Young carers in Islington

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Young carers in Islington
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Contents

Summary of key findings..............................................................................................................................................3
Key recommendations ....................................................................................................................................................8
Introduction .................................................................................................................................................................10
   Aims of this research ...............................................................................................................................................10
   Methodology ..........................................................................................................................................................10
Section 1. Literature Review.....................................................................................................................................12
Section 2. Focus group ...............................................................................................................................................30
Section 3. Interviews with young carers ..................................................................................................................39
Section 4. Services for young carers in Islington ....................................................................................................47
Conclusion .................................................................................................................................................................56
Bibliography ...............................................................................................................................................................57
Appendix ....................................................................................................................................................................61

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Summary of key findings

This research was commissioned by Islington LINk primarily to explore why young carers in the borough, aged 16 to 25, did not access services for carers. A qualitative methodology was adopted to maximise the effectiveness of the study and triangulate the findings. The methods used were: a review of existing literature, in-depth interviews with young carers, a focus group with key agencies in the borough and an analysis of existing provision for young carers in the borough.

Literature review

The Literature review found that this was a vibrant area of study and the wealth of research and investigation in itself is indicative of growing interest in this subject.

The 2001 Census figures found there to be 175,000 young carers under 18 in the UK. Returns for Islington evidenced that there were at least 1515 carers under 25 in the borough. However there was general agreement in the literature that available counts probably significantly underestimate the true picture. Targeted studies and surveys, most notably those conducted in schools, have found much higher numbers of young carers and indicate that young caring may be much more prevalent than previously thought. For example a recent survey suggests that one in 12 of school-age children are carers giving an estimated total of 700,000 young carers in the UK.

Under-recording is attributed to an interaction of multiple factors, not least: the sensitivity of the Census methods and questions; a failure on the part of professionals and agencies to identify or acknowledge young carers; widespread low awareness of young carers’ entitlements and needs; and reluctance among young people and their families to make their situations known, in turn largely related to fears of the consequences of involving statutory professionals.

What also emerged from the literature was a wide spectrum of caring, in terms of how much care is provided in hours per week, as well as the type, circumstances and intensity of caring, associated responsibilities and the proportion of a young person’s life spent as a carer.

While young carers have been found to be more mature and responsible than their peers, evidence overall points to long-term negative consequences, including the impact on their own physical and mental health, education, employment, economic independence and social and emotional development. Moreover, being a young carer is commonly layered on top of other indicators of social exclusion, such as long-term familial disability, poverty and poor housing.

It is clear from the existing literature that the needs and rights of young carers are very closely intertwined with the needs of the people they look after and the needs of the family as a whole.

Legislatively, at least four Acts of Parliament aim to provide carers with both thorough assessments of their needs and services in response to these. In addition official guidance advises that where a family member is disabled and in need of care from a young carer the whole family should be assessed under the children in need provisions of the Children Act (1989). Possibly the number of different pieces of legislation and the nuances between them create confusion about young carers’ legal entitlements as few young carers are formally assessed.
While many young carers have contact with carers’ projects and/or get support from local authorities, it is widely believed that the known numbers are merely the tip of the iceberg. Much of the available literature comes from contact with those already using young carers’ services. Both these points raise questions as to the availability of services, their ability to locate and cater for young carers, and whether the needs of those not already in contact with services differ from those who are. This study attempted to bridge some of that knowledge gap for Islington.

Findings from the focus group
A focus group was conducted with representatives from seven Islington voluntary sector agencies. Two of these organisations focussed on carers and the other five provided a spectrum of services for BME communities in the borough and within that work catered for young carers as well.

The numbers of recorded young carers in Islington were believed to be an underestimate for many reasons, most notably the low numbers of recorded young carers from Asian communities.

A combination of interacting factors were reported to result in young people becoming carers while simultaneously undermining the likelihood of them being known by professionals:

- lack of information and low awareness, combined with language barriers;
- attitudes and stigma relating to illness and disability within many communities;
- cultural expectations for care to be provided by the family, especially by women and children;
- culturally related reluctance to come forward and a shame associated with involving external agencies, rather than looking after your own family; a particular fear of social services’ power to divide the family and remove children;
- a failure on the part of education, health and social work professionals to identify, acknowledge and cater for young carers;
- lack of self-recognition within the term ‘carer’; and
- previous negative experience. For example even where carers had made themselves known to authorities or requested help, their role was not necessarily acknowledged or services provided.

Suggestions made by the group for improving matters for young carers in the borough, included:

- improving information and awareness for carers and their families, especially for those who do not read or speak English fluently;
- directly addressing different cultural attitudes to illness and disability, caring responsibilities and expectations on children;
- increasing coordination and mutual awareness across relevant voluntary, community and statutory agencies, principally health, social care, children’s services and education;
- statutory services to be more active in identifying young carers, assessing their needs and in providing sensitive and responsive services for both them and the ill or disabled person;
- providing specific services for young carers, most notably respite and time out from caring, counselling, advice and practical support, within a holistic approach to the whole family.
Findings from the interviews with young carers

Face to face, in depth, qualitative interviews were conducted with five female and three male young carers, aged 16 to 25. Interviewees came from a range of backgrounds, all lived in social housing, on low incomes, and all but one lived with the people they were looking after.

Locating young carers who were not already in receipt of services proved challenging and informative in itself, and perhaps indicated some of the issues faced by professionals trying to identify young carers. Three of those interviewed were found via carers’ agencies.

All the interviewees provided substantial and regular care for members of their families, who had a range of physical conditions, mental health problems, learning disabilities and drug and alcohol dependency. Most provided care for more than one person and bore sole responsibility for that care. All had been in this role for many years.

The type of tasks ranged from supervision, administering medication, accompanying to doctors, help with physical functions such as dressing, washing and walking and dealing with mood swings, emotional outbursts and other aspects of mental illness. In addition most were responsible for the day-to-day running of the house, including shopping, cooking, cleaning, care of siblings and much or all of the paperwork, finances and budgeting.

These young carers reported that their caring responsibilities had already significantly impacted on their lives, most obviously on their education, career potential, social lives and mental and physical health. All described feeling constantly tired and stressed by their situations. Lack of support and a sense of isolation were other constant themes.

None of the eight interviewees had had a carer’s assessment, nor any awareness of carers’ assessments or what difference these could mean to them. The reasons given for the lack of assessment emerged as two-fold. On the one hand these young carers and the adults in their lives were unaware of their entitlements as carers, for example to assessments or support in their own right.

On the other hand, and possibly more significantly, these young carers were mostly not recognised as carers by relevant professionals and agencies, or referred or assessed for services, despite their regular contact with statutory bodies, including doctors, social workers, mental health workers, teachers and other educational professionals. It was commonly felt that professionals had a blind spot about these young people’s caring role, tending to take this for granted and focussed solely on the disabled person, rather than looking at the family as a whole and probing who was holding it all together.

The three young carers who had used the carers’ agencies in the borough fully endorsed these agencies and had found them extremely beneficial. All who had had access to support services or advice valued that help. Despite low awareness of legal entitlements, all were clear about what assistance they would like, which included: recognition of their role and input; respite care and breaks from caring; time with other carers; information and advice on the condition, how to best deal with it and on their own rights; general support as well as support in emergencies; advice on education, training and career options; and support for the ill person and the family as a whole.
Services available for young carers in Islington

Four agencies provide the bulk of services for young carers in Islington, mostly funded by the Carers’ Grant from the local authority. Their work is described more fully below. Some of the black and minority BME organisations and faith groups were also found to support a number of young carers as part of their general work.

Aside from these agencies, the findings indicate that awareness of young carers or their needs was low and not a priority for Islington voluntary agencies, even those dealing with health, disability or young people.

The numbers of young carers recorded as receiving services in the borough were relatively low (60 at any one time out of 1515 under 25’s). Possibly this tally is slightly low than the real figure as it only counts those in contact with Family Action, but, on the experience of this research, the overall total counting those in contact with all known services is unlikely to be more than 100. It is not easy to ascertain if there are any patterns, or if demographically some young carers in Islington are less likely to get services than others.

Across the different sources, a number of issues and service gaps were reported for carers of all ages. These included the size and types of services, responsiveness and their ability to address the often complex interplay of the needs of both carers and the people being looked after.

Overall, the findings of this research confirm many of the messages from the literature review, namely that young carers remain largely unacknowledged, despite increasing evidence of high prevalence. Their caring roles contribute significantly to the lives of ill and disabled people and arguably in keeping family members living within the community. But unfortunately these same activities have a predominantly negative impact on the young carers in the short and longer term and are aggravated by poverty, poor housing and familial disability. Multiple factors were found to contribute to young carers’ non-use of specific carers’ services. Their own low awareness of their entitlements or presumptions of negative consequences are compounded by a generalised failure to recognise them.
Comments and recommendations

A number of themes emerged repeatedly throughout the different sources and closely match those arising from the literature. These fell under four broad categories: improve steps to identify young carers, assess needs, provide appropriate services for young carers and meet the needs of families as a whole.

Improved identification of young carers by professionals and others

- Shift the onus of responsibility to make professionals and agencies responsible for actively identifying young carers, rather than waiting for young carers to make themselves known.
- More could be done to highlight and promote awareness of young carers especially among professionals and statutory and voluntary agencies.
- Target disability agencies, BME groups and others to encourage identification of young carers within their client groups, albeit this may not be these agencies’ primary function.
- Provide training and tools to promote understanding of the issues and help identification, not least to health professionals, teachers and other educational professionals.
- Increase coordination and information sharing across relevant professionals and agencies
- Encourage relevant professionals to work with local voluntary and BME agencies in recognition of the latters’ ability to engage with specific communities and work with families as a whole. These can help reach more young carers, get a comprehensive view of how caring roles are spread within families, relay information regarding entitlement and in turn increase access to services.
- Increase publicity around the borough about rights of and services for young carers
- Improve information and awareness for carers and their families, especially for those who do not speak English fluently.
- Address different cultural attitudes to illness and disability, caring responsibilities and the expectations on children.

Assessment

- Assess all individual young carers’ needs fully. Assessments are a crucial starting point. They would provide a transparent, standardised, method to both find out what individual young carers need and collate and analyse the needs of the borough’s young carers as a whole.
- Use or amend the existing carers’ assessment procedures and/or the Common Assessment Framework (CAF) and other available tools.
- Explore amending the CAF form to more clearly incorporate illness, disability and caring.
- Provide multi-agency training on how to identify and assess young carers.
- Provide specific training to those assessing people under community care legislation to fully incorporate other family members in those assessments.

Service provision

- Provide sensitive, appropriate and responsive support for young carers, according to what would make a difference for them.
• In particular provide respite care and time-out from caring, as well as counselling, advice and practical and emotional support.
• Increase coordination across relevant health, social care, educational and children’s services.
• Work closely with BME and faith groups to help develop appropriate and mutually acceptable services.
• Train health and care professionals to respect the roles played by young carers and include them in decisions on health treatment plans and care packages.
• In both identifying more young carers and service provision a very sensitive approach needs to be taken, to address fears, avoid alienation, stigmatisation, labelling or bullying.
• Given the evidence found here, services for young carers in Islington could be said to be in their infancy and in need of substantial expansion and development. Therefore this area needs to be protected from anticipated general public sector cuts.

Addressing the needs of the whole family
Much is spoken of a ‘whole family approach’ in social care and children’s services. This issue seems to cry out for it. The ‘Think Family’ pilot which ran in Islington might provide useful pointers in how to implement such an approach. Many of the physical, practical, emotional and domestic tasks, stresses and strains shouldered by these young carers could be significantly reduced by meeting the needs of the disabled and ill people they look after and looking at the needs of the family as a whole.

This directly brings up one of the most challenging issues emerging: balancing both the needs of children as children, with the needs of those requiring care. It seems necessary to deliberately attempt to allay potential parental fears that their condition and need for care may be translated as being inadequate parents and result in the family being divided. It should be possible to support the parents both as parents and as disabled people and thus relieve potential pressures on the child. If this balance is ensured it could assuage many of the fears behind families’ reluctance to engage with social services.

Key Recommendations to London Borough of Islington

1. Develop and implement within the revised Young Carers’ Strategy an action plan to increase awareness about the rights of and services for young carers.

2. Promote this action plan through schools, frontline healthcare professionals and local BME and disability organisations.

3. Highlight the need to formally assess young carers amongst healthcare professionals, social workers, and voluntary organisations. Encourage professionals to check whether anyone within the household is providing care for the service user they are working with, and where there is a carer ensure that their needs as carers are formally assessed.

4. Revise and develop the young carers’ assessment process to ensure that it is simple and accessible for everyone involved in the process to reduce barriers to access. This should be done in liaison with service users and front-line staff.
5. Continue and expand work undertaken to engage with young carers and local groups and develop appropriate services and support based on their input.

6. Explore providing a whole family approach along the model developed by the ‘Think Family’ project, but apply this to all groups/types of illnesses and disabilities.
Introduction

Young people with caring responsibilities are reported to have a range of poor outcomes, not least in regards to education and employment. Data from the 2001 Census and reported in Islington’s Young Carers’ Strategy 2008-11\(^1\) indicated there to be at least 800 young carers under 19, and over 1500 under 25, in the borough, who provide substantial personal care to others, typically family members. However, despite legal entitlement, only a tiny proportion access specific carers’ services.

Islington Local Involvement Network (LINk)\(^2\) is an independent network of individuals and agencies in Islington, which provides a means for local people to have a say in improving health and social care services in the borough. Islington LINk is supported by Voluntary Action Islington (VAI). Public consultations in Islington found that services for young carers were a concern. As a result LINk prioritised this issue and commissioned independent research to find out more about the circumstances of young carers and in particular why they don’t access services and how the situation could be improved.

Aims of this research
The aim of this research was to investigate the needs of young carers in Islington, aged 16 – 25\(^3\), who were not accessing services, and to explore the reasons behind this.

Research questions
- What is known about young carers nationally and in Islington?
- What services are available in LBI for young carers and who uses these?
- How did the young carers’ caring role come about and what types of care do they provide?
- What are young carers’ perceived physical, mental and emotional needs?
- What are the main effects of their caring role on other aspects of their lives?
- What support do young carers currently get and what are their views on support?
- What are young carer’s views on available services and barriers and enablers to accessing services?
- What do young carers and relevant agencies feel would help address barriers faced?

Methodology
A qualitative approach was considered the most appropriate for this study. A range of methods were used and data from different sources triangulated in order to enhance the validity and reliability of the findings.

The methods used were:
- A literature review to review to set out what was already known
- Qualitative interviews with young carers, aged 16 to 25 in Islington (n = 8)
- A focus group with agencies in Islington (n = 7)


\(^2\) Set up under the “Local Government and Public Involvement in Health Act 2007” by the Department of Health.

\(^3\) The upper age limit of 25 was used as this matched the age limit adopted by LB Islington. Initially the age range for this study was 18 – 25, but this was subsequently lowered to include 16 and 17 year olds.
- Interview with the Commissioning Officer, London Borough of Islington
- Web-searches, e-mail, telephone contact and interviews with agencies in Islington

The interview topic guides are given in the appendix. Data was analysed using a thematic and Framework\(^4\) approach. Ethical approval for the research was sought from, and granted by, the London Borough of Islington.

### Definitions used in this research

It had to be considered how ‘caring’ should be defined for this study. This and other implicit constructs, particularly ‘carer’ and ‘young carer’ do not have a universally accepted meaning, despite the existence of legislation and official policy. Other aspects requiring operational definitions included the type of ‘caring’ and whether any hour thresholds applied and how to refer to the people who received care.

**Young carers**: The term ‘young carer’ has been used to incorporate both children and teenagers, but the upper age limit was found to be variable, with thresholds shifting, most typically to mean 16, or 18, or 25. Moreover those aged 18 - 25 were sometimes called ‘young adult carers’. To add a little confusion in the UK most ‘adult’ law pertains to people aged 18 and over.

Legislation refers to the provision of ‘regular’ or ‘substantial’ amounts of care and the term is applied to care provided voluntarily, as in not for payment or profit. However, no more precise definition exists, in terms of any ‘threshold’ or amount, or type of care, which makes one eligible to be described as a ‘carer’.

The criteria for selecting young carers for interview for this study were that they were:
- resident in the London Borough of Islington;
- aged 16 - 25\(^5\);
- caring for someone who was ill or disabled, which was taken to include mental illness, physical illness, learning disabilities and addiction to drugs or alcohol;
- providing ‘regular’ and ‘substantial care’, which was interpreted to mean at least 20 hours per week;
- not assessed, by social services, or receiving carer’s services as a result of such an assessment.

It was initially thought that a qualifying period might be needed, but in practice this was not necessary: all those interviewed had been carers for many years. A few young carers, who otherwise met the criteria, were declined because they lived outside the borough and others because they were not deemed to meet these thresholds.

**People being cared for**: There is no single term or universal terminology to encompass all the types of people who may require care. Mental illness and some long-term physical conditions are often referred to as ‘illnesses’ rather than ‘disablments’ and so both terms are used in this report. For instance in this study a wide range of physical illnesses and disablements, mental health conditions and learning disabilities as well as long term drug and alcohol misuse arose.

The report follows the definition of disability laid down in the Equality Act 2010:
- they have a physical or mental impairment
- the impairment has a substantial and long-term (meaning one year or more) adverse effect on their ability to perform normal day-to-day activities (including everyday things like eating, washing, walking and shopping)

Different terms are used in this report to reflect as closely as possible the individuals in question and their

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\(^4\) Framework is a method of analysing qualitative data, developed by NatCen (http://www.natcen.ac.uk/about-us/our-approach/framework). Qualitative data is summarised and inputted into charts, structured according to subjects & themes.

\(^5\) Originally the age range was 18 – 25. It was widened to help attract interviewees
Section 1. Literature Review

Introduction
The aim of this literature review was to provide a brief, ‘rapid’ overview of the existing literature, rather than a ‘systematic’ review, to summarise the main findings from available literature in the field and present the primary and recurrent concerns or issues emerging from the literature.

Definitions and scope of this review
To ensure maximum coverage, this review used ‘young carer’ as the search term and reports any distinctions made regarding different age groups. Particular attention was paid to studies relating to carers aged 16 to 25. It is likely that at least some of the issues pertaining to ‘adult’ carers are also important, although these sources were not reviewed, but some are included below where it was impossible to get separate or discrete figures for young people.

Scope of available literature
A substantial body of literature on ‘young carers’ was found, mostly dating from the early 1990’s onwards. This is in itself suggests that the subject is topical and has attracted considerable attention over the past two decades. To narrow the field and to get the most up to date sources, this literature search was limited to items published from the year 2000 onwards and to UK publications. Books, journal articles and online reports as well as some ‘grey literature’ (studies or reports not published) from reputable bodies were included in the search. Searching focused mainly on research, especially primary studies, but also included some policy documents, legislation and guidance. The following databases were used: ChildData, the British Library, Social Care Online and Google Scholar. Using the terms ‘young carer’ and ‘young carers’, the search of ChildData returned 114 relevant sources. The British Library search found 16 references since 2000 and 61 since 1990. Social Care Online returned 85 and the Google Scholar search 58. In addition an internet search was conducted across reputable research bodies and agencies with a known interest in this field, such as Loughborough University’s Young Carers’ Research Group, the Joseph Rowntree Fund, Barnardo’s, Carers UK and The Princess Royal Trust for Carers. Searches in different locations yielded many of the same resources, indicating that a saturation point was being reached. The main themes found in the reviewed literature, judged to be most pertinent to this piece of research and covered in order below are:

A. What is known about young carers, prevalence, demographics and characteristics
B. What are the reported effects of providing care on young people
C. Young carers’ entitlements and needs Explanations behind the non take-up of services by young carers
D. The inter-relationship with issues and service needs of those receiving care

Some of the sources provide an overview of the issues (for instance SCIE, 2005⁶; Roberts et al, 2008⁷), whilst others deal with individual themes. Some of these are inter-related: for instance


Berni Graham
Young Carers in Islington 2011
Page 12
knowledge about the numbers or characteristics of young carers might well influence the availability and supply of services.

A. The prevalence of young carers, demographics, characteristics and roles

A.1 National data on young carers

Most of the statistics and reports available are based on analysis of the 2001 Census. The 2001 Census asked:

“Do you look after, or give any help or support to family members, friends, neighbours or others because of long-term physical or mental ill-health or disability, or problems related to old age? (Do not count anything you do as part of your paid employment).”

The answer options provided were:

- • No
- • Yes, 1–19 hours a week
- • Yes, 20–49 hours a week
- • Yes, 50+ hours a week

It is widely suggested that the Census figures are underestimates, which is discussed further below. Moreover, as mentioned earlier, the use of different upper age thresholds needs to be borne in mind when comparing data, as it is sometimes difficult to get comprehensive and comparable figures for the age group 16 to 25. Indeed figures relating to working age people may also include those aged 16 and over. Distinctions are made clear for the figures given below.

Using the 2001 Census, the Princess Royal Trust for Carers estimated that of the 6 million carers in the UK, 175,000 were aged under 18; that of these 50,000 provide care to someone with a mental health problem and that over 13,000 young carers provide more than 50 hours care per week. Secondary analysis of the 2001 Census by Becker and Becker (2008) showed that there were 61,051 carers aged 16 and 17 in the UK, 12% of whom provided 20 to 49 hours care per week and 7% more than 50 hours per week. They also show that there were 229,318 ‘young adult carers’ aged from 18 to 24, representing 5.3% of the UK 18-24 population, or 4.8% in England alone or 5.7% in Wales. Of this age group, 13% provided 20 to 49 hours care per week and 12% 50 hours or more per week, which is slightly higher than their younger counterparts.

Dearden and Becker (2004) examined the profiles of 6178 young carers across the UK who used carers’ projects. They found the average age to be 12, that one in ten cared for more than one

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10 Dearden,C., and Becker, S., 2004, Young carers in the UK, London, Carers UK
person and that half provided up to 10 hours care per week, but that two per cent provided more than 50 hours per week.

Young carers have been found to look after relatives with a range of conditions, including mental or physical illness, disability, or alcohol or substance misuse. In other words, no typical types of disability prevail. Nationally, the rates of young women being carers are somewhat higher than those for young men: 4% of young men aged 16-29; and 6% of women aged 16-29 are estimated to be carers.

Young, Grundy and Kalogirou, (2005) found clear geographic and BME variations in the proportion of the population providing informal care. They used a threshold of 20 hours or more of care-giving per week in their analysis across people aged 16 or over and also employed geographical and population-wide indicators for poor health as potential indicators for incidence of care giving. Once other factors were controlled for, they found that the likelihood of care-giving was highest in Wales and the North of England and lowest in the South East of England generally. However the London boroughs of Newham, Tower Hamlets and Barking and Dagenham were among the local authorities with the highest proportions of the population providing intensive unpaid care in the UK. They found that poor health and deprivation, both at an area and individual level, were associated with an increased propensity to provide care.

They also found clear BME differences in the likelihood of providing intensive unpaid care: with people from Bangladeshi and Pakistani communities more liable to be care givers than those from other BME groups, once other factors including socio-economic status, age and sex (of young carer or person being cared for?) were controlled for. However they also state that it is hard to be accurate about rates of providing unpaid care among the BME populations for a variety of reasons. Their analysis of the 2001 Census data also indicated that half the BME carers lived in London, with generally higher rates among Bangladeshi, Pakistani and Indian people.

Using data from both the 1991 and 2001 Census for those who were aged 20 to 29 in 2001, Young, Grundy and Jitlal (2006) found that:

- The likelihood of care-giving for 20 or more hours per week was higher among young women and was also higher among those who had been living with one parent rather than two parents in 1991;
- Care-giving was strongly age-related and on the whole increased as people got older. It was higher among 25–29 year olds than those aged 20–24. Moreover the proportion of people aged 20–29 with care giving responsibilities in 2001 was 1.3 per cent.
- Becoming a carer earlier may have a greater lifelong impact on income and socio-economic status, in terms of, for example, reduced opportunities for education, employment, saving and pension entitlement;
- A common reason for young women aged 20 to 29 becoming carers was having a child who was disabled or long-term ill;
- Across both genders, the proportions providing extensive care were highest among those with fewer or lower educational qualifications and those not in the labour force, regardless of their background or other factors.

• Young women providing at least 20 hours care per week were 62% less likely to be in full-time work than their peers; and for young men the rate was 34%. But part-time work did not seem to be affected. The researchers could not determine how much of this was mainly related to care-giving as opposed to other factors, such as low qualifications, or indeed which was cause and which was effect: did those with the lower employment prospects find care-giving a suitable option, or did care-giving impact on their ability to get better qualifications or employment.

In terms of carers from BME groups, there is a lack of studies available for the 16 to 25 age group. However the findings of a national study commissioned by Carers UK and conducted by the University of Leeds\(^\text{15}\) is interesting. They collected 1,909 survey responses and subsequently interviewed 134 BME carers aged 25-64 in ten different areas of Britain. Their findings are arguably relevant nonetheless given Islington’s ethnic diversity. The key findings include:

• Non-White carers in this study were more likely than White British carers to be ‘struggling’ financially;
• Ethnic minority carers were especially likely to be caring for a sick or disabled child or for someone with a mental health problem;
• Proportionately more ethnic minority carers were caring in circumstances where Direct Payments were being used to arrange services;
• Ethnic minority carers were especially likely to say they felt restricted in using services because they lacked information, or because services were too expensive, lacked flexibility, or were not suitable for their individual needs.

A.2 Regional data for London

The Department of Health commissioned Leeds University (2010) to conduct an analysis at regional level for each of nine English regions, to provide information about numbers, characteristics and trends of carers as well as their health and well-being, based on the 2001 Census. Table 1 below is borrowed from their report\(^\text{16}\).

Table 1: London young carers by sex and hours caring per week from ‘Carers in the Region’ report

<table>
<thead>
<tr>
<th>Carers’ Age</th>
<th>Male</th>
<th>1-19hrs</th>
<th>20-49hrs</th>
<th>50+hrs</th>
<th>Female</th>
<th>1-19hrs</th>
<th>20-49hrs</th>
<th>50+hrs</th>
</tr>
</thead>
<tbody>
<tr>
<td>5-15</td>
<td>5304</td>
<td>549</td>
<td>543</td>
<td>6133</td>
<td>651</td>
<td>636</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-24</td>
<td>15,284</td>
<td>2465</td>
<td>1442</td>
<td>17,104</td>
<td>3158</td>
<td>3132</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Their London profile estimated there to be 30,574 young carers under 20 in London and that young carers were more likely than their peers to: live in workless households; be in lone parent families; have a limiting long-term illness themselves; live in social housing; have fewer or no qualifications; and not be in either employment or education. Indeed regardless of gender or the amount of care they provided, carers aged 16-24 were found to have much lower levels of


employment and to be less likely to be in paid work than older carers, which in itself could have long-standing consequences. Young carers aged 16-19 who provided 20 hours or more care per week were found to be much more likely than other young people to not be in employment, education or training.

“Young carers aged 16-19 who provide 20 or more hours of care per week also face potential disadvantage in the labour market for many years to come, as they are less likely to have any formal qualifications”.

In total, roughly one third of the capital’s carers were from a BME group which is partly attributed to both the generally younger age profile and higher rates of illness and disability among some BME groups in the capital. In all BME groups more women than men were carers. This study also found a much higher incidence of care giving among Bangladeshi, Indian, Pakistani and mixed raced children as well as a higher incidence of care-giving among young people in London compared to other regions, although the vast majority (82%) of identified carers in London 496,913 were aged 16-64. The authors predict that the number of carers in the capital will increase by 22% because of projected increases in long-term limiting illness, disability and longevity. According to their analysis for 2007/8, a total of 405 young carers under 18 in London had a carer’s assessment and/ or review from their local authority and most of these received a respite break as a result.

A.3 Estimated rates of care-giving among young people in Islington

The London Borough of Islington Carers’ Strategy 2008-11, itself based on analysis done by the Princess Royal Trust for Carers of the 2001 Census data, estimated that there were 802 carers aged 19 and under in the borough, about 10% of which received carers’ services. As this research focussed on young people up to 25, further analysis of the Census data was undertaken. Statistics supplied to the researcher by LBI indicated a total of 1513 young carers aged under 25 in the borough. The numbers and their ages are shown in Table 2 below. On the basis of these figures, approximately 11% of Islington’s estimated carers (13,535) are under 25.

Table 2: Numbers of young carers by age in LB Islington, from 2001 Census

<table>
<thead>
<tr>
<th>Age</th>
<th>Total – LBI population</th>
<th>Total Providing no care</th>
<th>Total providing care</th>
<th>Providing 1 to 19 hours -</th>
<th>Providing 20 to 49 hours pw</th>
<th>Providing 50 + hours pw</th>
</tr>
</thead>
<tbody>
<tr>
<td>All People, of all ages, in LBI</td>
<td>172,253</td>
<td>158,718</td>
<td>13,535</td>
<td>9114</td>
<td>1668</td>
<td>2753</td>
</tr>
<tr>
<td>aged 0 to 4</td>
<td>11,106</td>
<td>11,106</td>
<td>0</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>aged 5 to 7</td>
<td>5986</td>
<td>5971</td>
<td>15</td>
<td>6</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>aged 8 to 9</td>
<td>3842</td>
<td>3815</td>
<td>27</td>
<td>18</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>aged 10 to 11</td>
<td>3899</td>
<td>3850</td>
<td>49</td>
<td>43</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>aged 12 to 14</td>
<td>5717</td>
<td>5550</td>
<td>167</td>
<td>121</td>
<td>30</td>
<td>16</td>
</tr>
<tr>
<td>aged 15</td>
<td>1655</td>
<td>1588</td>
<td>67</td>
<td>59</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>aged 16 to 17</td>
<td>3639</td>
<td>3386</td>
<td>253</td>
<td>203</td>
<td>23</td>
<td>27</td>
</tr>
<tr>
<td>aged 18 to 19</td>
<td>3351</td>
<td>3127</td>
<td>224</td>
<td>172</td>
<td>28</td>
<td>24</td>
</tr>
</tbody>
</table>

17 As above
18 Table extracted from 2001 Census - standard tables, Table: S25 Sex and age by general health and provision of unpaid care ONS Crown Copyright Reserved [from Nomis on September 5 2007]; Area type local authorities: district / unitary; Area name- Islington. Most of this data can also be found in LB Islington Young carers Strategy 2008-11, Appendix 3.
At first glance, Table 2 appears to show a positive association between age and caring responsibilities, with much higher rates from the age of 16 upwards. However this relationship is not linear, as those aged 15 in 2001 did not follow this trend and there is a clear spike for those aged 12-14.

Further analysis of the Islington data shows that:

- Out of the total of 1513 carers aged under 25, 905 (60%) were female and 608 (40%) male, which seems in keeping with national trends;
- 357 provide 20 hours or more care per week and of these 189 provide 50 hours or more care per week; and
- Out of 322 carers aged up to 15\textsuperscript{19}, 148 (46%) were from BME communities. Table 3 provides a more detailed breakdown of ethnicity.

### Table 3: Ethnicity breakdown of LB Islington young carers aged 5 - 15

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Number of carers in group in LBI</th>
<th>Percentage of this LBI population who are carers</th>
<th>Total LBI population, 5-15 yr olds</th>
</tr>
</thead>
<tbody>
<tr>
<td>White English</td>
<td>174</td>
<td>1.69%</td>
<td>10,309</td>
</tr>
<tr>
<td>White Irish</td>
<td>15</td>
<td>3.46%</td>
<td>433</td>
</tr>
<tr>
<td>White Other</td>
<td>35</td>
<td>1.87%</td>
<td>1871</td>
</tr>
<tr>
<td>White &amp; Black Caribbean</td>
<td>12</td>
<td>1.43%</td>
<td>840</td>
</tr>
<tr>
<td>White and Black African</td>
<td>3</td>
<td>0.88%</td>
<td>341</td>
</tr>
<tr>
<td>White and Asian</td>
<td>3</td>
<td>0.90%</td>
<td>333</td>
</tr>
<tr>
<td>Other mixed race</td>
<td>9</td>
<td>1.78%</td>
<td>507</td>
</tr>
<tr>
<td>Indian</td>
<td>0</td>
<td>0</td>
<td>244</td>
</tr>
<tr>
<td>Pakistani</td>
<td>0</td>
<td>0</td>
<td>136</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>6</td>
<td>0.56%</td>
<td>1068</td>
</tr>
<tr>
<td>Other Asian</td>
<td>0</td>
<td>0</td>
<td>202</td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>24</td>
<td>1.95%</td>
<td>1229</td>
</tr>
<tr>
<td>Black African</td>
<td>30</td>
<td>1.23%</td>
<td>2437</td>
</tr>
<tr>
<td>Black Other</td>
<td>11</td>
<td>2.20%</td>
<td>501</td>
</tr>
<tr>
<td>Chinese</td>
<td>0</td>
<td>0</td>
<td>371</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>0</td>
<td>0</td>
<td>292</td>
</tr>
</tbody>
</table>

Using these figures, some groups show higher rates of providing care than others, most notably young Irish people and those who identify themselves as ‘Black other’. However what is most striking about this data is that the rates for those from Asian backgrounds do not tally with other national or London studies mentioned above. This could be for any number of reasons, such as: Asian carers or Census completers in Islington being less likely to recognise themselves as ‘carers’ than in other areas; the Census collection methods; the relationship with literacy levels; or simply that Islington does not follow the trend.

\textsuperscript{19} Unfortunately figures were not available for older age groups.
A.4 The reliability of available data, suspected under-recording and other studies

As stated, most of the data and analysis reported above is based on the 2001 Census which was over nine years old at the time of writing. The value of the Census is that it is national and the most comprehensive, feasible and known data collection method to cover the whole population. However some communities may be under-recorded for numerous reasons and further under-counting of carers is considered likely because of the concepts and context: for example the Census relied on those completing the returns to recognise their children as carers and/or themselves as having health problems or disabilities; and being prepared to say as much in the return. The 2011 Census also inquires if respondents provide unpaid care and if so for how many hours per week. It will be interesting to see if this is any more successful at capturing the numbers of young carers.

A number of small-scale studies provide some indication of potential prevalence, such as Warren (2008)20 and Barnardo’s. The latter conducted a YouGov survey across a sample of 1000 primary and secondary school teachers, asking among other things how they identified and supported young carers. They found that 91 per cent of teachers believed that some young carers remain unidentified; 78 per cent believed that young carers’ families deliberately took the decision not to inform social services for fear of unwelcome consequences; about 75 percent felt that young carers themselves hid their situation from both teachers and other children; and 50 per cent felt that the systems used by schools to identify and support young carers were inadequate. Barnardo’s also conducted interviews with 83 members, aged 6 to 19, from its young carers’ projects. Most were aged between the ages of 13 and 15, and on average provided 17 hours of care a week. But a small proportion provided substantially more: one fifth (16) provided between 20-30 hours a week and six children and young people provided between 30-40 hours per week. The most commonly mentioned conditions requiring care were a physical disability, mental health problems and poor physical health21.

In November 2010 the BBC reported on a survey conducted across 4029 school children they had commissioned through the University of Nottingham, using a validated assessment tool. One in 12 of those who responded said they had caring responsibilities. On the basis of this the BBC calculated that there are 700,000 young carers aged 5 to 18 in the UK22.

A House of Commons Select Committee described young carers as ‘under the radar’ and reported that despite recent improvements many remained unidentified23. Becker (2004)24 identifies young carers aged 18 to 24 as an even more likely to be hidden than their younger counterparts and says there is a need for further research on their particular needs, as well as the development of appropriate services. He reports that caring is commonly a long-term role: many who were carers as children will continue providing care as they grow older and into adulthood.

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24 Becker,S., 2004, Carers, in Research Matters, special issue, pp 5-10
A.5 The nature of the care provided by young carers

In one of the largest surveys of its kind, Dearden and Becker (2004)\textsuperscript{25} collected responses from 6178 young carers, who were using 87 young carers’ projects around the country. The only drawback to this study is that by definition it focussed on young carers already known and accessing services to some degree. Nonetheless their results are extremely interesting and illustrate the significance of the help provided by young carers. They provide useful definitions of different types of caring and conclude overall that the situation for young carers had improved somewhat over the previous seven years, but that there was no cause for complacency. Some of their key findings were:

- These young people provided care to people with a range of illnesses and physical and mental health problems. Half of all the conditions were of a physical health nature; 29 per cent were mental illness; 17 per cent learning difficulties and 3 per cent sensory impairments.
- Just over half (56\%) of these young carers lived in lone parent families.
- The majority of people with care needs were mothers; especially in lone parent families.
- In two parent families just under half (46\%) of those receiving care were siblings, and of these just under two-thirds (63\%) had learning difficulties.
- One in ten young carers provided care for more than one person.
- A small percentage of the adults with care needs were in employment.
- Over eight in ten (82\%) of the young carers provided emotional support and supervision; two thirds domestic help in the home; just under a half (48\%) general and nursing-type care; 18 per cent intimate personal care; and 11 per cent child care.
- Intimate care was most common where the person with care needs had a physical health problem or disability; and emotional support where the person had mental health problems.
- Overall, girls were more involved in all types of caring tasks, especially as they got older.
- Half the young carers were caring for 10 hours or less per week; one third for 11-20 hours per week; and about one-sixth (16\%) over 20 hours per week. Some (2\%) were providing over 50 hours each week.
- Young carers at both primary and secondary school experienced problems at school. These were greater for those caring for someone who misused drugs or alcohol.
- Roughly one in five (18\%) of these young carers had been assessed, which was seen by the researchers as an improvement on earlier data.
- Both young carers from BME backgrounds and young carers caring for someone with drug or alcohol problems were found to be more likely to have been assessed, especially under the 1989 Children Act.
- Caring was quite a long-term commitment for many children, and could start at an early age. Over two-fifths (44\%) of these young carers had been caring for 3-5 years; over one-third (36\%) for 2 years or less; just under one-fifth (18\%) for 6-10 years; and 3 per cent for over 10 years.
- One fifth of the young carers and their families received no other support except for the young person’s contact with a specialist young carers’ project.

\textsuperscript{25} Dearden, C., and Becker, S.,2004. \textit{Young carers in the UK, the 2004 report}, London, Carers UK.
Aldridge and Becker (2003)\textsuperscript{26} conducted a qualitative study with 40 families and found that the type and extent of the care required or provided by children and young people was directly related to the nature and extent of the parent’s illness and commonly included taking on (additional) domestic duties, household management and providing emotional support, although the latter was more difficult for both carers and those cared for to quantify. They also report that the need for assistance from the children persisted even where parents got additional support from outside the home.

Aldridge and Sharpe (2007) gave cameras to 20 young carers who were providing care to parents with severe mental health problems, to help record their daily caring activities and to overcome the inadequacies of interviews and other research methods in accurately capturing details of their lives and responsibilities. Amongst other things, this study demonstrated the wide range of duties undertaken by young carers, including the administration of medication\textsuperscript{27}.

In recognition of the aspect of relativity and presumed norms, Warren (2007)\textsuperscript{28} surveyed 390 children and young people aged 11 to 15, including 12 known young carers, to explore and compare the types of tasks provided by young carers to those undertaken by their peers who were not carers. Overall, she found that young carers spent substantially more time on all types of tasks and had greater responsibilities. For example most of the young non-carers were found to have little or no responsibility and provided less than two hours light help per week in the home, mainly associated with tidying their own rooms. The young carers on the other hand tended to spend much longer in time, had wider roles in the ‘everyday running of the family home’ (such as cooking, cleaning, shopping, laundry, gardening, looking after financial matters, official paperwork and other general tasks), and provided ‘intimate personal care’ and ‘emotional support’ and often bore full responsibility for these. She also found a small group who had not previously been recognised as carers, providing even more in terms of domestic duties and caring tasks.


\textsuperscript{27}Aldridge, J., and Sharpe, D., 2007. Pictures of young caring, Loughborough, Young Carers Research Group. Available at: \url{http://www.lboro.ac.uk/departments/ss/centres/YCRG/downloadable_publications.html} [Accessed 4\textsuperscript{th} Nov 2010]

B. The effects of providing care on young carers

On the whole, most of the research focuses on the negative effects on young people of having a caring role, in terms of their own health and well being, poverty, social exclusion, education and transition to adulthood.

Dearden and Becker\textsuperscript{29} conducted interviews with 60 young people aged 16 to 25 who either provided care at that time, or had done so when younger, for a parent with a long-term illness or disability. Among other things, they found that:

- Many had educational problems, missed school and had not gained any educational qualifications. Combined with caring responsibilities, this served to exclude some from the labour market.
- Leaving home was problematic for many young carers, particularly if they had a parent who required considerable help and support.
- On the other hand, where a parent had a severe and enduring mental illness, a number of young people had reached crisis point and had left home prematurely, sometimes to be taken into care.
- Young carers matured quickly and gained practical skills that aided independence. However, these gains were outweighed by decreased educational, social and employment opportunities.
- Virtually all these young carers’ parents were in receipt of welfare benefits and were outside the paid labour market. Experience of poverty and social exclusion was common.

Howard (2001)\textsuperscript{30} echoes this latter point and through case studies illustrated problems of poverty, isolation and social exclusion facing carers, including young carers. This could compound a greater risk of poverty for some young carers resulting from having disabled parents\textsuperscript{31}. Roche and Tucker (2003)\textsuperscript{32} looked at the isolation and social exclusion concomitant with being a carer and found that this was similar to that experienced by young disabled people.

The Young Carers’ Research Group (YCRG) (2000)\textsuperscript{33} explored the experiences of young people aged 16-25 who had been caring for parents with a long-term illness or disability and found that many found the transition to adulthood difficult.

Doran, Drever and Whitehead (2003)\textsuperscript{34}, examined the 2001 Census data and established that the health of young carers under 16, who provided at least 20 hours care per week was ‘not good’. Cree (2003)\textsuperscript{35}, in a study of young carers in Edinburgh, found increased prevalence of mental health problems among young carers and that these were associated with age, gender and how long the young person had been a providing care.

\textsuperscript{29} Dearden, C., and Becker, S., 2000. Growing up caring: Vulnerability and transition to adulthood – young carers’ experiences, Leicester, National Youth Agency (A summary is available from JRF- www.jrf.org.uk)
\textsuperscript{30} Howard, M., 2001. Paying the Price, Carers, Poverty and Social Exclusion, London, CPAG,
\textsuperscript{31} Preston, G., (ed), 2005. At Greatest Risk: The children most likely to be poor, London. CPAG
\textsuperscript{32} Roche, J., and Tucker, S., 2003. Extending the Social Exclusion Debate: An exploration of the family lives of young carers and young people with ME. In Childhood, 10 (4) pp439 -456
\textsuperscript{33} Young Carers’ Research Group, 2000. Bulletin, No 1, Autumn, pp2-6
In terms of educational consequences, Dearden and Becker (2002)\textsuperscript{36} conducted a meta-analysis of other research findings, mainly from earlier small-scale studies. This showed a number of patterns and repeated problems experienced by young carers in relation to schooling, including: absenteeism, lateness, tiredness, difficulty participating in extra-curricular activities, bullying, fewer peer networks in school, poor attainment, problems with completing homework and coursework, anxiety and behavioural problems. Teachernet, a government online resource for teachers, echoed many of these concerns, but it is difficult to ascertain the source for the information cited. They report problems such as young carers falling behind with school, missing time, low achievement, bullying, isolation, emotional and behavioural problems, reluctance to disclose family circumstances, as well as having to potentially deal with bereavement, addiction and loss of income\textsuperscript{37}. In research conducted on behalf of the then DfES, Kendall et al (2005)\textsuperscript{38} identified young carers as one of the groups experiencing particular barriers in accessing examinations at the end of Key Stage 4 (GCSE level). Morgan (2006)\textsuperscript{39}, the CSCI Children’s Rights Director, reports from a workshop held with young carers where they gave their views on a number of factors, including the generally negative impact of their caring roles on their schooling.

In their large scale survey of 6178 young carers in carers’ projects, referred to earlier, Dearden and Becker (2004)\textsuperscript{40} found that the overall incidence of missed school and educational difficulties had decreased between 1995 and 1997 and again between 1997 and 2003. However, 27 per cent of their secondary school-age respondents and 13 per cent of those of primary school age experienced some problems with school, while a higher rate, about 40 per cent, of the children caring for someone who misused drugs or alcohol had educational difficulties.

The Manchester Carers Forum and the Young carers Research Group explored the mental well-being of 50 young carers, aged 7 to 17, who at the time were not in receipt of services. Using a validated psychological measuring tool they found indicators of both positive mental well-being among respondents, such as emotional closeness, resilience and optimism, but also some worrying negative trends\textsuperscript{41}:

“\textit{The findings show clearly that older participants (in the 14-17 year age group) were less optimistic about the future, had a poorer self view, depleted levels of interest (in new things) and did not feel as close to others in their lives. These children had been caring for twice as long as the younger children in the study before receiving any formal support services and this is an important factor in the degree of negative responses among this age group. Gender was also a significant factor in the data. Female participants had lower relaxation and energy levels, a poorer self view and less interest in new things than their male counterparts”}. (p5)

\textsuperscript{36} Dearden, C., and Becker, S., 2002, Young Carers and Education, Loughborough University, London: Carers UK
\textsuperscript{37} http://www.teachernet.gov.uk/teachingandlearning/library/youngcarersandschools/youngcarers, accessed 5/10/10
\textsuperscript{40} Dearden, C., and Becker, S., 2004. Young carers in the UK, the 2004 report, London: Carers UK
SCIE (2005)\(^\text{42}\) in its meta-analysis, reports high incidences of stress, anxiety, low self-esteem and depression, eating problems, difficulties sleeping, self-harm, social isolation, bullying and fear of bullying.

**Positive effects**

However, several sources want to counter the general pessimism and report some positive impact. Thomas et al (2003)\(^\text{43}\) like others reported negative consequences, but also found that young carers in that study had a greater sense of family closeness and more developed life skills than their peers. The latter is echoed by a US study (Stein & Rotheram-Borus Lester, 2007)\(^\text{44}\) which returned to study a group of young carers, whose parents had HIV or AIDS, after a gap of six years. They concluded that the young carers were more mature, less likely to smoke or use drugs and had not expected a similar role reversal of their own children.

C. **Young carers’ entitlements and service delivery**

Many young carers’ needs for support and services seem to logically follow from the difficulties highlighted above: for instance recognition, educational attainment, stigma, isolation and their own physical and mental well-being.

C1. **Entitlements**

Since 1990 four pieces of primary legislation have attempted to strengthen carers’ rights to an assessment of their needs and increasingly to have these assessed, even if the person they provide care to does not have or want an assessment. All but one of these Acts applies to young people under 16. This legislation is summarised in the appendix. In addition official guidance from the Department of Health recommends that young carers under 18 be assessed under the Children’s Act 1989 as children in need:

> An assessment of family circumstances is essential. Young carers should not be expected to carry inappropriate levels of caring which have an adverse impact on their development and life chances. It should not be assumed that children should take on similar levels of caring responsibilities as adults. Services should be provided to parents to enhance their ability to fulfil their parenting responsibilities.

In practice this means that young carers can request their own assessment, albeit these rights are stronger and clearer from the 16\(^\text{th}\) birthday. But up to their 18\(^\text{th}\) birthday, young carers can have their needs assessed and provided for either under specific carer’s legislation or under the Children Act 1989.

At a local level, services are funded by the annual Carers’ Grant paid to local authorities, which tends to focus on carers’ breaks, promoting well being and young carers. 2007/8 official statistics


show that in Islington 695 carers were assessed or reviewed, 405 received carer’s specific services, and 210 information only. In 2007/8 £1,241,202 was provided to LB Islington. According to Islington's Young Carers Strategy 2008-2011 60 young carers received carers’ services in the borough. However it was unclear if this figure includes all young carers known to access all potential services for young carers in the borough, or just those using Family Action services – see below.

Young carers aged 16 and over who are not working or in full-time education, can claim the weekly carers’ allowance (£54 per week) if the person they look after gets disability living allowance care component, or attendance allowance. However carers can face problems getting it due to some of the eligibility rules.

C2 Young carers’ service needs

In an earlier study, Dearden and Becker (1996), conducted a number of ‘road-shows’ with Crossroads to help identify service needs of young carers. Participating professionals repeatedly identified four broad requirements: information; recognition as carers; services; and being able to be children or experience childhood. Cline et al (2009) found young carers by surveying over 1000 15 to 18 year old young people, in schools and colleges in the South East and South coast and then conducted in-depth interviews with 46 young carers who responded. From their findings, they advocate that ‘atypical’ roles undertaken by children and young people, such as care-giving or interpreting should be ‘normalised’ and seen as part of the diverse landscape of family life; that more support and peer support should be made available to young carers; and that pastoral care at schools and colleges should aim to acknowledge and cater for young people’s obligations to their families. Small (2009) echoes this, advocating that support should be provided via schools and by teachers, given their unique contact with young carers. This article provides details of the Trafford Young Carers Project support for families and their guidance for teachers.

Taylor (2007) calls for greater coordination at Government policy level to ‘consider carers’ needs as a matter of course in mainstream policy making’. She illustrates that a number of legislative and policy initiatives aimed to improve the situations of families facing challenges often overlooked young carers or undermined other policies, intended to promote their rights. Examples given include anti-truancy policies which fail to investigate whether a child’s caring role lies behind their poor attendance; extended schools which many young carers find difficult to access because of their responsibilities and the official guidance at the time for the assessment of disabled adults. While that ‘Fair Access to Care Services’ guidance was superseded in 2010 by new guidance, the references therein to acknowledging the needs of carers and the sustainability

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of that caring (pp32-34) does not mention young carers or their specific needs. Taylor also advocates the routine use of the Common Assessment Framework for children when social workers are assessing the ill and disabled members of the family.

Some work has been done on finding out from young carers themselves what they feel they needed. For instance from a workshop held with young carers, Morgan (2006) reports that young carers want to be understood and listened to; have their roles and the impact it has on their lives and futures acknowledged; flexible services; practical help; and emotional support and information, especially from health and social services personnel. Underdown (2002) reports from a weekend festival organised for young carers. Among the feedback were desires for more support at school and improved partnership working between health and social services.

A collaborative study by YCRG and Rethink (2000) found that for young carers caring for a relative with severe long-term mental health problems the division between adult and children's services aggravated their non-recognition, even where the parents received reasonable services. Also the parents' parenting and the impact on children was commonly overlooked, even in statutory assessments. The researchers call for increased professional awareness of young people’s potential caring role; a combined family orientated and non-discriminatory approach to mentally ill patients; and assessments of children’s needs as well. Fox et al (2007) were concerned that the separation from adult social services and reshaping of children’s services into Children’s Trusts would make it harder for young carers and their families to access services. Frank et al (2008) advocate a set of key principles including a whole family approach by policy makers and professionals to support young carers and their families. Tunnard (2004) provides a useful overview of a number of evaluations of various interventions directed at supporting families where parents have a mental health problem. The Princess Royal Trust for Carers has a number of resources and tools available online to help in the assessment of young carers.

Becker and Becker (2008) provide an overview of a number of schemes mainly run by carers’ projects to support young carers. They stress that a particular focus is needed for young carers aged 16 to 25, especially to help in the transition from children’s to adults’ services. They also

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54 Underdown, A., 2002. 'I’m growing up too fast’ messages from young carers. Children and Society, 16(1) pp 57-60
found that working with younger carers aged 18 to 24 sometimes proved challenging for carers’ centres which mainly focused on older carers.

Positive pointers may be available from an evaluation conducted by Ronicle and Kendall (2011)\(^6\) of a pilot initiative across 18 local authorities, including Islington. This aimed to promote ‘family focused’ support systems to help families with young carers, especially in cases of parental mental illness or substance misuse. These were designed to provide families with ‘personalised, integrated and holistic packages of support that address the underlying factors causing young people to take on inappropriate and/or excessive caring responsibilities’ (P1). Following intervention, the researchers found a reduction in ‘inappropriate’ caring responsibilities, an improvement in young carers’ participation in activities outside the home, enhanced parental awareness of their children’s needs, as well as improvements in terms of reduced families’ needs and increased family support networks. Some areas developed a whole family assessment tool which was considered essential to underpin this work.

It is unclear however how much these new practices and approaches had become embedded in local authority practice once the pilots finished. Interestingly the researchers also note that despite agencies’ contact with and awareness of the mental health or substance misuse issues within these families, young carers had been generally unacknowledged.

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D. **Explanations behind the non take-up of services by young carers**

Much of the available literature points to a failure on the part of statutory and voluntary services and professionals, notably social services, children’s services, education and health, to identify young carers, consider their needs, or assess them even when they do come to light.

A survey of eight local authority areas in late 2008, by Ofsted (2009) found that:

- Councils and voluntary agencies had only identified a portion of the estimated young carers locally.
- Young carers whose parents had drug or alcohol-related problems or mental health problems were particularly difficult to locate.
- Young carers were not being routinely identified during assessments of their disabled parents, few were asked their views during those assessments and their needs were also routinely overlooked in the provision of services.
- The young carers interviewed for this survey (n=50) were unaware of their rights to request assessments.
- Joint working between partners to provide a holistic service to families was described as ‘work in progress’ by most of the councils examined.
- Problems were highlighted regarding the resources and sustainability of the young carer’s projects visited. Eleven of the 12 projects reported capacity problems and six had to maintain waiting lists.

As part of his role as Children’s Rights’ Director, Morgan (2006) reported from a workshop with young carers. The young people participating described how they were usually overlooked by social services, even when their ill or disabled parents were assessed for services:

> “Some had experienced social services staff coming to their homes to do assessments, but these had not often led to help for the young carers and their families. Some young carers had met social workers who were looking at what their parent needed, and those often seemed satisfied if the young carer was doing a good job looking after their parent, but didn’t seem to pay too much attention to what the young carer was going through themselves. What often happened, we were told, was that social services did an assessment but decided that all was well because the young carer seemed to be coping.” (Morgan’s emphasis)

Golding (2007) perceives the cause of the failure to recognise young carers’ needs as the split in responsibilities and activities between adults social care services and children’s services. In research commissioned by the National Assembly of Wales, Thomas et al (2003) found extensive failure to recognise young carers and their needs by many professionals working within education, social services and health spheres.

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Similarly Fox (2007) noted that despite school nurses’ potential contact with young carers, the latter’s caring roles often remain hidden. In this and in Obadina’s (2010) report, which looked mostly at parents with mental health problems, the potentially important role of school nurses in identifying young carers was stressed. Hirst (2005) suggests that, given their relatively good contact with carers, GPs could play a crucial role in identifying and providing information and advice.

Jones et al (2002) conducted mixed methods research, including peer interviews among mainly black and BME young carers and their families in Manchester. They found a failure on the part of professionals and agencies to recognise the caring and domestic roles of the young people, or provide adequate support to young people with caring responsibilities and that this occurred alongside a high level of unmet social, personal and in some cases medical care needs among those being cared for. They attribute this invisibility of children’s and young people’s contributions to their family life and to supporting disabled people within the community to: the low status accorded to children’s labour and skills within wider society; cultural assumptions about how black families cope; institutional racism; and fears that the parents will be seen as ‘inadequate’ and that it may result in children being taken into care, which in turn was noted as a statistically higher probability if parents are both black and disabled. Moreover even when requests for assistance had been made by the families in this study, these were rarely met. As a result, the child becoming a carer was not so much a choice, as evidence of the lack of alternatives:

“Parents were sometimes forced into dependency on their children because there was no alternative source of support. Although young people seemed to manage in these circumstances, it was usually at considerable cost, for example completing homework at 2 am, once all the household tasks were completed.”

Greene et al (2008) echo some of these findings in a study on BME parents who had mental health problems. They starkly conclude that people from BME communities with mental health problems are poorly served by mental health services and are reluctant to use services because they are not culturally sensitive and that the resultant lack of treatment and support can impact on their children.

Tisdell et al (2004) report on a Scottish qualitative research project which interviewed service providers and children to explore how children were affected by their parents’ HIV status and the adequacy of service provision. Despite the children’s involvement in their parent’s HIV care few statutory services were received, but they appreciated support received from voluntary services.

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69 Jones, A., Jeyasingham D., and Rajasooriya, S., (2002) Invisible families: The strengths and needs of black families in which young people have caring responsibilities, Bristol: Joseph Rowntree Foundation
E. The inter-relationship with issues and services for those requiring care

One feature emerging from the above is the difficulty separating young carers’ responsibilities from the conditions, context, needs and professional interactions of the person to whom they provide care (Greene et al, 2008). The Child Poverty Action Group describe a ‘double jeopardy’ for young carers: they are one of the groups of young people most likely to live in poverty and experience relative deprivation due to their parents’ ill-health or disability and then later in life this heritage is compounded by their own low academic attainment and low employment rates (Preston, 2005). Dearden and Becker (2000) interviewed 60 young carers and found that many families received no or inadequate social care services and even where services were provided they were sometimes inappropriate, intrusive, or too costly.

Schofield and Walsh (2010) review research on the complexity of the interrelationship between parental mental health problems and their children’s needs and the difficulty balancing the two in extreme cases. They focus in particular on the impact that the reversal of the caring role may have on ‘attachment’ and find that while some caring may help young people mature and develop, being ‘overwhelmed by caring demands’ can impair development.

In a slightly different vein, Wates (2001) a member of the Disabled Parents’ Network, argues that too much emphasis has been placed on supporting young carers to continue in inappropriate roles, rather than addressing the support needs and rights of their parents and thus enabling children to be treated as children. In a study for the Joseph Rowntree Foundation in 2002, she followed this up by examining what disabled and ill parents needed to support them in their parenting roles. Taylor (2007) highlights contradictions in the current legislative framework and official policy between the rights of children as carers and the rights and responsibilities of parents who are disabled.

Olsen and Wates (2003) review research on disabled parents and young carers and advocate a more co-ordinated and holistic approach across adults and children’s services and other voluntary and statutory agencies. Again, the Department of Health official guidance, referred to previously, provides a framework to consider both sets of needs.
Section 2.  Focus group

A focus group was conducted with Islington agencies to get their perspectives and gather as broad a range of views as possible on the issue. As well as the local authority, expressions of interest were invited from local Islington voluntary organisations, on the basis of their potential contact with carers, ill or disabled people, young people and BME communities. In the end a shortlist of thirteen agencies were invited and seven attended. Five of these represented different African groups with one working as an umbrella agency for the whole continent. No-one from an Asian organisation, disability group or the statutory sector attended.

The key discussion points were:

- What is known about young carers in Islington?
- Why, on the whole, do young carers not access services?
- What can be done to increase young carers’ use of services and the appropriateness of services for young carers?

Key findings

1. What is known about young carers in LB Islington?

The group looked at data from the 2001 Census on the number of recorded carers under 25 in the borough (1513) and discussed how this compared with their contact with and experiences of young carers.

Whilst the Census figures for the number of young carers in Islington were higher than those present had expected, there was broad agreement that these were likely to be an underestimate for a number of reasons:

- some people would not have completed the Census;
- language barriers, especially difficulty in reading and writing in English would have resulted in fewer returns from certain communities;
- adults completing the forms may not have recognised their children in the terminology or questions relating to carers;
- some families would have been reluctant to report their children as carers to officials; and
- the statistics were already ten years old.

Everyone was surprised that the Census reported no Indian or Pakistani young carers in the borough and believed that the real rates of young carers in these populations were probably higher.

In terms of age, the group members provided examples of children as young as 5, 7, 8 and 9 who were the main carers for adults with conditions such as multiple sclerosis, HIV and mental health problems and for siblings with learning disabilities. Some lived in lone parent families and the absence of other adults may have had some causal effect in them acquiring a caring role.
Agencies experienced broadly equal numbers of male and female young people providing care and suggested that the borough-wide and national statistics showing higher numbers of female carers might possibly reflect young men’s reluctance to identify themselves as carers.

For time reasons, the caring duties undertaken by young carers were only briefly discussed and the conversation mainly concentrated on extra domestic chores and interpreting taken on by young carers. Different cultural norms emerged as important in relation to domestic duties. Children and young people in many African communities may be expected to take on more domestic duties that their peers and it may be difficult to distinguish between those ‘normal’ expectations and any additional responsibilities arising from becoming a carer. Interpreting was said to be often inappropriate, especially where it involved discussing intimate symptoms such as incontinence, sexually transmitted disease, or mental health. Using a child to interpret was also said to affect the detail and comprehensiveness of the information flow in both directions and lead to other problems.

It was reported that young carers were generally much more mature than their peers, which could also create problems with forming friendships.

2. Why, on the whole, do young carers not access services for carers?

This was the main focus of discussion. Given that most of those present represented African groups, much of the discussion centred on African communities and indeed on the Somali Muslim community. It is not possible therefore to say how much this information is transferrable to other BME communities.

Low access to carers’ services was attributed to a complex interplay of several factors, which were grouped as follows:

- Cultural attitudes to illness and disability, caring duties and involving external services
- Lack of awareness, coupled with inadequate information, language barriers and the jargon and terminology relating to ‘carers’
- The approach of professionals, failure to identify carers, the assessment process, lack of cultural awareness and attitudes to involvement with Social Services.

- Cultural attitudes

Here the predominant issues raised by the group were: stigma attached to illness and disability; expectations that family members, especially women and children, should look after others and concomitant shame and reluctance attached to involving the state or external services to do so.

There was said to be a huge stigma around disability in general and that this was even worse in relation to certain conditions, namely mental illness, learning disabilities, HIV and AIDS. In the Somali community it was said to be as unthinkable to openly discuss disability or HIV as it would be to talk about child abuse. As a result families or disabled people may not use services advertised for ‘disabled people’ for fear of being labelled or known as such.

Within the realms of illness and disability, the group agreed that the greatest stigma was attached to mental illness and learning disabilities, to the extent that people would try to conceal
these from others in the community. The fear of being branded as ‘mad’ was said to be very high, even where the mental illness could be attributed to torture or other recognised stresses. All this was aggravated by a general lack of understanding about mental illness, stereotypes, myths and media misrepresentations, to the extent that others in the community commonly feared people with mental health problems. This was exacerbated by difficulties in defining and translating mental health terms into different languages and for different cultures. This shame resulted in isolation for many with these conditions and in turn for their carers, to the extent that neighbours might shun the family and the carers would keep themselves and the disabled person inside the house. In turn, hiding mental health problems caused more stress and led to further problems.

An example was given of a woman being helped by a community organisation to apply for funding from a local charity to pay travel costs. The grant criteria meant that this money was only paid to disabled people with assessed difficulties. However, the woman did not want the worker helping her to disclose to the charity that she was ‘disabled’ nor provide any details relating to her condition. “Don’t tell him anything about me; just tell them I can get it”.

In many BME groups coming forward to use a carer’s service was described to be another barrier in itself, as it involved overcoming cultural expectations on the family to look after their own and the triple shame: disclosing the existence of disability within the family; not caring enough for your own family; and seeking help from outside the family. Expectations on family members to look after their own, even when they could not, made it difficult to request external or state services as it would be seen as shameful. This stigma was said to be deeply embedded in individuals’ psyches. However, the question was raised if certain services or parts of services were more culturally acceptable than others. For example, what were the relative differences in perceptions to going to the GP, or having a grab rail installed? But it was clear that letting your parent or grandparent enter residential care was most absolutely out of the question.

‘If for example [my grandparent] lived with me and needed care and the council provided a care centre near to us, we could not take her there, because it would be a huge shame: people would say “[name] put his grandmother somewhere …”… It just would not take the place, even if the council can provide good [services] to look after my grandparent, medical or other care, better than me. The difficulty is the stigma and culture… What we need is to educate the people and get some from the African community to know the benefits of care services. But if the council just say “here’s a carers’ centre”, it would not be used.’

The expectations on the family to care for each other were said to be most commonly shouldered by the women and children (of either gender), who were expected to do so without seeking external help. In turn this raised the issue of cultural relativity: for example what type and amount of domestic chores or caring tasks are acceptable for children to undertake; and consequently what amount, or which tasks, would count as unreasonable?

Besides the taboo surrounding disclosing disability, it was also said to be unacceptable for women or children to express feelings of not being able to cope with these demands to others outside the home and a degree of social humiliation would be attached to doing so. In turn this was reported to create additional pressures and mental stress on women. It was said to be hard for female professionals from that community to encourage women to open up and talk in these circumstances, which suggests that it would be even harder for professionals from outside the
community. It is likely that many young carers would absorb the same attitude to disability and caring.

- **Lack of awareness of entitlement**

There was said to be generally poor understanding among carers and agencies of carers’ entitlements or available support for carers, either in the borough or nationally.

Language barriers were said to contribute to this poor awareness within families. Those who did not speak or understand English were said to be commonly vague about their diagnosis or treatment, let alone rights or services as disabled people, or the rights of their children as carers. It follows that much written material and websites were of little use. Moreover, some of the common terms used such as ‘disability’ and ‘carer’ were reported to create obstacles to understanding: these concepts were said to be somewhat alien and not easy to translate meaningfully into many languages.

Although professional interpreters were often used in medical and social services appointments, the group reported that this was not always the case, if they could not be arranged in time, or the appointment was not seen to warrant it, or there was a risk of missing the appointment. The absence of an interpreter was said to undermine the sharing of information and in turn awareness of rights. However, using children and young people to interpret at doctors’ and other appointments undermined adults’ openness with professionals and aggravated any existing reluctance to divulge intimate or difficult symptoms and issues. Examples were given of crucial details being withheld and parents not disclosing the full facts of their condition, such as the details of mental distress, or continence, or gynaecological or sexual health problems. In addition, the young interpreter may not always fully understand the nuances or significance of what the professional or ‘patient’ was asking or relaying.

As with domestic chores, it was difficult to ascertain the point at which children providing interpreting becomes unacceptable. But everyone present felt that involving them in discussing or interpreting intimate and detailed information about physical or mental health symptoms, or relaying legal or technical details was inappropriate.

Lack of accurate information about entitlements could also perhaps be at the basis of what the group described as cultural fears of being branded as ‘lazy’, or ‘scrounging’ or being perceived as wanting things ‘for free’.

- **The approach of professionals**

The focus group participants felt that young carers were largely invisible to doctors, social workers, teachers and other professionals, and that their role and contribution to the care of others went largely unacknowledged.

Doctors were said to focus their attention on the disabled or ill person to the extent that the carer, more so if a child, was invisible. GP appointments were described as short and rushed and in many practices only one issue was allowed per consultation. If carers attend with the ill or disabled person there is only time to discuss their immediate problems and the carer would need to make a separate appointment for their own issues, as well as find the time and opportunity to
attend on their own. It was recognised that many carers eventually get ill, but may be too
distressed and absorbed in their caring role to seek help for themselves. In turn even if they do,
the short appointment times allowed can undermine their scope to talk about their issues,
especially if this is culturally unacceptable to start with.

Islington Carers Centre reported that they had developed a protocol with GPs in the Borough to
identify and refer on any new patients who are carers, and that GPs get funding for identifying
carers. But the staffing resources towards this work have been reduced at PCT level and there
were considerable worries that initiatives like this would be undermined when PCTs are
abolished. Furthermore the forms use the term ‘carer’, which many might not identify with and
additional measures may be needed for young carers.

Everyone felt a lot more work needed to be done with and by schools. They were criticised for
failing to recognise when a child or a young person was a carer and not acknowledging how this
might affect school attendance, work, behaviour and achievement. Serving as the interpreter can
result in lots of school absences, when accompanying a parent or sibling to GP, hospital, or other
appointments. In turn the family might not be aware of the school’s views on this, as again the
young person may be the main hub for information exchange. Accounts were given of young
carers being bullied because of inadvertently disclosing a parent’s illness or symptoms, such as
mental health problems. Besides being a carer, children may be coping with bereavement and
other stressful circumstances, including loss of income, poverty and housing problems which
could also impact on their school work. Schools were said to fail to adequately investigate the
home circumstances, or to assume that the family did not care about the absences or poor
performance or behavioural problems. Hence exclusions commonly followed.

Several points were raised about the relationship with social services departments and social
workers. These were said to largely take young carers’ roles for granted, rather than as
warranting any individual consideration. The group reported that generally when social workers
assessed a disabled person they overlooked the carer and indeed failed to enquire about who
provided care and were usually too pressed for time to do so. This was said to be even more
likely if it was a young carer. As a result it was believed that separate assessments were rarely
conducted. It was generally felt that if adult carers were not identified and helped, young carers
had even less chance of being acknowledged or having their ability or willingness to continue
providing care ascertained.

An example was given of a young child who was the main carer for their mother who had a
serious neurological condition which caused general physical weakness. One weekend the
mother burnt herself badly and destroyed the cooker, while attempting to cook. A voluntary
agency requested an assessment by social services and an emergency payment for a replacement
cooker and food. But this did not happen. It was some time before the mother was assessed
under community care provisions, but neither the family’s nor child’s needs were assessed under
the Children’s Act 1989 or carers’ legislation. Luckily in this instance this organisation had the
resources to buy a replacement cooker. The difficulties encountered by the agency in getting an
assessment, were said to exemplify how hard it could be for a family who were unaware of their
rights, or who were not fluent in English, to do so.

The formal disability and carers’ assessments were criticised for being too long, complicated and
time-consuming for both social workers and those being assessed. The disability assessment form
was described as 40 pages long and by the end of that process carers would be reluctant to undergo another similarly lengthy exercise for themselves.

Legally the fact that young carers can be assessed under different pieces of carer’s legislation, and/or under the Children’s Act 1989, was said to further undermine the likelihood of being assessed at all. Indeed there was some uncertainty in the group as to which piece of legislation applied in which circumstances and the related age limits. In addition the separation between children’s and adult services was felt to aggravate the chances of a young carer falling between two services, and being overlooked by both.

Another problem raised was the cultural awareness and sensitivity of council staff and services. Employing staff who had little knowledge or understanding of a minority culture was believed to aggravate many of the problems mentioned above and undermine the collection of relevant information.

Families’ preconceptions about social services were also said to be central. A reluctance, approaching fear, to involve social workers, especially if the parents were likely to be perceived as wanting, was said to further undermine the chances of either the family or young carer requesting social services help. There was reported to be a fear that involving social services automatically resulted in children being taken into care. Although this attitude was not felt to be limited to BME communities, some groups were reported to find it particularly difficult to perceive statutory services as potentially helpful.

“In my community if they hear social services, they say “oh they’re coming to take the children”, or “they’re coming to take me away from mum”

Those present were worried that the negative image of social services, especially vis-a-vis families with children, might worsen if there were service cuts.

In contrast, the image of and reaction to voluntary agencies were said to be more positive, even if operating under the same legislative powers. They were reported to be seen as more helpful, less authoritarian, less likely to divide the family and as a result encountered fewer obstacles to engaging with families. One organisation had recently had a referral for a family who had said they would not work with social services but were willing to work with them. In another example a girl had refused a referral to CAMHS due to the mother’s belief that this would lead to her being removed, but the family were happy to be involved with a voluntary organisation.

Last but not least, it was reported that even when carers were assessed to have needs, these were not necessarily met, as the social worker’s manager might refuse to pay for the care package, or meet the assessed needs. Moreover the existing services were felt to be unresponsive to many minority communities’ needs. Another moot point was how statutory or voluntary services would manage if all the 1515 recorded young carers, plus the remaining as yet unidentified young carers, actually came forward for services.

3. What can be done to increase young carers’ use of services and the appropriateness of services for young carers?

The group believed that a combination of the following was essential:
- Improve information and awareness for carers and their families
- Address cultural attitudes to pertinent issues, including towards statutory services
- Adapt the approach of statutory services
- Increase coordination across relevant statutory, voluntary and community agencies
- Provide specific services for young carers

**Improving information and awareness**

Raising awareness of the issues and the potential entitlements of young carers was felt to probably be the most effective strategy. It was strongly believed that success depended on approaching this in a culturally sensitive way, rather than imposing ‘rules from above’ or relying on anything that would be perceived as punishment, such as removing children. More information and education on relevant considerations, services and rights were considered essential for many minority communities, in particular information on specific illnesses and dispelling myths and stigma around certain conditions. Attention to terms and wording and possibly using circuitous language might be necessary to get around cultural barriers. Alternative methods and better links into communities were said to be required to achieve this, including using community leaders and existing structures and processes, as messages and information coming through these channels would command more respect and trust.

An overriding message was the need to work with BME cultures and faith groups which may have different approaches to children’s duties and responsibilities in the home. It was felt to be crucial to find ways to work with or around cultural practices and norms, rather than either condemning these or totally ignoring them under cultural relativism. This in turn would require discussing and establishing a bottom line of what is acceptable across the board:

> ‘Saying “don’t do it will only mean it continues, but behind closed doors... if you say “don’t let children do this and not that”, once the professional is gone they will continue as before. Need to look after the child and the parent as well’

It was felt that this necessitated working with or employing people from a given community, to overcome both language and conceptual barriers. In turn it was believed that this would help women in particular to integrate a bit more and help them pass on useful information to their children.

**Approach of statutory services**

The process of assessment, and the language and approach used, were said to be key in gaining both a complete picture and trust with families. It was recommended that the assessment process be shortened and made more culturally aware. This might mean making the questions themselves more culturally sensitive and professionals employing different terms, angles and alternative questions to overcome stigma and barriers but nonetheless gathering a complete picture. In many communities, greater sensitivity was said to be required around gender related topics, and gender specific roles may need to be recognised, for example by employing female staff to work with young female carers. This approach may require longer time than is allowed for currently.
Given that young carers were said to be generally ignored, it was felt essential that those assessing disabled people or adult carers should encompass the situation of any children in those assessments. Primary Care Trusts and Social Services were said to need to increase their awareness of the support needs of young carers and to acknowledge the amount they do and their emotional input, especially as many young carers were at risk of developing physical or mental health problems themselves. Improving the image of social services was felt to be essential. Misconceptions that their engagement always resulted in children being removed needed to change, so that they were seen as potentially supportive to families rather than punitive. Schools were also in a unique position to identify young carers and should be encouraged to look behind children’s poor behaviour or attendance record for the reasons.

Those present felt that any success of their own services was attributable to spending time developing trust, overcoming fears and providing comfort and support, so that people could explain themselves in their own way and without fear of the consequences. Building trust was said to be essential, rather than presuming that people would automatically consider a service to be beneficial. Finding out from communities what services would be useful and appropriate and trying to meet these would go some way to bridging the gaps. Encouraging word of mouth recommendations of services by members of the community was said to help pave the way to using external professionals.

- **Improved collaboration across agencies**

Closer collaboration between adult and children's services when there was disability or illness in a family was advocated. Statutory, voluntary and community agencies were said to need to learn more about each other; develop more mutual understanding of each others’ roles and services; and improve their cooperation and sharing of ideas and good practice.

At the same time, the group acknowledged that the future of both the Carers’ Grant and Breaks’ Fund, both currently fundamental to carers’ agencies, was uncertain. The latter not only funded respite breaks away for carers, but other forms of time-out such as gym membership and educational courses. Many of the BME agencies relied on tiny incomes by contrast, but were also anxious that these might dry up due to the public sector cuts, which would reduce their services and occasional respite breaks for young carers.

**Specific service suggestions**

Numerous specific suggestions were made, based on agencies’ direct experience of working with young carers, as well as on what young carers had told participants. These were broadly grouped as follows:

**Financial**
- Maintain and increase funding for services for young carers in the borough
- Provide general financial support, advice on social security entitlement and increase grants and services available in emergencies.

**Assessment**
• Address both immediate and longer term needs. Assessing and supporting the ill/disabled family member also helps tackle carers’ needs.
• Approach a family’s needs holistically, such as poverty, inadequate housing, language barriers and fuel poverty.

**Services**
• Provide training on both general needs, such as lifting, manual handling, medication and on the specific issues relevant to the person they look after.
• Supply equipment, such as rails and hoists to help with lifting and mobility and avoid young carers injuring themselves.
• Create opportunities for psychological, physical and emotional time-off and provide short and long respite breaks and trips away.
• Enable access to mental health support, relaxation, time to see friends, time to ‘forget they are caring’ to be ‘children’ or ‘young’ and ‘let their hair down’ and to get peer support.
• Arrange informal and formal discussion sessions on relevant topics for young carers.
• Increase access to counselling for young carers.
• Provide specific careers advice and mentoring to help young carers find out about courses and/or work which would suit them and their circumstances.
• Offer services at hours which young carers can access
• Provide a dedicated, confidential, telephone help line
• Improve consultation with young carers.
• Employ more culturally sensitive staff, processes and approaches within social services

**Ideas for health professionals and services**
• Use GP surgeries to provide information, identify carers and link carers into services.
• Run advice services for carers and disabled people within doctors’ surgeries.
• GPs should liaise better with other services.
• Allow more time for GP appointments with carers and encourage doctors to talk to the carer as well as to the ill or disabled person.
• Provide interpreting at all health facilities and at all appointments.

**General**
• Be careful in the use of terminology in relation to disability and carers, to overcome pre-conceptions and barriers.
Section 3. Interviews with young carers

Hearing directly from young people about their roles and experiences as carers was central to this research project. In depth, qualitative interviews were considered the most suitable to enable the young people to provide a subjective account of their lives and roles as carers from their own perspectives. It was also feared that a more structured interview or questionnaire with issues and questions framed by the researcher would restrict the interviewees and fail to grasp important aspects of their lives and their own interpretation of their caring roles and how these impacted on them.

Eight young carers were interviewed. The process of trying to locate young carers to interview proved challenging and in itself illustrative of some of the hurdles facing these young people in trying to access services and of the effort required by agencies trying to find young carers too. The methods used were asking voluntary agencies, sixth forms and colleges in Islington to distribute publicity and help contact young carers; adverts in GP surgeries, adverts in local newspapers and displaying leaflets and posters in public places.

A common barrier to locating young carers to interview was found to be a lack of awareness of young carers and lack of contact with them by agencies, colleges and schools. One head reported that they had to go 'underground' and felt that for them the research request “had opened a can of worms they were previously unaware of”.

Given the subject, the experiences and reasons given for non-participation is significant to both the research questions and possibly to other agencies trying to contact young carers. Despite assurances regarding confidentiality, anonymity and the researcher’s independence, many young people either declined or initially agreed and then changed their minds. Some agencies reported that young carers were reluctant to be interviewed, or that their parents were unwilling for them to be interviewed. The main reasons given were:

- Reluctance to talk about their lives
- Fears regarding the confidentiality of the interviews
- Fear of the impact on other parts of their lives, especially of their peers finding out. One was reported to have said “if my friends found out they won’t be friends with me”.
- Fear on their part, or on their part of parents, of the repercussions of social services’ involvement especially of care proceedings and families being separated.
- ‘Young carers’ not recognising themselves as such, or in the term ‘carer’, especially young parents looking after their disabled child, or those caring for siblings, as described by one worker:

  “... it is difficult to engage this group of carers as they do not recognise themselves as ‘carers’. ... a large group of young carers who go unrecognised are siblings ... they do take on caring responsibility but they themselves do not recognise themselves as a carer”.

Ultimately, three of the interviewees emanated from the newspaper adverts; two from contact with specialist disability agencies; and three from contact with carers’ organisations. These young carers:
people qualified at the time as they did not have a social service assessment as carers. Indeed more young carers in contact with carers’ agencies could have been interviewed, but it was felt that this would be inappropriate given the purpose of this study and efforts continued to find those who did not get any support.

2. Who was interviewed?

Five of those interviewed were female and three male. Ages ranged from 16 to 25 and the young people were from different ethnic and cultural backgrounds. Four had moved to the UK as children. Six lived in lone parent households and all but one lived with the people they were looking after. One shared feature was that they all lived in low income households and in social housing. In addition to their caring roles, four were studying at A level standard or equivalent; one worked full-time, two were full-time parents; and one person signed on as unemployed (having been refused carer’s allowance).

3. Details of the care provided

Between them, the young interviewees looked after parents (5), siblings (3), their own children who had disabilities (1) and other members of the family (1). Four looked after more than one person and nearly everyone interviewed was the sole carer. All had been providing this level of care for many years.

The underlying conditions of the people requiring care were: physical illnesses such as diabetes, arthritis, back injury and chronic pain; mental illness (depression, manic depression/bipolar); learning disabilities; and long-term alcohol and drug misuse. Some had multiple conditions and, as stated, four of the carers looked after more than one person, each of whom had different conditions.

The care which the young people described was substantial, intense, thorough and responsive to the needs of those they were looking after. Dealing with medication was a constant. This included supervision to ensure that medication was taken at the right time, that the correct dose was taken and in some cases actually administering tablets or injections. Dealing with health and other professionals was also a common task; including accompanying those cared for to GP and hospital appointments. For those with physical health problems, the help required encompassed dressing, bathing, personal care, help moving about, walking, fetching and carrying but also watching over the person, for example, to prevent falls or hypo- and hyper-glycaemia. Those whose parents or siblings had mental health problems or drug and alcohol misuse issues tended to provide a supervisory type care. They described having to continuously offer reassurance; minimise danger; help cope with volatile mood swings including aggression, anxieties, confusion, memory loss and depressive feelings; provide motivation; deal with third parties on their behalf; help manage money; and deal with fall-outs from each crisis:

‘[I need to be around to] ‘pick up the pieces whenever and wherever’.

Those looking after siblings with learning disabilities were also engaged with managing emotions, trying to avoid upset and keep things on an even keel; providing stimulation; practicing speech and other therapies; and negotiating with services, professionals and authorities. One young person had been responsible for investigating and getting a sibling a diagnosis from a specialist as
well as a Statement of Special Educational Needs and bore responsibility for ongoing relations with the sibling’s school.

On top of their special caring role in response to the illness or disability, many also provided general care to other members of the family, most notably siblings, and generally augmented or served as substitute parents to their brothers and sisters, because of the parent’s condition. This included getting younger children out for school in the morning; supervising homework; getting them to bed; playing with them, taking them on outings, attending school meetings; and generally caring for their siblings.

In addition to the above, the routine running of the house and domestic chores often also fell to these young people, including the housework, cleaning, shopping, cooking, budgeting, ensuring that bills were paid and general paperwork. This included carrying the weight of budgeting on a very limited income. Indeed many used their own wages or Educational Maintenance Allowances to pay for household bills or essential food. While clearly cleaning or cooking are more peripheral to ‘personal care’ than say giving medication, they are nonetheless part of ‘caring’ and were essential in these examples to maintaining familial health and well-being. Moreover this role had only become necessary because of the parents’ disability and if the young person did not do it, it would not get done. As mentioned earlier, relative to other young people in modern day Britain it is uncommon for young people to undertake the bulk of these tasks or have the main responsibility for them (Warren, 2006).

The timing of the care required also signifies the importance of these young people’s roles. Caring was a constant: seven days a week, 52 weeks a year. Moreover many of these young people had disturbed sleep as they had to stay up late until everyone else was in bed. Some had to get up in the night to help the person they looked after to the toilet, or help reassure them and soothe them back to sleep, or help administer medication. Indeed a few of the interviewees seemed to survive on four hours sleep a night. It was late by the time everything was done and they got up early to get food cooked or to do housework before getting the other children up for school and then went to college or work themselves. Moreover beyond the physical input, it was evident that those interviewed carried a near constant sense of responsibility about the people they looked after.

It was also telling that these carers tended to underplay the help they gave and often forgot to mention significant aspects of care required until the end of the interviews or needed prompting to recount details. This could possibly be attributed to a normalising of their caring duties over time for them.

The significance of the care these young carers provided is also important, in terms of the part it played in supporting the ill or disabled people involved. As mentioned above, in all these cases there were no other adults available, or willing, to take on the caring responsibilities. In other words, if it wasn’t for these young people, it is unclear what would have happened to those they looked after.

4. Awareness of and use of services

4.1 Assessments
None of those interviewed had a carer’s assessment, nor any awareness of carers’ assessments or what difference these could mean to them.
The reasons for not having an assessment emerged as two-fold. On the one hand, these young people were simply not aware of their entitlements as carers, for example to an assessment in their own right or to services to support them. The adults in their lives, which in many cases were the people they provided care to, were by all accounts similarly unaware of such entitlements.

‘would be a nice thing, I guess’

On the other hand, relatively high contact with professionals and statutory bodies for those receiving the care and the young people providing it had provided ample opportunities to have been identified as entitled. All those being cared for had regular contact with medical professionals. Indeed one saw their doctor each week. Others had mental health support workers or social workers and some clearly had had their own community care assessments and had had equipment installed as a result. However while it was reported in most cases that professionals knew that these young people were the main carers, they were on the whole not formally recognised as such, let alone referred for services or offered support.

One of the young carers interviewed had had a social worker, presumably under the Children’s Act while their parent was sectioned, but the social worker’s involvement ended when the parent returned home. In another instance where the parent was disabled the parent’s social worker was said to be arranging for the young carer to get a carer’s identity badge, but no mention of an assessment had been made, nor specific support offered.

A picture which emerged was that even if the ill or disabled people received some help the needs of young carers went ignored. In one case the younger children were suddenly removed from the family home because of the parents’ conditions, but their older sibling who had been and remained the main carer still received no support.

“The way they treated us for ...years is just disgusting, no support. They’re supposed to support families. .. don’t listen ...really unsupportive... They’ve done anything but support me”

The young people interviewed said that professionals tended to simultaneously acknowledge them as the carers, whilst ignoring them and the role they played, or perhaps took those roles it for granted. It was felt that professionals had a ‘blind spot’ about young carers and focussed solely on the disabled person, rather than looking at the whole family and who was ‘holding it all together’. Disbelief, or a reluctance to accept this reality, was also said to be common.

“You get some people who don’t believe you ..... I’m saying ‘I’m her carer’ and they’re looking at me, like whatever”

All had attended school or college at some point and many still did. However on the whole, teachers and other school staff had not picked up on the carers’ home situation, despite arguable tell-tale signs such as regular lateness, low attendance, tiredness, bullying and academic underachievement. One school was an exception perhaps and had responded, but only after some years when the young carer broke down as a result of a family and financial crisis. In this case the school provided practical and emotional support and referrals, including to a carers agency and legal advice.
4.2 Use of voluntary sector services
As stated, three of those interviewed had contact with carers’ agencies and valued the support they got from these, in particular being able to spend time with others who understood their caring roles and being able to have some time-out from their duties. Nonetheless this had not increased their awareness of carers’ assessments or their potential entitlement to these. One young carer had found the agency quite accidentally when walking past. Other contact with voluntary agencies was reported, such as housing associations and in one case an advice agency. However, on the whole, contact was low, awareness lower and even those with regular contact were still unaware of their entitlements.

4.3 What services were desired?
Interestingly, although these carers were unaware of their legal entitlements, they nonetheless had clear ideas of what would help them in their lives. To an extent this would seem to undermine suggestions that young carers do not want services. The desires they had were modest but insightful:

- Time out or respite care to give them a break. This was for both regular breaks so that they could get time to study, or socialise, and for occasional longer time away
- Time with peers who were also carers
- Information about what services are available for carers
- Advice and advocacy on their rights as carers
- Professionals, especially medical staff, to recognise their role, acknowledge them as carers and share information with them appropriately
- Information about the condition of the person they provided care to, including medication, other treatments and the care implications
- Training pertinent to their caring role, such as lifting, medical care and first aid
- Emotional support
- Someone to turn to for advice and in emergencies
- Advice and help with social security benefits, housing and other issues
- Careers advice which took account of their caring responsibilities
- Holistic support to the whole family: both the children and adults involved

5. The impact of caring on young carers’ lives
Those interviewed reported that their caring role had already had an extensive impact on their lives in terms of education, friendships and social life, their own well-being and their future prospects.

5.1 Education and work
Education was explored as it was very relevant given their age-group. Not succeeding as well at school as they had expected was a common outcome and many of these young people were
dealing with the repercussions of this at the time of interview. Two of the interviewees had left school at 15 without any GCSEs.

“I had so many dreams”

Interviewees attributed their low achievement to aspects of their caring roles, such as:

- low attendance at school and being regularly late because of what was happening at home, or needing to take the people they cared for to appointments;
- insufficient time to do homework or coursework;
- tiredness during the day while at school and in the evening when attempting coursework and homework;
- disrupted routines and in three instances numerous house and area moves; and
- dealing with crises.

Bullying at school had been a problem for some and was ascribed directly to their caring role or how fellow pupils perceived their ill parents. Another factor, although not raised directly in relation to education, was a dearth of support, which may also have impacted on their educational achievements. In only one case had the difficulties experienced by the young carer been spotted by their school and steps taken to help. In that case the young person was given emotional and practical support as well as facilities to study at the college before going home.

All those interviewed were very motivated to do well and to overcome any barriers. Many had continued to study beyond 16 and had deliberately selected further or advanced courses which fitted around their caring roles, such as enabling them to start later in the morning, or study at night. Others were taking more circuitous routes to get their qualifications, again due to missing out on adequate grades at GCSE or A Level.

However the scope for this was not unlimited and there were fears as to what they would do in the short to medium term future. For example some who wanted to pursue university courses in particular fields were worried what to do if they did not get places in London universities. Longer-term careers were even more difficult for the young carers to envisage or plan for. None could imagine the people they provided care to being able to cope without them being there, yet some also wanted to develop their own lives and careers and move away. Some had found it impossible to combine work with their caring roles.

“I find looking for a job a lot harder and if I get a job looking after mum will be much harder”

“I've been looking for part-time work - but hard to find at times to suit [person's] needs”

5.2 Social life

Pursuing a social life or friendships emerged as huge challenges for these young people. On the whole they felt they had not got enough free time to be able to go out, or socialise with their peers.

“not having as much freedom to do what I’d like to do”
“I don’t get any personal time free time to go out with friends. When I’ve finished the housework and shopping etc all my friends have already gone home”

Interestingly, a strong tendency emerged not to want to talk, or tell other people, about their caring roles or share experiences of being a carer. Commonly they had grown up either feeling they should, or being directly told to, keep details of their home life private, to the extent that this was now second nature. Moreover these young carers clearly felt more mature than their peers and reported finding it difficult to strike rapport with others of their age.

“I don’t want friends to know too much about what I do. ..... They’re too immature to understand”

Very few reported having a close friend or confidant with whom they could share their feelings although such friendships were clearly highly valued and often described as the main source of support. Indeed sometimes just spending time with someone outside the family was appreciated even if they did not talk about their caring role. Romantic relationships were a further hurdle. There was a common sense of despair of ever having the opportunity to meet someone or form a long-term relationship because of the constraints of their caring roles. Indeed one young carer reported that any ‘potentials’ they had hitherto met had been frightened off by her obligations:

“... just so busy all the time. I get a bit lonely at times... but would like [a relationship]... mainly because they can’t cope with my commitments. [Caring is] such a big part of my life”

5.3 Impact on health and well-being

It emerged from these interviews that being carers was having a serious and detrimental impact on these young people’s physical, mental and emotional health and well-being. Physically, the most obvious consequences described were constant tiredness, disturbed sleep, inadequate rest, relaxation or sleep, as well as physical impacts such as from lifting people without the benefit of specific training. Those interviewed were very aware of how their roles affected their emotional and mental health.

“I can’t ever relax fully... Can’t be ill, can’t stop, can’t stop ‘til certain hour of the day. Then I get a few hours to myself.”

All reported feeling continuously stressed by their responsibilities and anxious both on a day-to-day level for the welfare of the person they were looking after, but also about the future and what it held for all of them. All felt totally isolated and shouldered most of these responsibilities and anxieties on their own and had already done so for a long time. Whilst none resented the care they provided, and by all accounts provided it willingly and lovingly, they also expressed feelings of being trapped in their caring roles. It was also clear that lack of support and isolation pertained to most if not all areas of their lives and in turn their caring responsibilities undermined most opportunities to engage with others or get relief from their responsibilities. Some spoke of feeling depressed at times, but normally dealing with that themselves. But for one young person things had become so bad and he had felt so hopeless that he had attempted suicide. Even then he had not opened up to the health services and explained what was causing his distress.
A strong sense of having missed out on their childhood, and possibly on an essential part of growing up, also emerged despite these young people’s apparent maturity.

“I never had a childhood, I want to go back in time and be a child. I started caring when I was nine. The pressure is hard. Not being able to know who I really am, because so much responsibility. I became so mature so early”

The sense of curtailed expectations and anxieties regarding careers and relationships aggravated this sense of despair. While career aspirations were clear and voiced, it was difficult to ascertain how these were going to fit with their caring responsibilities, a dilemma the young people were fully aware of, as their lives felt totally intertwined with those of the people they looked after. So attachment, separation and independence emerged as quite complicated issues.
Section 4. Services for young carers in Islington

The researcher contacted agencies in Islington for three reasons:

- To compile a picture of agencies which had contact with young carers and the services provided;
- To scope the interest for a focus group on this subject, as detailed above; and
- To help locate young carers willing to be individually interviewed.

It is believed that what is described here is a reasonably comprehensive description of what is available in Islington from the voluntary, not-for-profit sector. In the time available it was not feasible to compile a more complete mapping of all the services in the borough.

The process started with discussions with key personnel in LB Islington, including the carers commissioning officer and the lead person for young carers. Overall Islington was described as a very ‘forward thinking’ local authority on carers’ issues and to have demonstrated good insight, understanding and thoughtfulness about young carers’ needs. The 2007–2010 Strategy for Carers referenced some research on young carers, included some details and ideas about young carers’ particular needs and recommended the drawing up a further strategy.\(^{82}\)

Through the Carers’ Grant, the borough supported much of the specific work for carers provided by voluntary agencies most notably Family Action and Islington Carers’ Centre. The development of the ‘Think Family’ pilot project which ran from 2008–11 was considered by many as very progressive. This multi-disciplinary initiative (part of the national pathfinder pilots described above\(^{83}\)) was based in Family Action. It was set up to acknowledge that the whole family might need support in cases of parental mental illness and substance misuse and aimed to bridge the gap between adult and children’s services and develop support from wider family and friends for the young carer. It provided support and counselling to both parents and their children, in two Islington wards. After its demise, the multi-disciplinary approach was expected to be embedded into other borough services, so that young peoples’ services would be being more mindful of the adult’s situation and vice versa. The Think Family Protocol for the Borough was launched in January 2011.

Besides support to voluntary agencies, general social and children’s services and CAMHS, another statutory service which occasionally works with young carers is the borough’s Annexe service. They were said to mainly work with young people aged 8 to 19 who are using drugs or alcohol themselves but also with a small number of young people affected by their parents’ drug or alcohol use. The Annexe collaborated with CASA and FA on the FAB group for children and young people aged 8 to 14, which is described in a little more detail below.

\(^{82}\) http://www.islington.gov.uk/Health/carers/default.asp

Contact was made with all voluntary agencies listed in VAI’s database, which seemed likely to have contact with young people, ill and disabled people, carers, BME communities, refugees, asylum seekers and faith groups (n=62). All were initially e-mailed and subsequently telephoned. Most only worked in Islington, but some were local branches of national agencies (eg Age Concern) and others of regional, London-wide bodies, such as St Mungo’s.

From their responses, agencies were categorised into five broad groups:

I. Those, including disability bodies, reporting no direct contact with carers, nor any method to identify or contact them.

II. Organisations, typically related to one particular illness or disability, which provided some services carers, but in invariably for older carers.

III. Disability organisations which had no direct contact with young carers, but which were interested and willing to advertise and promote the research.

IV. BME and faith groups which provided a broad spectrum of services although no distinct ‘carer’s’ services as such, but which nonetheless had some young carers using their services.

V. Organisations which had direct contact with, and some distinct services for, young carers.

What follows are details of the main four agencies identified as catering for young carers in Islington: Family Action, Islington Carers’ Centre, Centre 404 and CASA. This is followed by some general points raised by them and other agencies.
Family Action Islington\(^4\) (previously Family Welfare Association) has worked in Islington for many years. As a result of merging with FSU some years ago, FA took on the young carers’ service in Islington and provides services for carers aged 5 to 25. Family Action Islington also provides a family support service. Both services share resources and cross refer. At the time of writing the young carer’s service had six staff, including the Think Family Young Carers’ team, but this was expected to reduce to three in March 2011 as the Think Family pilot came to an end.

FA’s Islington young carers’ service is funded by the LBI Carers’ Grant and caters for about 60 young carers at any one time, providing in-depth case-work for approximately 40 of these inclusive of those seen by the Think Family team. The service normally holds a waiting list of around 20. According to data supplied, FA got 19 new referrals in a 3 month period and maximum capacity was reached in Spring 2010 to the extent that no new referrals were accepted for a while\(^5\). In terms of ethnicity, statistics for April to June 2010, show that out of 63 cases the largest group gave their ethnicity as Black (37%), followed by White British (30%), Mixed Ethnicity (17%), Turkish (8%), Asian (5%) and ‘Other’ (3%).

Case-work was said to typically last about twelve weeks, although some young people needed longer. Common themes included loss, bereavement, self-esteem, anxiety about the person they provide care to and understanding the parents’ condition and needs, especially mental health or substance misuse issues. Young carers can also access groups and activities and, along with their families, attend events, such as pamper days and Christmas parties. Fortnightly drop-in sessions for both children and parents were planned for 2011, to give advice, problem solving, crisis support, sign-posting and referrals for those young carers not getting one-to-one help. These aimed to provide a ‘security blanket’ and reduce pressure on the waiting list, as once young carers have contact with the agency they were found to be reluctant to stop attending as in most cases they remain a young carer into the long-term.

A carers’ assessment is not essential to use FA services, although many had a CAF assessment. FA used a range of assessment tools\(^6\), but felt that these tools needed development, especially around assessing emotional impact. It was reported that FA’s case work was increasingly forced to concentrate on those with the highest needs, with priority given to young people whose parents had mental health or substance misuse issues. Data for the period April to June 2010 shows they saw slightly more carers looking after people with physical disablement or frailty (41%), than mental illness alone (30%) and a number with at least two conditions (17%). The webpage advises professionals to refer ‘Level 2 and 3’ young people. FA see few children whose parents have learning disabilities and reported challenges in being able to respond to rapidly deteriorating conditions and meeting needs generally: ‘Trying to make service go into a thousand pieces.’

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\(^5\) Family Action report: ‘Referral and Closure breakdown: January to March 2010’ & Monitoring for the period January to March 2010

\(^6\) Joseph, S., Becker, F., and Becker, S., 2009. *Manual for Measures of Caring Activities and Outcomes for Children and Young People, Essex, Princess Royal Trust for Carers and another self-esteem measuring tool. The Think Family assessment tool was also said to be very thorough and outcome focussed.*
FA reported excellent relationships with Islington Carers Centre, and run the monthly young adult carers’ group jointly with them. While age is the main distinction, the links between these recognise that many young people will remain carers as they get older. As well as the multi disciplinary approach of the Think Family initiative which was based at FA, they have also worked closely with CASA and ran a joint ten-week ‘Fab’ programme group in 2010 with them. Overall links with statutory services were reported to be good, but FA felt that adult services need to take on board that many of their clients have children.

**Islington Carers’ Centre**

Islington Carers’ Centre (ICC) is part of the Princess Royal Trust for Carers network and describes itself as a ‘one stop shop’ for carers across Islington. It is supported by LB Islington’s Carers’ Grant and its own fundraising.

**Who ICC work with**
ICC works primarily with adult carers aged 18 and older, but recently reduced their age limit to include young people aged 16 and over. According to their own data supplied to the researcher, over the year from April 2009 to March 2010 ICC saw 207 carers, 18 of whom were under 25. Carers they work with tend to mainly look after adults with physical disabilities and illnesses. According to their data for the year April 2009 to March 2010, 41 per cent of their carers described themselves as White UK, 15 per cent Black, 11 per cent White Other, 6 per cent Asian, 7 per cent Cypriot and 3 percent ‘other’. ICC aimed to increase the number of young carers on its books through a marketing campaign with schools, local services and radio stations.

**How young carers find out about ICC**
According to available data for the year April 2009 to March 2010, of the 207 cases, 31% were referred by social services and roughly similar proportions were self referrals (19%) or referred voluntary organisations (19%) or by health professionals (15%). Many of the self-referrals were said to emanate from the annual Carers’ Week, contact with older carers and word of mouth recommendations.

**Services provided**
ICC aims to provide a holistic service to carers and their families. These include: information, advice and advocacy on finances, benefits, housing and other matters; outings; support groups; training to carers and professionals, for example on lifting; grants for respite breaks and emergencies and help in applying to other grant-giving charities; alternative therapies and talking therapies; referrals to other agencies; and the Carers Identity Card. ICC employs social workers who can do the formal carers’ and other statutory assessments. However they did not believe that all their carers had assessments. It was also felt that in families with more than one carer only the main carer, typically the adult, received an assessment. ICC felt that carer’s assessments should take into account the needs of everyone in the family.

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87 [http://www.islingtoncarerscentre.org](http://www.islingtoncarerscentre.org)
88 Plus 17% unknown
As part of the Princess Royal Trust network of carers’ centres, ICC can access hardship funds for young carers. Examples of payments to date include a laptop, school uniforms and driving lessons. As these are not statutory funds they can also help asylum seekers who have been refused access to ‘public funds’.

Since June 2010, ICC has jointly convened a monthly young carers’ group, in conjunction with Family Action. This is run by experienced youth workers, and advice and all other ICC services are signposted and made available. At the time of writing this was attended on average by eight young people each month. It is hoped that those attending the group will in turn access other services. The group’s direction and activities are very much directed by the young carers. Feedback from those attending has been very positive.

**Centre 404**

Centre 404\(^{89}\) (previously Islington MENCAP) has three service areas, family support, ‘learning and leisure’ and supported housing. It aims to combat discrimination against people with learning disabilities, promote their standing in the community and campaign for changes.

Family Support offers information, advocacy and support to families of children with disabilities and adults with learning disabilities. The service currently works across two boroughs, Islington and Camden, and is intending to develop further across into neighbouring boroughs.

Under ‘learning and leisure’ Centre 404 provides a variety of daily, weekly and seasonal clubs and activities for children and adults with a learning disability and their siblings. These include social, creative and physical activities. Supported housing is provided to 20 adults within Islington. This service is an accredited ‘Supporting People Provider’, local authority domiciliary care provider and achieved an ‘excellent’ rating by the Care Quality Commission. They aim to support tenants and promote their independence and participation in decision making and also assist people to manage direct payments and personal budgets.

**Specific services for carers**

While Centre 404 caters for all ages, a number of its services were particularly relevant for young carers. These included:

- Information, support and advocacy for family members and carers of children and young people with disabilities, and for adults with learning disabilities.
- A weekly young siblings group, mainly for those aged 12 to 14, whose brother or sister is disabled and who might be providing some care even if they are not the primary carer.
- Family support, drops-in and individual support for: carers of children with a disability, which includes parents under 25 whose children have a disability; carers and siblings (who are

\(^{89}\) Centre 404 website accessed 4/10/10 [http://www.centre404.org.uk](http://www.centre404.org.uk)
young carers) of a child with a disability going through transition from child to adult services; and older carers of adults with a learning disability.

- A support group for family carers to share their experiences and discuss the issues related to personalised budgets and enable family carers to make better informed choices.
- Free professional complementary therapies and treatments for family carers. These include massage, homeopathy, reflexology, aromatherapy and shiatsu.
- Monthly surgeries with local borough councillors.
- Focus groups for family members of adults aged 18 with a learning disability. This provides an opportunity to find out about or raise issues affecting the carers and/or their family members to whom they provide care. Issues emerging in this forum are raised with commissioners for learning disability services to help improve local services.

CASA

CASA\(^9\) runs a number of different services for people with alcohol and drug related issues, two of which involve working with young carers; the CASA Family Service (CFS) for children and young people up to 18, and the Families, Partners and Friends Service (FPF) for those aged 18 and over.

CASA’s work with young carers focuses on ‘hidden harm’, where adult use affects the care of children and young people, and aims to reduce their isolation and build on their resources. They provide advice, information and therapeutic and practical support around minimising the impact of familial or partner alcohol or other drug use.

Referrals come from a wide range of mainly statutory services and self-referrals are welcomed. Most children that CFS sees are under 12. While numbers were said to be increasing, overall CASA gets fewer referrals for young people over 14. This was attributed to: lower identification of their potential vulnerability; young people going elsewhere, or preferring peer support rather than a family focused service, or not seeking help anywhere; younger children may only attend because they come with their parents, which is less likely as they get older; and young people possibly wanting to ignore the drug and alcohol issues in their families.

CASA works closely with all drug and alcohol agencies in the borough, family related services such as Family Action, Children’s Centres and schools and domestic violence agencies. It sits on the borough-wide Hidden Harm Steering Group and reports that joint working on this issue is improving across Islington. Primary schools were said to be more receptive than secondary schools to hearing about this subject, but that there was a general tendency to presume that few pupils were affected by substance misuse.

CFS focuses on ‘family functioning’ as well as supporting parents who are still using to seek support. Following assessment, the focus is therapeutic and aimed at developing children’s and family ‘resilience’ and parents’ capacity to protect their children. Ongoing support includes individual support for the child, individual support for the parents and work with the whole family. Support can be both intensive and long-term, and is not strictly time limited. For young

\(^9\)http://www.casa.org.uk/service-family.html
carers over 18, the FPF provides advice and information on substance misuse and treatment, work around family relationships as well as individual support and counselling.

Both CASA services report that young carers need help and support around: the emotional burden of care; money; anxieties around the parent’s drinking or drug taking and what they’re doing when the child is not around; isolation; bad memories; care for younger siblings; and physical tasks. They have also found that while physical care needs and duties may fluctuate, the mental and emotional burden often persists.

Children and young people were reported to enjoy individual counselling, desire openness and to be listened to in the family; and can need help around education, especially in relation to persistent lateness and attendance. Younger children sometimes want CASA to talk to the adults on their behalf. CASA often serves as a go-between for schools and families and between child-focused and adult-focused services. CASA have run groups in conjunction with other agencies, such as the ‘Fab’ group for young carers 8 – 14 years old with Family Action, Children’s Social Care and Think Family. In 2010 CASA co-ordinated the first pilot group with families for the national Strengthening Families 10-14 UK programme, which parents and teenagers attend together.

Young carers over 18 can join a weekly support group run by the FPF, or access any of the other adult carers’ services, such as alternative therapies and the Islington flexible break scheme or participate in the borough-wide drug and alcohol carers forum facilitated by FPF.

**Common points raised by the agencies consulted**

**Why young carers may not access services or be identified as carers**

Young carers’ reluctance to access services was attributed to a combination of the following:

- Fear of triggering safeguarding procedures and being removed from the family, especially where mental health and/or drug and alcohol misuse featured;
- Stigma and embarrassment in relation to particular conditions, especially mental health, drug and alcohol problems, and more so in certain communities;
- A fear of the consequences of others, such as school or peers, knowing and the young carer getting bullied as a result;
- Lack of awareness of entitlements as young carers;
- The concept of ‘carer’ being alien. Many would not conceptualise or identify themselves with that term; and
- Young asylum seekers and refugees were said to face additional hurdles and barriers accessing services.

It was felt that referrals could be increased in the following ways:

- Young carers can sometimes be identified through the identification of older carers in the household, which could be by social workers or other agencies
- Many other professionals and organisations often have contact with the ill or disabled person and their families and are therefore in a good position to identify and refer young carers. In particular this was said to include GPs, other health professionals and agencies, schools and colleges.
The records of those with disability assessments could be used to identify potential carers entitled to assessments in their own right.

The process of locating agencies and responses received in itself suggests that awareness of the presence of young carers was generally low across third sector agencies in the borough and that more could be done to highlight the issue, promote awareness of young carers and encourage organisations to identify young people in this role, albeit this was not being their primary function.

**Carers’ assessments in Islington**

Several concerns emerged in relation to the formal assessment of carers, although having a carer’s assessment was not a criterion for getting services from any of the agencies interviewed. Indeed most were unsure how many of their clients had formal assessments as carers and there was some confusion around the minimum age for a carer’s assessment, with a presumption that it was 16. There was also some uncertainty whether young carers could have a carer’s assessment if someone else already had a carer’s assessment in that household. What was clear was that few of the young people on these agencies’ caseloads had, or were referred for, a formal carer’s assessment. Even if the carers assessment was believed to only apply to those over 16, given that this study was looking at carers aged 16 or over they should have had one. In addition a general view prevailed that the ‘threshold for social work involvement is quite high’ although no specifics on this were supplied.

Roughly one quarter of the young carers in contact with Family Action had a CAF assessment. But it was said that these were mainly prompted by concerns arising from the parents’ conditions, particularly in cases of mental illness or drug and alcohol use, which had identified them as potentially in need. It was not known how much these assessed the young people’s caring role, let alone their ability to provide and continue to provide care, or their own needs as carers, which is the purpose of the carers’ legislation. The CAF form does not ask specifically if the child or young person is a carer, or for any details about caring duties within the household or the interface with familial illness or disability.

As well as pointing to a need for clarity around assessment criteria and procedures, this further begged the question for those young carers already in contact with agencies, as to what additional advantage there would be to having a formal assessment. Moreover even if assessed, both the threshold for eligibility to services and the range of further services available in the borough were also unclear.

The existing carer’s assessment form, albeit mainly used for older adults apparently, was said to be too lengthy and the process excessively bureaucratic and off-putting. It was believed that few carers, of any age, were informed of, or understood, the positive benefits of being assessed. Moreover the disability assessment process may exclude the carer and the ill or disabled person may not disclose carers’ roles or existence, especially in the case of children. There was said to be poor awareness and training of staff doing the community care assessments about identifying the needs of young carers.

While most agencies used their own assessment tools, many felt it would be good to have a shared document, and ideally a live tool for different involved agencies and professionals to contribute to, similar to or building on the Common Assessment Framework.
**Responsiveness and capacity of services**

A number of issues and service gaps were reported for carers of all ages. These included resources and scope to cater for both known and unknown carers; provision for older teenagers and young adults; types of services; responsiveness; and addressing the often complex range of needs of both the carer and those they looked after. Greater funding problems were anticipated from April 2011.

While existing services clearly have developed considerable expertise in working with young carers, the findings question their capacity to meet the needs of known numbers of young carers in the borough, let alone the suspected additional numbers. Firm numbers were difficult to assemble, but for example Family Action catered for approximately 60 young carers at any one time and at times had to operate a waiting list and ICC saw less than 20. The findings suggest that at most an estimated 100 young carers under 25 may be accessing services in the borough.

In addition there was found to be a particular gap in provision for those aged 16 - 25, who might neither identify with, nor access, adult carers’ facilities, but simultaneously feel too old for children’s services. The young carers group run by FA and ICC aimed to bridge that gap somewhat, but to date was used by relatively low numbers. It was reported that young people reduced their use of existing services as they approached 20 which the young adults’ carers group hoped to address. It was not possible to ascertain if any particular groups of young carers were less likely than others to use these services.

Accessing respite breaks was said to be quite complicated for young carers, with three parallel systems (NHS, flexible breaks and a children’s route). It was reported that few weekend services or emergency services were available. Other gaps appeared around the provision for certain conditions. Indeed some described a ‘hierarchy’ of conditions, with those caring for someone with learning disabilities firmly at the bottom of the pile and mental illness ranking not far above that. There was also felt to be a reluctance to recognise emotional care and anxiety about the ill person to be as valid as physical hands-on care. A lack of responsive provision was described for young carers looking after someone with a condition which had a sudden onset or rapid deterioration, as may happen with some cancers and neurological conditions, or extreme fluctuations.
Conclusion

According to available research, Islington is not alone in having more suspected than known young carers and in turn only providing services to a small percentage of those identified as such. What emerged was a picture of complex and intricately interwoven issues, with the findings from all the different sources tallying with the evidence from the literature review.

This research found two key drivers which undermine the likelihood of young carers getting services. On one hand, young carers show reluctance to make themselves known because of the combination of factors such as poor awareness of their rights, expectations arising from their family or culture, shame, reluctance from their family for their situation to be known and fear of negative consequences of social services involvement, especially breaking up the family. Cultural and language factors add another layer of barriers to finding out about services and reluctance to access them.

On the other hand, this research found a widespread lack of awareness and disinclination among professionals and agencies to identify or recognise young carers and the contribution they make to looking after ill and disabled people, or to respond adequately to their needs. Even professionals with whom young people have regular contact fail to see their caring role. Young carers are equally unacknowledged by the health and social care personnel dealing with the person requiring care. All this is compounded by what emerged as confusion regarding the entitlement of young people to carers' assessments, or a reluctance to apply same, albeit some young carers in Islington get services without a formal assessment.

One big question which is posed by the evidence here is why, despite at least four specific pieces of primary legislation, as well as the Children’s Act 1989 and official guidance, the majority of young carers receive so little formal recognition? Perhaps for those under 18 the potential application of two areas of legislation and policy (children’s and carers’) results in young carers falling between two stools, not being recognised by either and failed by both. Effective implementation of the law and policy would rely on: training and knowledge; smooth multi-professional, cross-agency and inter-departmental collaboration; and encompassing young carers in already tight budgets. In practice the onus currently rests on these children and young people to understand the legislation and then assert their respective rights, which seems an unfair expectation. This study also indicates that much more needs to be done to help identify young carers across the board and allay fears of consequences of local authority involvement amongst families. The difficulties experienced and list of desires provided by those young carers interviewed and others reported in the literature undermines suggestions that young carers do not want services.

In terms of long-term impact, the interviews and focus group echoed the concerns arising from the literature. All pointed to major, predominantly negative, physical, emotional, mental, developmental, educational and career effects on young carers. These were commonly combined with poverty, poor housing and disability, all of which alone are predicatrors of poor outcomes and social exclusion. On the positive side young carers were frequently found to be significantly more mature and responsible in comparison to their peers. Arguably, this very ability to manage could be taken for granted and contribute to their lack of acknowledgement. The evidence from
the literature indicates that young carers are likely to continue as carers into adulthood, making it all the more necessary to address their needs when young.

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And the following websites:
- [http://professionals.carers.org/young-carers/assessments](http://professionals.carers.org/young-carers/assessments)
- [http://www.carers.org/key-facts-about-carers](http://www.carers.org/key-facts-about-carers)
1. Legislation and statutory guidance regarding entitlement to services

Entitlement to assessment
A number of key pieces of legislation and official guidance provide legal entitlement to carers, including young carers, to have their needs assessed and ideally met:

- Ill or disabled people requiring services, care, equipment or adaptations are entitled to an assessment of their needs, including their need for care, under several different pieces of legislation, enacted over many decades and brought together under the National Health Service and Community Care Act 1990. Such assessments are also expected to take into account the views and needs of carers (regardless of the amount of care provided), as well as the sustainability of their ability to continue to provide care. In addition the carer should be made aware that they have legal entitlement to an assessment in their own right.

- Under The Carers (Recognition & Services) Act 1995, carers of any age who provide, or intend to provide care to a disabled adult or child for ‘a substantial amount of time, on a regular basis’ are entitled to request an assessment of their needs as carers in their own right (such as practical support, respite, or emotional help), when the person they look after gets an assessment as a disabled person. The carer’s assessment must be taken into account by the local authority in any decision they make about community care services for the person being looked after. This put carers in a slightly stronger position than what the 1990 legislation provided, but their assessment here is linked to the disabled person also being assessed.

- The Carers & Disabled Children Act 2000 applies to carers aged 16 or over and provides entitlement to an assessment in their own right, whether or not the person they look after gets assessed. Parents with parental responsibility for a disabled child can also get an assessment under this act, which should inform the provision of services under s17 of the Children’s Act 1989. Services to carers are not defined, nor limited, but local authorities are enabled to provide any services which in their view will help the carer provide that care, with specific provisions enacted to subsidise respite breaks for carers and make direct payments to carers in lieu of services. This Act also tries to help local authorities clarify the provision of services to either or both the person requiring care (under community care legislation) and/ or the carer (under carers’ legislation).

- The Carers (Equal Opportunities) Act 2004 applies to all ages of carers. It sets out to ensure that carers are identified and informed of their rights by local authorities, including their rights to an assessment; that their needs for education, training, employment and leisure are taken into consideration; and that public bodies recognise and support carers. The Act applies to carers of any age who provide, or intend to provide (eg if coming out of hospital) a ‘substantial’ amount of care on a ‘regular’ basis to someone over 18; and to carers with parental responsibility for a disabled child, who provide or intend to provide a substantial amount of care on a regular basis for that child.

- In addition, young carers under 18 can, and according to official guidance should, also be assessed under the Children’s Act 1989 as potentially ‘children in need’, if it can be shown that their welfare or development would suffer if support is not provided under this Act. Time limits (normally 35

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days) apply for completion of the more thorough ‘core assessment’ part of this process\textsuperscript{92}. If they are assessed to be a ‘child in need’ they are entitled to practical or financial assistance following from that.

In practice this means that young carers can request their own assessment, whether or not the person they provide care to is aware of, or in agreement with, such action. Their rights as carers are stronger and clearer from the 16\textsuperscript{th} birthday. But up to their 18\textsuperscript{th} birthday, young carers’ can have their needs assessed and provided for under specific carer’s legislation and/or under the Children Act 1989.

According to Clements (2009)\textsuperscript{93}, official guidance advises social workers to use the Children’s Act 1989, s17 children in need criteria, while being mindful of the provision of the carers’ legislation such as strengthened rights to education, training or leisure, which would for example require a local authority to help with transport to school or college for a young carer, and recognise a young carers’ desire to work. He also states that it may prove necessary to use the 1995 carers legislation as well to assess young carers ‘as it is recognised that some adult services have in the past, failed this group’. The 1995 Carers (Recognition & Services) Act obliges adult social services to ensure that children and young people providing a substantial amount of care on a regular basis are not left with unreasonable caring responsibilities in the first place and additionally they must (as a result of the 2004 Carers (Equal Opportunities) Act) address not only their desire to work but also whether they wish to undertake education, training or leisure activities.

Guidance, from the Department of Health, which is as binding, on assessing the needs of young carers and providing for those needs, states:

\begin{quote}
3.62 An assessment of family circumstances is essential. Young carers should not be expected to carry inappropriate levels of caring which have an adverse impact on their development and life chances. It should not be assumed that children should take on similar levels of caring responsibilities as adults. Services should be provided to parents to enhance their ability to fulfil their parenting responsibilities. There may be differences of view between children and parents about appropriate levels of care. Such differences may be out in the open or concealed. The resolution of such tensions will require good quality joint work between adult and children’s social services as well as co-operation from schools and health care workers. This work should include direct work with the young carer to understand his or her perspective and opinions. The young person who is a primary carer of his or her parent or sibling may have a good understanding of the family’s functioning and needs which should be incorporated into the assessment.
\end{quote}

3.63 Young carers can receive help from both local and health authorities. Where a child is providing a substantial amount of care on a regular basis for a parent, the child will be entitled to an assessment of their ability to care under section 1(1) of the Carers (Recognition and Services) Act 1995 and the local authority must take that assessment into account in deciding what community care services to provide for the parent. Many young carers are not aware that they can ask for such an assessment. In addition, consideration must be given as to whether a young carer is a child in need under the Children Act 1989. The central issue is whether a child’s welfare or development might suffer if support is not provided to the child or family. As part of the National Strategy for Carers (1999a), local authorities should take steps to identify children with additional family burdens. Services should be provided to promote the health and

\textsuperscript{92} http://www.nhs.uk/CarersDirect/guide/assessments/Pages/ChildrenActsassessments.aspx - accessed 12/10/10

\textsuperscript{93} Clements, L., 2009. Carers and Their Rights, The Law relating to Carers, 3\textsuperscript{rd} Ed, London: Carers UK. (Chapter 10 deals specifically with young carers)
2. Tools used

A. Topic guide for interviews with young carers

Intros

- Me, researcher, independent, who are LINk
- Reminder re scope and purpose of the research:
- To investigate the needs of ‘young carers’ in Islington who are not accessing services and explore why not accessing same services.
- How findings will be used – report for LINk with recommendations and how LINk will use the report – eg to press for improved services
- Confidentiality and everything anonymous: no one knows who I’m eventually interviewing and no names or identifying features will be used in reports or other outputs
- Consent – you can withdraw at any time, don’t have to answer any question you don’t want to
- Happy for interview to be recorded? – explain what will happen to recording
- Happy to proceed?

First, just a few brief details about you r
What age are you?
Are you living at home/ with the person you provide care to?

Your caring role
Briefly what kind of condition does the person / people you look after have?
Their age and any other aspects
Are you the main carer or are others involved too?

History
How and when did you start providing care?
(→ eg gradual/ sudden; was it a ‘decision’ – if so why, or something drifted into?
Were others involved in the decision? Any reflections?)

Care provided
Can you describe a typical day and week for you, - if there is such a thing?

Explore types of care – (how intimate, nursing; time spent, day/ night, supervision – risks/ danger...)
(→ eg domestic, cooking, dressing, bath/washing, mobility, sight, hearing, writing, understanding, dealing with medical personnel, medical treatment (dressings/ injections/ tablets?)
supervision re danger, anger/ depression/ anxiety, psychological / mental health management.
Follow up from type of condition described

How much does this vary day to day / week to week/ month to month?
Do ‘emergencies / crises’ happen – if so how often?
Can you describe what happens in a crisis and what you have to do – any examples?

Is this the same/ more/ less than what you were doing a year ago/ 2 yrs ago?
Do you expect it to remain the same for the year or so?

Needs and support

How do you find providing this amount/ type of care?
→ explore physical/ mental/ emotional aspects)

Does the person you look after use any services (day centre, nurse, respite, support groups....)
What do you and they think of these?
How helpful do you both find them?

Does anyone else help you?
→ Probe – individuals (family, friends, neighbours); or council, or health, or vol org

What happens if you fall ill/ can’t do it one day?
How do you feel about this?

Ideally what help would you like/ what do you feel would make it easier/ help you look after x?
Ideally, what services do you feel would help the person you look after?
→ Probe understanding of their ID as ‘carer’
→ and views on ‘entitlement’ or need for help/ support
  o entitlement to assessment, services, benefits
  o entitlement to support by person who they provide care to
  o or informal help and support – eg group

Have you ever tried looking for help/ more help?
→ Probe their or ‘carees’ contact with statutory professionals and vol orgs
Did you ever raise it at school
Describe experience/ what happened?

  - If aware, why not used (probe: stigma/ subjective non recognition)
    o Probe understanding of entitlement to support and how to access it
    o Knowledge of routes into getting service , eligibility rules and availability
    o Ever been offered an assessment/ what happened

Effects of caring on other aspects of their lives

What do you feel are & have been the main effects of this role on you?
  o Look for both positives as well as negatives

→ Own health - Probe any changes/ effects over time
  Day to day activities – friends, going out, recreation, sport,
  Education / training (now and in the past),
  Work/ employment/ earnings
  Moving on / living independently / moving house/ area
  Romantic relationships,
  Aspirations for the future – now, effect of caring role on these?
  What have you gained from it?
  Try to distinguish what they think they would might be doing otherwise- seek concrete examples

At end any other demographics if not already covered
Eg, ethnicity/ race /culture – what impact does that have – eg expectations, support from others?
social situation, eg income levels
B. **Focus group with Islington agencies Oct 2010**

**Introductions** (briefly): your name, name of your agency, what contact you/ your agency has with young carers

**Aims:**

To explore some issues around young carers in Islington and in particular why so few access services.

This research is sponsored by Islington LINk and VAI. I am conducting a literature review; providing an overview of what services exist for young carers in the borough; this focus group and interviewing 5 – 10 young carers. Focus is on young carers aged 16 - 25.

**Basics:**

- Want to hear views **based on** your experience & from your agency
- Confidential – stays in room (what I report will be confidential and anonymous)
- Please speak one at a time
- Don’t have to agree: looking for the range of views / issues— **not nec consensus**
- When we seem to have aired the range of views on one Q, we’ll move on
- My role is to ask the questions on what may seem blatantly obvious, no presumptions
- **Permission to record?** Only I will listen to it.
- Happy to continue?

**Key questions (on flip – to come back to / remind where we are – keep age clear)**

1. **What is known about young carers in LB Islington:** (what do they know – from own or agency’s experience – to supplement/ augment what we have from the Census – present Census data)
   - Age
   - Gender
   - Ethnicity/ race/ religion
   - Who they provide care to relationship, illness/ disability)
   - How long they provide care in their lives (How starts it – why/ how does it end YP/ caree?)
   - How much / how regular, eg pw
   - What impact have you seen/ been told about the caring role on these young people: *(prompts: usually perceived as negative, but what are the positives, eg maturity, mr organised, closer relationship with family – ve: scope to be ‘a child’, boundaries/ unusual intimacy translating; types & levels of responsibility; schooling, employment, independence – leaving home, relationships)*

2. **What services are there to support young carers in LB Islington?**
   National- here, borough level,
   - who provides,
   - all funded by the carers’ grant?

3. **Why, on the whole, do young carers not access these services?**
   a) What are the issues around the services
(prompts: What’s on offer - suit needs?
Timing
Publicity – promotion – outreach - awareness
Capacity – could your agency cope with any more young people?
Are they treated with same priority as older carers?)

b) What are the issues coming from/ around the young carers themselves

4. What can be done to increase young carers’ use of services/ services appropriateness for young carers?
   - How to address issues identified under a) or b)
   - What are your key messages to the PCT? (which LINk can pursue)
   - Key messages for LB Islington

5. Lastly can you help me get in contact with young carers? – aged 16 – 25

(Provide leaflets and cards, etc)
C. **Questions to Islington agencies**

Intros, purpose of the research, confidentiality, etc

Confirm agency name

Can you tell me what your agency does, what services are provided, to whom, on what basis, any eligibility criteria

(If applicable) how does it differ from other agencies in Islington/ (named specific agency)

What work do you do with young carers? Which young carers use you / any patterns (age/ ethnicity, area...???)

How do YCs find you/ find out about you/ you them? If referrals – who refers?

What needs have you identified for young carers?

Are all your young carers assessed by LBI as carers, or have CIN assessments?

What other support is available to YCs in LBI

Which other agencies do you work most closely with?

What if any other support do you feel is needed?

Why do you feel YCs might not access services available?
2. Methods used to get in contact with young carers

Recruitment of young interviewees
The process of trying to locate young carers to interview for the research was challenging and in itself illustrative of some of the hurdles facing these young people in trying to access services and of the effort required by agencies trying to find young carers too.

The main methods used were:

- E-mail and telephone requests were made to over 60 voluntary and not for profit agencies, faith groups and those working with BME populations in the borough. A common way to find young interviewees is through ‘gatekeeper’ organisations that work with them, can explain the research, establish that it and the researcher are trustworthy and broker initial levels of consent. But logically, young people already in contact with such groups might be expected to also get services. However for practical reasons, seeking assistance from such agencies was the most promising first step. All were asked to help recruit young people, by passing on details of the research, including articles in newsletters, using their own mailings and distributing leaflets and posters. This resulted in ten potential contacts, but just five interviews;
- All Sixth forms and colleges in the borough were contacted, but no interviewees were recruited this way.
- Digital adverts were created and displayed in all GP surgeries in the borough. These provided the researcher’s contact details and gave a brief description of what was being sought. No interviewees came forward as a result of these.
- Large display adverts were placed in local newspapers. This resulted in quite a number of contacts, but there was some attrition. Eventually three interviews resulted from these adverts.
- Leaflets and posters were distributed around organisations with public venues such as advice centres.

Recruitment materials asked those interested to ‘opt in’ and contact the researcher. As time went on, gatekeepers and other agencies were asked to seek initial consent from potentially interested young people to have their details passed to the researcher. Consent was again sought by phone after fuller explanation and subsequently in person before the interview.