

This factsheet should be read in conjunction with the full needs assessment document to access full information (e.g. Best Practice, Recommendations sections, & References).

### Summary

- Young people with caring responsibilities are often hidden. Many families do not recognise their children as 'carers', some children do not recognise or identify with the role, and there can be a degree of reluctance or anxiety among families in disclosing caring responsibilities.
- There is an adverse impact of caring on health outcomes, social activity, educational engagement, and employment opportunities for young carers.
- Young carers may miss school due to caring duties, are at risk of being bullied, are more likely to have a special educational need or a disability, over a 1/3rd have a mental health problem, and are more likely to report their general health as 'not good'.
- 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. 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 (May 2018). However, national research carried out by the BBC and Nottingham University in 2018 found that a fifth (22%) of the children (aged 11-12 and 14-15) questioned provided some care for a family member, with 32% classed as carrying out a high level of care.
- Kingston young carers feel like they are missing a childhood. The majority sometimes or always feel stressed, anxious, isolated and lonely, tired, upset, down, sad, and angry because of their caring responsibilities.
- Adequate and reasonable steps are not being taken locally or nationally to meet the statutory duties of identifying and assessing young carers.

### Definition - a 'young carer':

- ★ Does not apply to everyday or occasional help that may occur in all families.
- ★ Is specific to unpaid care that is relied upon in maintaining the health, safety, or day to day wellbeing of the person receiving support or care.
- ★ Is someone who is aged between 5 and 18 years old
- ★ 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'.
- ★ May provide care on a long or short term and when they (and their families) have unmet needs.

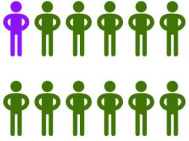
### Definition - a 'young adult carer'

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).

# Key Issues affecting the Health & Wellbeing of Young Carers in the UK

1 in 12 young carers is caring for more than 15 hours per week.



Young carers are subjected to financial hardship. The average annual income for families with a young carer is **£5,000 less** than families who do not have a young carer.



Young Carers are.....

**1.5 times more likely to**

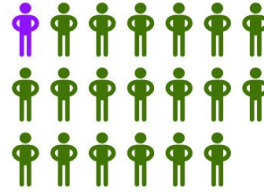
be from Black, Asian, or Minority Ethnic background

**1.5 times more likely to**

have a special educational need or disability



2/3rds young carers have been bullied at school



Around 1 in 20 young carers miss school because of caring responsibilities



**5 times**

- average number of times more young carers are likely to report their general health as 'not good' compared to non-carers

Over a **1/3rd** young carers say schools are not aware that they are young carers & only **1/2** schools which are aware are supportive.

There is no strong evidence that young carers are more likely than their peers to come into contact with support agencies.

Young carers have significantly lower attendance and educational attainment at GCSE level, the equivalent to nine grades lower overall than their peers



Young carers are more likely than the national average to be not in education, employment or training (NEET) between 16 and 19.



Over a **1/3rd** young carers report mental health problems

Caring for someone with mental health needs presents different challenges for their carer compared with a physical illness or disability.



Up to **2/3rds** of children caring for a parent with a mental health problem experience difficulties themselves.

Nearly **3/4** of young carers reported suffering long-term psychological effects.



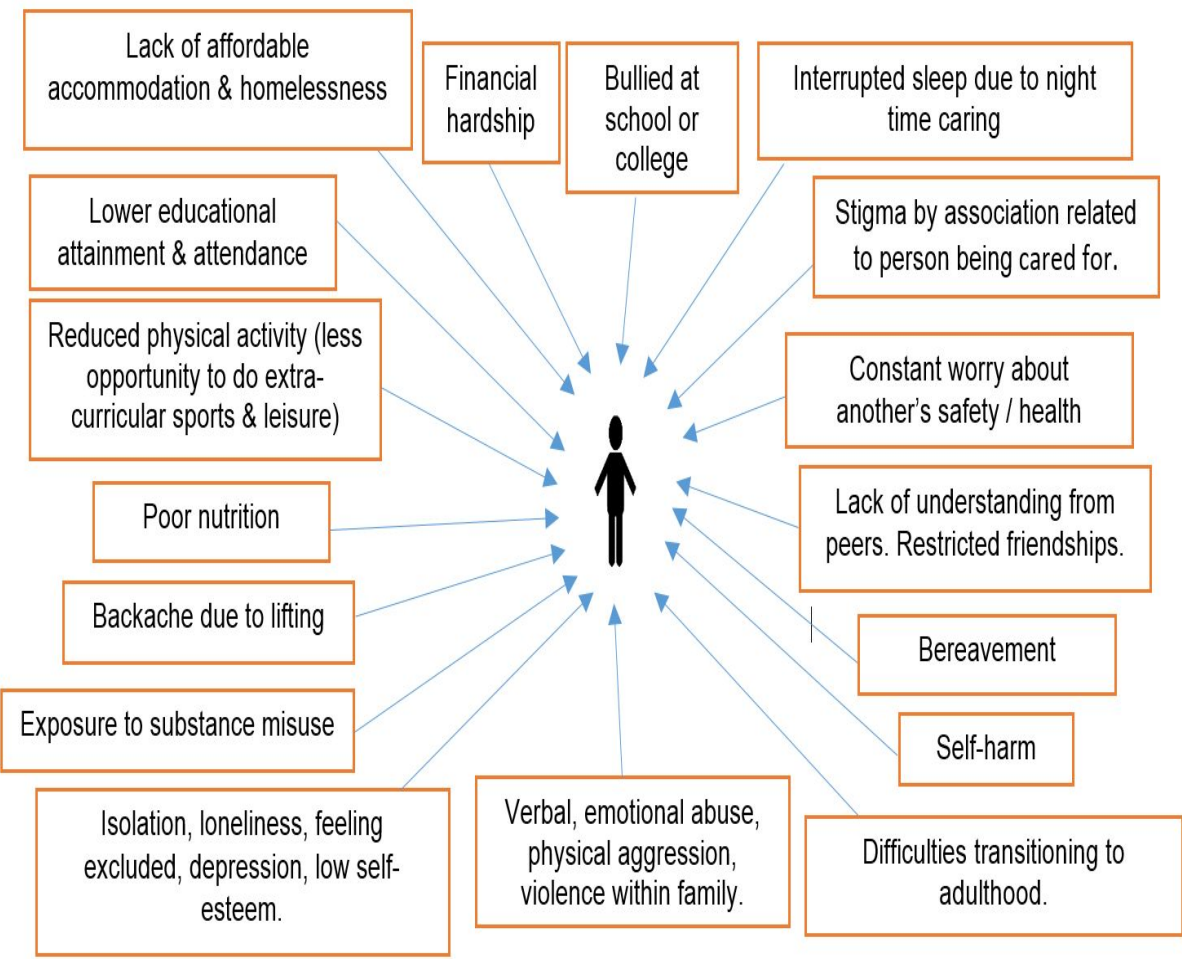
Up to **14%** of young carers of parents with severe mental illness will develop a psychotic illness during their lifetime.

2.6 million children (**1 in 5**) live with a hazardous drinker 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.



**7%** of young carers are looking after a parent or relative with drug or alcohol use problems. Of these, only **28%** had received a whole family assessment and **40%** were missing education, employment or training or had other indicators of educational difficulties.

# Potential Key Issues affecting the Health of Young Carers and Young Adult Carers.



## Key Issues affecting the Health and Wellbeing of Young Adult Carers aged 16-24 Years

The [Time to be Heard for Young Adult Carers Bridging the Gap: Young Adult Carers in Scotland \(2015\) report](#) cited that:

- 1/4 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.
- 1/4 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.

## Key Drivers

Carer's challenges are to be considered alongside the government's national strategy for social care (as yet unpublished).

[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
- 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 young carers and their families of their needs for support. 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.'

[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.

Government's analysis shows that, whilst an increase in the numbers of carers being assessed and supported would lead to an increase in demand for resources, it [would be cost effective to meet carers' needs as a preventative measure](#).

[NHS England's commitment to carers NHS \(2014\)](#)

NHS England has carried out engagement with carers to identify what is important for carers of all ages.

The [2015/16 Planning Guidance for the NHS. Five Year Forward View into Action](#), states "*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 provide better support*".

***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.***

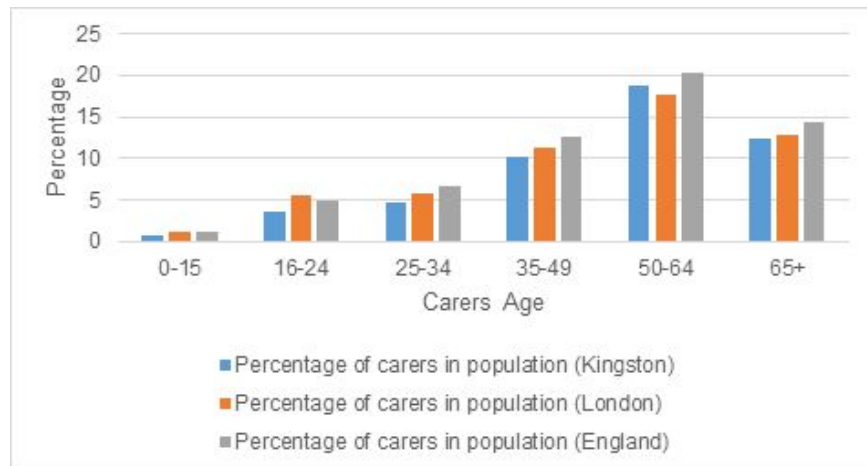
## Scope and Aims of the JSNA

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.
4. To assess the extent to which multi-agency services address the needs of young carers and the whole family.
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 carers 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 young adult carers are heard and identify mechanisms to capture their voice.
8. To identify issues that occur at transition (from childrens' to adults' age).

## Key Data and Outcomes

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 more than 20 hours care a week.

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



Source: from Census 2011 Data

[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.

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. By May 2018 there were 96 young adult carers aged 18-24. 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. 58% of the young carers at YCP are female and 42% are male.

Kingston Young Carers Project estimate that over a third of young carers will be caring for a parent with a mental health condition.

The CCG does not collect data on carers aged under 18.

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

	Kingston	London	England
<b>Under 15 years</b>	0.15	0.22	0.21
<b>16-24 years</b>	0.7	1.5	1.3

Source: 2011 Census accessible via Vulnerable Children and Young people Profile on PHE Fingertips

## Local Services and Support

- Kingston [Young Carers' Project](#) (YCP - part of Kingston Carers Network) provides the following services for 5-18 year olds:
  - information and advice, including 1-to-1 support
  - opportunities to meet other young carers
  - fun activities, outings and breaks away from home
  - regular drop ins
  - awareness raising of the needs of young carers, particularly in schools
  - advocacy and whole family support.
- Since Spring 2018, 16-19 year old carers can also access a regular drop-in at with YCP.
- 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.
- Schools systems to identify and support young carers and young adult caress is highly variable between schools.
- 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.
- In General Practice, Care navigators are being trained to help on the frontline with signposting services. There are no specific systems in place to identify or support young carers.

## Community Engagement - Methods

1. Literature review.
2. Call for information at the April 2017 Kingston Voluntary Action Health Conference
3. 4 Focus groups of 33 young carers that took place during the regular sessions at the Kingston Young Carers Project (YCP).
4. Semi-structured surveys with 23 young carers aged 9 – 18 and 2 young adult carers aged 18-24.
5. Face to face interviews with 5 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.
7. Semi-structured questionnaires sent to 25 primary, secondary, special, and independent schools across Kingston.

# Community Engagement - Findings

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.
2. Statutory and voluntary services' (including schools') 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 1/2 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.
5. Nearly a 1/4 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 (2014).
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.

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

*[One of the most difficult times is] 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.*

*[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.*

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

9. Young carers relied on more female than male 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.

*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.*

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

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.
14. 1/3rd 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 carers 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 YCP. However it is unclear to what extent young carers, young adult carers, and other relevant agencies are engaged and also with regard to including transition to adulthood.
18. Professionals were generally very supportive of the introduction of a MOU between Children and Adults Social Care in Kingston on condition that it is inclusive in its development, is aligned with existing policies and protocols, is embedded in the other relevant strategies 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.

# Best Practice

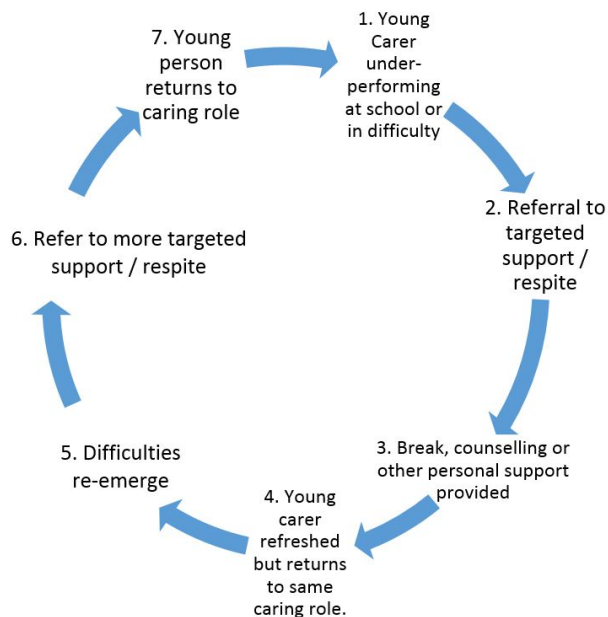
- [Making a step change: Putting it into practice](#) programme.
  1. MACA YC-18: Multidimensional Assessment of Caring Activities
  2. PANOC YC-20: Positive and Negative Outcomes of Caring
  3. Common Assessment Framework (CAF)
  4. Outcomes Star
  5. My Life Now Wheel
  6. The YCRG screening tool (YC-QST-20).
- 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)
- Best Practice for [Meeting the health and wellbeing needs of young carers \(Local Government Association, 2018\)](#)
- [The National Carers Action Plan 2018-2020 'Supporting Carers Today'](#)
- DoH [good practice guidance on whole-family approaches to assessment](#).
- Three-level Commissioning Model for Carers
- [Commissioning for carers. Royal College of General Practice 2013](#) for primary care and schools, carers organisations, and statutory or third sector providers.

- [Invisible and in distress: prioritising the mental health of England's young carers \(2016\)](#)
- Young carers and parental substance or alcohol misuse – examples of good practice, Carers Trust
- NHS England Health and Social Care Professionals – Carers Toolkit
- NHS Young Carer Health Champions Programme
- A Young Carers Toolkit for General Practice Staff
- Supporting Carers Learning Resource for General Practice Nurses, School Nurses, and Community Nurses, Queens Nursing Institute Carers Resource Project
- Dept of Health, DoF, Carers Trust: School Nurse Programme: Supporting implementation of the new service offer: Supporting the health and wellbeing of young carers.
- [Young Carers in Schools Programme](#)
- [Supporting Young Carers in School: A Step-by-step Guide for Leaders, Teachers and Non-teaching Staff](#)
- Government guidance (DfEE, 1999; DfES, 2006) recommends schools should consider designating a member of staff to have responsibility for young carers.

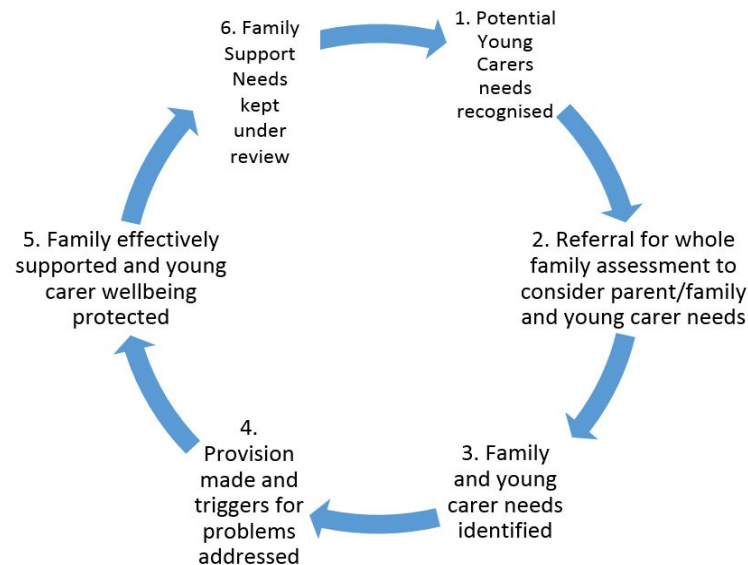
## Best Practice for Commissioning Services for Young Carers and their Families (Carers Trust, 2012)

### The Limitations of supporting a Young Carer in Isolation:

#### Pattern which can emerge



### The Whole Family Approach can have better Outcomes





# Recommendations

## 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 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, 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 after-school 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.

# Recommendations continued

## C. Improving Support continued

### 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 \(Carers Trust, 2012\)](#) 'Effective commissioning for young carers and their families'.
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.