGHT YOUNG
CARERS PROJECT:
EVALUATION REPORT**

EXECUTIVE SUMMARY

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**Written by
Dr Allister Butler**

INTRODUCTION

This document will report on an evaluation of the Isle of Wight Young Carers Project (IOWYCP). It will offer practise and policy guidelines and recommendations that could inform future planning and service delivery. 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). The IOWYCP identified the following aims 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

METHODOLOGY

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.

Demographic distribution

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.

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

Focus groups with young carers

Focus groups were conducted with three groups of young carers (from various age categories), namely: 7 to 11 yrs; 12 to 15 yrs; and 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 23 participants, 7 were female and 16 were male, and their ages ranged from 8 to 18.

Structured interviews with project workers

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, provided information pertaining to the fieldwork aspect of the project.

Interviews were audio-taped and subsequently thematically analysed by the evaluator. All of the themes were then sorted into meaningful categories.

RESULTS AND DISCUSSION

Demographic profile

Age

The age distribution of identified young carers in the IOWYCP fell predominantly into the 11-15 year age range (56%, n=45). 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.

Gender

The gender of the 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.

Geographical locality

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 relates more to the difficulty that the project encounters when endeavouring to identify young carers in isolated areas (due to staffing and financial constraints).

Referral systems

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 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.

Conditions of Cared for Person

The most significant illness is physical disability (42%, n=34), followed by a learning disability (34%, n=27). As articulated throughout the focus group interviews, 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. 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).

Length of registration with the project

In reviewing the data it is evident that the young carers maintained their involvement in the project over a significant period of time. 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.

Young carers' perspectives

Complex nature of caring

7 to 11 years: 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.

These range from epilepsy, degenerative illness, to a brother with downs syndrome.

12 to 15 years: 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.

16 to 18 years: In many instances, a young person in this cohort provides 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.

Caring responsibilities

7 to 11 years: 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.

12 to 15 years: 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

16 to 18 years: Young carers commented on the cyclical and repetitive nature of their caring role. They also spoke about the length of day and time commitment that they invest in these roles. Young carers commented on the impact that negative social perceptions has on their caring for their parent(s). A lack of social understanding and negative stereotyping exacerbates the functions that they perform on a daily basis. They also provided supportive evidence re: the quasi-professional roles that some young carers fulfil as part of their responsibilities, for example: young carers are required to conduct physiotherapy sessions as well as using a hoist to support their parents. Young carers also spoke about the duality of caring for both of their parents as well as trying to hold down a part time job.

Likes and dislikes of being a young carer

7 to 11 years: 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.

16 to 18 years: In terms of what they appreciated about being a young carer, numerous responses focused on the transition from adolescence to young adulthood. They commented on the way in which their attitudes have changed towards people with a disability, as a result of their caring responsibilities. Young carers felt that there is a positive impact that caring had on their personal development as young adults. Some young carers expressed their anger at the impact which public ignorance and lack of sensitivity has on their caring role.

Pharmacological management

16 to 18 years: 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. 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. 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. 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. A major concern is the lack of education and relevant information sharing regarding pharmacological management provided by the GP's. Young carers also demonstrated an "adult" appreciation of the consequences inherent in the inaccurate administration of their parents' medication.

Personal, emotional and mental health

7 to 11 years: Within the focus group young carers voiced strong feelings of being "burned out." Even when young carers receive support from their extended family they are still expected to continue with their daily caring tasks and routine. This attests 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.

12 to 15 years: 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.

16 to 18 years: 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.

School environment

7 to 11 years: Their insights 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.

12 to 15 years: 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.

Relationship with family and friends

7 to 11 years: 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.

12 to 15 years: Many of the young carers in this age cohort felt that they had lost opportunities in comparison to the lives of their peer group and friendship networks.

16 to 18 years: Young carers mentioned the difficulties they have in trying to explain their caring situation to their friends, and the fear of potential humiliation if they decided to disclose their role. There is also a sense of 'differentness' in relationship to friends.

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 young shoulders.

Service provision (external to IOWYCP)

12 to 15 years: 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.

16 to 18 years: 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. The young carers singled out Social Services for discussion. 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.

Role of the IOWYCP

7 to 11 years: Young carers in this age group voiced numerous benefits of being involved in the IOWYCP, for example: being away from the home context in an enjoyable environment. 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. Furthermore, 7 to 11 yr old young carers offered the following words in describing the ways in which they valued the IOWYCP: "*Fun, Loving, Great, Exciting, Helpful*"

12 to 15 years: 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. 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*"

16 to 18 years: 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. Young carers also valued the time out and break away from their everyday roles and tasks as young carers. 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 provided them with support and confidential counsel. "*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

7 to 11 years: Their recommendations centred on issues of more time with the project, and fun recreational activities.

12 to 15 years: Young carers in this focus group suggested varied and sometimes longer respite opportunities.

16 to 18 years: Some of their suggestions centred on extended respite opportunities and additional one to one contact with the project workers. 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. 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.

Project Coordinator and Development Worker's perspectives

a) Project coordinator (PC)

The structured interview with the Project Coordinator (PC) aimed to elucidate information regarding the various aspects of the IOWYCP. 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.

The IOWYCP services have been provided in partnership with the full range of social, health and community services on the Isle of Wight. A variety of methods were used for building partnerships. These included meetings with individuals and groups, presentations to meetings, conference attendance and presentations, participation in 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.

The projects quarterly reports have provided 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 influencing service delivery to the Island's young carers. 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.

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. 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. 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.

The PC identified the following areas of success/achievement:

Newsletter

Volunteer Training

Young Carers Festival

Schools Work; Awareness raising through IW schools about children and young people with caring responsibilities.

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 IOWYCP.

The PC identified unstable funding as a key barrier to service delivery. The project coordinator 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 issue of volunteers leading outings was also raised. The fact that volunteers are unable to lead trips puts pressure on project staff to lead trips – which are usually carried out voluntarily. The PC provided numerous aspects of the job which she found rewarding, namely: benefits to the young carers, role of the volunteers, working relationship with local authorities, Spurgeons and funders, as well as the network aspects of partnership working and multi-agency collaboration, to name a few.

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

The PC provided a commentary as to the "way forward."

- 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

b) Development worker (DW)

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. The DW explained that the project aims to provide activities and respite opportunities that are cultural, physical, and educational. The DW also described how the project sought the young carers feedback when looking to book trips. He described how the children and young people's ideas were discussed with the volunteers through a volunteer planning meeting. The IOWYCP began to run weekly club nights in a response to some of the young carers requesting that they have the opportunity to meet on a more regular basis. The new clubs also helped the project fully embrace the tenets of the Every Child Matters Agenda (ECM).

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 project coordinator, into meaningful thematic categories. This evaluative feedback from the parents was gathered by the project coordinator 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.

Impact of caring role on young carers

Parents were acutely aware of the pressures placed on their children in their role as young carers, and the impact of this role on their daily lives and socialisation processes. They recognised that their children's social activities were restricted. They also expressed concern about the impact of the young carer role on their children's self-esteem and sense of self.

Perspectives regarding IOWYCP

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, for example: parents felt that their children's confidence had been enhanced through involvement with IOWYCP, their children had been given the opportunity to mix with children who have similar life experiences, their children were given the opportunity to relax and be themselves, parents appreciated the mentoring, advocacy and volunteer aspects of the project, and knowing that their children are being given support in their role of young carers has helped to alleviate parental pressure.

Suggestions for the future development of IOWYCP

Their suggestions focussed predominantly on group activities and individual support. They felt that more opportunities should be provided for outings. 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.

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 project coordinator and project workers 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 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, for example the Summer Outings and the Club Nights. The PC and 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 when they attend the club nights, call to the newsletter (in which they can offer ideas and suggestions for future activities) ,and written reports on each child's activities and respite opportunities.

Links to Every Child Matters (ECM)

Evidence has been provided in support of the numerous ways the project has linked with the ECM

Be healthy

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 has built 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 IOWYCP criteria. 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. 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 and secure environment for children and young people to meet via project groups/activities. Club Night activities have also included, for example, karate (fun and safety). Other examples of the projects planning re: 'staying safe' are: ongoing guidance and training provided for staff/volunteers on how to recognise and raise child protection concerns, risk assessments be performed for all outings/activities to avoid unforeseen incidents, and ensure sufficient child: adult ratios are observed at all times.

Enjoy and achieve

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 Independent Break Scheme, which can be used by young carers (or their family) 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, and 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.

Make a positive contribution

A few examples of the projects work in this regard are: offering 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 consulting 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, and. 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 project coordinator has also identified the following areas as ways to support young carers in 'achieving economic well-being': discuss benefits and 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

PROGRESS AGAINST IDENTIFIED AIMS AND OBJECTIVES

The following strategies have been adopted by the IOWYCP in successfully achieving its identified aims and objectives.

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

Formal and Informal Assessment
 Continuous Assessment
 Data Capturing
 Monitoring and Evaluation

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

Statutory and Voluntary sector involvement
 Signposting

Good referral base
 Response to isolation
 Every Child Matters
 Providing respite sessions
 Club Nights
 Attending National Young Carers conference
 Volunteer recruitment and ongoing training
 Diverse service provision

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
 Young carers training
 Newsletter
 Publicity events
 Record the unmet need and report this to the Steering Group
 Record reasons for discharge
 Data Collection
 Report writing and reviews with stakeholders and funders
 Good quality assurance/accountability

PROJECT ACHIEVEMENTS

Steady Growth: One of the projects most salient achievements is the way in which it has grown and developed throughout the last five years. The IOWYCP has increased its number of registered young carers with the project from 30 in 2001/2002, to 80 in 2005/2006.

Volunteers: 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.

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).

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.

Working within constraints: 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.

Service user consultation: 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.

Monitoring and evaluation: 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.

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 linked these national initiatives and government drives to their own aims and intended targets.

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.

RECOMMENDATIONS

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

Action steps: 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). (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 a mentor for a young carer who has recently joined the project.

Schools

Action steps: (a) to continue to access as many school 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

Action step: Social Services need to be more flexible and ensure that their assessment form, and any forms relating to young carers, are not just generic forms but they are sensitive to the needs of young carers. Ideally revisiting this form should be completed in consultation with the project worker and the young carers themselves. In this regard, the PC explained that they are now moving toward the JAF form to be used alongside Your Shout.

GP referrals

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

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

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

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

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

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

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

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

Monitoring and Evaluation

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

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

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. The IOWYCP roles of signposting and advocacy are important, as they not only link families with valuable support but ensure that the voices of young carers are heard in this regard. It is encouraging that inter-professional collaboration including the role of young carers is beginning to enhance the well being of family systems. 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 that 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+

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. 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

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.

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 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. 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. 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.