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Unseen and Unheard

The invisible Young Carers

*An overview and insight into the debate about
Children with Caring Responsibilities - Young Carers.
Based on the work of the
Carers Lewisham
Young Carers Schools Development Project*

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Quotes given in this report by Young Carers with whom Carers Lewisham's Young Carers Schools Development Project worked, are printed with their permission, however all names have been changed to protect their identities.

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Key Recommendations

What do you do as a Young Carer for your mother?

"I help her get her medicines and try to calm her down when she's mental"

The need for:

1. ALL Agencies and Policy Makers to agree once and for all that Young Carers **do** exist.
2. Agencies and Policy Makers to come up with a clear agreed definition of a "Young Carer" that can be used by everyone working with and supporting children who care and their families.
3. Government and Policy Makers to take another look at the legislation relating to supporting families where there are children with caring responsibilities.
4. The appropriate Agencies to identify Young Carers at the earliest possible stage, for example at the discharge from hospital of the cared for person.
5. The recognition of the importance of assessing the impact of caring on Young Carers.
6. The provision of services and support to THE WHOLE FAMILY, to enable, where possible, the parent to be a parent and to minimise the impact of caring on the children.
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10. The support and development of Young Carers projects around the country.
11. Joined up working by all Agencies supporting Young Carers and their families.

Introduction

When a relative is diagnosed with a disability, long-term physical illness, mental illness, or has a substance misuse problem, it can have varying and wide-ranging implications on individual family members depending on:

- a family member's relationship with that relative
- the relative's role within the family unit [e.g. parent, sibling, grandparent, etc.]
- the nature of the family unit [e.g. lone parent family]
- the speed, expectancy and impact of the relative's deterioration in health and/or their disability
- the economic consequences on the family as a result of the relative's illness and/or disability [*especially if the sole or main bread winner is now disabled and/or ill, or is the primary carer*]
- the efficacy and strength of the support network available to family members
- the efficacy of statutory services to meet the needs of the disabled and/or ill relative [*where applicable*]
- the cultural perceptions and implications of the illness and/or disability

The way in which the disability and/or illness affects the relative can also vary, depending on:

- the short and long term consequences of the illness and/or disability
- the physical and emotional impact of the illness and/or disability
- the level of physical and/or emotional dependency resulting from the illness and/or disability
- the speed and expectancy of the illness and/or disability

All these factors can influence the way in which a family manages the changes that arise as a result of a relative's change in health status. Sometimes care will be provided by a family member to that relative at home, and occasionally their physical and emotional well-being may be affected by the care they give.

Although caring for a relative at home is not a recent phenomenon, the impact of caring in a climate where the traditional family unit is no longer commonplace and where health and social services are both understaffed and under-resourced, can be far-reaching – especially when the carer is under the age of 18.

Identifying young people with caring responsibilities for a relative at home is difficult - they may not have the language, confidence or self-awareness to relay the physical and/or emotional impact of living with a relative who requires care, let alone identify themselves as having caring responsibilities.

Carers Lewisham developed the Young Carers Schools Project to take the issue of Young Carers into the classroom of two Lewisham secondary schools in acknowledgement of the benefits of stepping into a child's environment to raise awareness of caring. The Project set out to identify pupils in the school with caring responsibilities and to provide support to them and their families.

This report initially sets the scene by detailing why Young Carers exist in our society, how they are defined and the comparative efficacy of various legislations designed to meet their needs.

The aims and objectives of the Young Carers Schools Development Project, together with the work carried out in the two Lewisham secondary schools and the outcome of it, is presented in depth. What then follows is a series of policy and procedural recommendations to Government, health, social care and education professionals made on the basis of evidence gained from the young people and families with whom the Project has worked over the past two-and-a-half years.

Although the debate on Young Carers has already continued for many years, what it will take for the existing evidence from ground-level to reach the makers of social policy, will very much depend upon the National Government's willingness to effectively address the rights and needs of children, parents and families in our society. It is hoped that the findings of this Project can go some way towards influencing the very real need for change.

Young Carers: Reasons, Definition and Resources

- Why Young Carers exist
- Defining a 'Young Carer'
- Efficacy of current legislation in meeting the needs of Young Carers and their families

Why Young Carers Exist

"My mother is profoundly deaf and cannot speak. I have been caring for my mum since I was about 3 years old. That sounds stupid I know, but it's true. Ever since I was 3 years old I knew how to do sign language. This meant everywhere we went, I was interpreting for my mum". [Jenna, 14]

Whether you agree or disagree with children providing care to a relative at home as a result of a long-lasting physical illness, mental ill health, disability, substance misuse problem or frailty, the reality is that it happens and has done so for many years.

When considering why Young Carers exist, one must take into account the individual rights of the young person, parents and other individual family members. The way in which individuals within a family unit live and/or cope with the changes that arise as a direct result of their own, or a relative's illness and/or disability and the care needs that ensue, are influenced by many economic, cultural, social and psychosocial factors. Young people can therefore find themselves caring for a relative at home because:

- 1] A disabled and/or ill family member who requires physical and/or emotional care, may not access support outside of the family as:
 - they may be in denial of their health status [this is especially so of those with a mental health, drug or alcohol problem].
 - they may be in denial of the impact their health status has on family members
 - they, or their family, may not want strangers coming into the family home to provide for their care needs - especially if personal/intimate care is required.
 - family members may prefer to provide the care themselves.
 - there may be an expectation on family members, including children, to provide care
 - if they are a parent, they may not access support outside of the family as they may fear their child[ren] would be taken into local authority care
 - they may not be aware of the availability of, or how to access care or support services
 - they may not be aware of their rights to statutory care services
 - they may choose not to seek professional support, or they may fear the response by professionals if they were to seek support.
- 2] A disabled and/or ill family member who requires physical and/or emotional care, may not receive access to statutory care services and so turn to family members to provide care as:
 - they may experience time-limited episodes of illness for which there exists no effective provision of short-term statutory support. For example, if a person has a mental illness, by the time the episode of illness is brought to the attention of social work teams, it may have ceased by the time an assessment is carried out, although it could return at any time.
 - the local authority may not have money enough to provide all the care services required
- 3] Even if the disabled/ill family member receives statutory care services, family members may still provide care as:
 - they may not be able to afford, or be given access to receive the full range of services they require
 - there is no community provision for a person that requires 24-hour care
- 4] Adults giving primary care may seek support from children in the family to help manage the care given to a relative as:
 - they may not be able to cope with or manage the care on their own and perform all the other duties associated with their family role
 - they may need to work to generate a sustainable family income
- 5] If a disabled and/or ill family member received all the statutory support services required, it would not necessarily stop a child from being emotionally affected by their relative's disability and/or illness. Issues of loss, anxiety, stress, anger and panic are common feelings experienced by children who live with and help care for a relative, especially where

the disability and/or illness has previously caused disruption to the stability of the family unit. It is also recognised that a child or young person is more likely to experience a loss of family stability, and to suffer as a result [Heller, K et. al, 1984¹] – Young Carers are no different.

It is therefore imperative when working with families in which children provide care, to remain aware of the reasons why they are caring in the first place, otherwise any action taken to try and support the young people and their family may in fact do more harm than good.

It is also worth considering recent research statistics on Young Carers, to help gain a real insight into the lives of these young people.

In 1998, Chris Dearden and Saul Becker surveyed 2,303 Young Carers from 69 Young Carers Projects². The outcome of this research showed that:

- their average age was just 12 years
- 54% lived in single parent families
- 58% cared for their mother
- 1 in 3 regularly missed school or had educational difficulties because of their caring role
- 63% cared for a relative with physical health problems
- 29% cared for a relative with mental health problems
- 1 in 5 provided intimate care, and
- 1 in 4 had no external support [other than through their local Young Carers Project]

In April 2001, the London Young Carers Workers Forum mapped the demographics of Young Carers from 21 London Projects, the outcome of this exercise showed that of the 2,180 Young Carers registered with these Projects, on average:

- 41% gave primary care
- 50% lived in single parent families
- 64% cared for a parent

Estimates of the number of Young Carers in the UK have widely varied; research in 1990 [Fallon³], 1992 [O'Neill and Platt⁴] and 1994 [Siddall⁵] gave approximate estimates of around 10,000 children in the U.K. acting as primary, informal carers. By 1996 [Walker⁶] the frequency of Young Carers ranged between 19,000-50,000. However, the frequency of Young Carers in the UK is very much dependent upon the definition one were to adopt. Given all the reasons why they exist, how can 'Young Carers' best be defined?

Defining a 'Young Carer'

We all have different mechanisms for coping with changes in our life - children are no different. Two people exposed to exactly the same life experience may respond and cope very differently - one very well, the other not so well. It should therefore be the individual needs of people that we should consider, not what we assume they should be able to cope with [Moos, R.H.[Ed], 1990⁷]

There is still an extensive debate on how a 'Young Carer' should best be defined. Many variations exist - some focus on the objective - that the care provided by the young person should be 'substantial' or 'significant'. Other definitions focus on the subjective - that the care provided should in some way 'restrict', 'impact on' or 'limit' the life of the young person before they can be defined as a Young Carer.

Before reading through these definitions, it may be worth considering whether you believe that, when defining a Young Carer, the focus should be on the *impact* on the child or young person in providing care, or the *level of care given* by that child.

In 1995 the Social Services Inspectorate⁸ [SSI] defined a 'Young Carer' as:

"A child or young person who is carrying significant caring tasks and assuming a level of responsibility for another person, which would usually be taken by an adult [the term refers to children or young people under 18 caring for adults [usually their parents] or occasionally siblings. It does not refer to...those children who accept an age-appropriate role in taking increasing responsibility for household tasks in homes with a disabled, sick or mentally ill parent]" [DoH, 1995, p.16]

This definition indicates that a child can only be defined as a Young Carers if the care provided is:

significant and more appropriate to be taken on by an adult

This definition suggests that if the care provided by the young person is not significant, then they cannot be defined as a Young Carer, but when does care provided by a child become 'significant'? Does the child have to be caring for a quantifiable amount of time per week, or give nursing or intimate personal care? And what if the child or young person did not give 'significant' care, but found that their health or development was affected by the care they gave? – According to this definition such a child would not be recognised as a Young Carer.

This definition also suggests that there is a role for children to take age-appropriate responsibility for household tasks in the home, but the *volume* of tasks is not considered. At what age *should* a child be responsible for cleaning, dusting and vacuuming the whole house, or doing the family shopping, washing, and cooking of meals? At what age is it appropriate for a child to take responsibility for all these household chores on a regular daily basis, and would it make any difference if they were the eldest child catering for the needs of four younger siblings, or perhaps an only child, living in a lone parent family where the parent required care?

In 1998, Carers National Association⁹ defined a Young Carer as:

"Anyone under the age of 18 whose life is in some way restricted because of the need to take responsibility for the care of a person who is ill, has a disability, is experiencing mental distress or is affected by substance misuse"

This definition vastly differs to that put forward by the SSI in the same year, as it focuses on:

**the need to take responsibility for a relative's care, and
the subsequent restrictions on the life of that young person**

This was one of the first definitions to suggest that a child or young person should be regarded as a Young Carer, not on the basis of what they did, but the individual impact on the child as a result of them needing to take responsibility for the care of a relative.

By 1996, the definition of a Young Carer given by the Department of Health¹⁰ [DoH] was:

“Children and young people [under 18] who provide or intend to provide substantial amount of care on a regular basis” [DoH, 1996, p.2]

This definition is far more restrictive than that put forward by the SSI in the previous year, for it suggests that a child can only be defined as a Young Carer if the level of care provided is *both*:

substantial and regular

Again, the suggestion is that the care given by the child must be quantifiable; measured on the basis of what the young person *does and how often they do it*. This definition fails to mention the need to take into account the impact on the young person’s emotional and physical health, their development or indeed their individual ability to cope with their caring responsibilities. The DoH definition suggests that, as long as the care provided is ‘regular and substantial’, the young person can be regarded as a Young Carer. So what if the care was not ‘*regular and substantial*’, but had a detrimental impact on the young person’s health and/or development?

In 1998, the definition of a Young Carer suggested by Loughborough University’s Young Carers Research Group¹¹ was:

“Young Carers are [usually] under the age of 18 [i.e. with the legal status of children]; one or both of their parents [or other relative in the home] has some illness, disability or both; Young Carers are care givers in the absence of alternative professional or informal support; and they are performing a range of duties and roles which, in most cases, can restrict their lives” [Becker, S., et al, 1998, p.14]

This definition suggests that a young person can be defined as a Young Carer if:

**their life is restricted; they are performing a range of duties and roles
and there is an absence of formal or informal support**

Although consideration is given to the restricting impact on the life of a Young Carer by performing a range of duties and carrying a number of roles, mention is also made of the absence of available support - but what of those young people who provide for the remaining care needs of their relative, as a result of the shortfall in provision of formal or informal support? – they may also find their life is restricted and are performing a range of duties.

CONCLUSION AND RECOMMENDATION

The variations in the range of definitions of a Young Carer are that the care provided must either be:

- significant and more appropriate for an adult
- substantial and regular
- restricting the young person’s life, or
- given in the absence of formal/informal support

However the reason why defining a ‘Young Carer’ is so crucial is that the adopted definition could significantly impact on the number of young people who could reasonably be identified as a Young Carer - the more restrictive the definition, the fewer the number of Young Carers, and the less visible the demand for resources to be targeted to meet their needs.

There is a strong argument that if Articles 24, 27, 28, 29 and 30 of the UN Convention on the Rights of the Child are to be upheld when defining a Young Carer, one needs to consider the impact caring may have on a child's physical and emotional health, social and leisure opportunities, and their personal development.

An alternative definition of a Young Carer that encapsulates the many issues arising from this overview of recognised definitions and used by the Young Carers Schools Development Project is:

“A person under the age of 18 who lives within a family who finds that as a direct result of a relative’s long-lasting illness, mental ill health, disability, frailty, drug or alcohol abuse, their physical and/or emotional health is adversely affected and/or their life opportunities are increasingly restricted, by the care they provide to that relative.”

This definition encompasses:

- the impact caring and/or the relative's illness and/or disability may have on a young person's physical and emotional health, social and leisure opportunities and their personal development.
- the physical and/or emotional impact of the relative's illness and/or disability.

Undoubtedly the debate on how to define a 'Young Carer' will continue, but at some point one must ask at what cost? Furthermore, if defining a Young Carer is still ongoing, how far does current legislation really meet the needs of Young Carers in our society – the majority of whom, according to recent research¹², are primary carers living in single parent families and are caring for a parent?

Efficacy of current legislation in meeting the needs of Young Carers and their Families

"On a bad day mum can't walk because she can't catch her breath. She has to use her nebuliser 16 times a day. When she sleeps I need to check her breathing every 5-10 minutes to make sure she's OK - I feel panicky at times, worried and scared to leave mum alone. It was only when I met the Young Carers Worker at school who knew about the issues of caring that me and my mum got an assessment with social services. All I wanted was for my brother and sister to be taken to school and a stairlift for mum. Help with the housework and shopping would have been nice - it would make a difference and I wouldn't have abused it, it would just have made things easier for me. Nothing's changed though - I didn't get the support I wanted." Susan, [16]

If a relative with a long-lasting physical illness, mental illness, disability, frailty or substance misuse problem received statutory services to fully support and meet their individual needs, one could assume that this would, undoubtedly, reduce the number of children who provide care in the home. What's more, it could also be assumed that current legislative provision for children with caring responsibilities is addressed to meet the needs of those who find themselves caring, but the reality is quite different.

Provision for Young Carers is addressed very differently by the Children Act 1989, NHS & Community Care Act 1990, Carers [Recognition & Services] Act 1995 and the Carers and Disabled Children Act 2000.

The Children Act 1989, s17[10] states that:

- a) *"a child shall be taken to be 'in need' if he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority.....; or*
- b) *"his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services".*

The Children Act 1989 is a powerful piece of legislation, giving a local authority the power to provide almost any service to a child to help them achieve or maintain a reasonable standard of health or development. However, nowhere in the Children Act is there mention of 'Young Carers', neither does the Act have any bearing on the provision of services for any adult within the family who may be cared-for by a child. Moreover, there is no recognised statutory assessment procedure available to gauge the impact of caring on a young person. Yet, without giving the Young Carer an assessment, it is virtually impossible to establish if the child's caring responsibilities do, indeed, impair their health or development.

Parents who are cared-for by their children may also be deterred from seeking statutory support if they knew that their child would have to be deemed to be 'in need' or 'at risk' before any service is made available to them. What is more crucial is that unless statutory professionals are made aware of the mere existence of Young Carers, and the frequent effects on children providing care to a relative at home, they will not necessarily recognise that services could be made available to help them maintain 'a reasonable standard of health or development'.

Evidence of the recognition of the needs of Young Carers by statutory professionals comes from a comparative analysis in April 2001, of the numbers of Young Carers assessed in 12 London Boroughs. Greenwich Social Services Young Carers Projects assessed 175 Young Carers under the Children Act 1989. However, of the 1,379 Young Carers registered with 11 other Young Carers Projects in London - all of which are based in the voluntary sector - only 58 received an assessment.

The **NHS and Community Care Act, S47[1]** places a duty on local authorities to carry out an assessment of an individual's need for community care services. These services are provided under **Section 2** of the **Chronically Sick and Disabled Persons Act 1970**, and **Section 4** of the

Disabled Persons [Services, Consultation and Representation] Act 1986, and require the local authority to take the ability of the 'carer' – including the 'Young Carer' – into account when assessing disabled people for services, where:

- a] *a disabled person is living at home and receiving a substantial amount of care on a regular basis from another person [who is not a person employed to provide such care by anybody in the exercise of its function under any enactment], and*
- b] *it falls to a local authority to decide whether the disabled person's needs call for provision of any services for him under any welfare enactments.*

This piece of legislation not only gives a local authority the power to assess the cared-for person's need for services, but also the carer's ability to provide care. However, it fails to address the impact caring may have on a person's physical and emotional health - and in the case of children, the impact on their development. By negating the impact of caring, there is no opportunity to address or help maintain the carer's own health and well-being.

Furthermore, there is no formal assessment procedure specifically tailored to address the needs of young people with caring responsibilities. The impact of this effectively strong piece of legislation is further undermined as the cared-for person can refuse to be assessed for community care services, which would result in the Young Carer not receiving an assessment.

The **Carers [Recognition and Services] Act 1995 s1[b]** states that when:

- a] *a local authority carry out an assessment under s47 [1][a] of the NHS and Community Care Act 1990 of the needs of a person ["the relevant person"] for community care services, and:*
- b] *an individual ["the carer"] provides or intends to provide a substantial amount of care on a regular basis for the relevant person,*

"the carer may request the local authority...to carry out an assessment of his ability to provide and to continue to provide care for the relevant person; and if he makes such a request, the local authority shall carry out such an assessment and shall take into account the results of that assessment...."

This Act was a landmark in that it gave carers the statutory right to an assessment once the person for whom they cared received an assessment. However, carers need to provide 'substantial' care to receive an assessment, which will only then address their 'ability to care', not the impact caring may have on their mental or physical health – so how can the care provided be judged to be substantial to that individual?

Furthermore, even though the Act is known as the 'Carers [Recognition and Services] Act, carers are not entitled to receive any services under this piece of legislation, neither is there any mention of 'Young Carers'. Subsequently, any Young Carer that receives an assessment under this Act, would not be asked how caring may impact on their physical or mental health, school attendance, leisure time, or personal development.

The Carers and Disabled Children Act 2000 states that:

- a] *"if an individual aged 16 or over ["the carer"]*
 - *provides or intends to provide a substantial amount of care on a regular basis for another individual aged 18 or over ["the person cared for"]; and*
 - *asks a local authority to carry out an assessment of his ability to provide and to continue to provide care for the person cared for*

b] *the local authority must carry out such an assessment if it is satisfied that the person cared for is someone for whom it may provide or arrange for the provision of community care services”.*

The Carers and Disabled Children Act 2000 entitles all carers who are caring for someone over the age of 18 to ask their local authority to an assessment of their own needs in relation to their caring role, even if the person they care for chooses not be assessed, overcoming one of the limitations of the Carers [Recognition and Services] Act 1995.

For the first time local authorities are able to provide carers of adults with services in their own right and, although these services are not defined by the Guidance to the Act, local authorities are encouraged to be flexible in order to ‘maintain the health and well-being of the carer’.

Although this Act is the first to mention Young Carers, the Policy Guide makes specific reference to ‘*Promoting and Safeguarding the Welfare of Young Carers*’ [p. 6-7] and states that:

“the Carers and Disabled Children Act will only rarely be used by councils looking at the needs of 16 and 17 year olds”, but goes on to say that “there are...a small number of situations where a 16 or 17 year old is choosing to undertake a substantial caring role”

This is despite the evidence to the contrary which is well documented by many Young Carers Projects.

There are, however, many positive aspects routed in the “Practitioners Guide to Carers’ Assessments”, the most significant being that:

“Young Carers.... should not be expected to carry out inappropriate levels of caring which have an adverse impact on their life chances. It should not be assumed that children should [even at age 16 and 17] take on similar levels of caring responsibilities to adults.Services should be provided to parents to enhance their ability to fulfil their parenting responsibilities [under the Children Act 1989]” [p.4]

Although there is clear guidance for practitioners about children providing care, they are merely referred back to the Children Act 1989 - which makes no mention of Young Carers and has no formal procedure for assessing the impact of caring on the young person to establish if it does, indeed, have ‘an adverse impact on their life chances’.

CONCLUSION

Current legislation, even the most recent, does little to either *stop* or *support* children caring for a relative at home. Given that the majority of Young Carers live in single parent families and provide care to a parent, one must question the value of suggesting that parents must ensure they are fulfilling ‘their responsibilities under the Children Act’ – as stated in the Carers & Disabled Children Act 2000¹³, especially as their child must first be deemed to be ‘in need’ to even receive support through the Children Act 1989. How does this support parents who find themselves relying on their children to provide care as a direct result of their illness and/or disability, or caring responsibilities for a relative at home? Should the parent be to blame when their child provides care as a direct result of the shortfall in services to meet their needs of those of the cared-for relative?

What needs be addressed in practice, which is not mentioned by the principle of legislation, are the consequences of:

- The scanty nature of services to meet the needs of those who require physical and/or emotional support and/or care services, as a result of a long-lasting physical illness, mental illness, disability, frailty or substance misuse problem
- The failure of the legislation to address the impact on a parent’s ability to carry out their parenting role, if they or someone else in the family has a long term illness and/or disability.

- The failure to make available a formal procedure for assessing Young Carers which helps promote their health and development when living with and/or caring for a relative at home, without having to label them as 'in need'.

Young Carers Schools Development Project

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History of Carers Lewisham's Young Carers Schools Development Project

"Two weeks ago mum suffered a relapse. She couldn't catch her breath to call me and had to crawl downstairs to get her oxygen" [Carla, 13]

It has long been recognised that Young Carers rarely identify themselves as such - they do not necessarily have the knowledge or vocabulary to perceive the care they give to a disabled, physically or mentally ill relative, or one who abuses drugs or alcohol, as a caring responsibility.

Without entering into a child's environment, be it their home or school, identifying children with caring responsibilities is extremely difficult - much depends on the awareness of the existence of Young Carers by professionals across all sectors of the community. However many remain unaware of them, let alone the issues they face. Identification is therefore problematic.

In 1992¹⁴ Carers Lewisham worked with School Nurses to highlight the issue of Young Carers. In response to their raised awareness the nurses carried out a mini survey in their schools by asking a question about caring when they carried out their yearly health checks. 24 children of primary age and 30 children of secondary age were identified as having caring responsibilities.

In 1993¹⁵ a Social Work student, Michael Sheppard, on placement with Carers Lewisham, carried out some outreach work with two local Primary Schools, Gordonbrook and Hither Green. He did story telling sessions with the children where they were asked to contribute the major facts and characters. The children in the story faced a dilemma about caring for their mother or father and their school demands. Through this process it came to light that several children in each group did have caring responsibilities. He found that although the teachers knew that some of their pupils had caring responsibilities none of the teaching staff were aware of the extent of the issue. Many were surprised at how reluctant the children were to tell their teacher what was going on at home.

In 1995, Pauline Kennedy, then a Turning Point Community Work Apprentice based at Goldsmith College, part of the University of London, dedicated her placement at Deptford Green School to identify and raise awareness of the issue of Young Carers amongst pupils in, what was then, Years 8 and 9 (pupils aged 13-15). Pauline delivered assemblies and some awareness raising lessons on the subject of Young Carers - as a result twenty-five pupils were identified as caring for a relative at home. By liaising with Carers Lewisham's Young Carers Project, appropriate follow-up casework was carried out with these pupils and their families to ensure they were in receipt of all the services and benefits to which they were entitled.

It was recognised, even at this early stage, that the number of Young Carers identified may only represent a proportion of pupils in that school who were caring for an ill and/or disabled relative at home. Therefore, when Pauline's apprenticeship ended in June 1997, both she, the school and Carers Lewisham believed a dedicated Young Carers Schools Worker would be an excellent resource. By the end of the year, Carers Lewisham submitted a successful funding proposal to the Bridge House Estates Trust Fund, to run a 30 hour a week Young Carers Schools Development Project over a three year period within two Lewisham Secondary Schools. Deptford Green School had already agreed to participate in the Project, so the Director for Lifelong Learning in Lewisham was approached to identify another school in the Borough with whom the Project could work - Malory School was appointed as the second school to participate in the Project.

Although other Young Carers Projects had already begun to work in schools to identify Young Carers, most worked quantitatively with *all* secondary schools in their locality or district – for one such project this meant working with 42 Secondary Schools!

What made the principle behind Carers Lewisham's Young Carers Schools Development Project unique was that it was qualitative – designed to carry out in-depth work with just two secondary schools. The benefit of this was that there was, potentially, a greater opportunity to forge a

relationship with pupils. This was crucial if they were to identify themselves as a Young Carer and share aspects of their private and personal world of caring.

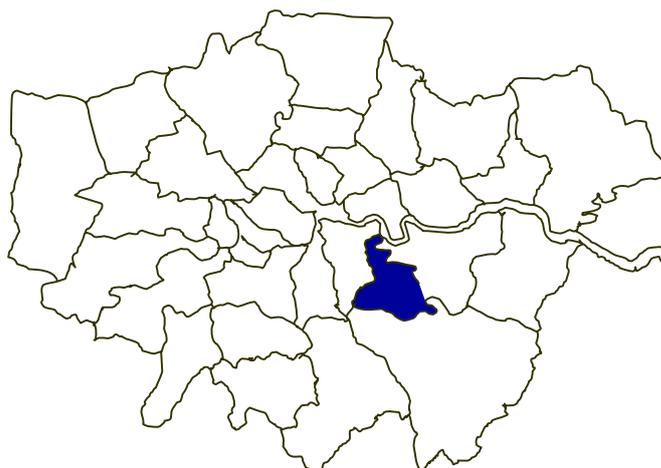
In October 1998, Carers Lewisham's Young Carers Schools Development Project had begun – the same year that national research had shown that, on average one in three Young Carers regularly missed school, or experienced educational difficulties because of their caring role.²

London Borough of Lewisham: A Profile

"I stopped going to school, instead I went to visit dad in hospital – this went on for 5 months. I had the school on my back and mum was too drunk to make me go....For a year after that I wasn't in school. I was at home clearing-up mum's mess" [Lee, 14]

To help set the scene of Carers Lewisham's Young Carers Schools Development Project, there are certain key facts about the London Borough of Lewisham and the schools appointed to work with the Project that should be considered.

London Borough of Lewisham

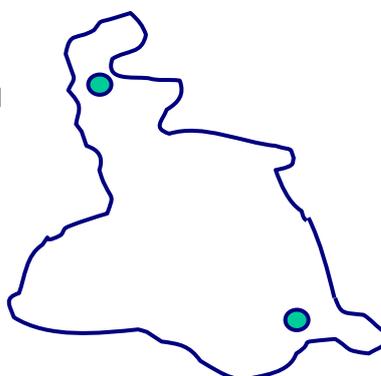


The London Borough of Lewisham is one of thirty-three London Boroughs. With a population of 243,000, ranked as the 8th highest population of lone parent families in England, and indexed as the 14th most deprived authority in England, it comes as no real surprise, given the known correlation between poverty and ill-health, that one in twelve of the population were known to have a long-lasting physical illness from the 1991 Census. However, consider also that this figure does not account for those of Lewisham's population with a mental illness, disability, substance misuse problem or those who are frail or elderly.

Locality of the Lewisham Schools involved in the Young Carers Schools Project

Deptford Green School - Deptford

1,005 pupils
55% of pupils receive
free school meals



Malory School - Downham

762 pupils
57% of pupils receive
free school meals

The areas in which the Project was appointed to work are known to be of high deprivation, this is evident from the percentage of pupils receiving free school meals; 55% of pupils at Deptford Green [in the North of the Borough], and 57% of pupils in Malory School [in the South of the Borough]. Children are only entitled to receive free school meals if their parent[s] is in receipt of statutory benefits.

Aims and Objectives of the Project

“As my fellow pupils got to know, they started to bully me because of mum’s deafness. It was physical and mental abuse. I was pushed, punched, kicked and called names. When children passed me they would wave their arms around trying to imitate me talking to mum....To this day my mum still doesn’t know. I couldn’t put her through the hurt” [Sian, 14]

When the Project started in October 1998, the following aims and objectives were established, these were:

- to give a minimum of one awareness raising session on Young Carers issues to every class in each school year, in both schools
- to identify Young Carers in both schools
- to set-up support networks and activities for Young Carers in both schools
- to give awareness raising sessions to all teachers in both schools
- to liaise and consult with all appropriate people within schools
- to recommend working procedures to identify and support Young Carers in schools
- to build links with Lewisham's Education Authority to highlight Young Carers issues
- to produce a procedural handbook to enable schools to identify and support Young Carers
- to produce an information pack on Young Carers issues for teachers in Lewisham
- to produce an information pack for Young Carers at both schools, outlining how to get support and information
- to produce a secondary curriculum resource pack on Young Carers and linked disability/mental health issues
- to disseminate the findings of the Project throughout London, and contribute to the national debate on how to best identify and support Young Carers in school.

- All that was now needed was for this work to get underway. Within a week of the Project starting the first visits were made to the two secondary schools assigned to work with the Project.

Introducing the Project to the Schools

“Halfway through the [school] year I started to let myself go. I could no longer be strong...instead I became a feeble little girl. Mum got worse, which meant more responsibility. I was cooking the dinner, doing 5-6 pieces of homework a night and looking after my sister. That was it, I had a nervous breakdown and became very withdrawn to society. I never went out much anyway. But I was constantly crying.” [Sam, 15]

Introducing the Young Carers Schools Development Project to the schools was a crucial first step to getting the Project started.

Separate meetings were initially held with the Deputy Headmaster at Deptford Green School, and the Head of the Pastoral Curriculum at Malory School. During these meetings, staff were assured that the Project Worker would:

- deliver all Young Carers awareness lessons
- manage all cases of all pupils who identified as a Young Carer, and
- set-up and run regular Young Carers Lunch Clubs in the school for pupils known to be caring for someone at home

It was clear from discussions at these meetings, that both schools were organised and managed very differently. Deptford Green School had a Head of Year system, whereby a Year Head managed each school year. Pupils in Year 7 and 8 (aged 11-14) were taught in the Annexe, and those in Years 9-12 (aged 15-18), were located in the Main Building - a five-minute walk away from the Annexe. At Malory School, pupils from Years 7 - 12 were housed in one central location. There was a Head of Year who managed pupils in Year 7, but from Year 8 upwards, pupils were subdivided into four different House Bases, managed by different Heads of House.

What also became clear at these meetings was the difference in the way lessons were timetabled; at Deptford Green School, the majority of classes had 'Personal Social and Health Education' (PSHE) lessons on different days and times during the school week; at Malory School, all pupils had PSHE lessons, or tutor time, at the same time - on a Thursday immediately after the school assembly.

The presentation of Young Carers awareness raising lessons was discussed; the Deputy Headmaster at Deptford Green School suggested that lesson plans first be designed and approved by the Head of PSHE at the school, before any lessons were timetabled. In the meantime, it was suggested that posters be displayed around the two school sites to advertise the day and time of the Young Carers Lunch Clubs.

The Head of the Pastoral Curriculum at Malory School suggested that an assembly presentation first be given to the whole school - so pupils at least knew who the Young Carers Schools Worker was, what work was planned to take place in the school, and the day on which the Young Carers Lunch Clubs were scheduled to take place. It was also suggested that only once lesson plans were approved, a meeting should then be arranged with the Head of Year 7 to timetable lessons on Young Carers.

During the meetings, staff agreed that specific rooms in the schools would be made available during the lunch hour so the Young Carers Lunch Clubs could take place each week. By the end of the meetings Young Carers Lunch Clubs were scheduled to take place on Monday for pupils at the Annexe, and on a Wednesday for pupils at the Main Building of Deptford Green School. The Young Carers Lunch Club at Malory School was to take place on a Thursday. Both staff members suggested that Club Cards be issued for pupils wanting to attend the Young Carers Lunch Clubs to permit an early entry into the Dinner Hall, to allow them into areas of the school during the lunch hour and for other facilities which helped them as Young Carers.

Within three weeks of these initial meetings, an assembly was presented to all pupils in Malory School; posters were displayed in both schools, advertising the time/day of the Young Carers Lunch Clubs, and the first Young Carers Clubs were held.

Example of the Poster Displayed in Schools:



Are things difficult at home because someone you live with is disabled, always ill, or sad all the time ?

Do you help care for, or help look after that person, and feel tired at school?



Worried about what the Doctors are going to say next?

Young Carers



If you would like some help, or someone to talk to, you can either

- a] Come to the Drama Room every Wednesday during the lunch hour to speak with Geraldine
- b] Call Geraldine or Gari at the Young Carers Project FREE on 08000 198 841
- c] Write to: The Young Carers Project, The Lodge, Waldram Crescent, Forest Hill, London SE23 2LA



This poster was designed to enable pupils to:

- identify if they could be a Young Carer
- be aware of the day and time of the Young Carers Lunch Club in their school
- access information and advice using the free-phone telephone number at Carers Lewisham's Young Carers Project

Example of the Young Carers Club Cards issued to Pupils Attending the Young Carer Club:

<p style="writing-mode: vertical-rl; transform: rotate(180deg);">Young Carers: 08000 198 841</p> <p style="writing-mode: vertical-rl; transform: rotate(180deg);">Remember, you can Call Geraldine on</p> <p style="writing-mode: vertical-rl; transform: rotate(180deg);">to go to the Dinner-Hall early on a Thursday</p> <p style="writing-mode: vertical-rl; transform: rotate(180deg);">This card enables</p> <p style="writing-mode: vertical-rl; transform: rotate(180deg);">Malory Young Carers Club</p>	<p style="text-align: center;">Malory Young Carers Club</p> <p style="text-align: center;">This card belongs to _____</p> <p style="text-align: center;">Card Expires: September 2001</p>	<p style="text-align: center;">The Young Carers Club Rules</p> <ol style="list-style-type: none"> Do not discuss personal information about a Young Carer in the Club without their permission. Respect all Club Members. Do not abuse this membership card by gaining access to an early lunch, knowing that you are <u>not</u> going to attend the lunchtime club. If you want to call home because you are worried about the person you care for, show this card to a member of staff in the office and ask if you can phone home. <u>Do not abuse this privilege</u> 	<p style="text-align: center;">Signed Agreement</p> <p>I, _____ accept the Young Carers Lunch Club Rules and agree to give-up this card if I break any of the club rules.</p> <p>Signed: _____</p> <p>Date: _____</p> <p>A Young Carer is a person under the age of 18 who helps emotionally support or physically care for a relative who may be disabled, or has a long lasting physical or mental illness, or one that abuses drugs or alcohol.</p>
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The Young Carers Club Cards were issued to:

- allow pupils into the Dinner Hall early, so they could spend the remainder of the lunch hour in the Young Carers Club, and to permit them entry into the school building during the lunch hour.
- allow pupils to identify themselves as a Young Carer, so if they wanted to use the a phone during the day to check on the person for whom they cared, all they need do, is show the card to a staff member, or a member of the school administration team, to gain access to a telephone - thereby increasing the chances of them remaining in school, and concentrating in their lessons.

Lessons on Young Carers

“The Young Carers Worker helps pupils cope with out of school situations, which means that work at school does not suffer.” [Dinesh, age 12]

Before any lesson-based awareness raising sessions were timetabled into the curriculum of the schools, a series of three lesson plans were drawn-up and shown to staff responsible for the PSHE Curriculum from both Malory and Deptford Green School, for comment and approval.

The first lesson was structured to encourage pupils to think about, make a note of and then share with the class their responsibilities at home. The definition of a Young Carer would then be presented to pupils, followed by fictional case studies on Young Carers which pupils would be asked to read through and to make a note of the problems they thought that Young Carer would face at school; with their friends; with finding leisure time, and in the future, as a direct result of their caring responsibilities at home - the aim being to encourage pupils to empathise with the situation of that Young Carer presented in the case study.

At the end of this first lesson, evaluation sheets were to be distributed to all pupils, so they could give feedback on how they found the lesson; what they thought of the case studies and teaching; what they learnt about Young Carers; whether they wanted more information on Young Carers for either themselves, or someone they knew and whether they were a Young Carer *“because you care for someone at home who is ill, disabled, frail, or has drug/alcohol problems?”*

Example of Evaluation Sheet:

<u>Evaluation Sheet</u>					
Please fill-out all sections on this evaluation sheet.					
Key:	1 = Poor	2 = OK	3 = Good	4 = Very Good	
1]	How did you find today's lesson?	1	2	3	4
2]	What did you think of the Case Studies?		1	2	3
3]	How did you find the style of teaching?	1	2	3	4
4]	What did you like most about today's lesson?				

5]	What did you like least about today's lesson?				

6]	What did you learn about Young Carers?				

7]	Do you have to look after younger brothers or sisters ?			Yes/No	
8]	Are you a Young Carer because you care for someone at home who is ill, disabled, frail or has drug/alcohol problems ?			Yes/No	
9]	Would you like more information about Young Carers either for yourself or someone you know?			Yes/No	
If you have answered 'yes' to 8] or 9], please fill-out your details below And further information will be sent to you.					
				[Please ✓ box]	
a]	I would like information sent to my home			<input type="checkbox"/>	
b]	I would like information to be given to me at school			<input type="checkbox"/>	
Name:	_____	Tutor Group:	_____		
Address:	_____				

THANKS FOR FILLING OUT THE FORM REMEMBER TO HAND IT IN AT THE END OF THE LESSON					

Before the start of the second awareness raising lesson on Young Carers, it was arranged that all pupils who requested further information on Young Carers or those who identified themselves to be caring on their evaluation sheets, would receive information packs consisting of:

- details of the work of Carers Lewisham
- information of the support provided by Carers Lewisham's Young Carers Project, and how to get in contact with the Project
- a copy of the Young Carers Club Poster, with details of the day and time of the Club
- known information about the numbers of, and frequent effects of caring on a Young Carer
- a copy of Carers Lewisham's Young Carers newsletter and a questionnaire - but only to those pupils who identified as a Young Carer

The second lesson was designed to address issues relating to the taboos and misconceptions of disability and mental illness. Pupils would initially be asked to come up with a definition of 'disability' and 'mental illness', and were then to be given two separate sheets with a series of 'true and false' statements - one relating to issues on disability, the other on mental illness. They would then be asked to state whether they believed these statements to be 'true' or 'false'.

The aims of this lesson were to not only raise awareness of the fact that everyone has different levels of physical and mental health, but to challenge pupils perceptions of disability and mental illness. It was hoped that this lesson would give pupils' an awareness of some of the issues Young Carers faced if they cared for a relative with a disability or mental illness, as a direct result of the stigma and misconception associated with having a disability or mental illness.

The third lesson plan addressed the concept of support networks. Pupils would be asked to map their own support network, using 10 people they knew well; to consider the reasons why they got on with some people more so than others, and to then map the support network of a Young Carer after reading a fictional case study. The aim of this lesson was to encourage pupils to think about the network of support available to them, and to consider the importance such a network may have on those who cared for a relative at home, or those who faced difficulties in their life.

Although all the lesson plans were approved, timetables of just two PSHE lessons were agreed by the Heads of Year and Heads of House from each school. Furthermore only those pupils in Years 7 – 10 were to receive these lessons because of the demands on pupils in Year 11 to prepare for their forthcoming exams. The timetable of lessons on Young Carers took even longer than expected because of:

- the days dedicated to running the Young Carers Lunch Clubs in the schools
- the way in which PSHE lessons were time-tabled, [especially at Malory School, although this was later rectified by staff agreeing to replace subject-specific lessons, with lessons on Young Carers]

Agreed Timetable of Young Carers Awareness Raising Lessons

October 1998	Awareness raising lessons began with Yr. 8 pupils at Deptford Green School [DGS]
November	Malory School [MS] Assembly
December	Completion of lessons to Yr.8 pupils at DGS.
January 1999	Awareness raising lessons began with Yr. 7 pupils at DGS and MS
February	Completion of lessons to five Yr. 7 classes at MS
March	Completion of lessons to all Yr.7 pupils at DGS
April	Awareness raising lessons began with Yr. 8 & 9 pupils at MS
May	Completion of lessons to all Yr.7 pupils at MS
June	Awareness raising lessons began with Yr.9 pupils at DGS
July	Completion of lessons to all Yr.9 pupils at DGS, and Yr. 8 & 9 pupils at MS

The delivery of lessons was both exhausting and enlightening - some pupils identified themselves as a Young Carer just by being asked in the very first lesson to share their responsibilities at home.

It was also apparent that the evaluation sheets were proving to be an invaluable tool by which pupils could identify themselves as having caring responsibilities for a relative at home.

Although awareness raising lessons continued in earnest up until July 1999, by June of that year the three lesson plans designed for presentation in schools now formed the basis of a teaching resource pack entitled "Supporting Young Carers in Schools – A Secondary Resource". This pack was designed to share what was evidently working in Lewisham, with other professionals working in school, to help identify and support pupils with caring responsibilities. Between February 2000 and June 2001 over 900 copies of the teaching pack had been sold.

Meanwhile, by July 1999 all pupils in Years 7-9 at Deptford Green School and Malory School had received awareness-raising lessons, and returned their evaluation sheets. It was evident from the evaluation responses that many pupils identified themselves as a Young Carer - 27% at Deptford Green School, and 25% at Malory School. However, some pupils had not given their name on their evaluation sheet, so there was no opportunity to clarify their caring situation.

For those pupils that *did* give their name and identified themselves as a Young Carer on their evaluation sheets, it was crucial that follow-up interviews took place to establish whether they were caring for a relative at home.

By September 1999 follow-up interviews with pupils identifying as a Young Carer began in earnest - this meant interviewing 130 pupils at Deptford Green School, and 85 at Malory School to establish:

- a] whether they had grasped the concept of a 'Young Carer' correctly and if so,
- b] the level of care they gave to their relative at home, and
- c] the support Carers Lewisham's Young Carers Project and Schools Project could give

By this time, both schools had a new intake of Year 7 pupils; awareness-raising lessons on Young Carers were timetabled to start in November 1999, and were completed by February 2000. Again, 89 Yr. 7 pupils from both schools identified as a Young Carer, adding to the volume of follow-up interviews, already taking place.

By February 2000 a total of 32 classes between years 7-10 had now received a minimum of two lessons on Young Carers issues at Deptford Green School, and 29 classes in Malory School. In total, 687 pupils in Deptford Green School and 461 in Malory School were present during the first lesson on Young Carers and had returned their evaluation sheets [although not all completed their forms]. The outcome to the feedback on the evaluation sheets was as follows:

How pupils found the Lesson on Young Carers	Deptford Green School	Malory School	Average % of Pupils	Total [Out of 1148 pupils]
<i>Poor</i>	27	24	4%	51
<i>OK</i>	209	93	26%	302
<i>Good</i>	245	176	37%	421
<i>Very Good</i>	206	168	33%	374
How pupils found the presentation of the Lesson				
<i>Poor</i>	30	24	5%	54
<i>OK</i>	127	57	16%	184
<i>Good</i>	225	159	33%	384
<i>Very good</i>	305	221	46%	526
Pupils identifying as a Young Carer	204	100	27%	304
Pupils requesting further info on Young Carers	230	218	39%	448

By July 2000 all pupils that had identified as a Young Carer and had written their name on their evaluation sheet, had received a follow-up interview. During the interview, pupils were asked in a non-leading way, "what is it about your situation at home that makes you think you may be a Young Carer?"

It became clear from some of the response by pupils that they had wrongly identified themselves as a Young Carer. However many of these children had significant child-care responsibilities for younger siblings, which impacted on their leisure time and ability to complete homework. Others lived with a sibling who had asthma or eczema and therefore believed they were Young Carers, but they did not have to do anything for these. However, the number of pupils identified by the Young Carers Schools Development Worker as actually having caring responsibilities as defined on page 10 of this report was overwhelming (see the following statistics).

Outcome of Follow-up Work

"What us Young Carers go through is shocking. While you are at home watching television there are many children at home caring for a relative. For everyone that reads this, please be aware of what you say to a Young Carer. They are probably feeling very insecure and sensitive" [Taken from an English assignment by Dean, 15]

Deptford Green School: 1999-2000

Level of Care [L = Low, M = Medium, H = High, F = Former Carer]

Class	Situation	Care
7CK	Mother: paralysed, brain haemorrhage	M
7CK	Lives with cousin: learning disability	L
7CK	Father: series of strokes	M
7CK	Mother: MS	H
7CK	Mother: Breast Cancer	M
7CK	Mother: Tumour in her abdomen	L
7LS	Brother [10]: deaf and mute	M
7LS	Nan: paralysed	L
7LS	Nan: Diabetes & Epilepsy	L
7RF	Father [78]: severe arthritis, in w/chair	H
7RF	Mother: ME	L
7RF	Father: arthritis in his back	L
7RF	Father: died 10/99	M
7HY	Step-father: alcoholic	H
7HY	Mother: mobility problems	M
7HY	Mother: Hodgkinson's Disease, Father: amputee	H
7KR	Father: alcoholic	H
7KR	Nan: heart problems	L
7KR	Brother: Downs	L
7KR	Both parents: diabetic	L
7KR	Mother: hip-replacements	L

Year 7 pupils [Aged 12-13]:

21 Young Carers, 4 pupils are former carers
6 pupils identified as a YC but didn't give their name

Class	Situation	Care
9AD	Mother: agoraphobic	M
9AD	Father: stroke, Mother: breast cancer	M
9AD	Mother: disabled, paralysed RHS	M
9AD	Mother: arthritis in hand	L
9MU	Mother: heart attack in 05/99, alcoholic	M
9MU	Mother: hypertension and arthritis	M
9MU	Mother: alcoholic	M
9MU	Former – Grandfather died	F
9BA	Brother: severe learning disability	M
9KA	Mother: MH problems + angina	M/H
9KA	Brother: behavioural difficulties	L
9KA	Brother: learning disability	L
9KA	Grandmother: restricted mobility	L
9PR	Older brother: autistic	M
9PR	Mother: paralysed, brain haemorrhage	M
9PR	Former: Grandfather died	F
9YD	Brother: mute, mother depressed	H
9YD	Younger sister: asthmatic	L
9IW	Former – grandfather died	F
9IW	Mother: severe MH problems	M

Class	Situation	Care
8BR	Mother: rheumatoid arthritis poor mobility.	M
8BR	Mother: 'something wrong with spine' and trouble breathing	M
8BR	Mother: asthma and arthritis	L
8BR	Mother: arthritis in back	L
8DW	Nan: diabetic	L
8DW	Brother: behavioural problems 'always hitting head against wall'	M
8DW	Nan: immobile, has hip problems	L
8HN	Younger sister: severe asthma	L
8HN	Nan: Parkinson's Disease	L
8PU	Sister: severe learning disability	M
8PU	Aunt: severe memory loss	M
8MG	Father: epilepsy	L
8MG	Mother: severe heart problems	M
8MG	Mother: arthritis; father: kidney fail.	L
8MG	Mother: mobility problems	M
8MG	Both parents 'v. sick', Uncle: Paralysed	H
8WN	Brother: learning disability	L
8WN	Father: incontinent and paralysed	M
8PD	Mother: alcoholic and depressed	M
8RI	Mother: heart problems	L
8RI	Mother: renal failure, hypertension	M/H

Year 8 pupils [Aged 13-14]

21 Young Carers

Class	Situation	Care
10BZ	Mother: sickle cell	M/H
10FN	Younger brother: Downs	L
10FN	Mother and father: disabled Cared for Aunt : died 06/00	M/H
10FN	Father: MS/Diabetes	M
10JO	Mother: breast cancer, sister died of Leukaemia 06/01	M
10JO	Mother: cancer	M
10LU	Mother died: 01/01 was depressed	F
10PH	Father: heart condition	L
10PH	Mother: heart problems	M
10SC	Mother: depressed/alcoholic	M
10SC	Mother: alcoholic	M
10SE	Mother: in a lot of pain, no diagnosis.	M

↑ Year 10 pupils [Aged 15-16]

11 Young Carers, 1 pupil is a former carer
10 pupils identified as a YC but didn't give their name

← Year 9 pupils [Aged 14-15]

17 Young Carers, 3 pupils are former carers
5 pupils identified as a YC but didn't give their name

Malory School: 1999-2000

Level of Care [L = Low, M = Medium, H = High, F = Former Carer]

Class	Situation	Care
7G2	Nan: breathing diff., mother: alcoholic	M
75B	Mother: severe MH probs. In F/care	F
7A1	Mother: severe breathing difficulties	H
7A1	Mother: heart problems - died 06/00	F
7A2	Father: alcoholic	M
7C1	Mother: alcoholic	M
7C1	Aunt : severe arthritis	L
7C2	Mother: amputee	L
7C2	Mother: panic attacks	L
7C2	Mother: depressed	M
7C2	Mother: alcoholic	M
7C3	Mother: v. bad epilepsy	M
7C3	Sister: sickle cell	L
7C3	Nan: immobile	L
7G1	Father: alcoholic	M
7G2	Mother: severe heart problems	M
7G3	Mother: acute bronchitis	H
7G3	Grand father: immobile	L
7G3	Father: alcoholic	L
7T1	Mother: depressed	M
7T1	Grandmother: stroke	L
7T1	Father: incontinent through stroke	M
7T2	Mother: alcoholic	M
7T2	Sister: learning disability	L

Class	Situation	Care
8A1	Mum bad back, walking difficult	L
8A1	Brother: severe sight problems	L
8A2	Mother: disabled	L
8A2	Mother: alcohol abuse	M
8C1	Mother: epileptic, alcoholic, severe speech impediment	M
8C1	Mother: MH problems	M
8C1	Mother: heart problems	L
8C1	Grandmother: terminal cancer	M
8G1	Mother: alcoholic	M
8G1	Mother: bad asthma, missed a lot of school in yr7	M
8G1	Mother: depressed	M
8G1	Helps care for nan	L
8G2	Mother: panic attacks	L
8T2	Father: MH problems	M
8T2	Mother: amputee	L
8T2	Mother: depressed	M

↑ Year 8 pupils [Aged 13-14]

16 Young Carers

7 pupils identified as a YC, but didn't give a name

← Year 7 pupils [Aged 12-13]

24 Young Carers, 2 pupils are former carers

5 pupils identified as a YC but didn't give a name

Class	Situation	Care
9A1	Mother: Sarcoma [cancer of liver]	M
9A1	Mother: Schizophrenia	M
9A1	Mother: deaf/mute/depressed/alcoholic	H
9C1	Father: alcoholic, disabled	M
9C1	Step-mum: Schizophrenia Father: depressed/alcoholic	H
9C2	Mum: diabetic and asthmatic	L
9G1	Mother: MS	M
9T1	Mother: 'bone disease'	L
9T1	Younger brother: leukaemia	L
9T1	Mother: died of alcohol poisoning Nan: heart problems	M
9T1	Mother: Hypoglycaemia	M
9T2	Mother & Father: heroin abuse	M
9T2	Mother: severe arthritis	L
9T2	Mother: bad back and ulcers	L
9T2	Mother: bad heart, Sister: severe disability	M

Class	Situation	Care
10C1	Mother: MH Problems	M
10C1	Step-father: alcoholic	L/M
10C1	Nan: Parkinson's disease	L
10G1	Mother: MS	M
10T1	Grandmother: heart problems Father: alcoholic	M

↑ Year 10 pupils [Aged 15-16]

5 Young Carers

5 pupils identified as a YC, but didn't give a name

← Year 9 pupils [Aged 14-15]

15 Young Carers

5 pupils identified as a YC but didn't give a name

Support to the Young Carers in School

“The minute I come home from school, I just get changed and go out again. Dad’s so depressed and is hitting the bottle again. The other day I had to rugby-tackle him to the floor ‘cause he was trying to O.D. – he’s stopped cooking for me and my sister and can’t be bothered to do any shopping. I shouted at him the other day to sort his bloody life out, he knows I’m angry and worry about him, I just don’t know what to do anymore”
[Jason, 14]

All pupils formally identified as a Young Carer were asked to tell their parent[s] they had spoken with the Young Carers Schools Development Worker and to seek approval from them to be referred to Carers Lewisham’s Young Carers Project, so they could access support and advice outside of school. They were also asked to check if their parent[s] would like the Young Carers Officer to make a home visit or carry out a benefits check.

On average 52% of pupils, identified as Young Carers, sought approval from their parent[s] to be referred to Carers Lewisham’s Young Carers Project. Many of the remaining pupils expressed a reluctance to tell their parents they had spoken about their caring responsibilities, although they were keen to receive support in school - the main reason given was that they were concerned that their parent[s] might be angry or upset if they were to discover they had spoken about private family matters. In such cases, pupils were advised to access support through the Young Carers Lunch Clubs.

Support from Teaching Staff

Teaching staff from both schools were keen to know which pupils had caring responsibilities at home, so they could give them support and avoid disciplining those who had valid reasons for falling behind in their work, difficulties concentrating in class, or changeable behaviour or attendance. Both schools agreed that Young Carers could access a classroom during break-time or the lunch hour to complete homework in recognition of the difficulties many faced in finding ample space and time to do it at home.

Pupils identified as a Young Carer were subsequently asked if they would agree to their Head of Year/House being informed of their caring situation, so if they experienced difficulties at home or with completing their homework as a direct result of their caring responsibilities, at least another person in the school would be aware of their situation. Most were keen to let teaching staff know about their caring situation, however a few expressed concern that telling their teacher would make no difference to the level of understanding given.

Teaching staff gave a great amount of support and understanding to pupils with caring responsibilities; rescheduling the timing of detentions so they could take place during the lunch hour rather than after school; allowing pupils access to a telephone to either call the Young Carers Schools Development Worker or the relative for whom they cared; showing leniency towards those Young Carers whose behaviour was challenging – in recognition that some Young Carers felt safe enough to let go of all responsibility when at school, as they couldn’t do this at home; giving support and understanding to pupils who were distressed, anxious or unable to concentrate in class because of the concern they had for the health of the relative for whom they cared.

The number of psychosocial issues teachers faced on a regular daily basis amongst their pupil population was certainly underestimated. Pupils were coming into school distressed after such instances as, the night before, having found their parent dead after successfully committing suicide; slumped on the floor through alcohol or drug misuse, or as a result of another unsuccessful suicide attempt; having been up all night comforting their relative as a result of emotional distress, paranoia, delusions or physical pain. The way in which most teachers responded to the needs of these pupils was not just admirable, but impressive. Occasionally pupils would feedback inappropriate comments made by a mere handful of teaching staff that left them feeling upset, but given that teaching staff are not trained to effectively manage the needs of such pupils, these responses were not wholly unexpected.

Support from the Young Carers Club

Throughout the duration of the Project the Young Carers Clubs were regularly attended by between 8-25 pupils. Primarily these Clubs served as an environment where the Young Carers could:

- meet other Young Carers - which in itself helped to reduce feelings of isolation by those who believed they were the only person in the school with caring responsibilities
- share their experiences of caring - thereby realising that many of their experiences were shared by other pupils.
- participate in age-appropriate activities, e.g. play games; design posters; watch videos; listen to music; have group discussions, etc.
- request access to age-appropriate health information, relating to the illness and/or disability of the person for whom they cared
- arrange an appointment with the Young Carers Schools Development Worker to discuss issues and/or difficulties at home or school, that related directly to their caring responsibilities
- request that issues they faced at home or school were relayed to an identified member of teaching staff, if they didn't have the confidence to do this themselves
- seek support and advice from other Young Carers and the Young Carers Schools Development Worker, on how best to cope with and seek support on issues they faced at home

Over time, it was clear that some pupils requesting to join the Young Carers Lunch Clubs did not initially present as a Young Carer, yet six to twelve months later they would disclose that they were, indeed, caring for a relative at home. This discovery resulted in pupils that wanted to join the Club being allowed to sign-up as a 'guest', until such time that a disclosure was made. These pupils were not given access to the Young Carers Club Card and were only allowed to stay in the club for the first 40 minutes of the lunch hour - leaving the remaining 20 minutes strictly for those that were known to be Young Carers.

The value of the regularity of the Lunch Clubs resulted in pupils who became Young Carers after the period of awareness raising lessons, and those who didn't initially identify themselves as a Young Carer, accessing support through the Clubs. However, some preferred to approach the Young Carers Schools Development Worker before or even after the Clubs took place for one-to-one support, others would seek support via telephone contact with the Project.

Support to Young Carers

All Young Carers could access the following from the Young Carers Schools Development Worker:

- one-to-one appointments when emotionally distressed, needing to off-load issues, or to seek advice and information.
- age-appropriate advice and information about the illness and/or disability of the relative for whom they cared.
- advice on issues they faced in school, and exploring ways in which the school could best respond to their needs.
- advice on the difficulties they faced at home, and ways in which either the Worker could best meet their needs, or the pupil could best resolve the difficulties they faced.
- advice on ways in which the pupil could relay to their parent[s] how they felt, or the difficulties they faced at home or school, as a result of their caring responsibilities.
- class-work and homework when absent from school as a result of their caring responsibilities to avoid falling too far behind with their studies.

Support to Teaching Staff

The Young Carers Schools Development Worker supported teaching staff by:

- giving support to those Young Carers who came into school feeling distressed, allowing teachers to continue with their school duties, rather than remain with that pupil.
- raising awareness of the needs of the Young Carers in the pupil population, and giving advice on how they could best meet their needs, given the health status of the relative and the responsibilities of the Young Carer.
- accessing information on national and local organisations, through which staff could seek further information on issues faced by Young Carers or other pupils within their school population

Example of the support accessed through the Young Carers Schools Development Project

In June 2000, a Year 10 pupil who cared for her mother made an appointment to see the Young Carers Schools Development Worker one hour before the Young Carers Club was due to take place. The pupil's mother had suddenly died only four days previously. After talking to the pupil on a one-to-one basis for nearly an hour, the pupil - a regular attendee of the Young Carers Club, wanted to tell other members of the Club that her mother had died - this was not an unfair request as other Club members had given support to this pupil as they knew a great deal about her caring situation.

As all the Young Carers made their way to the Club, the pupil began to cry and asked if the Young Carers Schools Development Worker could tell the Group her 'news'. As the death of this pupil's mother was shared with other group members, the 'flight or fight' scenario began to unfold - three pupils ran out of the room and of the nine pupils that remained, five began to cry. Two school support staff were called to sit with the Group while the Schools Worker went to find the pupils that had 'flown' from the Club, to bring them back into the room. Each pupil was then given as much time as they needed, to openly share what it meant to them hearing the death of this pupil's mother.

The domino effect of this pupil's recent loss on other members of the Club began to take hold: one pupil that cared for her Aunt for three years was told just the previous day that she had died; another pupil spoke of the time his mother had "died twice" while on a life support machine, and how he was alone in the hospital at the time; another pupil spoke of the time her mother nearly died as a result of a brain haemorrhage only 10 months previously, which eventually left her paralysed; another pupil spoke of her mother's recent admittance to hospital for alcohol poisoning; another pupil cried as she shared, for the first time, that her mother was an alcoholic; another recalled the death of her grandfather who had died after a long period of illness, through which she helped to nurse him, and another pupil spoke of his fear that his mother would soon die from her illness. Three other pupils remained silent, refusing to speak.

The importance of using therapeutic counselling skills to support pupils in the Young Carers Lunch Clubs could not have been made more explicit, yet this was the experience of just twelve Young Carers, from one of two Young Carers Lunch Clubs, in one of twelve secondary schools, in one of thirty-three London Boroughs.

Feedback from the Young Carers

In July 2000, pupils attending the Young Carers Lunch Clubs were given a feedback sheet, and asked to anonymously answer the following questions:

- would you like to see the Young Carers Club continue, and if so why ?
- has it made any difference to you, having someone at school who helps support and gives advice/information to Young Carers - if 'yes' please say in what way ?
- what do you like most and least about the Young Carers Club
- is there anything you would like to say about your experience of the Young Carers support in your school ?

The responses were as follows:

Would you like to see the Young Carers Club continue, and if so why?

I want it because all the carers like to go in there to have fun.

so other people get as much support as I have. for as long as possible

I would like to see it continue so I can still get help and advice on my situ

It give us a chance to open up and talk about there situation. I would like it to stay for till every has felt like they've had enough support and until they are comfortable with it.

Because it helps people for as long as it can last

because it helps many young people with their problems and it is fun hear.

I would like to see more people like me to have a 1 to 1 with a personal person to talk privately about their problems

Is there anything you would like to say about your experience of the Young Carers support in your school?

I think it is great have a worker in school.
She has brought many changes.
I think the worker should be able to
come to our year assembly weekly.

We should do something (like a play)
to show people what it is like. I like to
talk to Geraldine about my problems but
teachers ~~also~~ should try to understand how
it is like. I feel it is better to have
a young carers worker in the school.
So we can have someone to talk to.
She has brought about changes.

people should have a person
talk with someone they trust
I like the way Geraldine has
treated me and gave me
lots of advice I like her a lot
and I thank her for everything
She has done for me

Geraldine has said a
lot of supporting
things. ~~like~~ giving me
a lot of things like
paperwork and advice
to take.

I ~~would~~ never know
that I could get
so much advice from
such a caring person
it has changed my
mum and my life completely

Has it made any difference to you, having someone at school who helps support and gives advice/information to Young Carers - if 'yes' please say in what way?

It's made me feel sort of safe knowing that there are other people in my situation.

In lots of ways including helping me get ^{supportive} round problems I couldn't face on my own

She helps me cope with my life problem, she's helped me with stuff that I can't tell anyone else.

It has made me comfortable with who I am.

She has gave me lots of advice and helps me to understand

It has help because Geraldine has gave me advice on how to cope with stress and my problem and helped me to cope.

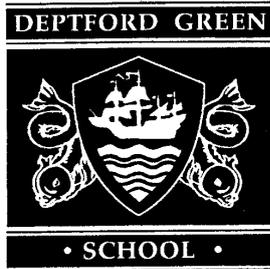
What do you like most and least about the Young Carers Club?

Like Most	Like Least
I like talking to the other young carers.	having to leave

people can trust everyone we all have fun.	there is nothing I like least.
--	--------------------------------

talking to Geraldine know that I am not the only young carer	having to tell other young carers about my problem
--	--

I have learnt alot about my problem and young carers	None
--	------



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Ms D Jones,
Chief Executive,
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London, SE23 2LA.

22nd June 2001

Dear Diana,

I would like to make a contribution to the report which is being compiled regarding the work of Geraldine Baker of Carers Lewisham which has taken place at Deptford Green School.

When the topic of Young Carers was raised at the school we were aware that we had a significant number in school, but we were all surprised at the numbers which have since been identified by Carers Lewisham.

The work that has taken place in the school has brought enormous benefit, not only to the young people, but to the school community as a whole. I would like to deal with these two areas separately, but I have no doubt that one impacts on the other.

Firstly the effect that has been felt within the school community as a whole. Through the development of our PSHE (Personal, Social and Health Education) both young people and staff have learnt a great deal about the issues that Young Carers in our society have to face as part of their every day life. This has allowed staff to be more understanding with the young people, also for peer groups to be supportive to each other when caring duties are being carried out. By providing a positive input this has allowed young people to identify themselves as Young Carers, without feeling stigmatised about their role, thereby feeling a valued part of their community within school and also within the wider society. This has assisted our school in regards to how we look at citizenship and how we become an inclusive organisation for all young people and their families.

Secondly, the effect that Geraldine's work has had on the Young Carers in our school has been very obvious to us. The work has given them the forum to discuss issues that they find difficult, and explore ways in which they can be dealt with in regards to both schools and home, also to share some of their experiences in working

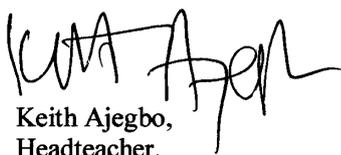
through these problems. But ultimately the groups have given them a sense of belonging and identity, which is very important especially to young people.

We have experienced some very significant changes in the behaviour and development of the young people who are Young Carers that attend the school. We have seen changes in the way in which some of the young people previously perceived themselves, they have started to view themselves as individuals with their own right and responsibilities within the community. Most of them still have to provide caring for a long period of time, but also carry this out with much more confidence, being open to both teachers and peers when they have difficulties.

Our year 11 group which are due to leave school this year were the first group that we identified in the early days as having a significant number of Young Carers amongst them. Although there are still difficulties a significant number of those identified are now going out into society and confident young people. This can be attributed to the work of Carers Lewisham and Geraldine.

Lastly, I would like to thank you for all your hard work in the past three years, and also Bridge House Trust for providing the grant so that this work could be carried out. I hope that Carers Lewisham's association with Deptford Green School can continue in the future, and that you will be successful in securing funding for this work.

Yours sincerely,



Keith Ajegbo,
Headteacher.

Concluding Remarks to the Outcome of Awareness Raising on Young Carers in two Lewisham Schools

“When I was in lesson one day, a lady called Geraldine pulled me out of lesson. She worked helping Young Carers and giving them support and advice. She was really nice and I saw her every Thursday. During the summer holidays she arranged for me to take the Stage 1 British Sign Language Exam. She came with me and I passed the exam. I now want to be an interpreter for the deaf when I leave school” [Nde, 14]

If the numbers of Young Carers from the two Lewisham secondary schools were replicated across all twelve secondary schools in Lewisham, it would equate to there being 12,000 Young Carers of secondary school age living in the London Borough of Lewisham alone. Given that 28% of Young Carers registered with Carers Lewisham’s Young Carers Project are of Primary School age, the true number of Young Carers in the Borough could be higher still.

Throughout the duration of the Project, many professionals asked the Young Carers Schools Development Worker, “*so why has Lewisham got so many Young Carers, when other Borough’s don’t have nearly so many?*” - the answer is that Young Carers in Lewisham are only now beginning to be identified, while many of those in other Boroughs remain unidentified, and will do so unless:

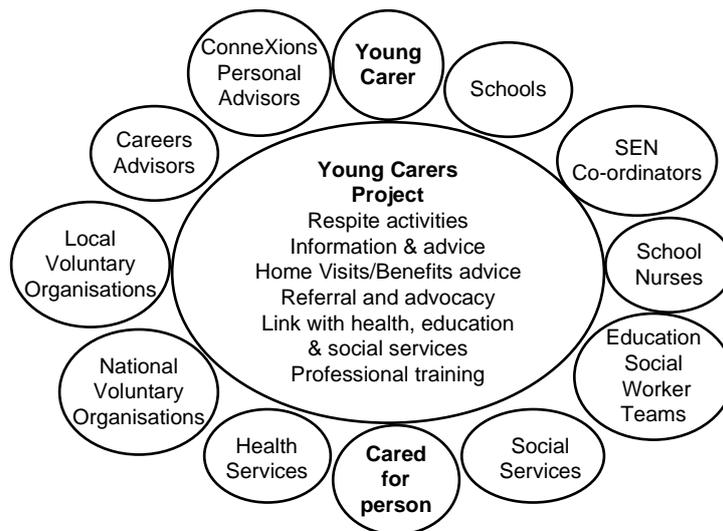
- Schools raise awareness of the issues faced by Young Carers in their PSHE curriculum and actively try and identify them through these lessons, and
- Health and social work professionals consider that a patient or client with a mental illness, long-lasting physical illness, disability of substance abuse problem may have a child at home who will be affected by and/or be giving primary or secondary care to that person.

Given the evidence of the number and experiences of Young Carers in just two Lewisham secondary schools, it is clear that something needs to change to ensure they and their families are effectively supported.

However at present, there seems to be no real sense of urgency in even prioritising services for Young Carers. It may come as a surprise that in the 4 years up to February 2001, only seven Young Carers received a statutory assessment from Lewisham Social Services. However, Lewisham are doing comparatively better than other local authorities - the total number of Young Carers assessed in the London Boroughs of Barnet, Brent, Bromley, Hammersmith & Fulham, Harrow, Kingston-upon-Thames, Merton and Westminster is ‘**zero**’ – although over 615 Young Carers are registered with the Young Carers Projects in these areas.

Surely change is now needed across all statutory and voluntary sectors to promote the health, development and well being of Young Carers affected by the ill-health and/or disability of a relative within their home. However, for any such change to be effective means that not only the rights of parents, but also the improvement of services to those who require community care must be urgently addressed.

Recommendations for Change



Joint Agency Work of Young Carers Projects

- **Recommendations to Young Carers Projects:**
Identifying and Supporting Young Carers in Schools
- **Recommendations to Teachers:**
Incorporating “Young Carer Friendly” Policies
- **Recommendations to Education Welfare Officers:**
Get Young Carers back on Track
- **Recommendations to Health Professionals:**
Look beyond the Patient and into the Home
- **Recommendations to Social Work Professionals:**
Support the Parent to Support the Child
- **Recommendations to Government**
Joined up Government
- **Standard Recommendations to ALL Statutory Professionals:**
Think “Young Carer”

Recommendations to Young Carers Projects *Identifying and Supporting Young Carers in Schools*

If Young Carers Projects want to identify and support Young Carers in local schools, the best approach to take depends very much on the time and resources available to the Project. Therefore, before any contact with schools is made, Projects need to initially consider if they are able to do one, some or all of the following:

- *deliver lessons about Young Carers in the classroom*
- *give an assembly presentation*
- *give awareness raising presentations to teaching and support staff*
- *carry-out follow-up work with pupils that have presented as Young Carers*
- *run a Young Carers Lunch Club*

- Consideration then needs to be given to the following:

Delivering Lessons on Young Carers in the Classroom:

- This will appeal more to teaching staff, upon whom there are already many demands
- Lessons take time - on average each school year comprises 8 classes, and lessons can range between 40 minutes to one hour in duration
- Personalised contact with pupils in the classroom will increase the chances of pupils self-referring
- Always ensure a member of teaching staff is present when you deliver your lesson [for insurance purposes]
- You need to put on a good performance in the classroom - good acting skills will come in useful
- Be aware of the school's procedure for dealing with disruptive pupils
- Be prepared to respond to some very technical/sensitive/inappropriate questions by pupils
- Be prepared to be swamped with requests for information on Young Carers and the Project
- Some pupils may become upset during the lesson because it may remind them of their own personal experience of caring
- Distribute an evaluation form at the end of the lesson so pupils can give feedback on the lesson and identify if they are a Young Carer
- You must follow-up all pupils that identify themselves as Young Carers [although not all will be Young Carers by our definition]

Giving an Assembly Presentation

- This is a great way to raise awareness of Young Carers to the whole school, but will not guarantee any referrals
- During the presentation, consider announcing that you will be at a specified venue in the school directly after the assembly, or will make a follow-up visit to the school one/two weeks after the presentation, either during the lunch hour or

break time, for pupils who think they are a Young Carer. Remember to specify when and where you will meet pupils who may want to talk with you.

- Not all young people necessarily have the confidence or skills to approach someone, who is relatively unknown, to talk about their personal experience of caring.
- Remember to bring along information on the Young Carers Project for distribution to pupils who may approach you after the presentation.

Giving Awareness Raising Presentations to Teaching and Support Staff

- Give staff details of national and local facts about Young Carers, [e.g. the percentage known to give primary care, caring for a parent and living in lone parent families] and the frequent effects on children providing care.
- Give staff tools with which to identify, support and refer Young Carers to the Project.
- Present case studies to bring home the reality of the issues faced by Young Carers.
- Give details of the number of Young Carers known to the Project who attend the school.
- Ask staff to put Young Carers issues onto their PSHE Curriculum – the Project Worker must be prepared to give teachers materials to deliver such lessons [try using Carers Lewisham's teaching resource pack "*Supporting Young Carers in Schools*"].
- Remind teachers of the importance of distributing evaluation sheets to help identify pupils that are caring for a relative at home – although Project Workers must be willing to carry-out the follow-up work to these evaluations as teachers just do not have the time to do this themselves.

Carrying-out follow-up work with pupils that have presented as Young Carers

- This can only be done if the school is prepared to incorporate Young Carers into their PSHE Curriculum, or gives permission for the Project Worker to present lessons on Young Carers.
- Be equipped with information on the Young Carers Project and letters to parents.
- Remember to ask pupils to seek consent from their parents so they can be referred to the Project.
- Ask pupils if they are willing to identify a member of teaching staff that they trust to whom they are willing to relay details of their caring responsibilities. This may be especially useful to those who are struggling to cope at home or at school and who do not want to be referred to the Young Carers Project.
- Be prepared for teaching staff to ask you to identify which pupils are Young Carers, after all how can they support those pupils who are caring if they do not know who they are?

Running a Young Carers Club

- Liaise with a senior member of teaching staff and request that a room be allocated for these Clubs to take place.
- Hold the Club during the school lunch-hour and ensure the designated room is in a quiet place in the school.
- Advertise the Club by distributing posters in the school [be prepared to replace them on a regular basis - they may not stay-up for long!].
- The Clubs must take place on the same day/time each week/fortnight/month.
- Design Club Cards to give the Young Carers 'membership' to the Club, to verify the reason why they are in the school building during the lunch hour [in case they are stopped by a member of teaching staff]. Also consider setting-up a system whereby pupils can show their Club Card to gain access to a school phone and get into lunch early.
- Set boundaries for all those coming to the club: no swearing, fighting, talking about other pupil's caring situation without their consent, etc.
- Consider setting-up a 'guest' system - some pupils may want to join the Club, but will not immediately identify themselves as a Young Carer until such time as they feel safe enough to disclose they are caring.
- Have a series of planned games and activities, or ask the Young Carers to plan how they would like to use the time in the Club.
- Be prepared for disruptive behaviour and arguments between Club members.
- Be prepared to deal with Young Carers who may be experiencing considerable distress. Therapeutic individual and group skills are essential.
- Keep a register of Young Carers attending the Club, and at some stage ask them to give written feedback on how they access and feel supported by the Club, for monitoring purposes

Once the Young Carers Project has decided what work it is able to carry out in schools, the Project can access schools by either writing to, or meeting with the local Councillor for Lifelong Learning or the Director of Education, or the Project could make telephone contact with the Head of PSHE/ Pastoral Curriculum in an identified school. If you send a letter it MUST be followed up with a phone call.

Depending what approach the Young Carers Project takes the Project Worker must be prepared to give details of:

- the support provided by the Young Carers Project to Young Carers and their families
- what work the Project is willing to carry out in schools
- known local and national statistics on Young Carers
- the potential benefits to the school in allowing the Project to identify and support pupils who are Young Carers

If the work of the Young Carers Project is to continue to be supported, it is essential that any outcome of work carried out in schools is relayed, with prior approval from the school, to:

- Senior teaching staff
- Councillors and Directors of both Lifelong Learning and Health and Social Care
- The Head of Education Social Work
- The Management Committee of ConneXions [where applicable]
- The Local Authority's Planning and Commissioning Department [Health and Social Care]
- Local MPs

The Young Carers Project Worker must also consider working with the following professionals as all work in schools and can help to support Young Carers:

- Schools Nurses
- Education Social Workers
- School Mentors
- ConneXions Personal Advisors
- Truancy Officers
- Special Educational Needs Co-ordinators
- School Counsellors

General

It is important that Young Carers Projects wherever possible try to work with and support the parent[s] of the Young Carer to ensure that the whole family is receiving the maximum services, benefits and support that they may be entitled to.

Recommendations to Teachers

Incorporating “Young Carer Friendly” Policies

- Do not assume there are no Young Carers in your school
- Consider including Young Carers issues into the schools PSHE curriculum - Carers Lewisham’s Young Carers Schools Development Project has produced a secondary teaching resource pack entitled “Supporting Young Carers in Schools”. The pack contains lesson materials, resource sheets and information for teachers, and strategies for schools to adopt to effectively identify and support pupils who are Young Carers.
- Ask the local Young Carers Project to work with the school, either to do an assembly, give awareness raising lessons to pupils, presentations to teachers, or to meet with pupils known to be Young Carers.
- Draw-up formal policies and procedures to support Young Carers within the School.
- If it is known that a pupil has caring responsibilities at home, permit them access to a school telephone if they appear concerned about the relative for whom they care. Allowing the Young Carer to check on the person for whom they care will help to reduce any anxiety they may have, encourage them to feel supported by the school, and help to keep them in school and able to concentrate on their lessons.
- If a pupil is known to be caring for a parent and is a poor attendee, consider what support the school is able to give in transporting that pupil to and from school – transport difficulties are one of the reasons why Young Carers who have siblings of, or who are themselves of primary school age, do not regularly attend school.
- If a parent does not attend Parents Evening, ask the pupil if their parent’s health status has prevented them from attending.
- If, on more than one occasion, a parent asks the school to allow their child to return home because a relative at home requires care, or the child needs to accompany that relative to a doctor’s or hospital appointment, consider asking the parent for permission to refer the pupil to their local Young Carers Project. A compromise should be reached between the school and the parent so that alternative arrangements can be made to avoid taking the pupil out of school. If no compromise is reached, at least ensure that the pupil is given access to lesson materials and homework details from all missed lessons.
- Set-up a Young Carers Club in the school. This could take place once a week/fortnight/month, during the school lunch hour. Ask the local Young Carers Project if it could help run such a Club.
- Consider giving Young Carers access to a classroom during the school day to complete homework. Some Young Carers may not have the time or space to do their homework after school, or they may rush through their homework because of the demands of their caring responsibilities at home.
- Distribute literature to parents about the local Young Carers Project with other mail-shots. Ask parents to contact the Project if they think their child may be a Young Carer and could benefit from the support made available through the Project.
- Young Carers are not easy to identify, but some of the indicators include: the pupil may be routinely late to and/or early to leave from school; their academic performance and ability to concentrate in class may be sporadic; they may be overly mature and responsible for their age; they may be quiet and withdrawn at times, or conversely, may display aggressive behaviour which seems ‘out of character’.

- Young Carers are often bullied – raising awareness of Young Carers issues and linked disability/mental health issues may help to reduce incidents of bullying by peers.
- Consider reviewing the school's Home School Agreement to include a question on the provision of care to a relative in the home, and the support given by, or impact on children in the family.
- Ask parents to inform the school if their child starts to carry caring responsibilities for a relative at home, emphasise the support the school would give to such pupils.
- Be careful to check the caring responsibilities of Young Carers given *after school* detentions - they may be expected to immediately return home from school to care, or to collect younger siblings. Consider detentions during the lunch hour, or alternative forms of discipline.
- Consider giving Young Carers extensions to complete their homework, if they appear to be struggling to maintain their usual academic performance.
- If a Young Carer is absent from school for a long period as a direct result of their caring responsibilities, consider sending homework to the Young Carer's home, to avoid them falling behind with their studies.
- Refer Young Carers, thought to be at risk of exclusion and with their consent, to the ConneXions Personal Advisor based in the school [where applicable]. Personal Advisors have a remit to support Young Carers.
- Ensure that all Young Carers with Special Educational Needs are brought to the attention of the Special Educational Needs Co-ordinators in the School. Individual Education Plans should highlight any impact caring may have on the Young Carer's academic or social/emotional development and make provision for that.
- Liaise with School Mentors to ensure they are aware of Young Carers issues, and identify a mentor who can work with pupils who are known to be Young Carers.
- Consider allowing Young Carers access to a school counsellor [where applicable], in case they could benefit from receiving such therapeutic support.
- Ask School Nurses to check if pupils have caring responsibilities for a relative at home, during routine health checks.
- Ensure procedures are in place to deal with bereaved pupils.

Recommendations to Education Welfare Officers

Get Young Carers back on Track

- If a young person is routinely absent from school, consideration must be given to the health status of a relative at home to whom that young person may be providing care.
- Young Carers may feel anxious to go to school and guilty about leaving the person they care for, because of their care needs. Childcare responsibilities for young siblings and/or the absence of assistance to the parent in transporting their child to school must also be taken into account when working with Young Carers who are frequent absentees.
- Consider providing home tutoring to pupils who are clearly unable to attend school as a result of their caring responsibilities.
- Ask the parent[s] what support and/or services they would like to access, to enable their child to return to school and to help ease the level of care given by their child to a relative at home. The longer a child is absent from school, the more anxious they may feel in returning to school because of the concept they have as to how far behind they may be with their studies in comparison to their peers.
- Ask the child what support they would like to receive from their school which may help them feel more confident in returning to school. Remember to ask if the child would feel less anxious leaving the person for whom they cared, if they were given access to a telephone during the school day. Also ask the parent[s] and child if they can identify a teacher who can be given details of their caring responsibilities at home.
- Liaise with the Young Carers' school, and ensure that the school has simple policies in place for supporting Young Carers returning to school after a period of absence.

Recommendations to Health Professionals

Look beyond the Patient and into the Home

- If a patient is discharged from hospital and is known to have a long-lasting illness and/or disability for which they require care, do not assume there to be an adult at home to care for them.
- Ask the patient/client if there are children in the family who may be affected by their change in health status, and if they could be referred to the local Young Carers Project for support.
- If a young person attends a doctor's or hospital appointment with a patient/client, ask what level of support that young person gives to the patient/client. Ask the patient/client if they would consider alternative arrangements so as to avoid the young person accompanying them to such appointments. Also ask what support the patient/client may require to avoid or reduce care given by young people in the family
- If a family member is diagnosed with a long-lasting illness and/or disability, ask if the patient/client would like other family members to receive age-appropriate information on that illness and/or disability. With approval from the parent[s], provide Young Carers with age-appropriate information on the condition of the cared-for relative, together with details of any associated voluntary organisations. This may help to alleviate some of the irrational fears Young Carers can have about a relative's illness and/or disability, through not being given access to, or enough information about the illness and/or disability.

Recommendations to Social Work Professionals

Support the Parent to Support the Child

- Adult Teams must consider the impact of services on all family members:
If a parent or other adult within a family is receiving community care services, it is vital that Adult Teams not only consider the role of that person within the family unit, but the impact the level of community care services may have on other family members. The level of services made available may not meet all the needs of the cared-for person - hence children may be 'filling the gap'. If the care-recipient is a parent, services must also be made available to adequately support them in their parenting role.
- Adult Teams must provide domestic support to the parent[s]:
72% of Young Carers perform domestic household chores as a direct result of the health status of the relative with whom they live. To avoid Young Carers taking on an *inappropriate volume* of domestic chores, there must be provision of domestic services to the family unit. This may also help to alleviate a parent's sense of guilt or disempowerment at not being able to perform such tasks themselves – either as a direct result of their illness and/or disability, or the demands of their own caring tasks.
- Adult Teams must support the parent, to support the child:
It is *imperative* that an ill and/or disabled parent is offered appropriate support for their disability and/or illness, which also takes account of the limitations their illness and/or disability may have on their responsibilities as a parent in that family unit.

Example:
A single parent with clinical depression may, during the course of a long depressive episode, be unable to keep the family home clean and tidy, cook meals and carry out all other household duties required of them, as a *direct result of their health status*. If children within the family are deemed to be at risk of 'neglect' because of the effect of the parent's depression, putting the children on the Child Protection Register without first offering support to meet the needs of the parent [i.e. access to support for their mental health and offering domestic support services to the family to prevent the children from taking responsibility for such household tasks], could be seen to be working against the best interests of both the parent and the children within that family. Furthermore, such action will do little to improve the depression of the parent, it may actually exacerbate it.
- Adult and Children and Families Teams must communicate:
A frequent weakness in the social care system is that departments do not talk with each other. If an adult in a family requires care, Adult Teams often forget the importance of liaising with Children and Families Team, to ensure that the needs of children within that family are also considered, alongside services given to the Adult. Likewise, Children & Families Teams often fail to liaise with Adult Teams to ensure that services given to the child[ren] correlate with the needs of adults within the family.
- Young Carers do their best to cope:
Remember that Young Carers placed on the Child Protection Register, either as a direct result of the impact of their caring responsibilities and/or the impact of a parent's ill-health and/or disability, may feel as though they are to blame or have failed, by not doing enough to keep the family together.

- Social Work Teams should seek to assess Young Carers:
If there are children in a family providing primary or secondary care, practitioners should seek approval from the parent[s] and child[ren] to make an assessment of the impact of caring. – please see pages 51-53.
- Offer counselling or play therapy to Young Carers:
With approval from the Young Carer and their parent[s], offer access to therapeutic support. This can be especially useful to those Young Carers who may have maladaptive coping skills, limited social support networks or display risk-taking or aggressive behaviour. Not all Young Carers may want or need access to this type of therapeutic support, but for some the transition from living in a family where a relative's health status is not an issue to one where it can impact on their physical and/or emotional development, can be both stressful and traumatic.
- Ensure Young Carers have regular access to leisure time:
Provide services to the cared-for relative to ensure Young Carers have at least an opportunity to participate in leisure activities on a weekly basis, thus allowing for social development.

Recommendations to Government

Joined up Government

The issue of Young Carers cuts across many of the policies and issues that are on this Government's agenda, such as educational attainment, minimisation of social exclusion, support to carers, modernisation of the NHS and Local Authorities.

Although the Government has acknowledged in the Carers and Disabled Children Act 2000, that there are a 'small number' of children aged 16 and 17 who may have caring responsibilities, the support of younger children in this position has been neglected. Defining a child in this situation as being 'in need' as defined by the Children Act can lead to stigmatisation of families who are struggling to cope in difficult circumstances and to families being even less willing to come forward and ask and accept help.

There is a need for:

1. Help to encourage Health, Social Care, Education and Young Carers Projects to work together nationally to agree a definitive definition of a 'Young Carer'.
2. Legislation that acknowledges there are children under the age of 16 who are carers, which encourages the identification of Young Carers and which encourages the assessment of the impact that caring may have on those children, without stigmatising the parents.
3. More resources to fund practical services to support parents who have disabilities or long-term health problems to enable them to adequately parent.
4. Educational policies and resources that encourage the identification and support of Young Carers within the school environment.

Standard Recommendations to ALL Statutory Professionals

Think “Young Carer”

- Reasons why Young Carers exist:
Be aware of the reasons why Young Carers exist [see pgs. 7-8], as this may subsequently help shape good practice when working with Young Carers and their families.
- Access training on Young Carers:
Contact the local Young Carers Project - they will be able to give an insight into the issues faced by, and frequent affects on children providing care. Training will also help to give an overview of the level of need of families affected by caring, and the support available to such families locally.
- Ask the Local Authority to review their transport policy for children whose parents have a long-term registerable disability:
If a pupil of secondary school age lives in a lone parent family with primary school age siblings and cares for their parent, the recommendation outlined in some Local Authority Transport Policies for children whose parents have a long-term registerable disability, is;

“The number and ages of other children within the household would...be relevant, and may have a bearing as to whether transport provision is agreed”.

It is therefore common to find secondary school age children accompanying their primary school age sibling[s] to and from school. This can not only impact on that secondary school age child’s ability to get to school on time, but their commitment to remain in school for the full school day – both of which can lead to the child being penalised by their school. Do not assume that the school is necessarily aware of the extent of a pupil’s caring responsibilities.

Current transport procedures also state that, if a primary school child’s parent has a long-term registerable disability, then to qualify for transport provision by the local authority;

“the pupil concerned should be attending at the nearest, or at least a local mainstream primary school. If the pupil is attending at a school some distance from his or her home, then consideration should be given to the pupil transferring to a primary school nearer to home”.

A parent with a disability and/or long-lasting illness has *as much right* to choose which school their child attends as any other parent. Current transport policies could be seen to be discriminatory as those parents who are physically unable to take their child to their school of choice may only be given assistance by their Local Authority in transporting their child to school if that child attends the school closest to their home - yet this may not be the school the parent[s] would prefer their child to attend.

From experience gained through running Carers Lewisham’s Young Carers Schools Development Project, if a parent with primary school age children requires assistance in getting their children to school, the rigidity of a Local Authority’s transport policy is such that the parent either has no other option but to wait until their child can be transferred to the closest school to their home before they can start attending school again, or rely on their secondary school age child [where applicable] to take their primary school age child to school, regardless of how far that school is from the family home – this merely undermines the responsibility of the parent.

Do not overreact:

When working with families where there is clear evidence of care given by a child, it is important to remember that the majority of Young Carers live in lone parent families and give primary care to a parent. Do not overreact or take punitive action just because a parent's health status may impact on their ability to parent – providing support that empowers them in their parenting is far more effective.

- Young Carers do their best to cope:
Remember that Young Carers often make enormous efforts to manage their caring responsibilities and maintain full school attendance. However some may struggle to cope all the time and subsequently their schooling, physical and/or mental health may be affected. Again do not overreact or take punitive action, Young Carers can often feel as if they have somehow failed, or feel extremely guilty for not coping.
- Liaise with the Young Carers school:
One in three Young Carers regularly miss school or have educational difficulties because of their caring role. Some Young Carers are routinely late for school, or struggle to concentrate in class. Completing homework can also be difficult if the young person has to provide care. Not all Young Carers are able to attend school every day because of the care they provide at home. If a Young Carer's school is made aware of their caring situation, the school is then in a position to give them support. It is therefore *vitally* important that, with the parent[s] and Young Carer's approval, the school is informed of their caring responsibilities.
- Refer to Young Carers Projects:
Ask the parent[s] of any Young Carers if their child can be referred to their local Young Carers Project. Having contact with other Young Carers can decrease a child's sense of isolation with their caring responsibilities. Young Carers Projects also work with the family, organise respite trips and other age-appropriate activities for Young Carers.
- 'Assess' the impact of caring on children and young people
All statutory professionals that have contact with children who may be caring for a relative at home should ask the parent[s] of that child, and the child themselves, if an assessment could be made to check the impact of their responsibilities. Depending on the needs and wishes of the child and/or their parent[s], the outcome of the assessment could trigger a referral to the voluntary and/or statutory sector for a whole range of services. The assessment may just help the Young Carer and parent[s] gauge the impact of the care provided to a relative at home. If the assessment form is used effectively, it would help to give recognition to families affected by the health status of a relative, and could help to encourage preventative working practice.

Professionals may want to refer to the Young Carers Assessment form given on the next few pages and adapt it to include the support parents may need with their parenting responsibilities - adaptations may be required to reflect the demographics of the local community.

PERSONAL DETAILS

a] Young Carer

Surname: _____ Miss/Mr Forenames: _____ Perm. Address: _____ _____ Postcode: _____ Tel. No: _____ Date of Birth: _____ Age: _____ yrs.	School/College: _____ Address: _____ _____ Tel: _____ Contact person [at school/college] _____ Does the Young Carer live with the cared for person ? Yes/No
--	---

Ethnic Origin:
 White Black African Black Afro-Caribbean Black Other Indian
 Pakistani Bangladeshi Chinese Turkish Turkish Cypriot
 Vietnamese Other [please specify] _____

b] Cared for

Mother Father Sibling Grandparent Other [Please specify] _____

Nature of illness/disability ?
 Physical illness Physical Disability Mental Health Learning Difficulty
 Sensory disability Substance misuse Heart/Stroke Respiratory
 Multiple disabilities Dementia HIV/AIDS Other [Please specify] _____

c] Nature of Caring Responsibilities

How long caring ? _____ years. How many hours a day caring? _____
 How many hours a week caring? _____

Tasks undertaken

ij Physical support
 Bathing Dressing Going to the toilet Getting in/out of bed Walking
 Eating/Drinking Medication Interpreting Shopping Cooking Laundry
 Cleaning Ironing Paying Bills Childcare Coping in Emergencies
 Hold them, to stop hurting themselves or someone else

ii Emotional Support
 Listen to them Comfort them if they feel sad or scared Keep an eye on them
 Look after them if they are drunk/have taken drugs Help them to calm down
 Help them to feel better about themselves

iii Other tasks [are there other tasks the Young Carer would like to mention?]

d] Impact of Caring

ij] Physical Health - does caring cause:

	All the time	Sometimes	Never
Interrupted sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tiredness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Backache	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aches, pains, strains	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bruising, cuts, injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ii] Mental Health - do you ever feel:

Angry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lonely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fed-Up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Is there anything else you would like to add?

Please describe the relationship between you and the person you care for ?

iii] Education - Has caring impacted on any of the following:

Time taken off from school?	Yes/No	Being late for school?	Yes/No
Finding time to complete homework?	Yes/No	Rushing homework?	Yes/No
Difficulty concentrating at school?	Yes/No	Exams?	Yes/No
Future career options?	Yes/No		
Does a teacher at school know about your caring situation?			Yes/No

What else can you say about the impact caring has on your education?

iv] Social - Has caring impacted on any of the following:

Going out with friends?	Yes/No
Pursuing hobbies or leisure activities?	Yes/No
Visiting other members of your family? [e.g. grandparents, uncle, aunt. etc]	Yes/No

Would you like to add anything else about the impact of caring on your social life ?

e] Support Required

What support would the Young Carer's parent like, to help them fully maintain their parenting responsibilities ?

What support would the Young Carer like at home, at school or with finding leisure time?

Would the Young Carer like any of the following to be made aware of their caring situation:

- | | | |
|---|--------|-------|
| a] their local Young Carers Project? | Yes/No | Name: |
| b] a named teacher at school/college ? | Yes/No | Name: |
| c] their school's ESW ? | Yes/No | Name: |
| d] their family doctor ? | Yes/No | Name: |
| e] their local Social Services department | Yes/No | Name: |

f] Action to be taken

Please give details of action to be taken to support the needs of the Young Carer, their parent[s] and other family members.

Please give details of needs that will remain unmet.

g] Summary

Supervision given by Young Carer	Little	Frequent	Most of day	Night & Day
Level of personal care given	Little	Frequent	Most of day	Night & Day
Risk of continuing care	Happy to Continue	Happy if given more help	Needs more help	Should not continue
Educational performance	Not affected	Sometimes affected	Often affected	Poor results
Education - attendance	Good attendance	Irregular attendance	V. Irregular attendance	Not attending
Young Carer's health [physical & mental]	Good	Some problems	Needs attention	Major problems
Leisure Time [on average/week]	5 days+ per week	3 – 4 days per week	1-2 days per week	No days in the week

Young Carers Assessment Completed by: _____
 Job Title: _____ Date: _____

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For a copy of “Supporting Young Carers in School: A Secondary Resource”
call Carers Lewisham on: 020 8699 8686

For details of your local Young Carers Project call either:

The Princess Royal Trust for Carers
020 7480 7788

Carers National Association
020 7490 8818

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“In the early days, Jack was affected by my drinking. He could make his own breakfast by the time he was three and there would be days when I was too hung over to get him to nursery....As I veered into a dysfunctional and occasionally violent relationship with another heavy drinker, Jack’s needs were regularly placed second to trying to cope with my increasingly chaotic life.... As time went on and things inevitably got worse, it became harder and harder to ignore the fact that I was hurting my son...Jack saw me with black eyes and a broken nose and he worried about me. He learned that I was unreliable and inconsistent. The house he lived in was dirty and chaotic, and often filled with strangers in the small hours I fell into that desperate alcoholic spiral of drinking to escape the colossal guilt and the vehement self loathing that grew bigger with every drink filled day.....[A] few days after my 33rd birthday...I was finally open to the suggestion that I go to an Alcoholic’s Anonymous meeting. That morning I took my last drink...trying to repair a relation ship with an understandably suspicious 8 year old boy...the enormity of how I had betrayed by son began to hit me....By and large children want to love their parents. Even in the most abusive home, the child yearns for reconciliation rather than escape. Certainly this was true for Jack. Did I deserve his forgiveness? I don’t know, but I do know that I was utterly grateful for it “

All names have been changed in this story. Taken from: **“Putting the Children First”, Alcohol Concern and the National Family and Parenting Institute 2001**