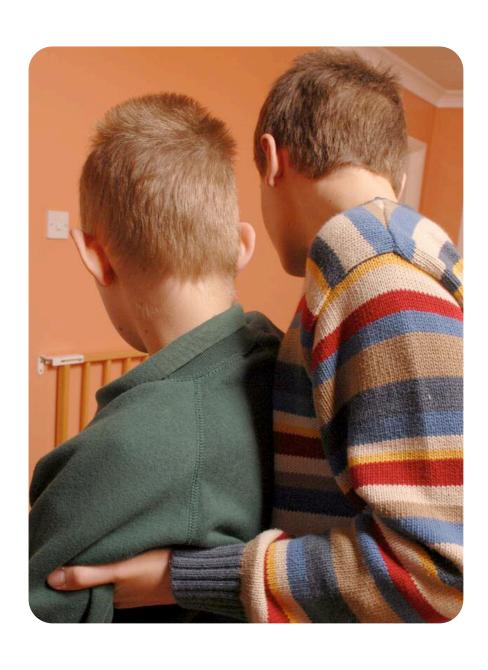


T 0 0 L K Supporting Young
Carers with Special
Educational Needs:
'Time-Out' Project
for Young People
who Need Time to
be Themselves



Executive Summary



Three years ago, Crossroads Care Richmond and Kingston upon Thames received funding from *Comic Relief/Princess Royal Trust for Carers* to explore the early identification of young carers with special educational needs, in order to support them and give them 'time-out'.

Building on our existing provision of *Saturday Clubs* for children with special needs, enabled us to refine our practice, collaborate with a range of professionals and develop a toolkit to demonstrate the process.

We believe that the information and learning incorporated within this toolkit, provides an invaluable resource to those organisations or groups with an interest in young carers, especially those young carers with special educational needs.

The pack details the learning journey of those involved, key messages, questionnaires, monitoring and referral templates to help develop a similar project and build and improve upon our experience.

Schools, local authorities, local charities, or any other organisations interested and involved with children and young people, may wish to use this toolkit to support young carers with special needs.

It is our hope that other organisations considering similar work will be able to use our experience and help such vulnerable groups enjoy time out from their caring role.

Eleanor Willett, Chief Executive Officer

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The Organisation: Richmond and Kingston upon Thames Crossroads

Our Vision:
Crossroads Care
wants every carer
to be recognised,
supported and
offered services to
help them maintain
their own health
and well-being

Crossroads Care Richmond and Kingston upon Thames is affiliated to the national network of Crossroads Association and was established in 1987. We are the leading local provider of support for carers and the people they care for.

We work with carers and their families, helping them make a life of their own outside caring. We provide the special quality of care that gives them the peace of mind to let someone else step into their shoes.

Our core service is home-based respite support: our skilled and dedicated staff take over the role of caring for a few hours whilst the carer takes a break. Our community-based projects include two *Saturday Clubs* for children with special needs, giving parent carers some weekend respite and, in partnership with the Alzheimer's Society South West Branch, *The Caring Café* for people affected by dementia.

We play a key role in the local voluntary sector and, together with Richmond Carers Centre, are the Key Strategic Organisation for carers, representing them and taking forward issues to inform the local Carers Strategy, the statutory sector and stakeholders.

Through working with carers, we are able to respond to their needs and the 'Time-Out' Project is an example of identifying and addressing such a need.

Crossroads Care Richmond and Kingston upon Thames is an organisation that constantly seeks innovative ways to support carers and the people they care for.

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September 2011

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The 'Time-Out' Project would not have been possible without the funding received from Comic Relief /The Princess Royal Trust for Carers which made this ground-breaking initiative possible. We would like to acknowledge the dedication and expertise of several individuals. First and foremost we extend our gratitude to the CEO Eleanor Willett for her guidance and leadership throughout the initiative. We would also like to thank Julie Da Costa, our Children's Services Manager, for her enthusiasm and dedication, as well as Val Wisdom, our Project Administrator/ School Liaison Officer, Naomi Benson, the Club Leader, and all the staff for their commitment to the project and to the children. Our special thanks to Chris Stewart, SEN Consultant, for imparting her expertise and assisting the project team support these young carers. We also extend thanks to the members of the Steering Committee who have helped guide us throughout. Last but not least, our thanks to Monica Hartwell, our Fundraiser, who helped capture the needs of young carers in developing a successful funding application.

Am Schanerman

Ann Schauerman, Chair of the Board of Trustees.

Central Project Team

Julie Da Costa

Children's Services Manager

Crossroads Care Richmond and Kingston upon Thames

Christine Stewart

SEN Consultant/Practitioner

Eleanor Willett

C.E.O Crossroads Care Richmond and Kingston upon Thames

Valerie Wisdom

Young Carers Project Administrator and School Liaison Officer

Crossroads Care Richmond and Kingston upon Thames

Steering Committee

Mark Gilbert

C.E.O The Three Wings Trust

Velia Hartland

Head of Services, Traveller Education Services, LBRuT

Linda Joyce

Carers Support - Team Leader and Young Carers Schools

Liaison - Richmond Carers Centre

Michelle Lane

Family Support Worker - Clarendon School, Hampton

Annie Marson

Psychotherapist - Clarendon School, Hampton

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Background to the project

IDENTIFYING YOUNG CARERS WITH SPECIAL EDUCATIONAL NEEDS

Crossroads Care Richmond and Kingston upon Thames has been running *Saturday Clubs* for children between the ages of 8 – 16 years old since 2002. These Clubs have been funded through the local authority Grants Programme, The Children's Fund as well as other grants and donations. The children attending these clubs have a wide range of needs: learning disabilities, behavioural and/or emotional issues or are socially isolated. Some have families with drug and alcohol abuse or are asylum seekers. Other children are themselves the subject of a Child Protection Plan.

Through working alongside Special Educational Needs Coordinators (SENCOs), class teachers and social workers, we have been able to develop and establish strong referral sources and it has, therefore, been possible to ensure that those parent(s) and children from the most 'hard to reach' communities, and those most in need, benefit. The main criterion for referral is either a Statement of Special Education Needs or the fact that the situation has been brought to the attention of the school nurse, Headteacher or SENCO. The principal aims of the Clubs have been to provide families with a respite break and, at the same time, provide a safe place in which the children can socialise through a variety of activities.

The Saturday Clubs, which run for two and a half hours, are located in identified areas of pockets of depravation that exist within Barnes and Hampton in the London Borough of Richmond upon Thames. The clubs are housed in buildings that have been deemed suitable for youth activities to take place.

Both clubs are staffed by a Club Leader, a deputy Club Leader, two care-support workers and volunteers. The clubs are overseen by the CEO and the Children's Services Manager from Crossroads Care Richmond and Kingston upon Thames. A staff/child ratio of 1:5 is maintained at both clubs.

What defines a young person with special educational needs?

For the purpose of this Toolkit, it was felt important that the definition of a young person with special educational needs should be explored before considering how this impacts on their caring role or situation; how this manifests and ultimately, how the young carer expresses and internalises his or her role. Moreover, how these young people differ from young carers without special educational needs.

The Special Educational Needs Code of Practice, ¹ published by the Department for Children, Schools and Families, states that:

"Children have special educational needs if they have a learning difficulty which calls for special educational provision to be made for them.

Children have a learning difficulty if they:

- (a) have a significantly greater difficulty in learning than the majority of children of the same age; or
- (b) have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority
- (c) are under compulsory school age and fall within the definition at (a) or (b) above or would so do if special educational provision was not made for them.

Children must not be considered as having a learning difficulty solely because the language or form of language of their home is different from the language in which they will be taught."

A young person with a statement of Special Educational Needs would have an intellectual or cognitive impairment, social or adaptive dysfunction or physical dysfunction that affects their learning or life capabilities. They would be regarded as having a barrier to learning.



Throughout the project, we have encountered a wide range of conditions and arising issues that may lead to special educational provision being made. The following list is included in order to highlight that range:

Mild to severe learning difficulties: these could range from poor literacy and numeracy skills, dyslexia, dyspraxia, speech and language delay.

Autism, emotional and/or behavioural issues: children on the autistic spectrum including Asperger's Syndrome, ADHD (Attention Deficit Hyperactive Disorder), challenging behaviour as a reaction to traumatic life events/environments present and past, Obsessive Compulsive behaviours.

Global development delay: this includes delayed speech and language, poor fine and gross motor skills, poor co-ordination, which could include mobility issues, poor concentration, weak auditory memory, poor eyesight or hearing.

Downs Syndrome
Cerebral Palsy
Epilepsy
Prader-Willis Syndrome
Hemiparesis
Dravet Syndrome
Sotis Syndrome
Cornelia de Lange Syndrome

What defines a young carer?

Over the years, the monitoring and observations undertaken by the staff, revealed that some of the children were demonstrating signs of also being 'young carers'. This was reinforced by the weekly communication reports from the staff.

Some of the children were exhibiting unusual levels of anxiety, withdrawal, low self-esteem, extreme tiredness, an over-concern with time and parent(s) and/or siblings' whereabouts; an inability to interact with other children at the club or an inability to 'play' or engage socially or to communicate with others adults in an age-appropriate manner and a pre-occupation with adult responsibilities.

The Children's Society Young Carers Initiative² has produced the following useful criteria for identifying young carers:

"'Young carers are children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility, which would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision."

While most children and young people help parents to some degree, some may be taking on caring responsibilities that are inappropriate for a child and that have a negative impact on their own well being.

The 2001 census found 175,000 young carers in the UK. Many of these will have significant unmet needs.

The key to change is the development of a whole family approach to needs led assessments, to ensure that service provision is child focused and family orientated."

² The Children's Society - *Include Project. Information for Health Care Professionals: supporting young carers and their families*, p2
³ Backer S (2000) 'Young Carers' in Davis M (ed). The Blackwell

³ Becker S (2000) 'Young Carers' in Davis M (ed). *The Blackwell Encyclopedia of Social Work*, Blackwell Publishers Ltd, p378



Young carers have to undertake a variety of tasks and the Include Project have identified a wide range:

- "Household chores including washing, cooking and cleaning on behalf of the whole family.
- Personal/Nursing care such as giving medication, changing dressings, assisting with mobility.
- Intimate care washing, dressing and assisting with toilet requirements.
- Emotional support monitoring and meeting the emotional needs of the person.
- Childcare helping to care for younger siblings, including escorting to school, in addition to other caring tasks.
- Other tasks household administration such as paying bills. Accompanying the cared-for person to hospital.
 Acting as a translator for non-speaking sensory impaired, or those whose first language is not English." 4

The Include Project also identified a variety of reasons as to why young people take on levels of care that are deemed inappropriate for their age:

"It may be because of:

- The structure of the family itself and the level of care needs.
- The nature of the illness or disability including speed of onset, its acceptability or whether it is an episodic illness.
- A lack of effective services from outside the family, if the person does not meet eligibility criteria or the services are inflexible."

The effects of being a young carer

In order to be able to establish the full picture of the effects on the young carer with learning disabilities, it is necessary to consider first what has already been identified as the effects on young carers without special educational needs.

To this end, The Children's Society ⁵ has produced a clear list of the effects of being a young carer.

"The following are examples of the effects on children and young people of providing care:

- Problems at school, with completing school work and participating in activities;
- Isolation from other children of the same age and from other family members;
- Lack of time for play, sport or leisure activities;
- Conflict between the needs of the person they are helping and their own needs leading to feelings of guilt and resentment;
- Feeling that there is nobody there for them, that professionals do not listen to them and are working only with the adult;
- Lack of recognition praise or respect for their contribution;
- Feeling that they are different from other children and are unable to be part of the group;
- Feeling that no one else understands his or her experience;
- Problems moving into adulthood, especially with finding work, their own home and establishing relationships." ⁶

⁶ Caring about Carers. DH 1999

⁵ The Children's Society - Include Project. *Information for Health Care Professionals: supporting young carers and their families*, p2

What defines a young carer with special educational needs?

Through observations, monitoring and recording at the *Saturday Clubs*, since the beginning of the *'Time-Out' project*, we have been able to compile examples of the generic signs exhibited by young carers with special educational needs.

Young Carer

- Tiredness/lethargy
- Back problems, general patterns of being unwell
- Poor physical appearance
- Anxiety
- Low self esteem
- Low self confidence
- Lack of motivation
- Late/ non attendance at school
- Withdrawn/isolated from peers
- Limited talking/communication
- Attention seeking/ antisocial behaviour
- Overly mature and nurturing

Young Carer with Special Educational Needs

- Poor health/hygiene
- Poor coordination and motor skills
- High levels of anxiety due to physical abuse, neglect, bullying, violence
- Behavioural/emotional issues
- Low self esteem/ self confidence
- Social isolation
- Lack of friendship network and inability to engage with peers
- Communication/language/speech issues
- Cognitive difficulties
- Poor concentration
- Limited or excessive talking
- Overly concerned and worried about family backgrounds learning disabilities, drug/alcohol abuse etc

It was noted that these young carers have fewer resources to communicate and express themselves on a verbal, cognitive or emotional level whereas mainstream children have greater skills to express themselves and their feelings on a higher level. In later years, they have more opportunities to take a break from their caring situation, particularly in education and through personal development. Young carers with special educational needs often have limited choices.

"Children with special needs who are also carers share many issues with mainstream children but they have additional problems, they are often more socially isolated and find communicating their experience very difficult, consequently they are much less likely to be aware that their life is different to other children: they can be angry, guilty, sad and withdrawn or feel shame but lack the skills needed to communicate these feelings. All of these children are unique in their needs and their abilities and we must be mindful of this if we are going to help them and their families."

Annie Marson, Psychotherapist and Integrated Play Therapist Clarendon School

The effects of caring on young people with special educational needs



The measurable effects of caring on young people with special educational needs can be broken down into the following four categories:

1. Relationships and social engagement Relationships

Young carers with special educational needs develop a lack of trust in peers and adults and can be emotionally 'shut down'. Relationships with others appear overly mature or nurturing.

Social Engagement

A young carer with special educational needs will have difficulty engaging on a social level and they will appear socially withdrawn, not engaged, distant, 'locked away'. There is often a record of poor school and club attendance; poor course work due to worry, anxiety or stress; poor coping skills, often 'letting go' and not feeling responsible.

2. Physical well-being and physical activities Physical Well-being

Physical contact can be excessive or withdrawn. Low standards of hygiene, dress and presentation are also noticeable. They exhibit poor eating habits and poor knowledge and understanding of food.

Physical Activities

Problems with fine and/or gross motor skills, together with balance and coordination, can occur. These difficulties often require specialist activities and support.

3. Emotional well-being

Young carers with special educational needs generally possess low self-esteem, low self-confidence and poor concentration.

4. Communication Behavioural Issues

They have fewer resources to communicate and express themselves on a verbal, cognitive and emotional level. It is important to provide an environment where they feel safe and secure on a regular basis.

Family Background

There is often an unsupportive or difficult family background to contend with; physical and/or emotional disabilities; dysfunctional adults; drug and/or alcohol abuse; broken family unit, living with non-family members; learning disabilities and limited parental capacity, where the parent is detached mentally and emotionally from their parental responsibilities. Young carers become overly concerned and worried about their family. In some cases there are high levels of anxiety due to physical abuse, neglect, humiliation, bullying, violence etc.

Children with parents of a limited parental capacity tend to develop or establish maladaptive or negative mechanisms to cope with their inappropriate parenting and caring roles and responsibilities. The predominant observable and measurable outcome of inappropriate caring is that of anxiety and its manifestations.

Research shows that parent(s) with limited parental capacity may have a number of issues which affect their parenting, including alcohol and drug abuse, domestic violence, learning disabilities and the inability to protect their children.⁷

What was already in place?

THE JOURNEY A WORKING MODEL PHASE ONE

Staff at the Saturday Clubs had noted and expressed concerns that certain young people were demonstrating signs of being young carers. It was felt by the Central Project Team that the current clubs had much to offer as an effective base from which to initiate the 'Time-Out' Project. With this in mind, it was important to clarify what was already in place in order to establish a comprehensive way forward. This would form an important foundation from which to build a practice that would address the issues of young carers with special educational needs.

- The Saturday Clubs with established, regular caresupport staff, experienced in working with children with special educational needs, and a group of identified young people already familiar with a range of social activities.
- A network of expertise familiar with the setting up of the clubs and with good connections established with the feeder organisations (schools) and other professionals.
- A group of nine young people with special needs, already attending the clubs, who had been identified as having the additional responsibility of caring. This meant that there was already a base from which to build upon and that staff already had experience of working with young carers with special educational needs.
- An established built-in programme which included: annual outings to Orleans House Gallery and other local venues and events, trips to Richmond Theatre.
- Weekly sessional activities including: football skills (led by a Brentford FC coach), dance, Arts and Crafts, computer, healthy eating and cooking sessions.

Step One - Setting up the 'Time-out' Project



In order that the project could move forward in a way that was productive and ensured that the aims and objectives were met, the following actions were taken:

- a steering group was created to ensure quality control and generally oversee the project,
- a series of meetings were set up to formulate the foundations of the project and establish best practice for the first phase,
- young carers within the clubs were identified and those previously identified within the clubs but who had left, due to reaching the club age limit of 16 yrs old, were offered further support within the 'Time-Out' community-based project,
- access to our existing Saturday Clubs for children with special educational needs would be provided, in order to reduce social isolation and increase emotional well-being for the young carer with special educational needs, thus giving them a sense of inclusion into wider community activities.
- staff were appointed to run the project through the two established clubs; their main role would be to identify young carers, risk-assess, take referrals and then establish a programme of activities,
- the project would be developed through activities, thus tailoring the project to the individual needs of each young carer

The committee members were specifically chosen for their ability and expertise in working with vulnerable children. Some of whom, not only had direct involvement with the children who attended the clubs but were also integral to the referral process

The Aims and Objectives of the Project

The aims and objectives of the project had been established earlier on at the funding application stage and it was envisaged that these aims would address the needs of those identified young carers through a range of strategies.

It was then necessary to appoint a central team who would be responsible for developing strategies to meet the aims and objectives of the project; strategies which would provide support for these young people who care for others and have responsibilities that do not allow them the freedom or time to have a substantial 'childhood' experience.

Aims	Objectives
To identify and reduce the extent of inappropriate or harmful caring responsibilities taken on by children.	 Identify the generic signs most indicative of caring responsibilities being taken on by a child/young person with special needs. Refine this evidence base to reflect different manifestation by children with differing special needs, i.e. their level of learning difficulty, physical mobility, sensory limitations etc.
To produce positive outcomes for the child/young person. This aim may be narrowed by defining the area of life in which positive outcomes will be achieved, e.g. the child's health, well-being, education etc.	Identify and capture a series of 'best practice' responses that allow each special needs child to 'let go' of their caring, confident that others will take over; in particular working directly with their family, social services, school and other agencies to provide reliable and trusted practical alternatives, as well as emotional support.
To produce useful learning resources for other organisations considering similar work.	Produce a 'fit-for-purpose' model of best practice in identifying and working with young carers with special needs, based on the Richmond experience and able to be applied across the UK.

Developing a model of good practice

Facilitating selfesteem and worth through....

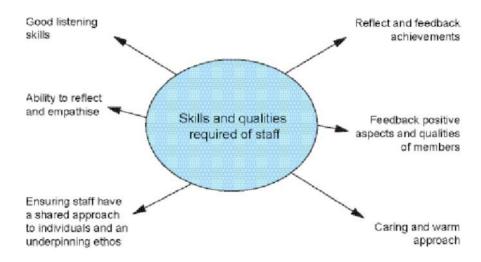


At the start of the project, it was agreed that the provision of a time and a place 'to be' would be central to its ethos. A holistic approach would be taken in order to provide opportunities for the young people to develop self-esteem and ways of expressing their needs. They would be given a place in which to experience joy and pleasure away from their 'caring environment'. The ethos would be reflected in the way the young people are related to, the environment in which they would be based and in the activities they would be offered. These would be the three main areas by which the ethos could be communicated.

These aspects are considered to be central to the model of good practice. However, alongside this is a keen eye and ear to meeting additional needs. For example, the environment must be sensitive to the needs of users who are physically and cognitively challenged. Issues such as the use of pictorial signs for 'wheel chair-friendly', must be considered. The term 'alongside' is used because our users are young people who are in a position of care but happen to have extra challenges physically, cognitively or the social challenges that a variety of syndromes related to the Autistic Spectrum may present.

It is an important part of our approach that we avoid using a deficit model and that the young people are seen as people first. It is for us to be sensitive to their challenges and for us to respond to and

1. Quality of Relationships



When developing self-esteem and feelings of self-worth, an effective method is through exploring the ways in which a young person is 'seen'. One way to help the young person understand how he or she can be seen positively is through the quality of the relationships which that person has. By being listened to and having those thoughts and feelings fed back in a positive way, feelings of worth or value can be built. The Central Project Team considered it essential to focus on the quality of the relationship between staff and young people: that it be one which promotes worth and self esteem. Also, that the skills are teased out in a way that shows the staff they are real and purposeful skills that can be learned.

Many of the useful strategies, qualities and skills that foster good self-esteem and work have come from the theories of Carl Rogers⁸ and his person-centred approach. Following on are some examples of the skills developed by Rogers that enable people to develop self-esteem and self-awareness.

Attentive listening

The practice of attentive listening has been proven to produce a greater sense of self-value and worth. The skills of listening attentively, reflecting the mood and the content of what a person is saying and empathising, is a proven method of encouraging self esteem.

Reflecting achievements and positive regard

Rogers felt that it was essential for the listener to view the person who is being listened to in a positive light, with warmth and in a non-judgemental way. In order to foster trust and self-worth, it is fundamental that this takes place.

⁸ Rogers, Carl. (1951). Client-centered Therapy: Its Current Practice, Implications and Theory. London: Constable. ISBN 1-84119-840-4. Rogers, Carl. (1969). Freedom to Learn: A View of What Education Might Become. (1st ed.) Columbus, Ohio: Charles Merill Rogers, Carl. (1980). A Way of Being. Boston: Houghton Mifflin

2. Activities



"To discover 'ways of experiencing joy and pleasure away from the caring environment'."

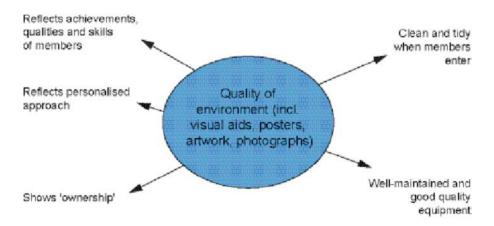
Activities were considered essential to the project in order to ensure that the young person is able to find ways of 'escaping the caring situation' and find ways of discovering themselves and their preferences. It is also important to develop the skills that will enable them to participate in the activities.

Ownership and self-advocacy

One way of promoting self-worth is through empowerment. Approaches such as ownership and self -advocacy are ideas that have emerged through the disability rights movement as a way of empowering young people with special educational needs. With this in mind, it was decided that the activities would:

- be user-led and users should be encouraged to have ideas at every opportunity and reflect upon the activities that they would like to take part in throughout the project,
- encompass a personalised approach, attempting to take into account the interests of individuals as well as the group, ensuring that the project members have fun, an opportunity to enjoy levels of escapism and assume rolls other than that of 'caring',
- promote health, physical and mental well-being, thus promote future caring for oneself as opposed to caring for others.
- enable participants to achieve physically, creatively and mentally, thus promoting self-esteem,
- allow participants to feel 'cared -for' as opposed to 'caring for'.

3. The Physical Environment



An element of increasing self-esteem and worth can be developed by paying attention to the physical environment: displays and work that reflect ownership, achievements and interests of the young people promote ideas of self-worth. For example, photographs of the users; reflections on the activities by users and creative work; a clean and thought-out environment, arranged in a way which is accessible; equipment that supports the challenges of the young user which also conveys caring, therefore concepts of being valued.

Step Two - Moving forward

Once the project was established, it was important that the central ethos of 'time out' was clearly identified and developed and that the aims and objectives of the club understood. This would be a process evaluated through regular meetings where feedback and ideas could be examined and discussed, initially by the Central Project Team but then presented to the Steering Committee for further discussion.

It was agreed that the Steering Committee would meet regularly, at least four times per year. The main areas of development throughout Phase One would be:

- to develop the initial approach and general ethos, setting the tone of the project,
- to implement some of the strategies and ideas that reflect the ethos.

A series of meetings were held. The first being the central team meeting to discuss the contents of the grant application, the framework of the project and the team's roles within that.

Outcomes of the initial meetings

a) The term 'carer'

One of the concerns raised at the start of this project was around the identification of the type of young person for whom this project was aimed at and the how to 'address' that young person. It was, without any doubt, a project aimed at young people with learning disabilities but the term 'carer' and the 'labelling process' was viewed as being problematic.

It was clear that the general concept of carer included this type of young person but the group felt that the fact that both the parent(s) and young person were often unaware of their roles and the dynamics of the relationship. For example, there were young people who were struggling to manage parent(s) with drug or alcohol problems and, in these situations, certainly the 'cared for' is unaware of the role of the 'carer'. To put too greater emphasis on the role could possibly set up resistance from the parent(s) or person being cared for. Therefore, necessary access to the young person to provide them with support could possibly be denied. There were families who were already very well known to Social Services and to the Child Protection Service and who had received a great deal of input so we were very conscious not to attach any form of negative labelling to any term in order that they would not retreat.



Other young children were caring for siblings in extremely large families and viewed their young caring role as essential to the family unit and a 'normal' occurrence. Labelling their role was deemed to be inappropriate on all levels.

The specialists who had most contact with the young people felt that a more 'sensitive' term could be created. It was agreed that the project was aimed at young people who, for some reason or another, were unable to spend a substantial amount of time on or for themselves. This, it was felt, resulted in a possible lack of self-awareness, self-esteem and general 'joy or pleasure' in their lives.

Therefore, the phrase 'young people who need time to be themselves' was coined. Also, a name was given to the project to underline this concept – "The 'Time-Out' Project".

b) Ways of meeting some of the aims and needs of the young people – a holistic approach

There was a strong consensus by the entire team (CPT and Steering Committee) that meeting the needs of the young people should be holistic and meaningful to the participants. A range of activities were considered, activities which proposed:

- self-esteem building developing a sense of self and self awareness,
- self-advocacy and emotional literacy,
- discovering ways of experiencing joy and pleasure away from the caring environment,
- looking at all areas of health from healthy eating to sexual health and awareness,
- expanding horizons past the care situation careers/educational opportunities and transition to adulthood.

c) Attracting young people to the project

In order to attract more young people to the project, it was agreed that they be encouraged to select themselves and that some way of advertising or providing a stimulus was needed. The team looked at a range of postcards that had already been produced by Crossroads Association aimed at supporting carers. The simple, colourful and very pictorial way the postcard conveyed the message to carers was considered to be attractive and appropriate. It was therefore decided that a similar attractive postcard be designed and produced and these would be handed out to schools and any other relevant organisations e.g. Social Services, Richmond Carers Centre.



As well as being offered the opportunity to take part in activities held in the Saturday Clubs, they would be welcome to take part in activities offered outside of the clubs, especially during the school holidays when their caring responsibilities were often at their highest.

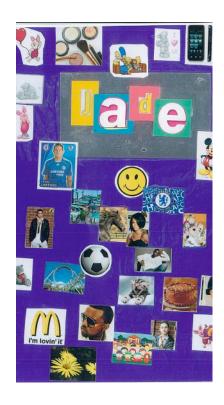
d) Focus Group - setting up a programme of user led activities

It was agreed that the activities at the heart of the project should be led by the users. The team agreed to set up a focus group with some of the young people already identified as being carers. A workshop would be structured to ascertain which activities would be suitable and bring 'joy' and a sense of self-esteem.

It was agreed that this initial workshop would have the following aims:

- to introduce the young people to the project,
- to find out the types of activities that would bring them pleasure as well as allow time away from their situation,
- to initiate the process of self-discovery and self-esteem building through a personalised activity programme approach.

Focus Group - initial workshop



The young carers were invited to spend some time with the Project Administrator and Schools Liaison Officer, Val Wisdom and Chris Stewart (S.E.N Consultant/ Practitioner). One of the feeder schools was chosen as a venue, which provided some familiar but neutral territory.

The project was introduced as a Comic Relief funded programme and that it was intended to use the funding to provide 'time out' to participate in activities that the group would enjoy and get pleasure from.

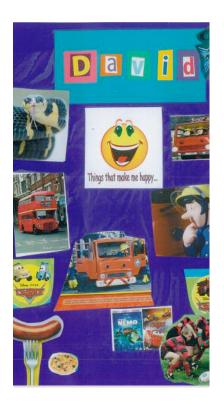
The session was devised by Chris Stewart who is an experienced practitioner of developing advocacy through social and life skills programs. Appropriate visual aids were used to help the group communicate their leisure needs. This would help to determine a programme of user-led leisure activities for the clubs to develop.

Each person in the group was asked to select a card with a category on it, such as - food, TV programme, activity and then say which was their favourite. For example, if a card with an illustration of a sport was picked then they would be asked to say which was their favourite sport; if an illustration of food was picked then their favourite food etc. At then end of the game a chart was made noting all the activities that they enjoyed.

Finally, each young person made a poster, headed with their name and listing all their favourite activities. During this time, opportunities were taken to chat to everyone on an individual basis and generally give value to their choice of ideas. Refreshment was provided during the course of the workshop

At the end of the session, each person was asked to evaluate their time at the workshop. The young people were delighted with the activities and their final results.

(A copy of the Focus Group evaluation sheet can be found in the Resources section page 40.)



The posters served as part of the physical environment, establishing a positive presence and ownership. They also served as further reference for the clubs' staff to use when relating to the young people. Knowing and acknowledging an interest that the young carer has is a good starting point for conversation and helps staff to support the development of further interests.

The list of activities arising from the Focus Group session was as follows:

Sports

Bike riding Swimming Football Cricket

Horse riding Rock climbing Badminton Tennis Rugby Rounders

Activities

Go Karting Paint balling Visit to Thorpe Park

Visit to Chessington World of

Adventures

Trips to the cinema Visits to farms Cooking/baking Going to restaurants Ten Pin Bowling

Visits to the theatre

Progression of the project

THE JOURNEY A WORKING MODEL PHASE TWO

The project started with nine young carers of varying ages. Seven of the young carers were aged between 8 -16 years (three boys and four girls) and were already attending the *Saturday Clubs*. It was explained to them that funding had become available for children who had to help out at home. They were invited to join the project and told that it would involve having some time for themselves to participate in activities which they were interested in. There was a positive reaction to this proposal.

The other two young carers were in the 16-21 age group (one male and one female). They had previously left the *Saturday Club* on reaching the age of 16 and moved into higher education. They had been identified as young carers prior to leaving the Club. Their parent(s)/guardians were contacted and told about the project and they were invited to join, along with their younger siblings who were still attending the *Saturday Club*.

Activities were mostly embedded into the *Saturday Club* timetable and were made available to all the club members. In 2010, additional funding enabled the *Saturday Clubs* to run throughout the summer months and half-term periods. Other activities were held outside of the *Saturday Clubs*, especially during the summer holiday period. These activities were set up on an ad-hoc basis specifically for the project members.

The 'Time-Out' postcard was distributed to all the local schools, Social Services and other carers' organisations within the Borough as a prompt for children with special educational needs to identify themselves as young carers. Our existing Saturday Club referal form was modified to incorporate young carers with special needs (see Resources section page 41). One of our SEN partner schools came up with a list of possible young carers. Their families were approached but some parents were negative and did not want their children to be part of the project, raising family issues as reasons why they could not attend.

The list did, however, increase the project members by six in Year 2, (5 boys aged 8-13; 1 girl aged 10) to be joined by four new members in Year 3, (2 boys aged 12-13; 2 girls aged 10-12).



PRE AND POST-INTERVENTION **QUESTIONNAIRES**

When the young carers joined the project they were asked to complete the pre-intervention questionnaire provided by Comic Relief⁹. This was found to be too complex for our project members especially due to the level of their learning difficulties. Although we were required to continue using the Comic Relief pre and postintervention questionnaires, we designed our own Crossroads pre and post-intervention questionnaires, relating it on a practical level to young carers with special needs and taking into account the level of their cognitive, emotional, attention and developmental ability. We made the questionnaire more accessible to the participants of the project and ensured the more sensitive questions were couched in a way that they would be understood and would not be too intrusive (see Resources section pages 46-57).

We discovered their likes and dislikes and what activities they were keen to participate in. As a result we were able to organize the following events:

- Ten Pin bowling,
- trips to the cinema,
- a home football match at Brentford FC,
- trips to Richmond Theatre to see the productions of Billy Elliott, Joseph and his Technicolour Dreamcoat.
- Christmas Panto to see Snow White and the Seven Dwarfs.
- golf lessons at Strawberry Hill Golf Club,
- a visit to the annual International Disability Day,
- Carnival Headdress Workshop at Orleans House Gallery in Twickenham.

DEVELOPING MONITORING SYSTEMS

From the beginning of the project, staff were noticing changes in the users. These observations were noted and then recounted at the staff review meetings which took place at the end of the sessions. In order that these observations and changes could be captured and recorded, a tracking/monitoring table was developed.

A 'traffic light' system was devised and piloted (see Resources section page 58). This system enabled staff to flag up areas that were going well; areas that carried some concern and areas for full concern.

The 'traffic light' system not only enabled staff to monitor positive developments in self-esteem and confidence but also had a dual purpose of serving as a 'safe-guarding' tool by which staff could raise real concerns around any decline in physical or emotional wellbeing.

PUTTING THE MODEL INTO PRACTICE SOME IMMEDIATE OUTCOMES

In line with our developing model of good practice, the areas focused on were physical, social and emotional well-being and communication skills.

Relationships and social engagement

Regular attendance at the weekly Saturday clubs encouraged an increase in engagement, interaction and communication. Friendships developed and the young carers became more open and trusting of adults. They were able to relate to adults and peers in an appropriate age-related manner (child-adult and child-child appropriate relationships).

"This is the first time I have made Valentine's Day cards. I have never received one but hopefully this could be my vear!" Quote from one of the boys at the club.

We noticed an increase in social activities and more interaction between children and adults. There was a noticeable decrease in anxiety, stress and worry as the young carers developed greater coping skills through support, engagement and interaction.

"I like to come to the club to hang out with my friends, play pool, football and have breakfast with everyone whilst have social time!" Quote from one of the older boys at the Barnes club.

Physical well-being and physical activities

Sports and creative activities were supported by trained and experienced staff and sessional staff. Activities included football lessons, Yoga, music, movement and dance, singing, art workshops, badminton, basketball, tennis, exploring and using sensory toys/equipment. These activities helped to developed physical stamina, coordination and fine/gross motor skills. They were also useful in developing behaviour, intervention and fitness skills.

Our young carers developed a more balanced approach to physical interaction. They appeared less withdrawn and with an established sense of boundaries which led to a reduction of inappropriate behaviour. There was a noticeable increase in awareness and knowledge of health, hygiene, safety and food issues.

Feedback from the pre and post-evaluation forms reflected an increase in knowledge and development in skills, particularly around dance and football.

However, the most noticeable reflection, from both staff and parental observations, was around the area of coordination, since many of the attending children had some degree of difficulty in fine and/or gross motor skills.

The football player Aaron, from Brentford FC, came to do his regular session with the children. All the children participated and there was a great deal of team interaction and fun to be had by all, especially **** who has severe mobility issues. *"I really enjoyed this game and now I feel really tired!"* After a short break he continued to play 'goalie' with his friends.

"Golf is really addictive, I would love to play every week with my dad!", said one young boy after playing his first round of golf with the captain of Strawberry Hill Golf Club.

Emotional well-being

The young carers were beginning to show a rise in their confidence levels in many areas: play, engagement, interaction and communication. They were able to engage in appropriate activities and social interaction for greater periods of time.

One week we hired a 'street dance' teacher to do a piece of sessional work. Everyone had so much fun learning to do street dance. At the end, the young people even performed their new found skills in "freestyle" and "Robot" dancing. "Can we do this again next week?" they all asked.

"I love coming to club as my friends from school come here! I wish I started earlier!" Quoted one girl who was recently referred after a space became available on our waiting list



Communication and Behavioural issues

Changes in general behaviour and focus are paramount at both clubs. There was a great deal of feedback from parents and staff reporting increased confidence and self- esteem levels together with greater levels of interaction and participation in activities. The older children who had been attending the club from 8 years old and are due to leave soon, have become positive role models for the younger children at the club.

The weekly social group, supported by experienced and trained staff, provided our young carers with a safe and secure environment. Within this environment there was an increase in positive behaviour, interaction, friendships, confidence, self-esteem, communication and well-being.

"****** made his parents a lovely card and was very kind to the other members, passing materials and making suggestions on how to decorate their cards! In comparison to how challenging and unpredictable his behaviour was when he first started at the club, ****** behaviour has improved immensely and he has become an absolute joy towards all the staff and his peers."

One of the class teachers reported a marked improvement in behaviour, confidence, social engagement and concentration within the class setting for one of our Project members, following attendance at the *Saturday Club* over a three month period.

Family background

As most areas of communication, engagement, concentration, interaction and well-being increased, we noticed an increase in openness. The stability of the Clubs' staff was paramount here since many of the children were from broken homes and some have many other adults passing in and out of their lives. Our young carers felt they were able to express any concerns they might have to the adult staff, as a direct result of this stability. Through play, interaction, support and communication, they began to develop coping mechanisms and skills.

REFLECTIONS

The success of the 'Time-Out' Project, providing such strong, positive outcomes, was undoubtedly due to the following factors;

- An experienced, well-trained and stable staff, already working with and supporting young people with special educational needs at the *Saturday Clubs*. From observations made by the staff it became clear that there were young people with an added caring role and this proved to be the catalyst for the *'Time-Out' Project*. Staff stability was essential in gaining the confidence of this particular group of young carers.
- The existing Saturday Clubs, which were already receiving separate funding. Without this funding, an increased requirement would have been placed on both the organisation and the project and the ability of the project to meet the needs of young carers with special educational needs would have been weakened.

Throughout the project, we managed to give many children respite through the clubs and during the school holidays. We gave them the opportunity to experience activities they would not have been able to access with their families. Many of the children, when they first started coming to the clubs, were withdrawn, shy with low selfesteem and self-confidence. They found it difficult to communicate with their peers and needed much encouragement to participate in activities and events. After a short period of attending the club, they started to open up and became more trusting of their peers and staff members. They made friends and were willing to participate in all of the activities. Two of the young carers were able to reduce their caring responsibilities and join a football club where they were chosen by their club to try out for the Brentford under-14 team.

Feedback on the usefulness of the 'Traffic Light' monitoring system indicates that it is a workable and effective system for the project. Being given a set of clear areas by which to observe and monitor the young carers, it soon became clear that positive movements in confidence were taking place as a result of the set-up and the ethos of the project. Although staff were previously aware of such movements in the progress of individuals, it was nonetheless much more helpful and effective to be able to pin-point areas of development, as set out on the monitoring grid, and to keep records. A review of this system will take place at the end of the project.

Case Studies and Feedback

Young Carer P has ADHD, emotional and behavioural problems and attends a local unit for children with behavioural and emotional issues. He can be impulsive as well as physically and verbally abusive.

Young Carer P was originally referred to us from the Social Services Initial Response Team due to multiple issues at home and in the community, regarding his behaviour. We initially provided respite care on a one-to-one basis during the school holiday period when his behaviour became increasingly unmanageable. His mother suffers from severe health issues and as a single mother found the situation difficult to manage, especially at the weekends and holiday periods. We, therefore, felt he would benefit from being in a supportive environment at our *Saturday Club* and also from our *'Time-Out' Project*. A taxi service was put in place to take him to and from the club. When Young Carer P first started at the club, staff observed he was very shy and reserved and needed encouragement to participate in activities. However, our Club Manager was his care support worker when he was being supported on a one-to-one basis and her presence was a reassuring factor. The following weeks he became more confident and willing to participate and interact with his peers and staff.

Young Carer P's attendance is good and he has participated in a vast majority of the activities with enthusiasm and excitement! When asked recently to comment on how he felt about attending the club and project he replied, "This is the best Club! I look forward to coming here every week!"

We continue to support Young Carer P both at the club and on the 'Time-Out' Project.

Young Carer E attended our Saturday Club for several years until he reached the age of 16 and left school. During his time at the club he showed signs of being a carer to the point where he told staff he was helping his alcoholic mother to bed every night and could not cope. Eventually he was removed and cared for by elderly family members. Young Carer E felt completely lost when he left school and was no longer able to attend the Saturday Club due to his age. He now attends College but does not have the opportunity to enjoy activities with his peers as he has to return home to his family members who live outside the borough. We believe he has some caring responsibilities but not as high level as he had when he lived with his mother. We recently contacted Young Carer E to invite him to take part in our 'Time-Out' Project and he was extremely enthusiastic and overjoyed. His family members were also very supportive and felt that not only would this help Young Carer E immensely with his self-confidence and self-esteem but it would also provide respite for them. We are also looking to possibly train Young Carer E as a Peer Mentor for the children at the Saturday Club as his past experience was such a positive one and feel he would be a good influence.

Young Carer F has hemiplegics with cerebral palsy affecting his left side. He also has speech and language difficulties, delayed fine and gross motor skills, ADHD and epilepsy. His mother has severe learning difficulties and it has been reported that he has to help considerably at home and with general day-to-day tasks. Young Carer F was referred to us by the school family support workers as they felt he would really benefit from attending the clubs. We organised a taxi to collect him and return him home each week. He has attended the club regularly since his referral and thoroughly enjoys socialising with the other club members. We have also spoken to mum who feels she has noticed a change in young carer F where he is very excited and looks forward to going to the club each week. We arranged for Young Carer F to attend our 'Time-Out' Project where we organised a trip to the theatre to see 'Billy Elliott'. He absolutely loved the show and asked if he could see it again!! We continue to support him at the clubs and include him on activities planned for the young carers project. His caring responsibilities are now reduced due to his attendance every week and mum now has someone else to help.

Feedback from schools and specialist services

A class teacher reported a marked improvement in behaviour in the class. The pupil has been attending the club as a member of the *'Time-Out' Project* for the past three months. She is now beginning to interact with her peers and engage in class activities. There is also a marked improvement in her attentiveness and quality of school work.

"The Saturday Clubs have been a real benefit to the children, it has enabled them to access supported activities in a safe and secure environment. The Clubs have given the children the opportunity to be involved in a range of activities which they would not otherwise be able to access." (Children With Disabilities Team, London Borough of Richmond upon Thames)

"The project has been very beneficial to Young Carer and has provided a really good service, encouraging his well-being and always going out of the way to support him and his family." (Family Intervention Team, London Borough of Richmond upon Thames)

Difficulties encountered

Referral issues:

Arranging appointments with SENCO's, family support
workers and social services. The project was generally
well received by the SENCOs but due to their busy
workloads, often only working part-time, the referral
process was slow and sometimes problematic.

Labelling issues:

- Many of the children who were from large families did not perceive themselves to be young carers. This was a role which they undertook on a daily basis as being part of a large family and not unusual in the least. Some children were caring for parent(s) who themselves had special needs and disabilities. Others were from backgrounds with parental capacity issues such as drug/alcohol abuse: backgrounds where they took on a high level of emotional caring. We had to be very careful how we approached the children regarding the project, due to their background and their parent(s) being suspicious of outside services: many of whom previously had high levels of Social Services/police intervention. This could lead to them becoming 'shutdown' and not allowing the children to attend the club.
- Some parents were anxious that the label of young carer may have a detrimental effect in terms of the children being removed from the family.

Parental capacity issues:

- A lack of parental commitment resulted in an unwillingness to bring the children to the club and in some cases a taxi service was used to transport the children to and from home.
- A lack of trust in outside services also resulted in a lack of commitment and proved to be a difficulty. In some cases, this issues was resolved over time. This was due to having a stable staff with a consistent approach who were able to establish trust.
- Paradoxically, some of the young carers who become too confident and more independent were removed by their parent(s) as they might go on divulge further details or issues relating to family dynamics and this was perceived as a threat.



Acquiring information issues:

- Using questionnaires in order to acquire information from the young carers regarding their caring situation is always problematic due to the level of their learning disabilities. Many have short attention spans which meant that the questionnaires had to be completed over several sessions.
- The use of questionnaires produced by other organisations presented a difficulty. The complexity of the questionnaires proved challenging, often forcing us to revert to making the session an informal chat where certain questions were asked in order to get a greater understanding of their caring role. As a direct result, we designed our own pre and post-intervention questionnaires.

Funding issues:

 We were pleased that we were able to provide many interesting activities that the young carers expressed an interest in. However, due to limited funds we were not always able to fulfil all their requests, such as trips to Thorpe Park and Chessington World of Adventure.

Where next?

With appropriate funding, the project could progress and extend in the following directions:

- Continue to support the young carers on the project and continue to identify them within the clubs and schools.
- Build a strong referral base by reconnecting with all the schools within the LBRuT and also creating a new referral base in Kingston upon Thames.
- Develop a young carers with special educational needs project and deliver services within Kingston upon Thames.
- Develop closer contact with Social Services and other outreach services.
- One of the difficulties was getting some young carers tothe clubs because of anxiety about leaving the cared for person behind (see difficulties). The idea of allocating a member of the project team to do some outreach work and meet the needs of the young carer on a one-to-one basis would be an area that the project could develop in the future. This would aim to provide a bridging process whereby the young carer could be helped to feel less anxious about leaving the caring situation and the person being cared -or would be more trusting in the project.
- Encourage the young carer with learning disabilities to link up with national young carers organisations. One young carers organisation arranged a national conference and a mini festival for all young carers to attend. This could be explored in order that young carers with learning disabilities could participate and express their particular caring issues.
- Help young carers to cope independently within the community by providing support and links to outside services. Encourage young carers to look at career prospects and link in with local colleges and organisations such as NIACE who have recently looked at how to progress the life and career of young carers with learning difficulties.



- Set up and deliver training for current project staff and future staff. This would use the Model of Good Practice and involve training in: observation, listening and reflecting, empathising and generally relating to the young carer with learning difficulties in a way that is positive and that facilities confidence and self-worth. Include issues which relate to the well-being of the young carer with learning difficulties, e.g. safe-guarding issues and understanding of various syndromes and barriers to learning and how to support young carers with special needs.
- Organise Health workshops, such as Sexual Health for all teenager young carers, promoting sexual awareness and safety.
- Continue to evaluate and develop ways for young carers with learning difficulties to voice their situation to a wider audience.
- Explore the 'whole family' approach and develop ways whereby the club could involve the whole family in some fun activities e.g. Family Fun Day.
- Produce a 'Filo-Fax' type folder for young carers with learning difficulties with sections on health, ways to have fun etc. plus useful contacts for emergencies or any other issues that they would have difficulty with.
- Produce a reflective log for the young carer with special educational needs with tips for their future, e.g. 'how to look after yourself physically and mentally'. This would contain personalised and tailored advice for the young person and could be developed through the project.
- Encourage schools to recognise the caring role and the generic signs and refer the young carer with special educational needs to the appropriate organisation.

Concluding Statement

The 'Time-Out' Project was committed to providing a purposeful facility for young carers with special educational needs. Purposeful in that it adheres to its ethos of promoting the development of self-esteem and self-confidence, mental and physical well-being and an opportunity to start to think about the future and an adult lifestyle.

The project has served to highlight the disparity and differences between young carers and those young carers with special educational needs. It has provided the young carers involved with greater ability and more opportunities to communicate and express themselves on a verbal, cognitive and emotional level; provided them with greater mechanisms to cope with their caring roles, a reduction in anxiety and responsibilities and offered them a direct break from their caring role.

The impact of this project has been significant on both an individual and community level. It has served to identify the generic signs or indicators of what defines a young carer with special educational needs, thus promoting early identification, intervention and support. It has strengthened communication and relations with statutory and other community resources and youth provisions. It has also highlighted the need for continued improvements in referrals and identification of those "hard to reach" groups. In particular, those children with caring roles/situations from socially isolated and economically disadvantaged families/environments and parent(s) with limited parental capacity, together with having special educational needs and the accompanied communication difficulties. It specifically highlights the need for the statutory and voluntary sectors, along with schools, to liaise and work together: giving young carers with special educational needs 'Time-Out' to be themselves.

Focus Group Evaluation Sheet

Focus group evaluation sheet



How did this session go? How did it make your feel?

Did you like the game and talking about what your favourite things were? What number out of ten. Put a circle around your score.

1 2 3 4 5 6 7 8 9 10

Did you like making a poster of your favourite things? What number out of ten. Put a circle around your score.



1 5 6 7 8 9 1



Did you like thinking about what activities you were going to do and making a list?



1 2 3 4 5 6 7 8 9 10



Would you like to do more sessions where we will be talking and thinking about ourselves and what we like and do not like?

No, I would not like that. I would like to think about it

Yes, I would like to.

Referral Form

	_		nation:			
Info Received From:			Info Received By:			
Date Info Received:						
Contac	ts - Care	ers				
Forename:		Surname:				
Male:	Female:	Ethnic Origin:				
		1				
		Emergency No.				
Contac	ts - Chi	ld				
		Surname:				
Age:		Male:	Female:			
	Ethnic Orig	in:				
Disabilities						
	Contact Forename: Male: Contact Age:	Info Received Date Service: Contacts - Care Forename: Male: Female: Contacts - Chi Age: Ethnic Orig	Contacts - Carers Forename: Surname: Male: Female: Ethnic Origin: Contacts - Child Contacts - Child Surname: Age: Male: Ethnic Origin:			

Medication:							Dosage:
			•		n: -l-	•	_
	МО	ving	čκΗ	iandiing	g – Risk	Asses	sment
Child's Name:					Height:		Weight:
Risk Factor	High	Med	Low	Un-aided	Supervised	Help	Additional Information
Weight Bearing							
Walking							
Chair In							
Chair Out							
Toilet On							
Toilet Off							
Wh'chair In							
Wh'chair Out							
Co-ordination							
Motor Skills							
Additional Infor	mation -	- Mobili	ity:				

Risk	High	Med	Low	Allergies	Comme	nts
Factor						
Eating						
Drinking						
Commu	unicatio	on &	Compre		Risk Assess	ment
		Med	Low		Comments	rege.
	High		LOW			
Risk Factor:	High	27200			Comments	
Risk Factor: Listening Skills	High	Jaca			Commence	
Risk Factor: Listening Skills Hearing	High	Jaca			Commence	
Risk Factor: Listening Skills Hearing Attention Skills	High	744			Commence	
Risk Factor: Listening Skills Hearing Attention Skills Eye Sight Speech/Verbal Skills	High				Commence	

	Ве	havi	ioura	al -	Risk	Assessr	nent		
Risk Factor:	H	igh N	1ed.	Low		Addi	tional Inform	atio	on
Social Interaction:		\top	\neg						
Obsessive Behaviours	:	\top							
Physically Aggressive	:	i							
Verbally Aggressive:		\neg							
Wandering:			\neg						
		ı	Fam	ily B	ackg	round			
Child's Name:						Date of Birt	h:		Age:
Risk Factor	High	Med	Low			c	omments		
"At Risk Register"									
Siblings									
Parents									
Emotional Difficulties									
Additional Information	on-Backg	round:							

Interests & Hobbies				
Identified Young Carers – Risk Assess. Responsibility				
Additional Tasks/Duties:				
Additional Concerns/Worries:				
Additional Responsibilities:				
Additional Physical Duties:				
Communicating for others:				
Confirmation Signature:	Date:			

Pre-intervention Questionnaire



Do you know what a young carer is? Yes or No

What is your name?						
(please write in)						
Are you a girl or boy? Girl 🗆 Boy 🗆 (please tick)						
How old are you?						
(Please write your age and date of birth)						
Today's Date						
Who lives with you	ı in your house?					
(please tick all the	at apply)					
Mother	No □ Yes □					
Step mother	No □ Yes □					
Father	No □ Yes □					
Step father	No □ Yes □					
Brother/stepbrothers	No □ Yes □ if yes, how many					
Sisters/step sisters	No □ Yes □ if yes, how many					
Grandparent(s)	No □ Yes □ if yes, how many					
Other adult relative						
(aunt, uncle, cousin)	If yes, please say who this is					
Family friend	If yes, please say who this is					
Other	If yes please say who this is					

Q1 Which of these pictures shows how you feel about yourself most of the time? (only tick one)

03 No hala	family at haman Van D. NaD
WE DO YOU HEID YO	our family at home? Yes 🗆 No🗆
If so, who do you	help?
Mother/Step mother	No □ Yes □
Father/step father	No □ Yes □
Brother/stepbrothers	No □ Yes □ if yes, how many
Sisters/step sisters	No □ Yes □ if yes, how many
Grandparent(s)	No □ Yes □ if yes, how many
Other adult relative	
(aunt,uncle,cousin)	If yes, please say who this is
Family friend	f yes, please say who this is
Other	If yes, please say who this is
O3 No yeu hele wi	Conjunction and the una det
Wa no you help mi	ith any of the following?
Shopping	
Cleaning/housework	
reparing food/drink	
lifting heavy objects	
ooking after family	
Helping to wash, dress or ca	re for others
Communicate for the person	you care for
Ami athan thinas was de fan	atheres Never and whee

Q4 Do you worry about		ng at	home	≥?	
Q5 Do you ever worry	about a	ny of	the	following	?
Family Friends Neighbours Where you live? Bullying Drugs/alcohol Money Health issues Any other concerns?	The state of the s	No No No No No No No No	If Yes,	please say wi	hat
Q6 Do you have anyboworries you may have?		an to Yes		about a	
Teacher Friends Club Staff Family friend	Yes Yes Yes Yes	No 🗆 No 🗆 No 🗆			
Anuhadu elce? Plence ctate wha?					

-4

Q7 Please answer th	ne follow	ing questions				
Do you have any friends outside of school? Yes □ No □						
Do you have any friends at School? Yes □ No □						
Do you have friends at the Saturday Club? Yes □ No □						
Do you feel good about helping?		Yes 🗆 No 🗆]			
Do you feel lonely?	No.	Yes 🗆 No 🗆				
Do you feel closer to your family		Yes 🗆 No 🗆				
Do you have trouble sleeping at a	iights?	Yes □ No □				
Do you feel stressed?	V 0.	Yes □ No □				
Are you coping with the things yo	ou do at home	? Yes□ No□	1			
Q8 Which of these	things do	o you do with yo	our family in			
your spare time? (ple	ease tick)				
How Often?	A lot	Sometimes	Never			
Play Sport						
Play Computer Games						
Play Outdoors						
Dance/Sing						
Read Stories						
Art/Crafts/make things						
Talk/text on mobile phone						
Go on trips						
Go shopping						
Watch DVDs/Video						
Watch TV						
Listen to music						
Attend Clubs						

Q9 How do you consider the following?

Are you healthy?	Yes 🗆 No 🗆
Are you fit?	Yes □ No □
Do you eat well?	Yes □ No □
Do you have friends?	Yes □ No □
Are you confident?	Yes □ No □
Are you stressed?	Yes □ No □
Do you get out of the house much?	Yes 🗆 No 🗆
Do you have much energy?	Yes 🗆 No 🗆
Do you feel good about yourself?	Yes 🗆 No 🗆
Do you have good coping skills?	Yes 🗆 No 🗆
-1011 1 1 611 1 0	
Q10 Have you been the following?	
Q10 Have you been the following? Have you been a happy person?	Yes □ No □
	Yes No
Have you been a happy person?	
Have you been a happy person? Have you been full of life?	Yes □ No □
Have you been a happy person? Have you been full of life? Have you felt calm and peaceful?	Yes □ No □ Yes □ No □
Have you been a happy person? Have you been full of life? Have you felt calm and peaceful? Have you felt worn out?	Yes No Yes No Yes No
Have you been a happy person? Have you been full of life? Have you felt calm and peaceful? Have you felt worn out? Have you been a sad person?	Yes No Yes No Yes No Yes No

Tell us about the caring jobs you like the most and why?
Tell us about the caring jobs you dislike the most and why?
Please tell us what sports or activities you would like to do on the project?
Are there any places of interest you would like to visit?

Post-intervention Questionnaire



What is your name?	
(please write in)	
Are you a girl or boy? Girl	□ Boy □ (please tick)
How old are you?	
(Please write your age and date	e of birth)
Today's Date	
Who still lives wit	h you in your house?
(please tick all the	at apply)
Mother	No □ Yes □
Step mother	No □ Yes □
Father	No □ Yes □
Step father	No □ Yes □
Brother/stepbrothers	No □ Yes □ if yes, how many
Sisters/step sisters	No □ Yes □ if yes, how many
Grandparent(s)	No □ Yes □ if yes, how many
Other adult relative	
(aunt, uncle, cousin)	If yes, please say who this is
Family friend	If yes, please say who this is
Other	If yes, please say who this is

Q1 Which of these pictures shows how you feel about yourself most of the time? (only tick one)

Q2 Do you help yo	our family at home? Yes 🗆 No
If so, who do you	help?
Mother/Step mother	No □ Yes □
Father/step father	No □ Yes □
Brother/stepbrothers	No □ Yes □ if yes, how many
Sisters/step sisters	No □ Yes □ if yes, how many
Grandparent(s)	No □ Yes □ if yes, how many
Other adult relative	
(aunt, uncle, cousin)	If yes, please say who this is
Family friend	If yes, please say who this is
Other	If yes, please say who this is

Shopping

Cleaning/housework Preparing food/drink

Lifting heavy objects

Looking after family

Helping to wash, dress or care for others Communicate for the person you care for

Q4 Do you worry ab	out anyth	ning at home	?
Yes □	No □	1000	
Q5 Do you ever wor	ry about	any of the t	following?
Family	Yes	□No □	
Friends	Yes	□ No □	
Neighbours	Yes	□ No □	
Where you live?	Yes	□ No □	
Bullying	Yes	□ No □	
Drugs/alcohol	Yes	□ No □	
Money	Yes	□ No □	
Health issues	Yes	□ No □	
Any other concerns?	Yes	□ No □ If yes, p	olease say what.
Q6 Do you have anyb	andy you	can talk to a	bout any
worries you may have	:?	Yes 🗆	No 🗆
Teacher	Yes □	No □	
Friends	Yes □	No □	
Club Staff	Yes 🗆	No 🗆	
Family friend	Yes 🗆	No 🗆	
Saturday Club staff	Yes □	No 🗆	
Anybody else? Please state who?.		•	

Q7 Please answer the following questions

Do you have any friends outsid	le of school?	Yes 🗆 No	
Do you have any friends at Sc	hool?	Yes 🗆 No	
Do you have friends at the 5a	turday Club?	Yes 🗌 No	
Do you feel good about helping	7	Yes 🗆 No	
Do you feel lonely?		Yes 🗆 No	
Do you feel closer to your fam	A STATE OF THE PERSON NAMED IN COLUMN 2 IN	Yes 🗆 No	
Do you have trouble sleeping a	t nights?	Yes □ No	
Do you feel stressed?		Yes □ No	
Are you coping with the things	you do at home	? Yes □ No l	
Q8 Which of these	things do	you do with yo	ur family i
your spare time? (p	lease tick	()	
How Often?	A lot	Sometimes	Never
Play Sport			
Play Computer Games			
Play Outdoors			
Dance/Sing			
Read Stories			
Art/Crafts/make things			
Talk/text on mobile phone			
Go on trips			
Go shopping			
Watch DVDs/Video			
Watch TV			
Listen to music			
Attend Clubs			

Q9 How has the club/project helped you?

(please tick all that apply)

Turning and health?	Yes □	NI- III
Improved my health?		
Improved my fitness?	Yes 🗆	No L
Improved my diet/eating habits?	Yes □	No □
Helped me make new friends?	Yes 🗆	No 🗆
Improved my confidence?	Yes 🗆	No 🗆
Reduced my stress?	Yes 🗆	No □
Get me out of the house more?	Yes 🗆	No □
Gave me more energy?	Yes □	No 🗆
Helped me feel good about myself?	Yes □	No □
Improved my coping skills?	Yes □	No 🗆
Involved me in new activities?	Yes □	No 🗆
Provided more time for myself?	Yes □	No 🗆
Increased my skills in		
Improved my relationship with		
Q10 Since joining the club/pro	ject have	you?

Been a happy person?	Yes 🗆	No 🗆
Been full of life?	Yes 🗆	No □
Felt calm and peaceful?	Yes 🗆	No □
Felt worn out?	Yes □	No □
Been a sad person?	Yes □	No 🗆
Been a nervous person?	Yes □	No □
Had lots of energy?	Yes □	No 🗆
Felt tired?	Yes □	No □

Q11 Have you enjoyed most of the activities? (Please circle)

Yes No

Tell us about which activities you liked the most and why?
Tell us about which activities you disliked the most and why?
Please tell us what has changed for you and your caring jobs since attending the Club/Project.

Young Carers "Traffic Light" Monitoring Form

Name: Start date: ATTENDANCE: If no, WHY NOT?	Indicator	Date	Comment	Date	Comment	Date	Comment
PHYSICAL WELL-BEING & DEVELOPMENT							
General appearance?							
· Hygiene?							
• Weight?							
• Eating?							
Engagement in activities?							
Physical contact Excessive or with- drawn?							

Name: Start date:	Indicator	Date	Comment	Date	Comment	Date	Comment
Co-ordination?							
Motor skills?							
Concentration?							
RELATIONSHIPS & SOCIAL ENGAGEMENT							
 Engagement with peers? 							
 Engagement with adults? 							
Openness, Excessive or Withdrawn?							
Trusting or Untrusting?							
Distant or Engaged?							
Appropriate Engagement? Overly mature or nurturing?							

Name: Start date:	Indicator	Date	Comment	Date	Comment	Date	Comment
EMOTIONAL WELL-BEING & ESTEEM INDICATORS							
• Anxiety?							
• Self-esteem?							
Confidence levels?							
Eye contact?							
COMMUNICATION							
 Talking? - Limited, Excessive or Appropriate? 							
Attention? Pre- occupied or Engaged?							
Expressions? Closed- off or Open? - Family Life, Caring Role?							

Useful Contacts and Websites

Carers UK

www.carersuk.org

Crossroads Care

www.crossroads.org.uk

Foundation for People with Learning Disabilities

www.learningdisabilities.org.uk useful download – 'Being a Carer and having a Carer's Assessment'.

Incentive Plus

www.incentiveplus.co.uk resources to promote social, emotional and behavioural skills in children and young people.

Independent Social Workers Cooperative

www.socialworkisi.com/parenting_capacity_assessments.php

Inspired Services

www.inspiredservices.org.uk/whocaresforus.html 'Who cares for us?' is a campaign to make things better and fairer for carers with learning difficulties.

N.I.A.C.E. National Institute of Adult Continuing Education

www.niace.org.uk useful publication – 'We are carers and we want to learn'.

The Children's Society

www.childrenssociety.org.uk/youngsters

The Princess Royal Trust for Carers

www.carers.org

Transport for London

www.tfl.gov.uk/gettingaround/.../1201.aspx 'Out and about in London – my guide' – a guide for people with learning difficulties.