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# Kingston Young Carers and Young Adult Carers Needs Assessment

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# Executive Summary

Children and young people who have caring responsibilities are a valuable asset within our communities, providing voluntary, unpaid care. [Young Adult Carers alone provide £5.5 billion of unpaid care per year.](#)

They assist the person they care for to remain independent through their good knowledge of that person, their health issues and the co-ordination and management of their care. However, young carers are often under the radar and do not get any support. The last census puts the official figure for young carers aged five-17 at nearly 178,000 for England and Wales and 166,000 in England alone<sup>1</sup>. Based on the 2001 census, BBC research<sup>2</sup> used a questionnaire designed at Nottingham University<sup>3</sup> in 2010 which suggested the true figure may be an estimated four times higher than official estimates claim. Research carried out by BBC News and Nottingham University in 2018 found that a fifth (22%) of the children (aged 11-12 and 14-15) provided some care for a family member, with 32% classed as carrying out a high level of care<sup>4</sup>. It means councils have to look at new ways of identifying carers before they even think about helping them.

The 2011 census shows 1,037 children and young people aged 0-24 and 251 0-15 year olds are providing unpaid care in Kingston.

In May 2018, there were 661 young carers (aged under 18) registered with Kingston Young Carers Project and 96 young adult carers (aged 18-24) registered with Kingston Carers Network.

Care provided by children may be long or short term and when they (and their families) have unmet needs, caring may have adverse impact on children's health wellbeing and transitions into adulthood".

[\(The Lives of Young Carers in England-DfE report 2017\).](#)

Young carers are at increased risk of missing out on education, employment, and social opportunities, and may be carrying a significant emotional burden<sup>5,6</sup>. As many as two-thirds (68%) have reported being bullied at school<sup>7</sup>. Young carers are 1.5 times more likely to have a special educational need or disability<sup>8</sup> and over a third of young carers (38%) reported

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<sup>1</sup> ONS (2013) Providing unpaid care may have an adverse affect [sic] on young carers' general health. <http://webarchive.nationalarchives.gov.uk/20160107224205/http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/provision-of-unpaid-care-in-england-and-wales--2011/sty-unpaid-care.html> Accessed 14/09/18.

<sup>2</sup> Number of Child Carers Four Times 'previous Estimate'. Published 16<sup>th</sup> November 2010. Accessed 14/09/18 <https://www.bbc.co.uk/news/education-11757907>

<sup>3</sup> Academics and alumni help uncover the true number of young carers. Published 16<sup>th</sup> November 2010. <https://www.nottingham.ac.uk/news/pressreleases/2010/november/youngcarers.aspx> Accessed 14/09/18.

<sup>4</sup> Kendall, C. Accessed on 14/09/18 at [https://www.bbc.co.uk/news/resources/idt-sh/Being\\_a\\_young\\_carer](https://www.bbc.co.uk/news/resources/idt-sh/Being_a_young_carer) Published 14<sup>th</sup> September, 2018.

<sup>5</sup> Aldridge, J. (2008) All Work and No Play? Understanding the Needs of Children with Caring Responsibilities. Children and Society, Vol 22, Issue 4, pp 253-264.

<sup>6</sup> Becker, S. (2007) Global perspectives on children's unpaid caregiving in the family: research and policy on 'Young Carers' in the UK, Australia, the USA and Sub-Saharan Africa. Global social policy, 7 (1), 23\_50.

<sup>7</sup> The Princess Royal Trust for Carers (2009), Supporting Young Carers – A School Resource Survey (The Princess Royal Trust for Carers).

<sup>8</sup> Hounsell D (2013) Hidden from view: The experiences of young carers in England. London: The Children's Society.

having a mental health problem<sup>9</sup>. Young unpaid carers are more likely to report their general health as 'not good' compared to non-carers (4.4 - 5.9 times more likely)<sup>10</sup>.

However, a significant proportion of young carers have not disclosed their caring responsibilities to their school, they are no more likely to be in contact with social services than are their peers, and only a minority have had an assessment of their needs or been informed about sources of help<sup>11, 12</sup>.

Many families do not recognise their children as 'carers'<sup>13</sup>, some children do not recognise or identify with the role, and there can be a degree of reluctance, even anxiety, among families in disclosing caring responsibilities. A significant proportion of young carers are caring for someone with mental ill-health, or who is a problem drinker or drug user. These carers can remain particularly hidden because of the associated stigma associated.

With the implementation of the Care Act 2014 (HM Government, 2014) and the Children and Families Act 2014 (HM Government, 2014) there is a legal duty for local authorities to identify and assess the support needs of young carers, regardless of the type of support they provide and if it appears that a child is providing, or intends to provide care, or if:

- They think the child has needs
- The child asks them to, or
- The child's parent asks them to.

A Template for a Local Memorandum of Understanding<sup>14</sup> offers a framework which professionals can use to provide personalised and joined up support for young carers and their families.

Young carers and families are experts on their own lives. It falls to professionals across all sectors to include them in shaping the personalised and integrated responses that best respond to their needs. This applies equally whether care needs arise as a result of mental or physical illness or disability, substance misuse and whether a parent or a sibling is the focus of support.

(No Wrong Doors: working together to support young carers and their families. A Template for a Local Memorandum of Understanding [MoU] between Statutory Directors for Children's Services and Adult Social Services, 2015)

Inappropriate caring roles or long hours of caring are likely to have a detrimental impact on young carers' lives and life chances, including their health and educational achievement. Children services commissioners have a statutory duty to support them to achieve their potential and to have the same opportunities that other young people enjoy.

Adequate and reasonable steps are not being taken locally or nationally to meet the statutory duties of identifying and assessing young carers.

<sup>9</sup> Sempik J, and Becker S (2013) Young Adult Carers at School Experiences and Perceptions of Caring and Education. Carers Trust.

<sup>10</sup> Office for National Statistics (2013) Providing unpaid care may have an adverse effect on young carers' general health.

<sup>11</sup> Barnardos. (2006) Hidden lives: Unidentified young carers in the UK. Available online: Barnardos Hidden Lives Young Carer Report.

<sup>12</sup> Dearden, C. and Becker, S. (2004) Young Carers and Education. Carers UK; The Children's Society (2013). Hidden from View. The experiences of young carers in England

<sup>13</sup> Smyth, C. Blaxland, M. and Cass, B. (2011) 'So that's how I found out I was a young carer and that I actually had been a carer most of my life'. Journal of Youth Studies, Vol 14, Issue 2 p145- 160.

<sup>14</sup> [No Wrong Doors: working together to support young carers and their families between Statutory Directors for Children's Services and Adult Social Services, 2015](#)

## Headline Conclusions

- Statutory and voluntary service's (including school's) identification of and support for young carers and for their transition to adulthood is patchy and uses an inconsistent, non-systematic approach, resulting in under-identification and lack of support of young carers. The work of schools is imperative here for young carers who access no other services.
- There was almost no evidence of any young carer/whole family assessments being undertaken across social care services, healthcare services, and education.
- Kingston young carers deemed any social care intervention to be ineffective.
- Caring without sufficient levels of effective support impacts negatively on Kingston young carers initiating and maintaining friendships, on their free time, on their physical health (by reducing their opportunities for physical activity), on family dynamics, on their educational opportunities (e.g. homework and ability to concentrate), on their financial opportunities, and on their perception that the cared for person was safe. This resulted in young carers having to rely on other family members (the majority of whom were female but in some instances were frail elderly relatives) to assist with their caring responsibilities.
- Kingston young carers felt like they were missing a childhood, and the majority sometimes or always felt stressed, anxious, isolated and lonely, tired, upset, down, sad, and angry because of their caring responsibilities.

*[Caring] is 24/7. Sometimes he wakes up in the night, and I have to go to school the next day which is pretty bad.*

*When they take their frustration out on you and you are doing the best you can. You have to deal with their frustration and yours.*

*A carer shouldn't say they are a young carer – even my best friends don't know about it.*

*I act like a mum, I sound like a mum and I don't like that. I feel I've grown up too fast – I'm more of a mother figure than a sister.*

Voices of Kingston young carer's Focus Groups, 2018.

## Recommendations

A number of recommendations are made to improve identification, assessment, and support of young carers and young adult carers across education, social care, and health services. See recommendations section (page 42) for further details.

### A. Improving Identification

**Police, social services (children and adults), NHS healthcare (including School Nurses and mental health), housing, education, careers guidance, and employment services should:**

1. Utilise best practice (see Best Practice section) to inform training on young carers and young adult carers which should form part of basic induction, ongoing training, and safeguarding training as standard. Delivery of this training should target independent schools, all areas of Youth Resilience Service (including young offenders), Kingston

College, Community Mental Health Trusts (CMHT), refugees, and Gypsy and Roma Travellers.

2. Include a question in their generic assessments on whether children and young people under 18 look after someone / have caring responsibilities.

## **B. Improving Assessment**

### **AfC and Adult Social Care should**

3. Adapt and adopt the 'No Wrong Doors' template [Memorandum of Understanding](#) to reflect local circumstances and policies and discuss and agree with all parties on the Health and Wellbeing Board.

### **Young Carers Project (YCP), AfC and Adult Social Care should ensure that:**

4. Appropriately placed services (e.g. within AfC, Schools) are fully trained to provide young carers whole family assessments and other services (e.g. YCP other voluntary and community services) are trained to use the pre-assessment tool and be aware of the referral pathway for a full assessment.
5. Young carers and parents should be informed of the rights of their young carers to access a whole family assessment and to access support from NHS providers (mental health, GPs, hospitals, School Nurses, Community Pharmacists).
6. The various [assessments tools](#) and the I-Care (Surrey) assessment are considered and developed with young carers and young adult carers. This should involve the consideration of a pre-assessment toolkit which YCP and other agencies can use.
7. Assessments and referral processes are effective and comprehensive.

## **C. Improving Support**

### **RBK, AfC, Adult Social Care, and NHS providers should:**

8. Examine the accessibility and usefulness of online support materials for young carer and young adult carers. This includes a creative approach to the use of digital technology such as health and learning opportunities, and social opportunities, and the Local Offer website and update and improve these as appropriate to make them relevant. This should include support information and advice from adult social care.
9. Ensure free or concessionary public transport at all times for young carers to reduce risk of being excluded from school and from afterschool based activities due to lack of transport or income to fund it.
10. Address and annually review the health and wellbeing of young carers by utilising best practice examples in [Meeting the health and wellbeing needs of young carers \(Local Government Association, 2018\)](#).
11. Ensure that families and carers involved in supporting a person who misuses alcohol have the opportunity to discuss concerns about the impact of alcohol misuse.
12. Utilise the [Young carers and parental substance or alcohol misuse – examples of good practice](#).

### **Schools and Sixth Form Colleges including Kingston College should**

13. Implement the [Young Carers in Schools Programme](#)
14. Utilise the [Supporting Young Carers in School: A Step-by-step Guide for Leaders, Teachers and Non-teaching Staff](#)
15. Consider designating a member of staff to have responsibility for young carers and young adult carers.

16. Establish a clear framework of support for young carers and young adult carers, which is embedded into the school's policies (including [bullying policy](#)) which are implemented and communicated to parents.
17. Ensure careers advice services review to guarantee that advice adequately addresses and takes account of caring responsibilities.
18. Provide clear information about the financial support that exists for young adult carers going to college and university. This information should be provided at an early stage so that the young people are able to plan their futures without the uncertainty that currently exists. This should include individual budgets and direct payments.

**General Practice, Community Pharmacies, Kingston Hospital, School Nurses, and Children's and Adults Mental Health Services should**

19. Establish a young carer's champion.
20. Better identify young carers' expertise in the care of the person they care for and improve in the health and wellbeing of the young carer. A Young Carers Charter may assist this as was developed in the Royal Surrey Hospital or [Sussex Partnership NHS Foundation Trust](#).
21. Utilise *Connected Kingston* by General Practice staff to link in young carers and young adult carers into a social prescriber or Community Connector to help address their health and wellbeing needs.
22. Ensure that care navigators in General Practice are trained on the needs of and services for young carers and young adult carers.
23. Utilise the [GP Practice toolkit](#) by General Practices to improve identification, assessment, and support of young carers and young adult carers.
24. Ensure that any Healthy Living Pharmacy work on carers should include young carers utilising [Engaging with Pharmacies: A Toolkit for Young Carer Services](#)
25. Ensure utilisation of [School Nurse Pathway](#) to help guide school nurses in supporting young carers.

**Mental Health Services should ensure that:**

26. A professional (e.g. health professional, social worker) who works with the person the young carer cares for takes a whole-family approach and offers them support as a young carer.
27. Counsellors are accessed through Kingston Young Carers Project, school, college or their GP.
28. CAMHS collects data on whether the children and young people receiving services have a caring role and whether young carers are referred to Kingston Council for a young carer's assessment (if that is the agreed pathway).
29. All mental health trusts implement the [Triangle of Care for Young Carers and Young Adult Carers](#) to make sure information and support is given to young carers.
30. South West London St Georges NHS Trust improve the effectiveness and efficiency of the autism spectrum diagnosis pathway so that it early identifies young carers.
31. Policies that aim to reduce waiting times and increase young people's access to services also consider young carers' needs.
32. A pathway with the Young Carers Project is agreed and established.

**Kingston Carers Board should ensure**

33. Education, Social Care, Housing, AfC, and Health work together to develop a strategy that covers the principles outlined in the [NHS toolkit](#), with the key objectives aligned with those from The National Young Carers Coalition's (NYCC) and [Commissioning Services for Young Carers and their Families \(Carers Trust, 2012\)](#).
34. The voices of young people are heard e.g. through a forum, council, *NHS Young Carer Health Champion* in order to inform health literacy, promote health and wellbeing and develop the capacity of young carers to participate in planning and the development of young carer friendly services.

35. That there is increased representation from young carers and young adult carers and from NHS colleagues (including mental health, Kingston hospital, and GP practices) at the Kingston Carers Board.
36. **AfC should increase** the sustainability and stability of Kingston Young Carers Project by ensuring the service specification reflects this needs assessments.

## **Improving Support for Young Adult Carers**

### **Kingston Council should ensure**

37. Formally designating staff role(s) to coordinate transition assessment and planning across different agencies.
38. That its Health and Wellbeing Boards uses its potential to commission the types of services for young adult carers that meet the requirements laid out in The Care Act 2014 and The Children and Families Act 2014, by bringing together, through Healthwatch, the local authority designated person, young adult carers, GP practices, housing services, employers, social care staff and learning providers to develop a flexible support package and approach to learning.
39. Access to the entitlement to Education Maintenance Allowance (EMA) for all young adult carers aged 16–19 years old in full-time education who are not receiving other bursary sources or Carer's Allowance.
40. Free or concessionary public transport at all times for young adult carers to reduce risk of being excluded from school/college and afterschool/college based activities due to lack of transport or income to fund it.
41. Improved access to more support to undertake training and employment opportunities and to sustain and succeed in these.
42. Carer specific policies with clear and accessible disclosure procedures are embedded across all health and social care services, education providers, training initiatives and employment sectors.
43. The services and support for young adult carers from Kingston Carers Network are clearly visible and seen to be effective. Procedures should be in place so that young adult carers know who to tell, how to access services and support, and are aware of the nature of the support they can receive.

## **Acknowledgements**

I would like to give my heart-felt thanks to all of the young carers and parents at Kingston Young Carers Project for providing me with the opportunities to learn directly from their experiences. I would also like to extend this thanks to the staff at Young Carers Project who were vital in helping set up the focus groups, interviews, and surveys.

I would also like to thank all of those professionals working across Kingston's voluntary organisations, AfC, Adult Social Care, health, and education who have contributed so helpfully to the interviews and to the schools survey.



# 1. Introduction

## 1.1. Definition of a Young Carer and a Young Adult Carer

The [definition](#) of a young carer is a child or young person under 18 who provides regular and ongoing unpaid care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances. The term ‘young carer’ does not apply to everyday or occasional help that may occur in all families. It is specific to care that is relied upon in maintaining the health, safety or day to day wellbeing of the person receiving support or care. Generally a young carer is someone who is aged between 5 and 18 years old<sup>15</sup>: ‘A young carer becomes vulnerable when the level of care-giving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her own emotional or physical well-being or educational achievement and life chances’<sup>16</sup>.

Care provided by children may be long or short term and when they (and their families) have unmet needs, caring may have adverse impact on children’s health wellbeing and transitions into adulthood<sup>17</sup>.

There is no legal age definition for young adult carers, although voluntary organisations support work focuses on young adults aged between 14 and 25 who care, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

For the purposes of this report, young adult carers refer to 18-24 year olds who are covered by the Care Act (2014).

Young carers and young adult carers may do some or all of the following:

- Practical tasks, such as cooking, housework and shopping.
- Physical care, such as lifting, helping a parent on stairs or with physiotherapy.
- Personal and intimate care, such as dressing, washing or helping with toileting needs.
- Managing the family budget, collecting benefits and prescriptions.
- Administering medication.
- Looking after or “parenting” younger siblings.
- Providing emotional support.
- Interpreting, due to a hearing or speech impairment or because English is not the family’s first language.

## 1.2 Scope and Aims of the JSNA

1. To estimate the size of the hidden and known population of young carers and young adult carers.
2. To understand locally the impact of caring on young people.
3. To assess the effectiveness of the implementation of the [Children and Families Act 2014](#) (5-18 year olds rights to an assessment) and the [Care Act 2014](#) (18-24 year olds rights to an assessment) in Kingston. The former act aims to prevent inappropriate

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<sup>15</sup> Association of Directors of Adult Social Services and Association of Directors of Children’s Social Services (2009) ‘Working Together to support Young Carers - A Model Local Memorandum of Understanding between Statutory Directors for Children’s Services and Adult Social Services’.

<sup>16</sup> Frank, J. and McLarnon, J. (2008). ‘Young carers, parents and their families: key principles of practice. Supportive practice guidance for those who work directly with, or commission services for, young carers and their families.’ The Children’s Society.

<sup>17</sup> The Lives of Young Carers in England-DfE report 2017.

caring roles impacting on a child's development and the latter should assist the child transitioning into adulthood.

4. To assess the extent to which multi-agency services address the needs of young carers and the whole family. This would include suggestions for overcoming barriers young carers face in accessing health, social care, social, and leisure services, finance, employment, and housing services.
5. To understand support that could be made available through communities and the voluntary sector.
6. To improve identification and self-identification of young carers and young adult and their families in order to improve timely access to appropriate and effective services.
7. To assess the extent to which the voice of young carers including older young carers are heard and identify mechanisms to capture their voice.
8. To identify issues that occur at transition (from children's to adult's age).

### 1.3 Barriers to Identification

Young carers are less likely to self-identify or let services know they have caring responsibilities if they are from the following groups<sup>18</sup>:

- Black, Asian, and minority ethnic communities which may include refugees and asylum seekers<sup>19</sup>
- Refugee and asylum seeker carers.
- Travellers.
- Aged 5–10 years.
- Aged 16–24 years.
- Young carers from rural areas who may experience increased isolation due to lack of transport and service provision.
- Children caring because of parental mental illness, substance misuse and other stigmatised condition such as HIV.
- Young carers who have offended or are at risk of offending.
- Young carers with special educational needs and disabilities.
- Sibling carers, although not a hard to reach group, form a significant group who can often go unnoticed or unsupported.

### 1.4 Key Facts – How many young carers does Kingston have?

In England there are 166,000 children and young people under 18 helping to look after someone in their family who was ill, disabled or misusing drugs or alcohol<sup>20,21</sup>. Providing unpaid care may have an adverse effect on young carers' general health. In England and Wales, there are twice as many young carers aged between 15 and 19 as there are in the 10-to-14 age range<sup>22</sup>.

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<sup>18</sup> Hidden from View; Experiences of young Carer in England, The Children's Society, 2013.

<sup>19</sup> National Assembly for Wales (2003) 'Challenging the myth "They look after their own": Carers services - access issues for black and minority ethnic carers in Wales'.

<sup>20</sup> ONS (2013) Providing unpaid care may have an adverse affect [sic] on young carers' general health.

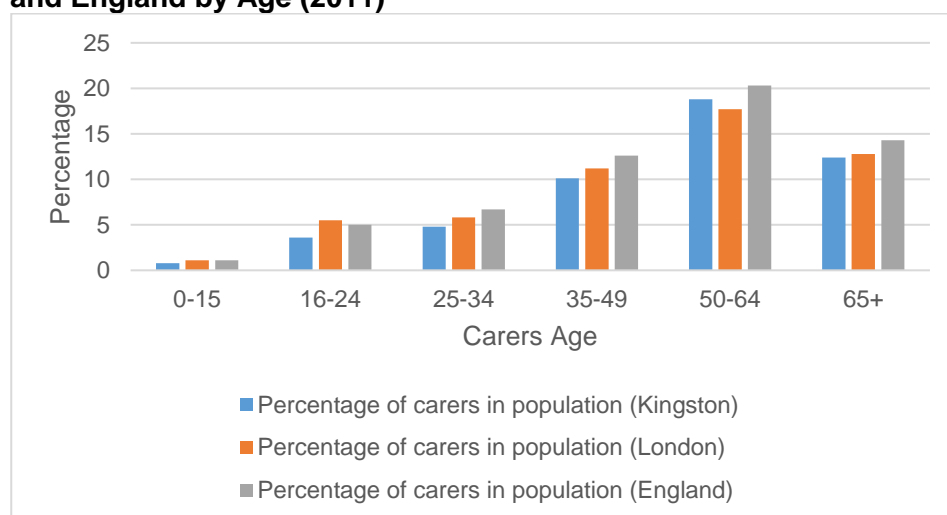
<http://webarchive.nationalarchives.gov.uk/20160107224205/http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/provision-of-unpaid-care-in-england-and-wales--2011/sty-unpaid-care.html> Accessed 14/09/18.

<sup>21</sup> Office for National Statistics (2013). Accessible via Key Data on Young People 2017 Latest information and statistics, Association for Young people's Health.

<sup>22</sup> Office of National Statistics (2011). Accessible via Young carers: Quarter of a million children provide care for others, BBC Report, 16 May 2013.

The 2011 census shows 1037 children and young people aged 0-24 are providing unpaid care in Kingston, with 251 0-15 year olds declared as providing unpaid care. This represents 0.8% of the population of 0-15 year olds. Of these, the majority were recorded as providing 1 to 19 hours of unpaid care a week. This is slightly lower than the England and London percentages of 1.1% of 0-15 year olds providing unpaid care. Kingston, London and England have similar rates of young carers aged under 15 providing 20 hours or more unpaid care a week.

**Figure 1: Percentage of the population providing unpaid Care in Kingston, London, and England by Age (2011)**



Source: from Census 2011 Data

**Percentage of Children aged 0-15 and 16-24 who provide unpaid Care, expressed as a percentage of the Population, 2011**

	Kingston	London	England
Under 15	0.8	1.1	1.1
16-24 years	3.6	5.4	4.8

Source: 2011 Census accessible via Vulnerable Children and Young people Profile, Public Health England Fingertips.

**Percentage of Children aged 0-15 and 16-24 who provide 20+ hours of unpaid care per week expressed as a percentage of the Population, 2011**

	Kingston	London	England
Under 15 years	0.15	0.22	0.21
16-24 years	0.7	1.5	1.3

Source: 2011 Census accessible via Vulnerable Children and Young people Profile, Public Health England Fingertips.

[BBC research](#) using a [questionnaire designed at the University of Nottingham](#) showed that there are likely to be four times as many young carers as that stated by the 2001 census. If this is also applicable to the 2011 census, there would be an estimated 1,000 (approximately) 0-15 year olds carers and approximately 3,000 16-24 year old carers living in the borough of Kingston which indicates that there are estimated to be a large number of 'hidden' carers given the numbers currently in touch with local services.

As of January 2017, there were 518 young carers aged 5-17 years registered with the Young Carers' Project (at Kingston Carers Network), by May 2018 this number had grown to 661. In May 2018 there were 96 young adult carers aged 18-24.

It is believed that the definition used in the 2017 School Health Education Unit (SHEU) survey was not specific enough and there was an over-reporting of young people self-identifying as carers. Consequently this data is unreliable and cannot be used to inform this Needs Assessment.

### **Mental Health, Substance Misuse, and Alcohol**

Nationally, up to 90% of the caseloads of children's social workers are made up of children whose parents have mental health, alcohol or substance misuse problems<sup>23</sup>.

Kingston Young Carers Project estimate that over a third of young carers will be caring for a parent with a mental health condition. Parental mental health issues were a factor in 42% of families considered at the Initial Child Protection Conferences in Kingston (data for April to December 2011).

In 2011/12, the crude rate of parents in alcohol treatment of children aged 15 and under was 69.1/100,000 in Kingston, 108.2/100,000 in London, and 147.2/100,000 in England.

A toolkit<sup>24</sup> indicates that Kingston has a higher proportion of met need than the benchmark and national proportion of adults with an alcohol dependency accessing treatment; however this represents a high percentage of unmet need that still requires intervention locally.

### **Number of Young Carers identified by Kingston's General Practices**

14.2% of the registered population aged 18 and over were recognised by Kingston Clinical Commissioning Group (CCG) as having a caring responsibility in 2015/16 (National General Practice Profiles, PHE). The CCG does not collect data on carers aged under 18.

### **Young Carers and Young Adult Carers (18-24 year olds)**

There has also been a 25% increase in the number of young adult carers up to age 24 between 2001 and 2011 across England<sup>25</sup>.

As of November 2017, Kingston University have 33 young adult carers aged 18-24 registered (the majority of whom were from another borough), whilst 96 young adult carers were registered with Kingston Carers Network.

Kingston potentially has a substantial number of unidentified, unassessed, and unsupported young carers and young adult carers in Kingston.

## **1.5 Key Issues affecting the Health and Wellbeing of Young Carers and Young Adult Carers**

### **Young Carers**

The vulnerability of young carers is far-reaching due to the large number remaining unrecognised by professionals<sup>26</sup>. Young carers are more commonly affected by educational underachievement which has a long term negative impact on future employment opportunities, life chances, and consequently their health and wellbeing outcomes. While at school, young carers may continue to worry about the person they are caring for and 39% of young carers have said that nobody in their school was aware of their caring role, while 50%

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<sup>23</sup> Department of Health (2010) Recognised, valued and supported: next steps for the Carers Strategy.

<sup>24</sup> Problem Parental Drug and Alcohol use: A Toolkit for Local Authorities, PHE 2018

<sup>25</sup> Hidden from view: The experiences of young carers in England Longitudinal Survey (The Children's Society, 2013)

<sup>26</sup> Becker S (2000) Young Carers. In: Davies M. (Ed) The Blackwell Encyclopaedia of Social Work, London: Blackwell.

of young carers say they do not feel supported by their teachers even if the latter are aware of their caring role<sup>27</sup>. Key issues are listed below.

1. The Hidden from view: The experiences of young carers in England Longitudinal Survey (2013)<sup>28</sup> stated that the experience of young carers is that:
  - One in 12 young carers is caring for more than 15 hours per week.
  - Young carers are 1.5 times more likely to have a disability, long-term illness or special educational needs,
  - Young carers are 1.5 times more likely to be from a black, Asian, or minority ethnic community and twice as likely to not speak English as their first language.
  - Young carers are subjected to financial hardship due to lower levels of employment and the high cost of disability and illness in their families. The average annual income for families with a young carer is £5,000 less than families who do not have a young carer.
  - There is no strong evidence that young carers are more likely than their peers to come into contact with support agencies, despite government recognition that this needs to happen.
  - Around 1 in 20 young carers miss school because of caring responsibilities
  - Young carers have significantly lower attendance and educational attainment at GCSE level, the equivalent to nine grades lower overall than their peers e.g. the difference between nine Bs and nine Cs.
  - Young carers are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19 (up to 40% where children were caring for a relative with drug or alcohol problems).

Figure 6 shows the factors that have a significant and strong association with being a young carer, in comparison with their peers.

**Figure 6: Significant and strong associations of factors affecting young carers**

Factor	Relationship
Family income	The median family income for families including a young carer was £5,000 less than families without a young carer
Adults in the household in work	Young carers are over four times more likely to live in a household where no adults are in work
Maternal education levels	Young carers are 1.6 times more likely to have a mother who has no educational qualifications
Adults with a limiting disability	Young carers are over twice as likely to live in households where at least one adult has a limiting disability
Number of children in the family	Young carers are 1.6 times as likely to live in households where there are three or more other children living in the family

Source: Hidden from view: The experiences of young carers in England Longitudinal Survey (The Children's Society, 2013)

2. Mental ill health of the young carer and the person cared for.  
 Nearly three quarters of young carers reported suffering long-term psychological effects and around 40% had experienced mental health problems. Up to two-thirds of children caring for a parent with a mental health problem experience difficulties themselves<sup>29</sup>. Up to 14% of young carers of parents with severe mental illness will develop a

<sup>27</sup> Carers Trust, 2010 Supporting Young Carers in School: An Introduction for Primary and Secondary School Staff.

<sup>28</sup> Hidden from view: The experiences of young carers in England Longitudinal Survey (The Children's Society, 2013).

<sup>29</sup> Office of Deputy Prime Minister (2004) Mental Health and Social Exclusion. Social Exclusion Unit Report, London, ODP.

psychotic illness during their lifetime<sup>30</sup>. Caring for someone with mental health needs presents the following different challenges for their carer compared with a physical illness or disability<sup>31</sup>:

- The fluctuating, unpredictable nature and extent of poor mental health. The need for, and levels of, timely support may therefore be unpredictable. Dependence on the carer can be really intense and prolonged at times yet minimal at others.
- Poor mental health is not necessarily as evident as a physical health problem or disability, therefore there may be less understanding or support forthcoming for the carer as there is with other health conditions.
- Because of the stigma surrounding mental ill-health, carers may be less willing to seek support or share with family members and friends. This may mean they have less of a social network to draw on themselves with a resulting risk of poor mental health in the carer themselves.
- Often mental ill-health is associated with other conditions, so this is not the only condition the carer is required to deal with.
- There are a number of legal and ethical issues surrounding mental health that can make the role of caring even harder.
- Carers need information, advice and support about carrying out their caring role, but also about understanding and coping with mental health conditions. Carers of people with poor mental health are dealing with taking on a caring role as well as learning how to respond to the behaviours and emotions associated with the condition. As a result of these issues, caring for someone with mental health needs may be even more emotionally draining than any other caring role. Suicide prevention research and recommendations all cite the need to include, support, identify and listen to carers<sup>32</sup>.

### 3. Alcohol and Substance Misuse.

Nationally, 7% of young carers are looking after a parent or relative with drug or alcohol use problems. Of these, only 28% had received an assessment and 40% were missing school or had other indicators of educational difficulties<sup>33</sup>.

In the UK, 2.6 million children (one in five) live with a hazardous drinker<sup>34</sup> and there are between 250,000 and 350,000 children of problem drug users – about 1 child for every problem drug user. Many of these children will have caring roles<sup>35</sup>.

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<sup>30</sup> Devlin, J.M. & O'Brien, L.M. (1999). Children of parents with mental illness. I: An overview from a nursing perspective. *Australian & New Zealand Journal of Mental Health Nursing* 8(1), pp19-29.

<sup>31</sup> Mental Health Factsheets, Carers Trust, 2017

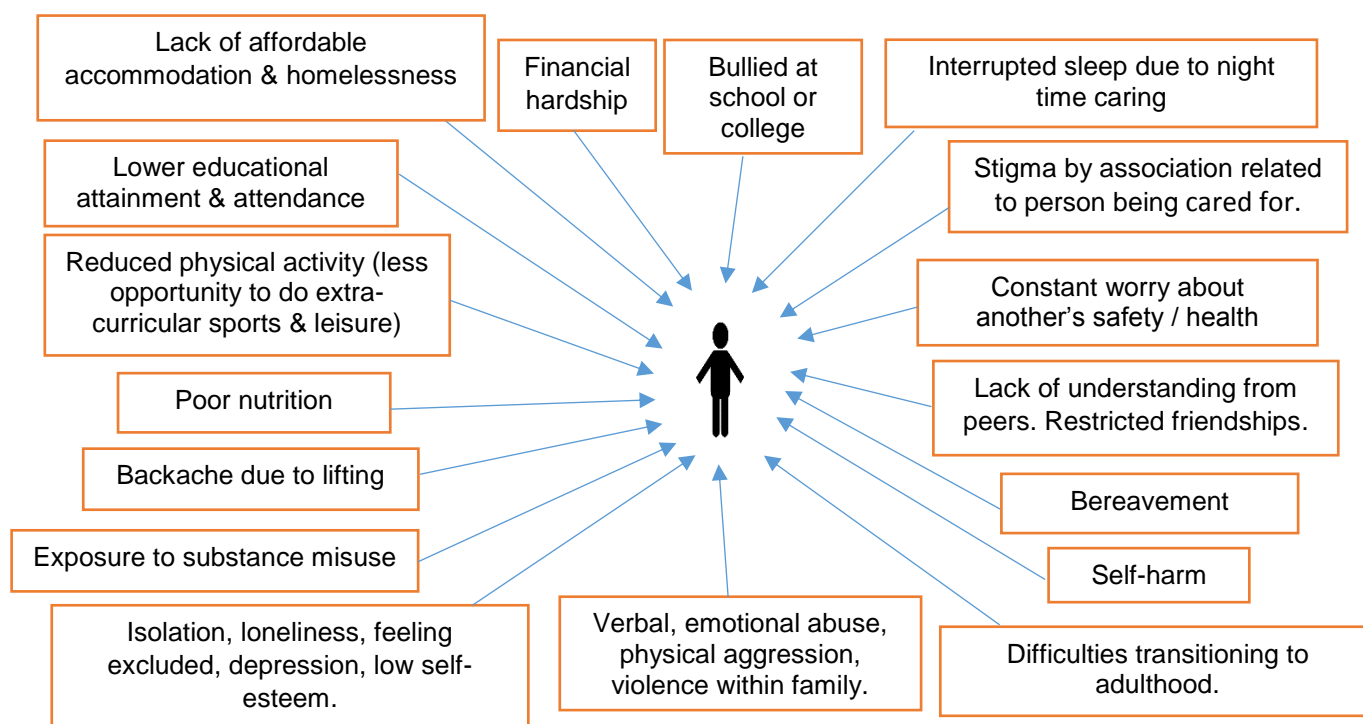
<sup>32</sup> Department of Health, 2012

<sup>33</sup> [Dearden, C. and Becker, S. Young Carers in the UK: The 2004 Report London: Carers UK. 2004](#)

<sup>34</sup> Manning, V., Best, D.W., Faulkner, N. and Titherington, E. (2009). New estimates of the number of children living with substance misusing parents: Results from UK national household surveys. *BMC Public Health*, 9, 377-389.

<sup>35</sup> ACMD: Hidden Harm: Responding to the Needs of Children of Problem Drug Users, report of an inquiry by the Advisory Council on the Misuse of Drugs. London: Home Office; 2003.

**Figure 7: Potential Key Issues affecting the Health of Young Carers and Young Adult Carers**



Sources:

- The Princess Royal Trust found 68% of young carers had been bullied at school<sup>36</sup>.
- Frank J, Tatum C, Tucker S. (1999) *On Small Shoulders: Learning from the experiences of former young carers*.
- Dearden C, Becker S. (2002) *Young Carers and Education*. London: Carers UK.

## Key Issues affecting the Health and Wellbeing of Young Adult Carers

The Time to be Heard for Young Adult Carers Bridging the Gap: Young Adult Carers in Scotland report<sup>37, 38</sup> cited that:

- One quarter of the academic year (48 school days) for young adult carers had been affected because of caring, each year.
- Young adult carers were four times more likely to drop out of college or university than students who were not young adult carers.
- A quarter of young adult carers in school had experienced bullying because of their caring role.
- 49% of the young adult carers who had left education were not in education, employment or training (NEET).
- Young adult carers in work missed 17 days per year and had a further 79 days affected because of their caring responsibilities.
- 45% of young adult carers reported having mental health problems.
- Only 22% of young adult carers had received a formal assessment of their needs by their local authority.

<sup>36</sup> The Princess Royal Trust for Carers (2010), 'Supporting Young Carers - A Schools Resource Survey'

<sup>37</sup> Carers Trust (2015) *Time to be Heard for Young Adult Carers Bridging the Gap: Young Adult Carers in Scotland report*

<sup>38</sup> 'Young adult carers' here refer to carers aged 16-25 years.

## 1.6 Carers Policies and Legislation

The United Nations Convention on the Rights of a Child (UNCRC) (1989) identifies that 'Every child has the right to participate fully in family, cultural and social life. It is an integral part of the role of all health and social care services to uphold this convention.

### National Strategy for Young Carers

The Carers Call for Evidence (2016) was launched in preparation for a Carers Strategy. However, the announcement of a social care green paper, for publication summer 2018, presented an opportunity to take a more fundamental approach to tackling the challenges carers face. Consequently, carer's challenges will be considered alongside the government's national strategy for social care.

Kingston has been considering an interim strategy to cover all carers (2015-2019) as its carers strategy (2013-2015) is now outdated.

Although it is vital to understand local needs, it is important to note that young carers services across the UK have very consistent messages in what they recommend should be strategic priorities. In its response to the Government during the refresh of the national strategy for carers, The National Young Carers Coalition (NYCC) identified five key priorities submitted by its member networks<sup>39</sup>:

1. Early identification and prevention of young carers.
2. Adoption of the ADCS/ADASS Memorandum of Understanding.
3. Outreach to hidden young carers.
4. Awareness-raising.
5. Support for young adult carers.

**The National Carers Action Plan 2018-2020 'Supporting Carers Today'** covers areas of:

- Services and systems that work for carers,
- Employment and financial wellbeing,
- Supporting young carers (intended to work to improve the identification of young carers, improve the education opportunities and outcomes of young carers and improve access to support services),
- Recognising and supporting carers in the wider community and society
- Building research and evidence to improve the outcomes for carers.

### Rights for Young Carers since 2014 enshrined in Law

The [Children and Families Act 2014](#) and the [Care Act 2014](#) aim to improve access to an assessment of support needs of young carers and their families. The rights afforded to young carers '[will be extended to all young carers under the age of 18 regardless of who they care for, what type of care they provide or how often they provide it.](#)' The Children and Families Act 2014 reduces needs through early identification, the provision of information and advice, integration, assessments and family based support (including Family assessments and care planning). The Care Act 2014 reinforces adult carers' right to an assessment; this includes the same rights for young adult carers aged 18 – 24. It also clarifies the local authority's responsibility for carers who are under 18 years old during transition to adulthood. The Care Act 2014 stipulates that support should be provided by Adult Social Care to ensure no young carer is relied upon to provide an inappropriate level of care to an adult.

The principle of the whole family approach to assessment was set out in the Care Act 2014 regulations and guidance and applies across all age groups and across all categories of care.

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<sup>39</sup> Carers Trust, 2012, Commissioning Services for Young Carers and their Families



It enables appropriate support to be put in place either for the carer, or the person receiving care, or both. This avoids the need for multiple assessments where children and adults find they are expected to give the same answers to professionals from different services coming into their home at different times. This may mean that children's needs are assessed by professionals who will not have the same familiarity with children's needs as social workers employed by children's services.

**All the children identified as living with an adult with a long-term condition that affects their ability to care for themselves, or as siblings of a child with a chronic disease or disability, are potentially young carers.**

[The lives of young carers in England Qualitative report to DfE, 2016](#)

Local Authorities can carry out this young carer's assessment if:

- They think the child has needs (i.e. the young carer or their parent does not need to ask the local authority)
- The child asks them to, or
- The child's parent asks them to.

The assessment must consider:

- Whether it is appropriate for the young carer to provide, or continue to provide, care for the disabled person or older person.
- The young carer's needs for support, their other needs and aspirations.

As well as the care the young carer is providing, local authorities must look at what the young carer needs for their own education or work, health, hobbies or activities. The assessor must be appropriately trained, have enough knowledge and skills to carry out that assessment; and to be appropriate (depending on the young carer's circumstances, in particular the young carer's age, sex and understanding).

Under the Care Act 2014, local authorities have similar duties to promote the "wellbeing" of adults with care needs and of their carers. The concept of wellbeing involves taking account of how a wide range of factors will affect how an individual chooses to live their life. These include:

- Their personal dignity (including treatment of the individual with respect);
- Physical and mental health and emotional wellbeing;
- Protection from abuse and neglect;
- Control over day-to-day life (including how care or support are provided)
- Participation in work, education, training or recreation;
- Social and economic wellbeing;
- Family relationships and the support offered by their family network;
- The suitability of their accommodation; and
- The support provided by their friendships and social networks.

**The primary responsibility for responding to the needs of a young carer rests with the service responsible for assessing the person they support, rather than depending on the age of the carer.**

Young Carers Needs Assessment: Supporting Information for Use in Conjunction with 'No Wrong Doors' Template for Local Memorandum of Understanding on Work with Young Carers (ADASS, ADCS, Carers Trust, The Children's Society, 2016)

This means that:

- young carers of disabled children are the responsibility of children's services; whilst
- It will usually be the responsibility of adult services to identify whether children in the household/ family network are expected to assume inappropriate or excessive caring responsibilities for parental figures, or other adults.

Local Authorities have a duty of market shaping, to offer more choice; and are expected to adopt an asset based approach of taking into account what individuals, family and community have to help people meet their own needs. The impact assessment of the Care Act 2014 found that the new duties would result in an increase in the numbers of carers being assessed and becoming eligible for support. The Government's analysis shows that, whilst this would lead to an increase in demand for resources, and a need to commission further carer's support, it would be cost effective to meet carers' needs as a preventative measure<sup>40</sup>. The focus on information and support follows studies and consultation with carers showing that involving carers provides better outcomes for the person with care needs; and provides peace of mind for carers that the person they care for is receiving the best and appropriate treatment; together these result in better health for carers. This is the basis for much of the Carer's Trust's [Triangle of Care](#) work (see Best Practice section).

#### **Transition for Young Carers - Transition assessments under the Care Act 2014**

- A local authority has a duty to carry out a transition assessment for a young person or carer, in order to help them plan if they are likely to have needs once they (or the child they care for) turn 18
- There are 3 groups of people who have a right to a transition assessment:
  - Young people, under 18, with care and support needs who are approaching transition to adulthood (the person cared for)
  - Young carers, under 18, who are themselves preparing for adulthood
  - Adult carers of a young person who is preparing for adulthood.

Transition assessments for young carers or adult carers must also specifically consider whether the carer:

- Is willing **and** able to care now and after the child in question turns 18;
- Works or wishes to do so;
- Is or wishes to participate in education, training or recreation.

[Transitions assessments](#) must place the needs of the young person at the centre and focus on their future hopes, wishes, feelings and ambitions.

The matters that should be included as part of this assessment could helpfully include:

1. Family relationships
2. Education, training and employment
3. Accommodation and independent living
4. Health, development and general wellbeing
5. "Financial literacy" and skills in financial management.

[The National Carers Action Plan 2018-2020 'Supporting Carers Today'](#) states that the Department of Health and Social Care will fund a project on transitions for young adult carers to look to identify and disseminate effective practices to support and enable young adult carers to make positive transitions between the ages of 16-24, and identify the types of practical and emotional support that can enable a young adult carer to achieve a positive transition.

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<sup>40</sup> Department of Health and Social Care (updated 2018) 'Care and Support Statutory Guidance'.

The National Children's Commissioner (2016) Report 'The Support provide to Young Carer in England stated that the assessment and support for young carers was found to be woefully lacking in many local authorities nationally<sup>41</sup>:

- Four out of five young carers are not receiving support from their Local Authority.
- Just over a quarter of young carers have additional needs of their own.
- There are young carers under the age of five.
- Not all local authorities are taking steps to identify children who may be providing care in their area.
- Of the children and young people referred to local authorities as potentially being a young carer, 70% went on to be assessed and 97% of those assessed were deemed to be in need of support. Of the children referred who were not deemed to be in need of support, 94% had **not** received a young carer's assessment.
- The emphasis on identification and assessment in legislation may lead to support for young carers being overlooked.
- Young carers want to enjoy their childhood and for services to listen to them and respect their views.

## The NHS and Young Carers

### NHS England's commitment to carers NHS (2014)<sup>42</sup>

NHS England has carried out engagement with carers to identify what is important for carers of all ages. The key themes were:

- Recognise me as a carer.
- Information is shared with me and other professionals.
- Signpost information for me and help link professionals together.
- Care is flexible and is available when it suits me and the person I care for.
- Recognise that I also may need help both in my caring role and in maintaining my own health and wellbeing.
- Treat me with dignity and compassion.
- Respect, involve and treat me as an expert in care.

"Carers are an integral part of the patient's support system. They are the ones with the day-to-day experience of the patient's condition and they carry the most intimate responsibility for the patient's welfare. The carer's voice in decision making about admission and discharge is ignored at everyone's peril and yet so often is."

Dr Mike Shooter, Past-President, Royal College of Psychiatrists.

[What are the benefits to your patients and practice in developing your work with carers?](#)

The [2015/16 Planning Guidance for the NHS, Five Year Forward View into Action](#), set out how the NHS will seek to implement its duties under the Children and Families Act 2014 and the Care Act 2014, including a clear expectation that, "CCGs alongside local authorities...draw up plans to identify and support carers and, in particular, working with voluntary sector organisations and GP practices, to identify young carers and carers who themselves are over 85, and provide better support". Further, "In developing plans, CCGs should be mindful of the significant changes to local authority powers and duties from April 2015 under the Care Act 2013 [sic]. Plans should focus on supporting young carers and

<sup>41</sup> [Young Carers: The Support provided to Young Carers in England \(Children's Commissioner 2016\)](#)

<sup>42</sup> NHS England (2014) NHS England's Commitment to Carers

working carers through the provision of accessible services, and services for carers from vulnerable groups”.

The NHS Outcomes Framework 2013/14 has an indicator for improving health related quality of life for carers as measured by the average health status score for individuals reporting that they are carers. As well as national measures like this one, commissioners can define local outcomes that reflect local areas for quality improvement and set expectations for how providers will add social value and deliver services that address what matters to people and families. Currently national practice profiles data collected by Kingston CCG is for carers aged 18 and over only.

The [General Medical Council Guidance for Doctors \(2007\)](#) requires that Doctors should also be aware of the needs and welfare of children and young people when they see patients:

- a. Who are parents or carers
- b. Who are cared for by children or young people, or
- c. Who may represent a danger to children or young people.

### **Schools and Young Carers**

Identifying and supporting young carers is an effective way of improving their attainment and attendance. Young carers are specifically mentioned in Ofsted and Estyn evaluation inspection schedules and frequently eligible for free school meals and pupil premium/development grant funding.

It is likely that there will be young carers at every school in England and Wales:

- A [survey by the BBC](#) in 2010 estimated that about 1 in 12 secondary aged pupils have caring responsibilities.
- The number of 5-7 year olds providing care increased by 83% between 2001 and 2011.
- 39% of young carers have said that nobody in their school was aware of their caring role<sup>43</sup>.

## **1.7 Best Practice to enable Identification, Assessment, and Support of Young Carers and Young Adult Carers**

### **Providing an Assessment for all Young Carers**

Local authorities must offer an assessment where it appears that a child is involved in providing care. There is no single recommended assessment tool. Below are some examples of assessment tools that could form part of an overall whole family approach to assessment. This guidance has been compiled by [Carers Trust](#) and [The Children's Society](#) as part of the [Making a step change: Putting it into practice](#) programme.

1. MACA YC-18: Multidimensional Assessment of Caring Activities
2. PANOC YC-20: Positive and Negative Outcomes of Caring
3. Common Assessment Framework (CAF)
4. Outcomes Star
5. My Life Now Wheel
6. The YCRG screening tool (YC-QST-20)

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<sup>43</sup> Carers Trust, 2010 Supporting Young Carers in School: An Introduction for Primary and Secondary School Staff.

### **Memorandum of Understanding between Children’s and Adults Social Care (by Associations of Directors of Adults and of Children’s Social Services, Carers trust, and The Children’s Society)**

Local authority services for children and adults are encouraged to develop a protocol to describe how they will work together when assessing both young and adult carers and the people in their care. The protocol will need to set out arrangements for sharing information in a way which facilitates joint working but has regard to issues of confidentiality and personal privacy.

All partners on the local Health and Wellbeing Board sign the Memorandum of Understanding in order to demonstrate commitment to the duties of co-operation and promotion of wellbeing, as well as the wider commitment to identifying, recognising, assessing and supporting Carers. The ‘No Wrong Doors’ template Memorandum of Understanding may need to be varied to reflect local circumstances. Such local variation should be discussed and agreed to by all parties on the Health and Wellbeing Board.

### **Best Practice for Meeting the health and wellbeing needs of young carers (Local Government Association, 2018)** include:

- Helping young carers prepare for adulthood
- Involving young people in decisions about service provision for young carers
- Getting adult and children’s social care to work together
- Developing a young carers app
- Working with schools
- Work with local businesses, schools and the voluntary sector
- Getting the NHS involved
- Easing everyday life with an ID card
- Training the wider workforce to help young carers.

### **The National Carers Action Plan 2018-2020 ‘Supporting Carers Today’**

The Department of Health and Social Care is working with Carers Trust on a young carers identification project which will develop and deliver a ‘train the trainer’ model to support local areas to identify potential young carers and enable individuals working with them to engage sensitively and signpost them to relevant services. Both partners will continue to promote, disseminate and evaluate the model. The materials for the model can be freely accessed from the Carers Trust Professionals website: <https://professionals.carers.org/>

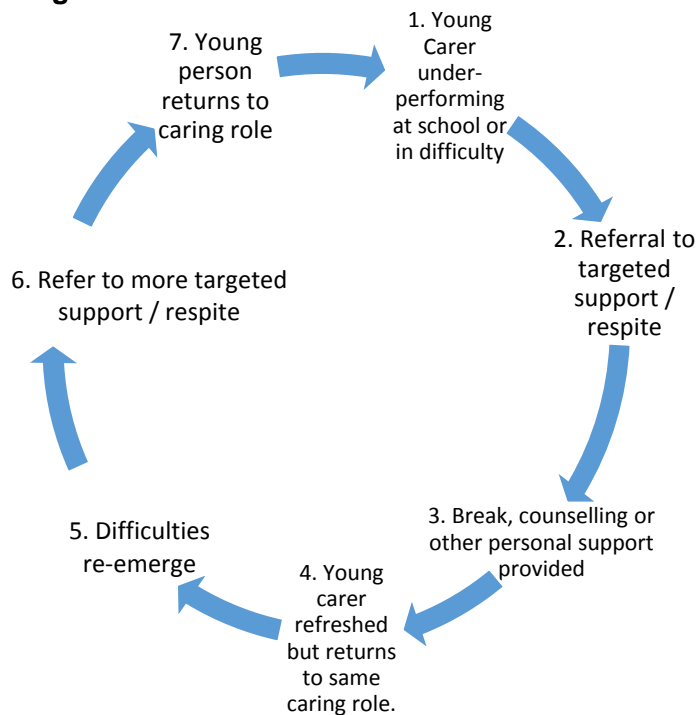
### **Best Practice for Commissioning Services for Young Carers and their Families (Carers Trust, 2012)**

Effective commissioning for young carers and their families should include:

- a. A whole family approach.
- b. Targeted support for young carers and families.
- c. Early intervention and prevention.
- d. Supporting access to education, employment and training.
- e. Improving access to transport for young carers.
- f. Improving and maintaining the health and wellbeing of young carers.
- g. Transition support: seamless support from young to adult carer.
- h. Personalisation: individual budgets and direct payments.
- i. Workforce development and raising public awareness.
- j. Giving young carers a voice.

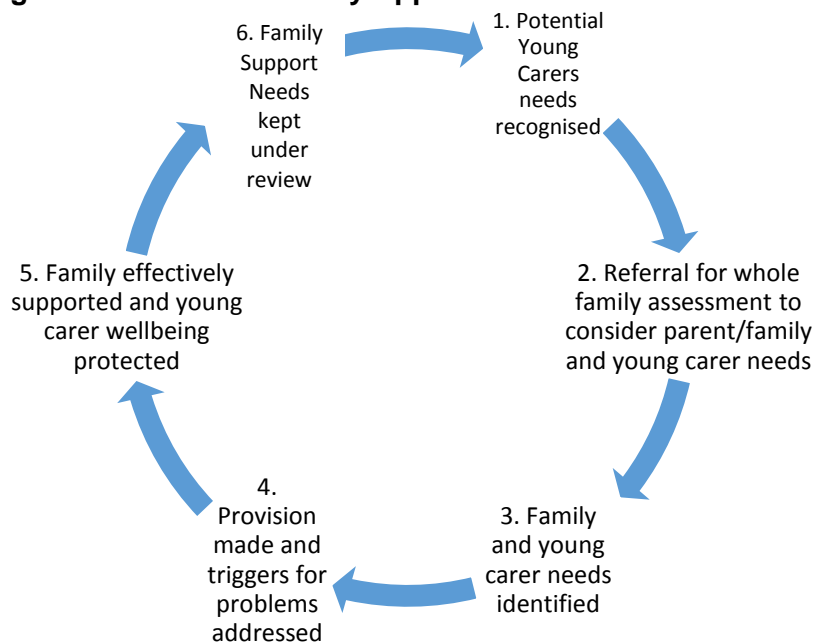
Figures 8 and 9 outline the contrast between a narrower approach where the sole focus is on the respite needs of young carers, whereas the whole family approach (Figure 9) focuses on affecting the unmet needs in a family and therefore will reduce the burden of caring on a young carer.

**Figure 8: The Limitations of supporting a Young Carer in Isolation: Pattern which can emerge**



Source: Department for Education (2010) 'Think Family Toolkits, Improving Support for Families at Risk, Guidance Note 9: Improving Support for Young Carers'. Department for Education, protected by Crown copyright.

**Figure 9: The Whole Family Approach can have better Outcomes**



Source: Department for Education (2010) 'Think Family Toolkits, Improving Support for Families at Risk, Guidance Note 9: Improving Support for Young Carers'. Department for Education, protected by Crown copyright.

The Department of Health has published good practice guidance on whole-family approaches to assessment. Examples from good practice suggest that the willingness of

services such as social care, education, housing, employment and health to work together with families can make a difference to the future of young people and their carers.

### **Three-level Commissioning Model for Carers**

[Commissioning for carers. Royal College of General Practice 2013](#) advocates:

#### Level 1: Primary care

All primary care providers and schools should:

1. Identify a carers' champion
2. Build and maintain a carer register
3. Input into and engage with work led by the CCG to co-ordinate support activities
4. Seek and find carers, including young carers, and those more hidden
5. Involve carers in care planning and by asking for permission to share confidential information with carers
6. Improve service access e.g. by providing appointments and flu vaccinations (nasal spray for under 18s) at convenient times for carers and proactively screening for depression.
7. Be able to signpost carers to useful information and support
8. Offer specific support to young carers including assessment of whether the young person is taking on an inappropriate level of care, and
9. Audit to measure improvements in carer support.

#### Level 2: Carers organisations provide:

1. Emotional support for carers through carers support workers, carers groups or peer networks
2. Financial and benefits advice
3. Advocacy
4. Information about issues that matter to carers
5. A hub to signpost carers to other services

Level 3: Statutory or third sector providers may also drive improvement through services commissioned specifically to meet the needs of carers, including:

1. Health care organisations e.g. district nursing services, intermediate care, specialised GP services
2. Social care organisations e.g. emergency plans, carer assessments, professional home carers, respite care
3. Third or voluntary sector organizations e.g. day centres, sitting services.

### **Mental Health – Best Practice**

**Support for the mental health of young carers** 'Invisible and in distress: prioritising the mental health of England's young carers'<sup>44</sup> promotes the use of:

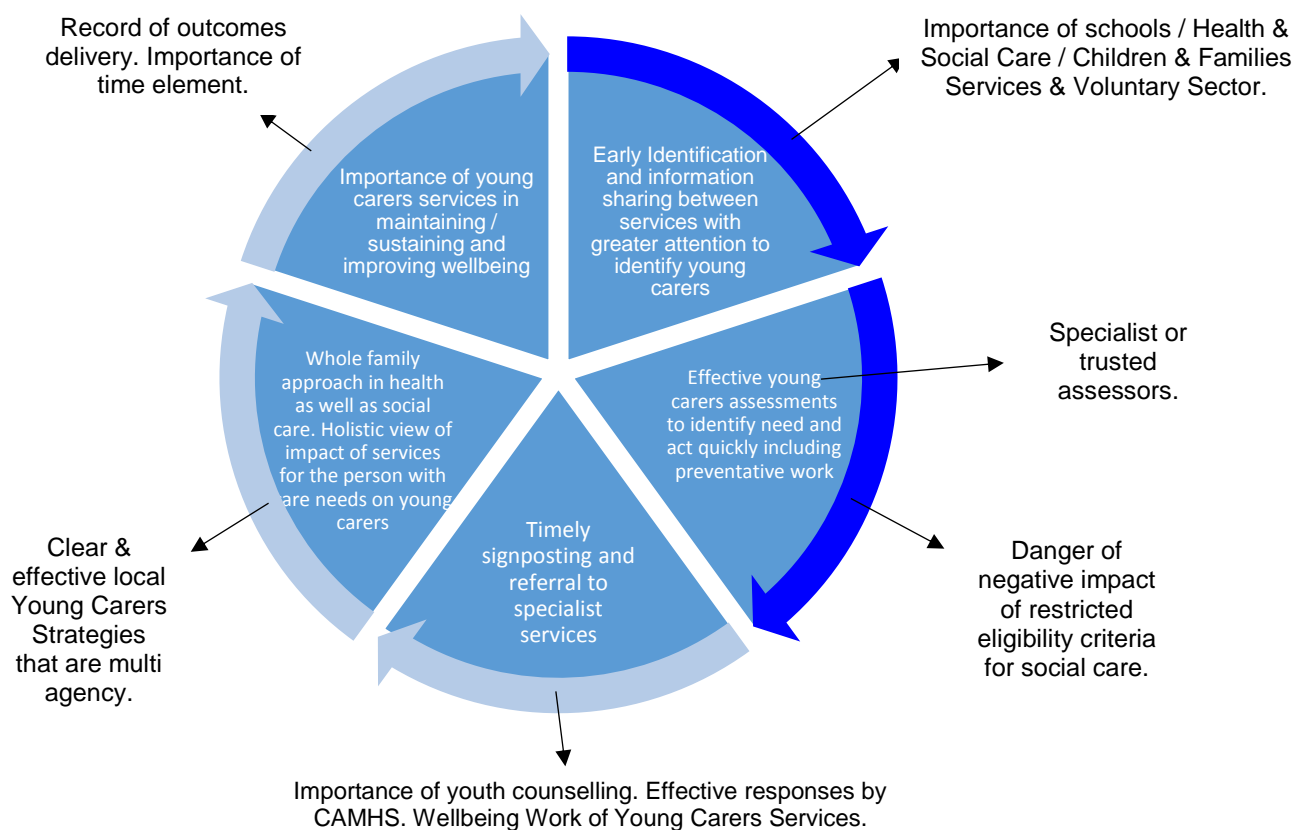
- A professional who works with the person they care for taking a whole-family approach and offering them support as a young carer. This may be a health professional, a social worker or someone from another service.
- Counsellors accessed through a young carers service, school, college or their GP
- Emotional support, understanding and flexibility from a teacher at school or college.
- Emotional and practical support from a young carer support worker or peer support at a young carers service.

The Virtuous Circle Model in Figure 10, developed by Northamptonshire Carers demonstrates the effectiveness of a partnership approach in supporting young carers and their families, making best use of all local services to create a team around the family.

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<sup>44</sup> Carers Trust (2016) Invisible and in distress: prioritising the mental health of England's young carers

**Figure 10: Virtuous Circle Model of the Partnership Approach**



Source: Model developed by Northamptonshire Carers from the Carer's Trust [Invisible and in distress: prioritising the mental health of England's young carers](#)

### **Alcohol Misuse and Young Carers Best Practice**

[NICE clinical guideline 115](#) recommends that families and carers, involved in supporting a person who misuses alcohol, should have the opportunity to discuss concerns about the impact of alcohol misuse on themselves and other family members.

The Carer's Trust [Young carers and parental substance or alcohol misuse – examples of good practice](#) include:

- Out of hours family support for young carers living with a substance misusing adult
- Support for young people affected by a parent's drug or alcohol
- Supporting families affected by drug and alcohol misuses.

### **Health and Social Care Professionals – Carers Toolkit**

NHS England and its partners have developed a [toolkit](#) to help health and social care organisations work together in identifying, assessing and supporting the wellbeing of carers and their families. This toolkit covers duties for NHS organisations brought about by the [Care Act 2014](#) and the [Children and Families Act 2014](#), and includes numerous examples of positive practice to make a difference for carers and their families, including young carers.

### **NHS Young Carer Health Champions Programme**

The Young Carers Health Champion programme was established in 2015 to support improved health literacy, promote health and wellbeing and develop the capacity of young carers to participate in planning and the development of young carer friendly services. It



aims to support service change through young carer voices.

The 12 month programme is made up of young carers (aged 16-24) from across the country. Young carers will experience self-development, be part of healthcare initiatives that aim to improve young carer identification and support and develop an action plan with outcomes that further support young carer friendly services. [More information here](#)

#### **A Young Carers Toolkit for General Practice Staff contains:**

- A [letter to general practice staff](#) with advice about using the pack in the surgery,
- A [guide for supporting, identifying and signposting young carers](#),
- [Posters for the waiting room and staffroom](#),
- [Booklet for young carers](#).
- [E-learning module](#) provides information and guidance for GPs and other community healthcare professionals to enable them to build carer involvement and support into their everyday practice.

#### **The Royal College of GPs Suggestions for GP practices to improve identification and support of their carers of all ages:**

- Developing a practice policy for carers and appointing a carer lead(s) who could be any member of staff.
- There could be one operational lead per practice and one strategic lead per practice.
- Involving carers and the patient participation group (PPG) in the development of the carer strategy
- Ensuring that the whole practice team, clinical and non-clinical, are involved and to include attached community nursing staff
- Using a variety of methods to identify carers, including encouraging self-identification
- Developing and maintaining a carer register which needs to be regularly updated to remain accurate.
- Supporting carers by providing information using a variety of different media
- Offering enhanced access and flexibility of appointments for carers to make it easier for them to access healthcare.
- Offering carer health checks to monitor physical and mental health and annual influenza immunisation
- Signposting carers to where they can get more information and support
- Developing close links with local carer organisations, social services and the voluntary sector
- Participating in a CCG carer champion network where available.

#### **Best Practice for Nurses working with Young Carers**

Queens Nursing Institute Carers Resource Project - The QNI has developed three free online resources to support nurses who work with carers. One specifically developed for [Nurses working in General Practice](#), to enable them to work effectively with carers who are supporting friends or family, including young carers. One specifically for [School Nurses](#), exploring their role in identification, support and wellbeing of young carers and one for [Community Nurses](#) to enable effective identification, assessment and support of carers, including young carers.

#### **Best Practice for School Nurses on Young Carers**

- School Nurse [Pathway](#) has been designed in partnership with the Department of Health, Carers Trust and Department for Education to help guide school nurses to the right support for young carers.
- An RCN toolkit for school nurses: Developing your practice to support children and young people in educational settings provides advice and guidance to school nurses developed by the Royal College of Nursing.

## Best Practice for Schools on Young Carers

- [Young Carers in Schools Programme](#) is a free initiative that makes it as easy as possible for schools to support young carers, and awards good practice. This should result in improved support at school, particularly with homework e.g. not being disciplined if homework is submitted late and understanding of lack of concentration as a consequence of caring.
- [Supporting Young Carers in School: A Step-by-step Guide for Leaders, Teachers and Non-teaching Staff](#) which helps early identify and support young carers in schools as easy as possible. This involves having a procedure to systematically identify caring roles on admission of all children to school.
- Government guidance (DfEE, 1999; DfES, 2006) that recommended schools should consider designating a member of staff to have responsibility for young carers.

## 1.8 Local Services

### Local Strategy Groups and Directives

- **The Children and Young Peoples' Needs Assessment (2016) states:**  
*Under the Care Act 2014, local authorities will have a duty to consider the needs of children living in households where there is an adult who has a disability or impairment that requires help or care as part of a "whole family assessment". The act also enables children to have their own carers' needs assessment carried out, and introduces a new right for young carers aged 16 to 18 who are transitioning to adulthood to have their specific needs assessed in light of how their role might change. The measures, alongside those introduced in the Children and Families Act 2014, aim to identify child carers and their support needs earlier.*
- **Kingston's Children and Young People's Plan 2017-2020 states:**  
*THE OUTCOMES FOR CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES WILL BE THAT...*  
*AfC and the voluntary sector will ensure children and young people with caring responsibilities are supported and have the same opportunities as their peers.*

*WE WILL KNOW IF WE HAVE BEEN SUCCESSFUL BY MEASURING:  
Number of young carers identified during single assessment process.*

This negates the statutory duty to assess all young people with caring responsibilities and assumes that the existing single assessment is fit for purpose in identifying all young carer's needs. Furthermore, there is no indicator for uptake of effective support in improving young carer's quality of life as evidenced by the young carer's voice.

- Quarterly Pan London Forum attended by Young Carers' Project and Kingston Carers' Network.
- The Kingston Carers Board has representation from the Young Carers Project, however there is no explicit reference to young carers in the Terms of Reference. The Terms of reference state the Board's aim is: *to make a reality of the Kingston vision of carers in which people who choose to take on or continue in a caring role are recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet the individuals' needs enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen.*

*These aims will be achieved by the following objectives:*

- *Starting with the voice of carers in Kingston*
  - *Developing and implementing Kingston Carer's Strategy and Action Plan*
  - *Influencing the development of commissioning intentions and specifications for improved outcomes for carers*
  - *Continuing to provide high quality and innovative support for carers in Kingston.*
- The Kingston Carers' Strategy (2013-2015) is now outdated and has not incorporated the 2014 Acts that affect young and young adult carers. The All Age Learning Disability Strategy (2018-2022) states that we [Royal Borough of Kingston, Kingston Clinical Commissioning Group, Achieving for Children and Your Healthcare] *will work with the Carers Board to maximise the support available to carers and look forward to the new Carers Strategy which is likely to be published alongside the Social Care Green paper later in 2018.*
  - Young Carers Protocol 'How to identify and respond to concerns about a vulnerable child at risk when they are working with an adult: a joint agency protocol between children's and adult services (2012) is now outdated as it refers to the Common Assessment Framework (CAF) instead of the Early Help Assessment (EHA) and has not galvanised effective joint working between children's and adults services.
  - At the time of publishing this needs assessment, Kingston's *See the Adult See the Child: How to identify and respond to concerns about a vulnerable child at risk when they are working with an adult: a joint agency protocol between children's and adult services (2014)* is currently under review in order to improve stakeholder engagement in its utilisation.
  - Kingston and Richmond LSCBs Safeguarding Children Affected by parents, carers or other adults' substance misuse: Protocol between Richmond and Kingston Services who work with children and adults April 2017 highlights the importance of recognising the needs of young carers.

### **Kingston Young Carers' Project (part of Kingston Carers Network)**

The Young Carers' Project provides the following services for 5-18 year olds:

1. Advocacy and whole family support including Wellbeing for parents in families where there is mental ill-health.
2. Run lunch clubs in some primary schools and six secondary schools themselves for young carers
3. One to one support
4. Mentoring and advice
5. Peer Support and Targeted work. Peer support includes fortnightly drop-in for 5-8s, 9s to 12s, 12-18s and 16-19s, weekly youth clubs for those aged 12 and above, Cook and Eat. Targeted work includes workshops for young carers with a family members with poor mental health and specialised work includes young carers with a family member with autism. Parents meet every half term and for lunch every school holidays.
6. Fun activities, outings and breaks away from home including whole family days and welcome days.
7. Awareness raising of the needs of young carers, particularly in schools
8. Attend team around the Child meetings
9. Promotion of YCP and Community and Voluntary Organisations
10. Links in with Pan-London Young Carers Network.
11. Join up with Adult social services e.g. housing and benefit issues.
12. Offers training and assemblies in schools to raise profile of Young Carers in order to increase identification and referral.

13. Individual care support planning and outcome monitoring using MACA (Multidimensional Assessment of Caring Activities) and PANOC (Positive and Negative Outcomes of Caring) tools.
14. Help to access grants and benefits.
15. Are part of the condom distribution scheme (Come Correct) and the Chlamydia Screening Programme.

Between June 2017 and May 2018, Kingston Young Carers Project had:

- 15 children who had mentors
- 370 out of 690 (53%) young carers attended one or more activities. Average number of times each young carer engaged was 9.3 times.
- 153 young carers attended a drop in or youth group an average of 7.1 times.
- 327 young carers attended a holiday activity, average number of holiday activities 4.2 per child. 52.8% didn't attend a holiday activity.
- 49 young carers attended a lunch club, average of 4.4 times.

All young carers on the YCP database received around 10 mail outs per year including six booklets of holiday activities.

As of June 2018, there were 661 young carers and 96 young adult carers aged 18-24. Of the young carers at YCP, 39% are from BAME groups; this corresponds to the proportion of children and young people aged 20 years and under from the general population in Kingston<sup>45</sup>.

58% of the young carers at YCP are female and 42% are male.

The majority of agencies referring young carers to Kingston Young Carers Project (YCP) are:

- Schools (27.0%)
- Family Support Workers (24.6%)
- Children Social Worker (13.7%)
- Self-referral (19.4%)
- KCN (9.5%)
- Adult Mental Health (2.8%)

YCP refers young carers to Welcare, Express CIC, Single Point of Access, CAMHS, KCN adult team for benefits/housing advice.

During 2017/18, YCP have been improving their data quality in order to improve the accessibility and experience of young carers using the projects' services. This has helped to ensure that all young carers irrespective of where they live are equally able to access YCP services.

The 2016 external evaluation of the Kingston Carers Network states that:

*There is clear evidence that the service provided by KCN is helping young carers and the families to achieve a wide range of outcomes, including:*

- *Improvements in mental health and wellbeing.*
- *Reductions in the negative impacts of the caring role.*
- *Improvements in family communication and relationships.*
- *Reductions in social isolation and the negative impact that this can have upon wellbeing in general.*

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<sup>45</sup> 2016-based Demographic Projections, © GLA 2016-based, Demographic Projections, LONDON DATASTORE (Housing Led Ethnic Group Projection Model) [online], Available at: <https://data.london.gov.uk/dataset/projections/> [Accessed 8 May 2018].

- *Improvements in the financial situation of whole families due to support received via the family interventions project.*
- *Improvements in educational prospects for young carers.*
- *Increased confidence and independence.*

*With regards to the financial value of the service, the social return on investment (SROI) that has been carried out for KCN clearly highlights the social value being generated by the service, to the sum of over £4 return for every £1 invested.*

*When young carers and parents were asked about ways in which the service could be improved, changes suggested by parents were in the main dependent upon additional capacity to provide more of what is already provided by the service. There were no suggestions for changes regarding the way in which the service is managed or run. Everyone that we spoke to felt very grateful to be able to access the support offered.*

### **Young Adult Carers**

A 2 year funded project finished in February 2016 for 16-25 year old carers. Since then engagement with young adult carers has been challenging in order to assess how Kingston Carers Network can better support young adult carers. Since the Spring 2018, 16-19 year old carers registered at Kingston Carers Network have their own regular monthly support group provided by Kingston Carers Network, which will be fortnightly from September, 2018. Budget constraints have limited any further service development for young adult carers at Kingston Carers Network.

KU Cares states that it provides a 'comprehensive package' of support for their Kingston University students who are young adult carers both pastorally and with some financial assistance. KU Cares won recognition as 'highly commended' at the Times Higher Awards, November 2014 and runner up at the 2015 Guardian University Awards, March 2015.

There are no known other dedicated support services for young adult carers in Kingston.

### **Schools**

During exploratory discussions it was felt that schools are not consistently using the Early Help Assessment.

In 2015, Tolworth Primary School (Nursery, Infants and junior school) was awarded the 3 yearly Gold award by the Carers Trust, whilst Lovelace (Primary) was awarded the Bronze award and Ellingham Primary were working towards the award. SENCO and INCO leads may have the young carers lead role for the school.

### **Achieving for Children**

The Single Point of Access and AfC use the Early Help Assessment (EHA) which is not statutory, is nationally recognised and replaced the Common Assessment Framework (CAF) in 2016. The Early Help Assessment is intended to be the one assessment that would be required with any child and is intended to involve the family. This assessment is undertaken by the referring agency, they would refer to SPA, who would then refer the child to Family Support, or Referral and Assessment (R and A), or Safeguarding as appropriate.

Exploratory discussions revealed that relevant agencies across Kingston and within AfC were not confident to utilise a comprehensive whole family assessment and there was confusion regarding which agency had the responsibility to undertake this assessment.

As part of this needs assessment, AfC were not able to provide the following data due to what was described as a lack of *formal mechanisms to capture this*:

1. How many children and young people are referred to Kingston Council as potentially being a young carer?
2. What percentage of these children and young people went on to be assessed?

3. What percentage of those assessed were deemed to be in need of support?
4. What percentage of those deemed to be in need of support actually gained access to support?
5. What percentage of those deemed to be in need of support reported that they found the support helpful?

As part of a Freedom of Information request, in 2016, 115 Early Help Assessments (EHAs) did not lead to full young carers / whole family assessment, whilst in 2015, 137 EHAs did not lead to full young carers / whole family assessment

The Local Offer website's health information on young carers is currently limited, offering only the NHS 111 non-emergency health number, but does not refer to local services. Instead it focuses on the rights young carers to access the patient record information of the person they care for. If the family or young carer refused to see a social worker, an EHA is used instead; this is non-statutory but is nationally recognised. Other organisations have their own tool e.g. Young Carers Project have an evidence-based tool.

### **Clinical Commissioning Group**

There is no specific ring-fencing for young carers within the Kingston CCG budget as there is with Richmond CCG.

### **General Practice**

Care navigators are being trained to help on the frontline with sign-posting services. This role is being developed to support anyone that comes through the front door, although it differs from a triage service but is more to educate patients about other local services that are available to them (e.g. pharmacy, smoking cessation services, sexual health services), as the GP may not always be the most appropriate professional to speak to. Carers of all ages can access this service, although not all surgeries have Care Navigators in post.

## **2. Exploring Local Needs - Methods**

A steering group was set up to specifically approve of the scope and format of the needs assessment and to scrutinise the types of questions that were being asked of the young carers.

Between December 2017 and May 2018, the following methods were undertaken in Kingston as part of this needs assessment:

1. Literature review.
2. Call for information at the April 2017 Kingston Voluntary Action Health Conference (see Appendix One)
3. Four Focus groups of 33 young carers that took place during the regular sessions that Kingston Young Carers Project (YCP) run for:
  - 7-10 year old boys (more vulnerable carers)
  - 9-12 year olds girls
  - 10-13 year old boys
  - 12-18 year olds boys and girls.
4. Semi-structured surveys with 23 young carers aged 9 – 18 and two young adult carers aged 18-24. The steering group decided not to include questions about young carer's demographics as this would discourage completion of the questionnaire.

5. Face to face interviews with five parents of young carers.
6. Face to face and telephone interviews with 17 professionals across healthcare, schools, Children's and Adults Social Care, voluntary organisations (e.g. Express CIC, Yorda Adventures, Refugee Action Kingston - RAK, and Kingston Young Carers Project - YCP).
7. Semi-structured questionnaires sent to 25 primary, secondary, special, and independent schools across Kingston (to their young carers leads when known).

Templates of the survey questions, interview questions, and Focus Group questions in methods 3-7 (above) are available in Appendix two.

In order to maximise engagement, the focus groups and surveys with young carers and interviews with parents involved convenience sampling where groups were held during the regular YCP sessions. YCP workers were also present in case any support was needed as a result of being asked some of the more sensitive questions.

The interviews and focus groups were transcribed and qualitatively analysed using thematic analysis<sup>46</sup>. Two people wrote young carers responses and notes were cross-checked to ensure that recording was maximised. Interviews with professionals were cross-checked with the interviewee to ensure information captured was an accurate reflection of their views. The findings from these interviews may not be generalisable to all young carers and their families, however they are useful for illustrating and understanding children's and families' experiences, and for providing an indication of the dimensions of caring and the nature and extent of support that young carers and their families need.

All participants were provided with written information explaining the purpose of the research, assurances of anonymity, confidentiality and the voluntary nature of the research, as well as clarity regarding disclosure in case of risk of harm. Consideration was given to the ethical issues of informed consent and impact of asking questions of young carers as a group alongside their ability to comprehend the questions as intended by the research. Where clarification of the questions was needed, the question was re-worded during use. Consent forms were sent to parents of young carers under the age of 16 and given directly to the young carers aged 16 and above two weeks before as well as on the day of the focus groups and distribution of questionnaires. See Appendix three for consent forms used.

The young carer's focus groups helped to inform and triangulate with the young carers survey questionnaires.

The questions in [The lives of young carers in England Omnibus survey report Research report January 2017](#) were used to inform the type of questions used with young carers focus groups and questionnaires.

A 10-question electronic survey was sent to all 96 young adult carers registered at Kingston Carers Network (KCN) and 33 young adult carers registered at Kingston University carers support service. Only 2 questionnaires were completed in total and returned (one from each setting).

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<sup>46</sup> Braun, V. and Clarke, V. (2006) Using Thematic Analysis in Psychology, Taylor and Francis publishers

## 3. Local Needs - Results

For fuller versions of the summaries below, please see Appendix 4.

Demographics of young carers attending the Young Carers Project can be found in section 1.8 (local Services).

### 3.1 Findings of Young Carers Focus Groups Responses

1. The focus groups consisted of a relatively equal proportion of girls (17) and boys (16), although two-thirds of girls were from the older 12-18s group, whilst over three-quarters boys were from the 7-10s and 10-13s group. The 7-12s group and the 12-18s group were analysed together for the same questions as well as separately to find out if there were any differences between the younger and older age groups.
2. Young carers felt that types and level of support offered varied greatly between schools. The support was felt to be most helpful from the lunch clubs, although young carers felt that schools could do more to support them, particularly during transition times between schools or when turning 18.
3. Young carers had high levels of awareness of the potential barriers that prevented young carers being identified, but added that there was also a belief that schools would not understand their roles and responsibilities as young carers.
4. Most support was gained from Kingston Young Carers Project with minimal support from school, their parents, CAMHS, art therapy, and Social Worker.
5. There was consensus that Kingston Young Carers Project support was invaluable (e.g. in making good friendships).
6. Those who had received social work support deemed it unclear, drawn-out, and ineffective.  
*'Someone did come in but she was really old and was unable to look after my brother properly or, you know, safely.'*
7. Time constraints, embarrassment, and lack of understanding by their peers featured strongly as barriers to initiating and maintaining friendships (outside the Young Carers Project) particularly amongst the older young carers.
8. Bullying featured commonly as negatively impacting friendships (outside YCP). This resulted in young carers carefully selecting which friends they informed of their caring roles and responsibilities:  
*'A carer shouldn't say they are a young carer – even my best friends don't know about it.'*
9. Generally the older young carers felt that caring had significantly reduced their free time.
10. Overall the older young carers felt that they could contact emergency services if they needed to and some already had. The younger groups (aged 7-13) did not know how to call emergency services.
11. Young carers felt that they were not being included in discussions with health care professionals about the care of the person they cared for and had to rely on other family members when this person was hospitalised despite these family members being elderly and unwell themselves in some instances.
12. Almost no young carers reported that they had had a young carers / whole family assessment and of the very few who did, it was deemed to be ineffectual in improving young carers quality of life.
13. Situations that made caring more difficult commonly included:
  - Expressions of anger and frustration by the young carers, other siblings, as well as by the cared for:  
*'When my dad gets frustrated, he takes his anger out on us because [of his condition].'*  
*'When [the person I care for] smashes things down when things get in the way.'*



*'My younger brother has anger issues – he gets angry over the slightest things. It's harder to care for mum when he is shouting. He is a carer for my mum as well.'*  
*'When they take their frustration out on you and you are doing the best you can. You have to deal with their frustration and yours.'*

- Negative educational and financial impacts of caring for the young carer as well as the cared for:  
*Calling in sick to work because my mum isn't well or I have to leave college early because my mum's sick.*  
*I never had time to study. My brother is really uncontrollable, unpredictable, he can't be left on his own. He will run away and sit on dad's doorstep for hours.*
- Lacking guidance when person being cared for has an acute episode.  
*If mum gets more ill and is in bed all the time and I wouldn't have someone to guide me.*

14. What young carers least enjoyed about caring was the high level of responsibility that they held which was disproportionate to their age and negatively impacted on their childhood and childhood experiences.

*I act like a mum, I sound like a mum and I don't like that. I feel I've grown up too fast – I'm more of a mother figure than a sister.*

15. What young carers most enjoyed about caring was:

- YCP and its informal, drop-in nature, that it provides activities, and the opportunity to talk with friends who understand
- Seeing the person they cared for not needing their care so much
- Enjoying time with the person they care for when that person is well enough.

16. To improve the lives of young carers in Kingston, young carers recommended:

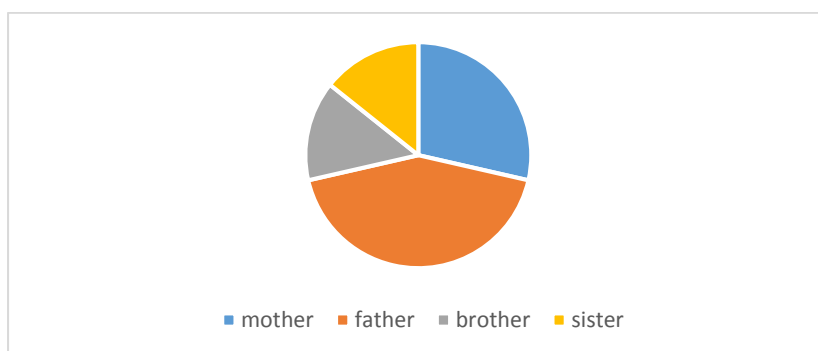
- More promotion of YCP and its mentoring programme and having more male staff at YCP
- Raising awareness about young carers
- More support for the people young carers care for so that the young carer can have more free time:

*Have more freedom to know you can go out. Having your sibling in good care. Feel safe leaving him.*

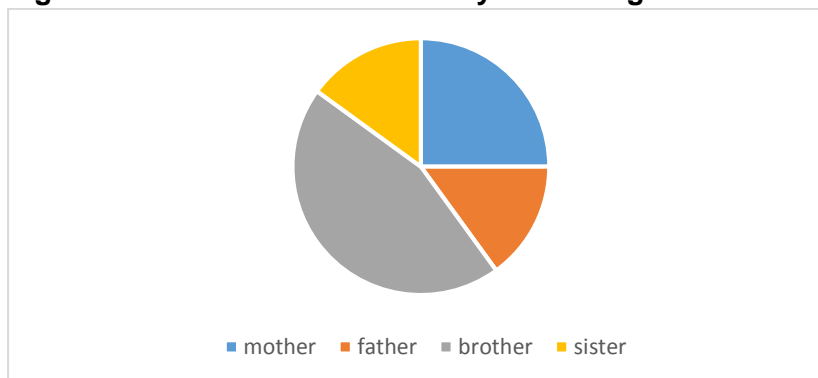
### **3.2 Findings from Surveys with 23 Young Carers aged 9-18 Years**

1. 23 young carers aged 9-18 completed the survey. No demography data was collected in order to keep the number of questions in the survey questionnaire to a minimum (to ensure completion).
2. Overall, there were very equal numbers of siblings as parents being cared for. The 9-13s cared for proportionally more parents than siblings and the 12-18s group cared for proportionally more siblings than parents (with three times more brothers than sisters being cared for).

**Figure 11: The Person cared for by the Young Carers who were aged 9-13.**



**Figure 12: The Person cared for by the Young Carers who were aged 12-18.**



2. Nearly a quarter of young carers had more than one person to care for.
3. The majority of reasons that the 9-18s young carers were caring for someone was because they had a physical disability (most common), ADHD or Autistic Spectrum Disorder (second most common), mental ill health (third most common), and learning disability (fourth most common). These reasons were proportionally very similar.
4. The most common types of care given were:
  - *Cook, shop, look after pets, sort out transport, drive* (61%, n=14),
  - *Emotional support - Listen to them, comfort them, help them calm down* (61%, n=14),
  - Personal caring (e.g. Help with washing, dressing, toilet, feeding) (24%, n=9).
5. Fewer than five carers performed four types of care for both of the people they cared for, with equal representation from 9-13s group and from the 12-18s group. Types of care include:
  - Personal caring (e.g. Help with washing, dressing, toilet, feeding)
  - Emotional support
  - Additional childcare
  - Cook, shop, look after pets, sort out transport, drive.
  - General caring (giving medication, applying creams, changing dressings)
  - Help the person move about
  - Work to help bring money in
  - Help with financial matters e.g. dealing with bills
  - Interpreted / signed for someone so that they can understand information

6. Nearly all young carers had someone else to help them perform their caring responsibilities and the person relied on most was their mother or sister. This mirrors findings from earlier studies about the gendered nature of caring<sup>47</sup>.
7. All of the young carers lived with the person they cared for.
8. Young carers perceived that caring had a negative impact on their family relationships.
9. Suggested ways in which more support would be beneficial to the 12-18s young carers included:
  - *School could do more.*
  - *More respite care.*
  - *There isn't enough support for my family financially, emotionally, or enough care, outside school hours.*
10. About one-third of the young carers stated that they were always involved in discussions and talks about the person they cared for whilst two-thirds stated that this was true sometimes.
11. Nearly half of young carers described themselves as having 'additional needs' e.g. requiring regular medication, asthma, diabetes, needing additional support in school. This exceeds the national proportion of just over a quarter as described in [Young Carers: The Support provided to Young Carers in England \(Children's Commissioner 2016\)](#)
12. Overall 9-13s perceived their health as good, while 12-18s perceived their health as only average, although there was a wide range of responses.
13. All of the 9-13s and the majority of 12-18 year old young carers felt that they sometimes felt happy or good about themselves, or able to have a laugh.
14. All of the 9-13s respondents said that caring had made them sometimes or always feel stressed, anxious, or isolated and lonely.
15. Among the 12-18 year olds, caring resulted in:
  - Three-quarters of them sometimes or always feeling tired, upset, down/sad, angry.
  - Half of them sometimes or always feeling stressed, anxious, sleep-deprived, lonely and isolated,
  - A third of them sometimes or always having back pain, missing meals, avoiding eating.
16. Young carers indicated good access to GPs, dentists, and school nurses but not community pharmacists. This implies potentially good linking in with early health intervention and underlines the opportunities for GPs, dentists, and school nurses to identify young carers and link them into assessment and support.
17. Generally the young carers showed relatively low levels of take-away food consumption with one-third taking away food once a week.
18. Only half of the 9-13s and only a third of the 12-18s were undertaking physical activity to the level needed to maintain a basic level of health.
19. For the 12-18s, lack of time and confidence were the seen as the biggest barriers to accessing activities, clubs, and hobbies.
20. Only a third of 9-13s and approximately one-quarter young carers confirmed that their GP surgery knew that they were a young carer. Nearly half of young carers didn't think the GP surgery needed to know and fewer than five stated that they were never asked whether they were a young carer. Responses from both age groups overall imply that GP staff have missed opportunities to identify and support young carers.
21. Nearly all of the 9-13s and two-thirds of the 12-18s stated that their schools were aware that they were young carers.
22. Schools had helped the minority of 9-13 year old young carers by allowing them to start school later or finish earlier, allowing to have mobile phone switched on during lessons, lunch clubs for young carers, and emotional support.

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<sup>47</sup> Aldridge, J. and Becker, S. (1993) Children who care. Inside the world of young carers. Leicestershire: Department of Social Sciences, Loughborough University.

23. Two-thirds of the 12-18 year old young carers felt that having lunch clubs helped support them as a young carer.
24. The average score was 5 for the the extent to which 9-13 year old young carers believed the schools helped them as a carer. The average score was only 3 for the 12-18s group. (Where 0 was no support and 10 was the highest levels of support).
25. All of the 9-13s young carers felt that caring sometimes affected their free time.
26. The majority of 12-18s young carers felt that caring sometimes or always negatively affected their homework, concentration, and their free time, while half felt that caring negatively affected their social life and interests.
27. Of the young carers aged 14 to 18:
  - More than three-quarters had not received any advice or support regarding *'Managing money. Benefits e.g. Carers Allowance; Housing / accommodation; Replacement care paid for while taking part in approved activities'* or *'Managing money. Benefits e.g. Carers Allowance; Housing / accommodation; Replacement care paid for while taking part in approved activities.'*
  - Two-thirds had not received support regarding *Education – learning new skills, additional qualifications, colleges, careers advice, funding options*
  - Half had not received information and advice regarding *'Employment – volunteering to build up work experience, writing a CV, interview skills, careers advice, self-employment; finding work after caring; 'Work preparation Support for Carers' scheme.'*
  - More than three-quarters thought that there should be more support (than there is) for young carers during key times such as moving to a new school and leaving school/college.
28. When asked about their level of anxiety about leaving Kingston Young Carers Project at 18, young carers aged 14 or older gave a score of 5 (where 0 is *not anxious at all* and 10 is *extremely anxious*).
29. Nearly all of the 12-18s were full-time students.
30. A need for increased awareness about employee's rights as carers is implied from the 12s-18 year olds responses.
31. Two-thirds of 12-18s believed that more had been expected of them in their caring role as they have become older (they have taken on more caring responsibilities).
32. All of the 12-18 year old young carers had between one to four other children living at home with them, with nearly half having three or more other children living in the family. None of the young carers had children of their own.
33. Half of 12-18s were not sure if *there was a plan in place to look after the person you care for if you were suddenly unable to care for any reason* and more respondents did not have a plan compared to those who did.
34. Although the Young Carer Project and School Nurses were accessed for support, none of the young carers were in contact with the following support services:
  - Community Pharmacy
  - SPA (single point of access)
  - Yorda
  - Express CIC
  - Macmillan Cancer Support
  - Citizens Advice Bureau
  - 'Carers UK' or 'Carers Trust'.
35. Young carers would like more free time, more awareness raising about young carers and young adult carers, more supportive activities by schools and outside of school, mores support to access emotional and physical health services, and more support with travel for those aged under 16.

### 3.3 Findings from Young Adult Carers Survey

This survey was only answered by two respondents.

Both young adult carers had someone else to help them in their caring responsibilities, sometimes caring interrupted their sleep, and they both experienced high levels of support for transition to adulthood in relation to education (*learning new skills, additional qualifications, colleges, careers advice, funding options*) but not in relation to family relationships, social support, accommodation and independent living, health, development and general wellbeing, “financial literacy” and skills in financial management. These two young adult carers differed in their responses to all of the other questions.

However some valuable information was offered to the last open question regarding any suggestion they had for recommendations to improve the lives of young carers and young adult carers. This included provision of support groups in schools, colleges, and universities, support and advice to support their study, provision of loans, and raising awareness of the impact of caring for young carers amongst senior members of staff in educational settings:

*‘First of all, setting up places and support groups within the university or within local schools, colleges, etc. can help those in a position of power reach out to young carers who might not want to or have the confidence to speak up and talk about what is happening with their caring role. Reaching out to people who might be having difficulty with their studies and offering that support and advice, e.g. using mitigating circumstances if it comes to that if their caring role gets in the way of their studies, putting loans in place to help if they come from a low income background, etc. I also think it’s important to have young carers and people who are familiar with how to talk about young carers and their issues reporting to those who are in positions of authority about improvements that they could make to benefit the lives of young carers and those they care for.’*

### 3.4 Findings from Summary of Five Parents Interview Responses

Five parents were individually interviewed using face-to-face interviews and the main themes were:

1. Parents of children who are young carers feel isolated and anxious for these children because:
  - The parents’ support network is limited – due to a perceived lack of understanding from other parents and friends; this is exacerbated when there is a family member who has an Autistic Spectrum Condition, substance misuse / alcohol, mental health condition as these conditions are not obvious / visible.
  - There is lack of support during extra-curricular times e.g. holidays and after school where available clubs cannot accommodate for the needs of the child being cared for.
  - The young carers lack confidence, are anxious, and experience aggressive or violent behaviour at home (due to the condition of the person being cared for). This negatively impacts on the young carer forming healthy relationships at school.
2. Young Carers Project and Express CIC were viewed as very supportive for parents of young carers.
3. However there was a consensus among parents that Young Carers Project should offer emotional support to young carers.
4. Parents made assumptions about schools knowing that their child was a young carer without informing the schools directly themselves.
5. Parents had not prepared or given much thought to transition at 18 or why it might be an important time for their child who is a young carer.

6. Parents were unaware of the role the School Nurse, GP, community pharmacist, and hospital in supporting the young carer in their family.
7. Parents were also unaware of the rights of their young carer to access flu vaccination.
8. The autistic spectrum pathway was criticised as being disjointed, inefficient, confusing, and drawn-out.
9. Parents had negative experiences of CAMHS which was viewed as ineffectual in improving their child's mental health, or their child didn't reach the threshold for continued support from CAMHS and so were left unsupported.

### 3.5 Findings from Professionals Interviews

17 professionals were interviewed. Responses were sought from a range of staff from NHS, schools, voluntary organisations, Adults Social Care, and Children's Social Care (AfC). The latter included the Youth Resilience Service - consisting of what were formerly separate young offending, Adolescent Referral, and substance misuse teams. These staff groups included senior strategic leads, heads of services, and those directly interfacing with young people.

#### **Routine questioning to identify Young Carers accessing their Service.**

Almost none of the services directly asked young people accessing their service whether they were young carers/ had caring roles, unless they already had another specific identified need. However each service also stated that they need to start including that question in their initial assessments.

#### **Identifying Young Carers**

- Overall professionals felt that services (particularly adults services e.g. in the NHS and social housing) lack clarity on how young carers are identified and all professional's interview responses showed that they do not explicitly ask specific questions during assessments of their service users whether there are children involved in caring responsibilities in the family, either directly of the child (in children's services e.g. school health, youth resilience service) or of the adult (in adults services e.g. substance misuse, alcohol, adult social care). However, all professionals also wanted to improve their assessments by including a direct question about young carers and welcomed information that could improve identification.
- Professionals had a full awareness of the barriers to identification of young carers.
- A young carers register should be considered.
- The role of social prescribing and of the London Ambulance Service with young carers are key in helping identify and promote assessment of young carers.
- AfC recognised that there is a £40,000 budget (through Troubled Families) for Kingston Young Care Project (YCP) but no service specification and the lifespan of the contract is coming to an end. Discussions between AfC and YCP had begun during the spring 2018. However AfC affirm that *any young person who comes to our service would be appropriately assessed holistically already* but that AfC are not able to identify those already referred to them who are young carers.

#### **Barriers to identifying Young Carers in Schools**

- Professionals felt that schools are in a pivotal position to systematically identify early those young carers not accessing other services and those who provide care on an ad hoc or temporary basis.
- Schools identification of young carers is considered as patchy.
- There was recognition of the limitation of schools to identify young carers due to not being equipped to do so and because of the different types of care that remain hidden.

- There was recognition of the limitation of Adult Social Care (ASC) in identifying young carers and the need to improve joint working between AfC and ASC.
- Schools workforce training is imperative in improving awareness in schools of young carers. Particular difficulties engaging independent schools was highlighted by professionals.

### **Assessment of Young Carers**

- Multi-agency agreement has not been reached regarding the type of assessment that would effectively identify young carer's needs.
- Multi-agency services (outside AfC) are not consistently undertaking even the basic Early Help Assessment.
- A substantial number of referrals from YCP to AfC are resulting in assessments being inadequately done or not being done and are resulting in no support for the young carer other than what YCP already provide.
- There is a common misconception among professionals that YCP undertake full young carer assessments.
- AfC and schools could be well placed to carry out full young carers / whole family assessments.
- AfC would look to fully assess existing children as well as new referrals.
- Young carers would be engaged with the design of these assessments, pathways, and protocols to ensure they are effective.
- Services need to be aware of what support services are available that are relevant for young carers.
- Children's services including Children's Social Care are not aware of what Adult's services including Adult's Social Care provide and vice versa.
- There was a recognised lack of a structured coordinated approach to AfC's working with and networking with agencies outside of RBK with regard to the Family Service Directory.

### **Organisations or Agencies best placed to undertake Young Carers Needs Assessments**

- YCP lack the capacity to undertake any future full assessments of over 600 young carers registered with YCP and of new referrals.
- Professionals recognised the vital role of services which know the child best in young carer / whole family assessments which should take place in a non-threatening environment. The importance of involving YCP because of their expertise was underlined by a number of professionals.
- Currently there is subjectivity determining whether a young carers / whole family needs assessment should take place.
- There was recognition that undertaking a full young carers / whole family assessment is a specialism and requires training and supervision of, for example, social work staff and possibly school staff.
- There was recognition of the need for a pre-assessment screening tool by other organisations (e.g. voluntary and NHS).
- Development of assessments, protocols and pathways, awareness training, and assessment training is underway between AfC and YCP but it is unclear to what extent other relevant agencies are engaged e.g. Adult Social Care and mental health.
- The *I-Care* tool used by Surrey should be explored.
- Improvements to the prioritisation of young carers issues at strategic level needs to be made e.g. at the Kingston Carers Board.
- The need for adult social care to financially support young carers transport needs were stated by a number of professionals.

### **Support for Young Carers**

- There were generally high levels of awareness of the Kingston Young Carers Project (YCP) but not of the different services that they provide and what other support might be available outside of YCP.
- Support in schools was deemed insufficient in schools generally, particularly:
  - Support for young carers of people with mental ill-health
  - Support for lone parent families without extended family support.
- Early Help Assessments, Child in Need Plans, and Child Protection Plans potentially lack any focus on a caring role by the child / young person.
- Services readily refer to YCP instead of carrying out any assessment or providing a co-ordinated, joined-up response.
- Services awareness of support that is relevant for teenagers or young adult carers was almost non-existent.
- Young carers need more:
  - Information and support about the condition of the person they care for.
  - Involvement in the planning for an emergency / crisis
  - Emotional support.

### **Systematic Identification and Assessment of Young Carers to support their Transition Needs**

- Generally, professionals believed that services substantially lacked awareness of identifying and supporting the transition needs of young carers.
- It was recognised that 14-16 year olds young carers were under-identified and underrepresented in Kingston.
- AfC would like to improve awareness of young carer's voices and the detail of what YCP provide in order to work more effectively with them.

### **Young Carers who are caring for Someone because they misuse Substances / Alcohol or have Mental Ill Health**

- Young carers in families where there is mental ill-health and/or substance misuse were considered to be under-identified nationally and locally, as demonstrated by *Serious Case Reviews*.
- There is a potential area for investment to improve this area i.e. Strengthening Families.
- Integration between YCP and AfC would greatly improve identification and support for young carers.
- Over a third of young carers at YCP have mental ill-health in their family.
- There is a lack of awareness among services of the role of young carers in a family where there is mental ill-health.
- The lack of verbalisation of need possibly due to stigma or a limited emotional vocabulary of families affected by mental health and / or substance misuse can exacerbate the difficulties services have identifying needs of young carers in these families.

### **Barriers to Identification of Young Carers and Young Adult Carers**

Professionals identified the following barriers to young carers and young adult carers being identified:

1. Lack of staff awareness of these carers - level, type, and frequency of care are highly variable.
2. Lack of joined up working and co-ordination between Adults Social Care (including Adults Healthcare services) and Children's' Social Care as evidenced by Serious Case Reviews. The example was given by a number of professionals of a nurse visiting an adult patient in the community and missing the opportunity to identify any young carers who may live there.
3. Young carers not wishing to identify as carers due to fears of being bullied or taken into care.



4. Young carers' strong sense of loyalty to their parents and fear of the consequences of disclosure.
5. Service's questions are not identifying young carers due to young carers themselves not knowing. This is more common when they provide care for someone with mental ill-health, or because their cultural background normalises caring, or because they act as interpreters.
6. Negative experiences of previous assessments where nothing changed following the assessment.
7. Competing assessments, pathways, and protocols that professionals have to prioritise.

### **Identifying Young Adult Carers**

- Despite YCP's work with Kingston College and Kingston University, there were very few referrals going to YCP or Kingston Carers Network.
- The professionals had almost no awareness about how young adult carers are identified in Kingston.

### **Assessing Young Adult Carers**

- Responses indicated a low level of awareness of the need to assess young adult carers as any other carer under the Care Act 2014 and to have a whole family approach to the assessment.
- Young Carers Project were able to ensure that young adult carers were assessed once they reached 18 if they were known to them as young carers but could not assure this for 18 year olds who are new to KCN.
- NHS services seemed unaware of how young adult carers were assessed.

### **Support for Young Adult Carers**

- Overall, children services were unaware of any support that is provided for carers once they reach 18.
- YCP are providing a regular support group sessions for 16-19 year olds but only YCP seemed aware of this.

### **Adapting and Adopting the [ADCS/ADASS Memorandum of Understanding](#) between Children and Adults Social Care for use with carers up to the age of 24 in order to better identify and support young carers and enable transition.**

Professionals were generally very supportive of the introduction of a Memorandum of Understanding between Children and Adults Social Care in Kingston but only if it:

- *Is embedded in the other strategies: Thrive, Carers, Autism, Dementia, in order to have any accountability.*
- *Aligned with other existing policies and protocols e.g. child and family assessment as part of the welfare checklist and the signs of safety questions which includes the signs of wellbeing, signs of children in need, and signs of success.*
- Includes the young carers voice
- Has comprehensive stakeholder engagement
- Is part of staff (including housing) induction
- Results in improved support for underlying issues e.g. as finance/benefits exacerbating mental health problems.

### 3.6 Findings of Schools Young Carer Leads Survey

Five schools responded with equal numbers of primary and secondary schools replied and one special school; however the total response was from five schools only. No independent schools responded.

Whilst the small sample of schools cannot be viewed as representative of all Kingston schools, (not least because of selection bias where these schools may be more proactive in engaging young carers than the non-responding schools) some indications can be given of how young carers are identified, assessed, and supported by these five Kingston schools.

1. Schools identification and support of young carers is patchy and uses an inconsistent non-systematic approach, resulting in under-identification of young carers in schools and highly variable types and levels of support.
2. Schools tend to identify that a child is a young carer rather than the family informing them in situations where parents have mental health issues or *other complicating issues* – such as *domestic violence issues*.
3. School staff significantly lack knowledge of and confidence in:
  - Using Early Help Assessments
  - Any pathway involved in engaging children's social care in the assessment of Kingston's young carers.
  - Engaging Adult Social Care when needed.
4. Schools recognise that they could do more to identify young carers however there is a lack of plan or forethought regarding what they intend to do.
5. Reduced staff capacity has negatively impacted on schools' capacity to better support young carers.
6. Parents are inconsistently asked if they would like their young carers to be offered support in school.
7. There is a focus on emotional health and wellbeing to the exclusion of the specific physical health needs of young carers.
8. None of the young carers received any First Aid Training (including calling 111 for non-emergency and 999 for emergency events).

## 4.0 Conclusion

There are a multiple factors that were found in this needs assessment that had an impact on the identification, assessment, support, and experience of young carers. This mostly qualitative study into the lives of Kingston young carers helps provide an updated understanding of the current context of caring among children and young people four years after the introduction of the new legislative framework (the Care Act 2014 and the Children and Families Act 2014). The needs assessment found that:

1. Given the number currently in touch with local services, a substantial proportion of young carers and young adult carers in Kingston remain unidentified and unassessed. According to the 2011, there are 1,037 children and young people aged 0-24 and 251 0-15 year olds providing unpaid care in Kingston. However, there are likely to be four times these numbers. 661 young carers (aged under 18) are registered with Kingston Young Carers Project and 96 young adult carers (aged 18-24) are registered with Kingston Carers Network.

2. Statutory and voluntary service's (including school's) identification of and support for young carers is patchy and uses an inconsistent, non-systematic approach, resulting in under-identification and lack of support of young carers. The work of schools is imperative here for young carers who do not access any other services.
3. Despite this, professionals including school leads and young carers had high levels of awareness of the potential barriers that prevented young carers being identified. There was also high levels of awareness of young carers being hidden in families where there is mental ill-health and/or substance or alcohol misuse.
4. Nearly half of young carers perceived that they had additional needs themselves such as diabetes, asthma, or needing educational support. This is double the proportion of young carers identified with additional needs nationally<sup>48</sup>.
5. Nearly a quarter of young carers had more than one person to care for.
6. Only a minority of young carer/whole family assessments have taken place and young carers deemed any social care intervention to be ineffective.
7. There was consensus that the Young Carers Project (YCP) support was invaluable for making good friendships, social and leisure activities. However services over-relied on YCP instead of recognising their statutory responsibilities under the Care Act 2014 and the Children and Families Act: providing a whole family assessment which would result in health, education, and social care support. Schools (viewed as offering the second biggest source of support) were highly variable in the types and level of support offered and young carers viewed this support as inadequate overall.
8. Caring without sufficient levels of effective support impacted negatively on young carers initiating and maintaining friendships, on their free time, on their physical health (by reducing their opportunities for physical activity), on family dynamics, on their educational (e.g. homework and ability to concentrate) opportunities, their financial opportunities, and on their perception that the cared for person was safe.
9. Young carers relied on predominantly female members of the family and in some instances on frail elderly grandparents to assist with their caring responsibilities.
10. Young carers felt like they were missing a childhood, and the majority sometimes or always felt stressed, anxious, isolated and lonely, tired, upset, down, sad, and angry because of their caring responsibilities.
11. Statutory and voluntary services have neglected to assess and support young carer's transition needs into adulthood. Parents were ill-prepared for transition at 18. Children's services and adult's services had low levels of awareness of what each other provide.
12. Social care, health, and education professionals showed low levels of awareness of how to identify and support young adult carers.
13. Young carers' awareness of how to respond in a crisis (e.g. contact emergency services, First Aid awareness, and contingency plans) was almost completely absent.

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<sup>48</sup> Young Carers: The Support provided to Young Carers in England (Children's Commissioner for England, 2016)

14. One-third of young carers stated that they were always involved in discussions and talks about the person they cared for whilst two-thirds stated that this was true only sometimes.
15. GPs, schools nurses, mental health services, and hospital staff have missed opportunities in better identifying and supporting young carers. Parents were unaware of the potential input these professionals should have.
16. Parents felt that they and their young carer were particularly unsupported during extra-curricular times e.g. after school, during school holidays.
17. Development of assessments, protocols and pathways, awareness training, and assessment training has recently begun between children's social care (AfC) and Kingston Young Carers Project. However it is unclear to what extent young carers, young adult carers, and other relevant agencies are engaged e.g. Adult Social Care and mental health, NHS and also with regard to including transition to adulthood.
18. Professionals were generally very supportive of the introduction of a Memorandum of Understanding between Children and Adults Social Care in Kingston on condition that it is inclusive in its development (e.g. including young carers voice), is aligned with existing policies and protocols, is embedded in the other relevant strategies (e.g. Thrive, Carers, Autism, Dementia) in order to have any accountability, is utilised by **all** relevant staff, and demonstrates improved outcomes for young carers.
19. A need was identified to increase the prioritisation and governance of young carers issues at the strategic level e.g. Kingston Carers Board and forthcoming Kingston Carers Strategy.

## 5.0 Recommendations

Based on the above information and the best practice (section 1.7), recommendations are listed below to improve the early identification and assessment of young carers and young adult carers and their families by Education, Social Care, and Health Services and their timely engagement with appropriate support.

### A. Improving Identification

**Police, social services (children and adults), NHS healthcare (including School Nurses and mental health), housing, education, careers guidance, and employment services should:**

1. Utilise best practice (see Best Practice section) to inform training on young carers and young adult carers which should form part of basic induction, ongoing training, and safeguarding training as standard. Content of training should include:
  - Caring roles and hidden carers particularly among families with problematic drinking or substance use or mental ill-health.
  - Impacts on health and wellbeing,
  - What may lie behind troublesome and apparent coping behaviour
  - Rights

- Assessment and referral processes e.g. which agency has responsibility for using a pre-assessment tool and which agencies have responsibility for a full young carers / whole family needs assessment.

Delivery of this training needs to target independent schools, all areas of Youth Resilience Service (including young offenders), Kingston College, Community Mental Health Trusts (CMHT), refugees, and Gypsy and Roma Travellers.

2. Include a question in their generic assessments on whether children and young people under 18 look after someone / have caring responsibilities.

## B. Improving Assessment

### AfC and Adult Social Care should

3. Adapt and adopt the 'No Wrong Doors' template Memorandum of Understanding to reflect local circumstances and policies and discuss and agree with all parties on the Health and Wellbeing Board. This should be done with the use of the Young Carers' Needs Assessment Supporting information and the good practice guidance on whole-family approaches to assessment.

### Young Carers Project (YCP), AfC and Adult Social Care should ensure that:

4. Appropriately placed services (e.g. within AfC, Schools) are fully trained to provide young carers whole family assessments and other services (e.g. YCP other voluntary and community services) are trained to use the pre-assessment tool and be aware of the referral pathway for a full assessment.
5. Young carers and parents should be informed of the rights of their young carers to access a whole family assessment and to access support from NHS providers (mental health, GPs, hospitals, School Nurses, Community Pharmacists).
6. The various [assessments tools](#) and the I-Care (Surrey) assessment are considered and developed with young carers and young adult carers. This should involve the consideration of a pre-assessment toolkit which YCP and other agencies can use.
7. Assessments and referral processes:
  - Comply with the Care Act 2014: the adult assessment form includes a question about who is providing care?
  - Include what the person wants to achieve in their day-to-day life and how care and support could contribute to this.
  - Who is going to provide care when a child (the young carer and if applicable the cared for) turns 18?
  - Include features of a transition assessment.
  - Incorporate an easy-to-understand system for young people to self-refer for assessments.

## C. Improving Support

### RBK, AfC, Adult Social Care, and NHS providers should:

8. Examine the accessibility and usefulness of online support materials for young carer and young adult carers. This includes a creative approach to the use of digital technology such as health and learning opportunities, and social opportunities, and the Local Offer website and update and improve these as appropriate to make them relevant. This should include support information and advice from adult social care.

9. Ensure free or concessionary public transport at all times for young carers to reduce risk of being excluded from school and from afterschool based activities due to lack of transport or income to fund it.
10. Address and annually review the health and wellbeing of young carers by utilising best practice examples in [Meeting the health and wellbeing needs of young carers \(Local Government Association, 2018\)](#) e.g. to help young carers prepare for adulthood, developing a young carers app, working with local businesses, schools and the voluntary sector, getting the NHS involved, easing everyday life with an ID card, and training the wider workforce to help young carers.
11. Ensure that families and carers involved in supporting a person who misuses alcohol have the opportunity to discuss concerns about the impact of alcohol misuse.
12. Utilise the [Young carers and parental substance or alcohol misuse – examples of good practice](#):
  - Out of hours family support for young carers living with a substance misusing adult
  - Support for young people affected by a parent's drug or alcohol
  - Supporting families affected by drug and alcohol misuses.

### **Schools and Sixth Form Colleges including Kingston College should**

13. Implement the [Young Carers in Schools Programme](#)
14. Utilise the [Supporting Young Carers in School: A Step-by-step Guide for Leaders, Teachers and Non-teaching Staff](#)
15. Consider designating a member of staff to have responsibility for young carers and young adult carers.
16. Establish a clear framework of support for young carers and young adult carers, which is embedded into the school's policies (including [bullying policy](#)) which are implemented and communicated to parents.
17. Ensure careers advice services review to guarantee that advice adequately addresses and takes account of caring responsibilities.
18. Provide clear information about the financial support that exists for young adult carers going to college and university. This information should be provided at an early stage so that the young people are able to plan their futures without the uncertainty that currently exists. This should include individual budgets and direct payments.

### **General Practice, Community Pharmacies, Kingston Hospital, School Nurses, and Children's and Adults Mental Health Services should**

19. Establish a young carer's champion.
20. Better identify young carers' expertise in the care of the person they care for and improve in the health and wellbeing of the young carer. A Young Carers Charter may assist this as was developed in the Royal Surrey Hospital or [Sussex Partnership NHS Foundation Trust](#).
21. Utilise *Connected Kingston* by General Practice staff to link in young carers and young adult carers into a social prescriber or Community Connector to help address their health and wellbeing needs.
22. Ensure that care navigators in General Practice are trained on the needs of and services for young carers and young adult carers.
23. Utilise the [GP Practice toolkit](#) by General Practices to improve identification, assessment, and support of young carers and young adult carers.
24. Ensure that any Healthy Living Pharmacy work on carers should include young carers utilising [Engaging with Pharmacies: A Toolkit for Young Carer Services](#)
25. Ensure utilisation of [School Nurse Pathway](#) to help guide school nurses in supporting young carers.

### **Mental Health Services should ensure that:**

26. A professional (e.g. health professional, social worker) who works with the person the young carer cares for takes a whole-family approach and offers them support as a young carer.
27. Counsellors are accessed through Kingston Young Carers Project, school, college or their GP.
28. CAMHS collects data on whether the children and young people receiving services have a caring role and whether young carers are referred to Kingston Council for a young carer's assessment (if that is the agreed pathway).
29. All mental health trusts implement the [Triangle of Care for Young Carers and Young Adult Carers](#) to make sure information and support is given to young carers.
30. South West London St Georges NHS Trust improve the effectiveness and efficiency of the autism spectrum diagnosis pathway so that it early identifies young carers.
31. Policies that aim to reduce waiting times and increase young people's access to services also consider young carers' needs.
32. A pathway with the Young Carers Project is agreed and established.

### **Kingston Carers Board should ensure**

33. Education, Social Care, Housing, AfC, and Health work together to develop a strategy that covers the principles outlined in the [NHS toolkit](#), with the key objectives aligned with those from The National Young Carers Coalition's (NYCC) and Commissioning Services for Young Carers and their Families (Carers Trust, 2012).
34. The voices of young people are heard e.g. through a forum, council, *NHS Young Carer Health Champion* in order to inform health literacy, promote health and wellbeing and develop the capacity of young carers to participate in planning and the development of young carer friendly services.
35. That there is increased representation from young carers and young adult carers and from NHS colleagues (including mental health, Kingston hospital, and GP practices) at the Kingston Carers Board.

### **36. AfC should increase the sustainability and stability of Kingston Young Carers Project by ensuring the service specification includes:**

- a. Involvement young carers and families in its development to ensure that service-level targets and measuring reflect the things that make a direct impact on the lives of young carers, young adult carers, and their families and are valued by them.
- b. Pathway development between Kingston Carers Project, mental health services, AfC, and adult social care.
- c. The gathering of good evidence and evaluation which can be time intensive and therefore must be factored into costs.
- d. Measuring and tracking of the impact of young carers and young adult carers' wellbeing.
- e. An expansion of the offer from Kingston Carers Network for young adult carers. This may include expanding the nascent support service for the 16-19 year olds offered by Kingston Young Carers Project.
- f. Development of a register of young carers by referring to Early Help hub for assessment so that families and their young carers can be kept regularly updated on all the services and support.
- g. Emotional and practical support from a young carer support worker or peer support at Young Carers Project. This should include partnering with Kingston Public Health in for example improving access to [health services and healthy lifestyles services](#) (to increase opportunities for physical activity), First Aid training, and what to do in an emergency (contacting services and contingency planning).

- h. Improvements to parents' awareness of the role that education, social care, health and mental health staff have in identifying and supporting young carers and through their transition to adulthood.
- i. Continued work to enhance data quality by recording the number of young carers who:
  - Have mental ill-health and/or mental ill-health of the person they care for
  - Have dual caring responsibilities (caring for a parent and a sibling/other),
  - Are from lone parent families<sup>49</sup> which are over-represented among families where there is a young carer, particularly where the mother is being cared for.
  - Have known additional needs themselves
  - Type and number of agency referring to YCP and from YCP to other agencies.
  - Who have been referred for a whole family assessment and who have actually received a whole family assessment, and who has accessed adequate and appropriate support.

## Improving Support for Young Adult Carers

### Kingston Council should ensure

37. Formally designating staff role(s) to coordinate transition assessment and planning across different agencies. This role will cover:
  - The importance of long-term interventions and continuity of support across transitions, on improving social value and positive long-term individual outcomes.
  - A holistic carer's assessment for young adult carers in advance of transition, with them fully involved throughout the process.
  - Improvement of awareness raising among children's and adults social care about the distinct needs of young adult carers and their rights to services (employment, financial literacy, housing, and educational) and transition support.
38. That its Health and Wellbeing Boards uses its potential to commission the types of services for young adult carers that meet the requirements laid out in The Care Act 2014 and The Children and Families Act 2014, by bringing together, through Healthwatch, the local authority designated person, young adult carers, GP practices, housing services, employers, social care staff and learning providers to develop a flexible support package and approach to learning.
39. Access to the entitlement to Education Maintenance Allowance (EMA) for all young adult carers aged 16–19 years old in full-time education who are not receiving other bursary sources or Carer's Allowance.
40. Free or concessionary public transport at all times for young adult carers to reduce risk of being excluded from school/college and afterschool/college based activities due to lack of transport or income to fund it.
41. Improved access to more support to undertake training and employment opportunities and to sustain and succeed in these.
42. Carer specific policies with clear and accessible disclosure procedures are embedded across all health and social care services, education providers, training initiatives and employment sectors.
43. The services and support for young adult carers from Kingston Carers Network are clearly visible and seen to be effective. Procedures should be in place so that young adult carers know who to tell, how to access services and support, and are aware of the nature of the support they can receive.

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<sup>49</sup> The Lives of Young Carers in England-DfE report 2017



## 6.0 Further Research

1. It was not possible to engage with young adult carers during this needs assessment; consequently a recommendation would be to:
  - Improve engagement with young adult carers by working with schools sixth forms, Kingston College, Kingston University, and Kingston Carers Network.
  - Improve awareness raising among children's and adults social care about the distinct needs of young adult carers and their rights to services (employment, financial literacy, housing, and educational) and transition support.
2. To improve response rate and the generalisability of the schools findings, and as part of further research, a shorter electronic version questionnaire would be utilised as well as interviews with more capacity given to engaging independent schools of whose pupils, an estimated 1 in 12 are young carers (among secondary schools).
3. Because of the sensitive nature of this questions about smoking, substance misuse, and alcohol, another more appropriate method (e.g. interview with an external interviewer in a setting external to school and to the Young Carers Project) might yield more valid results. This would form part of Kingston Public Health's forthcoming planned work to engage young people to identify the level of their substance misuse, alcohol, smoking and sexual health related behaviours.
4. Further investigation would be needed regarding whether the carer had hurt themselves when moving the person they cared for and the equipment/aid was inadequate, or they had hurt him/herself in some other way (see young carers survey).

## 7.0 Other Resources

1. [Carers Trust](#)
2. [Carers UK](#)
3. [Young Carer Assessment Tools](#)
4. [Supporting Young Carers: A resource for schools \(Carers Trust and The Children's Society 2012\)](#)
5. Fact sheet for [Head Teachers and Governors](#) and for [health and social care professionals](#) which outline facts and guidance that will be useful for those working with school nurses.
6. [Know your Rights: Support for young Carers and Young Adult Carers in England – Carers Trust](#)
7. [The really useful book of learning and earning for young adult carers](#)
8. [Refugee toolkit Supporting Refugee Young Carers and their Families - A toolkit for all Practitioners](#)'.
9. [GP online services for carers, including young carers Patient Guide](#)
10. [The Children's Society. 'Supporting Young Carers in Families with HIV, Information for HIV Professionals'](#).
11. [Rethink Mental Illness](#) to create a range of tools to be used with young carers to support their emotional wellbeing and mental health:
  - [Looking after myself: young people's wellness plan](#)
  - [Young and caring: assessing support](#)
  - [Young and caring for someone with a mental illness](#)
12. [Royal College of Psychiatrists – supportive information for young carers affected by mental illness or caring for someone with a mental illness](#)
13. [Triangle of care for mental health](#) - This guide can be used across all mental health services, not only in-patient, and includes a universal self-assessment tool as well as guidance notes.
14. [Time to change](#) working to end stigma and discrimination of mental illness.