

Appendices for Kingston Young Carers and Young Adult Carers Needs Assessment July 2018

APPENDIX ONE

Feedback from Consultation with Staff at KVA Health Conference 27/04/17

What services are young carers accessing already (apart from Kingston Young Carers Project)? e.g. Welcare, Growbaby, Yorda, EXPRESS CIC

1. Too numerous to mention - all services are likely to have young carers or family members accessing them whether they know it or not.
2. They are accessing services in partnership with KCN
3. School pastoral care where offered.
4. None other than KCN.

Who provides services to adults who may be supported by young carers? e.g. pharmacists, hairdressers, health and social care providers.

1. Again too numerous to mention.
2. Kingston Carers' Network provides a targeted service to support young carers at risk of excessive or harmful caring and this includes advice, advocacy and support to parents. Welcare support parents of young carers with mental health issues through the Public Health funded PMH project.
3. Pharmacists, health and social care providers, takeaway food companies that deliver to the door, supermarket delivery drivers.
4. Private therapists, private psychiatrists, friends, work colleagues, school club organisers, other parents hosting play dates.

What barriers do young carers face in accessing health, social care, social and leisure, finance, employment, housing services?

Language, Opening times are inappropriate (e.g. the need to attend local Mosque early evening on a week day), stigma, and anxiety.

What other barriers can you list?

1. They or their family do not recognise nor want the "carer" label.
2. Fear of family break up.
3. No knowledge that there is help available.
4. Ignored by services only focussing on their service user due to lack of time.
5. RBK and AfC not following a whole family approach.
6. No Memorandum of Understanding as in some local authorities.

7. No Young Carers Protocol.
8. Many services unaware that young carers have rights - young carers and families also unaware.
9. Age of young carer. Younger children (junior school age and below) are unable to access services designed for them unless they have someone that can get them to that service provider.
10. Kingston Young Carers Project endeavour to collect and drop home children in this situation but other possible sources of support do not as far as I am aware.
11. There seems to be no provision for **single parents with physical disabilities** that have very young children. If the parent requires assistance with bathing etc, carers are funded through the LA/PIP etc to do this, but the parent [cannot get assistance with] bathing their children for example. *Any older children in the family have to pick up the slack. None of the private care agencies cover work with children. This is a significant problem in some families with the **older child supporting the parent's needs and those of younger siblings.***
12. Unable to research services to organise travel due to condition.
13. Lack of acknowledgement of time commitments of faith eg the need to attend local Mosque Mondays to Fridays from 5pm to 7pm.
14. Isolation and loneliness of older generations, refugees and asylum seekers.
15. Effect of possibly higher numbers of BAME children excluded from school and in the CJS and who may also be young carers.

What more can be done to improve knowledge and awareness of young carers in order to aid self-identification as well as identification by children's and adult's services?

1. General: Mandatory training for all staff as part of induction and more publicity. Have a Kingston Young Carer day.
2. Schools: Have a Young Carer champion in every school, service and business etc. Raise the profile of young carers in the borough with a cycle of face to face talks in assembly starting within junior schools alongside a local campaign to raise awareness? Outreach based Emotional Literacy Support Assistants (ELSAs) and school based ELSAs, Dinner Ladies and school chefs to recognize young carers and really support their lunch planning and support at mealtimes. School budgets to provide clubs and activities at subsidized rates for young carers.
3. Community Healthcare: GP to recognize young carers' as a chronic condition - treat as if a physical condition, e.g. child diabetes. Requires regular monitoring, GP led support, dedicated/Champion Practice Health Visitors and Community Nurses.

What can be done to better hear young carer's voices?

- Have a forum for Voice of Young Carers.
- Utilise the views from KCN focus groups and regular consultations by Children's Services, commissioners and Public Health attending the Carers Board!
- Make it easier for them to say how they feel.
- Utilise innovative communication from a statutory perspective e.g. social media for feedback.
- Go into their homes to ask questions. Ask them questions via Skype and facetime. Enable what's app conversations. Host sessions in fun places, e.g. Build a Bear.
- Audit existing engagement with young carers particularly with regard to BAME Carers and transition from childhood to adulthood.

What else do we need to think about?

Improve:

- whole family working in RBK
- demand management demand for support for young carers
- How young carers needs are assessed.

- Identification of more young carers including substance misuse young carers (particularly hidden).
- How young carers are targeted so that they do not feel that they are treated differently from their non-carer peers (which would further inhibit self-identification).
- Awareness among GPs, Medical Centre & Schools regarding the competing stress posed by achieving in education and being a young carer, particularly where cultural traditions normalise young people's (especially young girls) role as young carers.
- Learn from Annual Analysis that Charities (e.g. local/National Child Help Lines) ~ maybe Department Of Education or Home Office (especially on Youth Crime) ~ if any Young Persons were ex-carers?

Have:

- a Young Carers Lead at the council in both Adults and Children's Services.
- a carers' allowance for parents for transport to enable their child to take part in activities at Kingston Carers Network.
- Therapy services - mental health (e.g. fast track for CAMHS) and particularly arts based therapies.
- Outreach support workers who can facilitate play, babysitting, respite nannying for young carers.
- Volunteer buddies - like Princes Trust for young carers. A need was identified for a young carer to have more adult company and support, as well as coaching to enable confidence to join other children for activities.

APPENDIX TWO:

Focus Group, Survey, and Interview Questions used with Young Carers, Young Adult Carers, Parents, and Professionals including School Leads

Focus Group Questions for Young Carers

1. What help is offered to young carers at your school? *And then* "What do you think of this?"
2. Do you think there should be more support (than there is) for young carers during key times such as moving to a new school and leaving school?
3. Why do you think some young carers don't get any help?
4. Would you want to see more help for young carers and young adult carers e.g. provided nearer your home / at your school, at a youth group?
5. If not, why not?
6. What other help or support outside Young Carers Project e.g. do you get support from people in your family or from other services?
7. Do you value the help that they provide?
8. If not, why not?
9. Has your caring role affected your friendships in any way? *Prompts: Are you able to meet other children and make friends outside of school easily?*
10. How has being a carer affected your free time?
11. Would you feel confident to contact emergency services by dialling 999 to get help?
12. Have you had an experience of the person you care for being taken into hospital? If so, what help did you have at this time and was it enough?
13. Have you received a Young Carers Needs Assessment from Kingston Council?
14. If you had an YC assessment, did it make things easier for you?
15. If not, why not? (*Was it that you were not happy / not satisfied with the support / services?*)
16. If you had an YC assessment, were you happy with how you were assessed?
17. If not, why not? (*was it due to how the assessment was delivered / worries about the negative outcome of the assessment*)
18. Are there any situations that make your caring role more difficult?
19. What do you least enjoy about the caring that you do?
20. What do you most enjoy about the caring that you do?
21. If you could make any recommendations to improve the lives of other Young Carers, what would they be?
22. How would you like us to feed the findings of this work back to you?

Thank you for your participation. That is the end of all the questions that I would like to ask. If there are any comments you would like to add, please feel free to do so. We are here until the end of the session today so if there is anything more that you would like to tell me, we would be happy to hear from you.

Are there any questions before we end the session?

Young Carers Questionnaire 9-12s and 10-13s Group

The questions below are about what caring / being a young carer is like for you. This includes your health, education, and leisure. We will not be able to trace anything of what you say back to you. We really would like to know how you as a group of young carers feel and think about your caring role. The reason we are asking these questions is to show where services could be working harder to support you better.

The questions that you are going to be asked might raise some difficult feelings for some of you. There are people here from YCP who you can talk to you after the session as well if you would like.

1. Who do you care for? If you care for more than one person, please tick the additional relevant columns in the table below, with Person One being the person you care for the most.

Answer Options	mother	father	brother	sister	grandparent	other relative	friend / neighbour
Person 1							
Person 2							
Other - please give example							

2. What is the age of the person you care for or look after?

Answer Options	under 18 years	18 to 34 years	35 to 64 years	65 to 74 years	75 to 84 years	85+
Person 1						
Person 2						

3. What is the illness / condition of the person you are caring for? eg do they need more support at school? Are they feeling sad? Do they have difficulty seeing/hearing?
-

4. What do you do to help the person you care for? Please tick the boxes that apply to you

Answer Options	Person 1	Person 2
Help with washing, dressing, toilet, feeding.		
Listen to them, comfort them, help them calm down		
Cook, shop, look after pets, sort out how to get to places e.g book taxis		

Give medication, apply creams, change dressings.		
Help the person move about.		
Help with money matters eg deal with bills		
Interpret / sign for someone so that they can understand information		
Other - please give an example.		

5. Does anyone else help with the caring that you do?

Yes	
No	

6. If yes, who helps you? eg brother, sister, grandmother, District Nurse.

7. Do you live with the person you care for?

Yes	
No	

8. How do you feel about the relationships you have with the rest of your family overall?
(please mark of the line)

Argue a lot;
relationships are difficult
relationships

Good, warm &
stable



9. Do you think that there is enough support for the person you are caring for?

Yes	
No	

10. If 'No', please tell us about any ideas you have of ways that can help you and your family.

11. How often are you involved in discussions and talks about the person you care for?

Always	
Sometimes	
Never	

12. Tell us about your health and your experience at school. Do you take any medication eg inhaler or insulin, or do you struggle with reading and writing?

Yes	
No	
Not Sure	

13. Can you describe how you feel about your own health? (please mark on the line)

Very bad

Very good



14. How often do you feel the emotions listed below?

Answer Options	Always	Sometimes	Never
I feel happy			
I feel good about myself			
I feel able to have a laugh			

15. Please tell us how caring has affected your health. Do you:

	Always	Sometimes	Never
Have back pain			
Have joint pain			
Feel tired			
Feel stressed			
Feel anxious			
Feel angry			
Keep myself clean			

Have interrupted sleep			
Feel down / sad			
Feel lonely / isolated			
Get upset			
Hurt yourself			
Miss meals and avoid eating			
Make yourself sick because you feel uncomfortably full?			
Worry you have lost control over how much you eat?			
Believe you are fat but others say you are too thin?			
Feel that food rules your life?			
Is there anything else you wish to add?			

16. Have you visited your doctor/ dentist/ school nurse in the last year?

Answer options	Yes
Doctor	
Other health workers based at your doctor's surgery e.g the practice nurse etc	
Dentist	
School Nurse	
Community Pharmacist	
Other – please say who	

17. Have you ever hurt yourself when caring for someone else?

Yes	
No	
Not Sure	

18. Does the person you care for have any equipment or aids to help move them?

Yes	
No	

19. How often do you get takeaway food eg from a takeaway restaurant or sandwiches from a shop?

Never	once a month	once a week	once a day

20. Do you vape?

Never	once a month	once a week	once a day	More than once a day

21. Do you smoke cigarettes / tobacco?

Never	once a month	once a week	once a day	More than once a day

22. Do you smoke cannabis?

Never	once a month	once a week	once a day	More than once a day

23. How often do you drink alcohol?

Never	once a month	once a week	once a day	More than once a day

24. Do you use drugs? Eg Xanax

Never	Once a month	Once a week	Once a day	More than once a day

25. How often do you do the following exercise activities:

	Never	Once or twice a week	3 or more times a week
Physical exercise such as swimming, jogging, aerobics, football, tennis, gym workout etc (this could include PE activities at school).			
Cycling, including cycling to school, college, work & during leisure time.			
Walking including walking to school, college & during leisure activities.			

Housework/physical caring/ child care / gardening.			
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26. Does your doctor's surgery (e.g. the person at Reception) know that you are a Young Carer?

Yes	
No	
Not Sure	

27. If you have not told anyone at your GP surgery, what has stopped you?

28. Does your school know that you are a young carer?

Yes	
No	
Not Sure	

29. If you have not told your school, what has stopped you?

30. If you have told your school that you are a young carer, in what way do you think that telling your school has helped you?

School has allowed you to start school later or finish earlier	
Allowed to have my mobile phone switched on during lessons	
Lunch clubs for young carers	
Emotional Support – helping you to feel happier	
Other – please give examples	

31. How much do you think your school has helped you as a carer? **Please mark on the line.**

Not at all

Very much



32. Does caring affect:

	Always	Sometimes	Never
Your attendance at school (including getting there on time)			
Your concentration			
Your homework			
Your social life and interests			
Your relationship with friends			
Your relationships with family			
Your free time			

33. Have you been bullied (because of your caring role) at or near school?

Never	
A few times	
1 or 2 times a month	
1 or 2 times a fortnight	
More than once a week	

34. Have you received a Young Carers Assessment where someone visits your home to ask you some questions about what you do as a carer and if you need support?

Yes	
No	
Not Sure	

35. If you had a Young Carers assessment, did it make things easier for you?

Yes	
No	

36. If not, why not?

I was not happy with the support?
Other – please give example

37. If you had a Young Carers assessment, were you happy with how you were assessed?

Yes	
No	

38. If not, why not?

I did not like how the assessment was carried out
I am worried about what might happen because of the assessment
Other – please give example

39. If you could make any recommendations to improve the lives of other Young Carers, what would they be?

**Many thanks for taking the time to complete
this questionnaire.**

Questions for Kingston young carers 12s-18s Group

The questions below are about what caring / being a young carer is like for you. This includes your health, education, and leisure opportunities.

Please be assured that we are not wanting to know your name and we will not be able to trace anything of what you say back to you. We really would like to know how you as a group of young carers feel and think about your caring role. The reason we are asking these questions is to write a report that will show where Kingston Council and other services could be working harder to support you better.

The questions that you are going to be asked might raise some difficult feelings for some of you. There are people here from YCP who you can talk to you after the session as well if you would like.

1. Who do you care for or look after? If you care for more than one person please tick the additional relevant columns in the table below, with Person One being the person you care for the most.

Answer Options	mother	father	brother	sister	grandparent	other relative	friend / neighbour
Person 1							
Person 2							
Other - please give an example							

2. What is the age of the person you care for or look after?

Answer Options	under 18 years	18 to 34 years	35 to 64 years	65 to 74 years	75 to 84 years	85+
Person 1						
Person 2						

3. What is the main illness or disability of the person(s) you care for? Please tick the boxes that apply to you.

Answer Options	Person 1	Person 2
Physical Disability (eg physical frailty / disability / illness / visual impairment / hearing impaired / uses wheelchair)		
Mental Health (eg depression, alcohol and/or substance misuse)		
Learning Disability (eg Downs Syndrome)		
Autistic Spectrum Disorders or ADHD		

Dementia		
Other (Please specify condition)		
Don't know		

4. What do you do for the person you look after? Please tick the boxes that apply to you.

Answer Options	Person 1	Person 2
Personal caring (eg Help with washing, dressing, toilet, feeding)		
Emotional support - Listen to them, comfort them, help them calm down		
Additional childcare (looking after brothers or sisters)		
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 eg dealing with bills		
Interpreted / signed for someone so that they can understand information		
Other - please state what.		

5. Does anyone else help with the caring that you do?

Yes	
No	

6. If yes, who helps you? Eg brother, sister, grandmother, District Nurse.

7. Do you live with the person you care for?

Yes	
No	

8. How would you feel about the relationships you have with the rest of your family overall? (please mark of the line)

Argue a lot;
relationships are difficult
relationships

Good, warm &
stable



9. Do you think that there is enough support for the person you are caring for?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

10. If 'No', please tell us what ideas you have of ways that can help you and your family?

11. How often are you involved in discussions and talks about the person you care for?

Always	<input type="checkbox"/>
Sometimes	<input type="checkbox"/>
Never	<input type="checkbox"/>

12. Can you describe how you feel about your own health? (please mark on the line)

Very bad

Very good



13. Tell us about your health and your experience at school/college. Do you take any medication eg inhaler or insulin, or do you struggle with reading and writing?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Not Sure	<input type="checkbox"/>

14. If you don't access activities, clubs, hobbies, what do you think stops you? (Tick more than one box if appropriate).

Haven't got the time
Travel – can't get there or back
Can't afford it
Haven't got the confidence
Other – please give example

15. How often do you feel the emotions listed below?

Answer Options	Always	Sometimes	Never
I feel happy			
I feel good about myself			
I feel able to have a laugh			

16. Please tell us how caring has affected your health. Do you:

	Always	Sometimes	Never
Have back pain			
Have joint pain			
Feel tired			
Feel stressed			
Feel anxious			
Feel angry			
Keep myself clean			
Have interrupted sleep			
Feel down / sad			
Feel lonely / isolated			
Get upset			
Hurt yourself			
Miss meals and avoid eating			

Make yourself sick because you feel uncomfortably full?			
Worry you have lost control over how much you eat?			
Believe you are fat but others say you are too thin?			
Feel that food rules your life?			
Is there anything else you wish to add?			

17. Have you visited your doctor/ dentist/ school nurse etc in the last year? Please tick all of the relevant responses.

Doctor	
Other health workers based at your doctor's surgery e.g the practice nurse	
Dentist	
School /College Nurse	
Community Pharmacist	
Other – please say who.	

18. Have you ever hurt yourself when caring for someone else?

Yes	
No	
Not Sure	

19. Does the person you care for have any equipment or aids to help move them?

Yes	
No	

20. How often do you get takeaway food eg from a takeaway restaurant or sandwiches from a shop?

Never	once a month	once a week	once a day

21. Do you vape?

Never	once a month	once a week	once a day	More than once a day

22. Do you smoke cigarettes / tobacco?

Never	once a month	once a week	once a day	More than once a day

23. If you smoke cigarettes / tobacco, would you like support to quit?

Yes	
No	
Not Sure	

24. Do you smoke cannabis?

Never	once a month	once a week	once a day	More than once a day

25. How often do you drink alcohol?

Never	once a month	once a week	once a day	More than once a day

26. If you drink alcohol, would you like support to quit?

Yes	
No	
Not Sure	

27. Do you use drugs? Eg Xanax

Never	Once a month	Once a week	Once a day	More than once a day

28. If you use drugs, would you like support to quit?

Yes	
No	
Not Sure	

29. How often do you do the following exercise activities:

	Never	Once or twice a week	3 or more times a week
Physical exercise such as swimming, jogging, aerobics, football, tennis, gym workout (this could include PE activities at school/college).			
Cycling, including cycling to school/college/work and during leisure time.			
Walking including walking to school/college/work and during leisure activities.			
Housework/physical caring/ child care / gardening.			

30. What do you think would improve your life including your health? (Tick more than one if relevant).

A break from caring	
Talking to someone	
Meeting with other young carers	
More time for social / sports / activities	
Help getting around (eg bus pass etc)	
Organised group holidays	
Activity days during school holiday time	
Time to talk to your doctor or school/college nurse	
Support and information on the condition of the person you care for	
Counselling	
Going on holiday	
Evenings out	
Other – please state	

31. Have you told your doctor's surgery e.g. the person at Reception that you are a Young Carer?

Yes	
No	
Not Sure	

32. If you have not told anyone at your GP surgery, what has stopped you?

33. Does your school / college know that you are a young carer?

Yes	
No	
Not Sure	

34. If you have not told your school / college, what has stopped you?

35. If you have told your school/college that you are a young carer, in what way do you think that telling your school/college has helped you?

School/college has allowed you to start later or finish earlier
Allowed to have my mobile phone switched on during lessons
Lunch clubs for young carers
Emotional Support – helping you to feel happier
Other – please give examples

36. How much do you think your school / college has helped you as a carer? Please mark on the line.

Not at all

Very much



37. Does caring affect:

	Always	Sometimes	Never
Your attendance at school/college/work (including getting there on time)			
Your concentration			
Your homework			
Your social life and interests			
Your relationships with friends			
Your relationships with family			
Your free time			

38. Have you been bullied (because of your caring role) at or near school / college / work?

Never	
A few times	
1 or 2 times a month	
1 or 2 times a fortnight	
More than once a week	

39. If you are aged 14 or older, do you receive or have you received support (from the age of 14) to help you continue education or training, and work? Please tick those boxes below that apply to you.

	Yes	No
Education – learning new skills, additional qualifications, colleges, careers advice, funding options.		
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;		
Managing money. Benefits e.g. Carers Allowance; Housing / accommodation; replacement care paid for while taking part in approved activities.		
How to contact social care to support your decision regarding whether or not you continue being a carer when you are 18 and older.		

40. Do you think 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?

Yes	
No	
Not Sure	

41. Are you anxious about accessing support when you leave the Young Carers Project at 18? Please make a mark on the line below for how anxious you feel.

Not anxious at all

Extremely anxious



42. Which one(s) of these apply to you at the moment?

I am a student full-time	
I am a student part-time	
I am employed full-time	
I am employed part-time	
I am not working, not in education, and not in training	

43. If you work, does your employer know about your rights, eg flexible hours and having time off in an emergency?

Yes	
No	
Not Sure	

44. Do you think that more has been expected of you in your caring role as you have become older (you have taken on more responsibilities)?

Yes	
No	
Not Sure	

45. Are there other children in your house?

No other children at home	
One other child at home	
Two other children at home	
Three other children at home	
Four other children at home	
More than four other children at home	

46. Do you have any children of your own?

I have no children	
I have one child	
I have 2 children	
I have more than 2 children	

47. Have you received a Young Carers Assessment where someone visits your home to ask you some questions about what you do as a carer and if you need support?

Yes	
No	
Not Sure	

48. If you had a Young Carers Assessment, did it make things easier for you?

Yes	
No	

49. If not, why not?

I was not happy / satisfied with the support / services?	
Other – please give example	

50. If you had a Young carers assessment, were you happy with how you were assessed?

Yes	
No	

51. If not, why not?

I did not like how the assessment was carried out	
I am worried about what might happen because of the assessment or what might result from the assessment	
Other – please give example	

52. Is there a plan in place to look after the person you care for if you were suddenly unable to care for any reason?

Yes	
No	
Not Sure	

53. What support services do you have contact with?

GP	
Community Pharmacy	
School / College Nurse	
SPA (single point of access)	
Yorda	
Express CIC	
Macmillan Cancer Support	
Citizens Advice Bureau	
'National Carers Service' for 13 - 19s - information, advice & guidance to help you make decisions on learning, training and work.	
'Carers UK' or 'Carers Trust'	
Other - please state which service	
None	

54. If you could make any recommendations to improve the lives of other Young Carers, what would they be?

Many thanks for taking the time to complete this questionnaire.

Questionnaire for Kingston Young Adult Carers

The questions below are about what caring / being a young adult carer is like for you. This includes your health, education, and leisure opportunities. Please be assured that we are not wanting to know your name and we will not be able to trace anything of what you say back to you. We really would like to know how you as a group of young adult carers feel and think about your caring role. The reason we are asking these questions is to write a report that will show where Kingston Council and other services could be working harder to support you better. It should take no more than 5 minutes to complete. Kingston Council would like to thank you for your time in completing these questions.

1. Does anyone else help with the caring that you do?

Yes	
No	

2. On a scale of 0-10 where 0 is 'very bad' and 10 is 'very good', can you rate how you feel about your own health?

0 Very bad

10 Very good

3. How often does caring make you feel stressed and anxious

Always	
Sometimes	
Never	

4. How often does caring make you feel down / sad

Always	
Sometimes	
Never	

5. How often does caring interrupt your sleep?

Always	
Sometimes	
Never	

6. On a 0 to 10 scale where 0 is 'not at all' and 10 is 'very much', how much do you think your college/university has helped you as a carer? Please mark on the line.

0 Not at all

10 Very much

7. Does caring affect your attendance at college/university/work (including getting there on time)

Always	
Sometimes	
Never	

8. Does caring affect your social life, interests, and relationship with friends

Always	
Sometimes	
Never	

9. Have you received support (from the age of 14) to help you continue education, training, & work in the following areas? Please tick those boxes that apply to you.

Education – learning new skills, additional qualifications, colleges, careers advice, funding options.	
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;	
Managing money. Benefits e.g. Carers Allowance; Housing / accommodation; replacement care paid for while taking part in approved activities.	
How to contact social care to support your decision regarding whether or not you continue being a carer when you are 18 and older.	

10. If you could make any recommendations to improve the lives of other Young Carers and Young Adult Carers, what would they be?

Interview Questions for Parents of Young Carers 14/02/18

1. Can you describe the family situation and what the young carer does?
2. Do you receive helpful support to look after your children that prevents a crisis happening?
3. Do you receive helpful support to look after your children that helps you in times of crisis?
4. Do you think that there is understanding about the role of young carers?
Prompt: More understanding, less discrimination?
5. Parent support groups.
How do YCP support you as a parent of a young carer?
Do you access any other parent support groups?
6. Freedom from fear of removal.
Some young carers are anxious about telling Social Workers or healthcare professionals about the level of caring that they provide in case they cannot continue to live under the care of their parents. Do you think this is quite a common anxiety among parents as well?
7. Health
Do you have any concerns over the health of the child who is a young carer?
8. Safety / Safeguarding
What about safety? Do you have any concerns over the safety of the child who is a young carer? It can be quite common for parents to be concerned over the safety / safeguarding of their child(ren) because that child is a carer.
9. Is there any key worker support provided for the person whom the young carer cares for? Is there continuity in this person / is it the same person / is there a high T.O?
10. Preparation for transition (starting school, starting a new school, child to adult) services)
Do you or your child (who is carer) have any anxieties about becoming 18 and linking into the relevant support and benefits?
11. What is your experience of awareness, identification, assessment, and support from:
 - Social services (children and adults) – experience of Young Carers Assessment
 - School – potential and actual barriers to informing school.
 - School Nurse – eg flu vaccinations for main carers.
 - Community Pharmacists
 - GP staff potential and actual barriers. Do GP staff (not just GPs themselves) e.g. receptionists provide information about local services.
 - Hospital Services – is the young carer included in the care planning and discharge planning?
 - Community and Voluntary Sector
 - Church / Faith
 - Youth Groups
 - Family and Friends

Interview Questions for all Professionals

1. What do you know about how young carers are identified in Kingston?
2. What do you know about the young carers assessment and how young carers are linked into having an assessment? What are the qualifying criteria to have such an assessment? Who undertakes the assessment?
3. Do you think that there are adequate levels of Young Carers identified in schools? (If not, why not – what are the barriers?)
4. What do you know about how young carers are supported after they have an assessment?
5. What do you know about how young carers are supported generally?
6. Are you aware of any assessment that would systematically identify and assess young carers in order to support their transition needs?
7. Are you aware of any young carers who are caring for someone because they misuse substances / alcohol or have mental ill health?
8. Does your service routinely ask whether a YC is involved in caring for the person receiving the service?
9. What do you know about how young adult carers are identified in Kingston?
10. What do you know about how young adult carers are assessed? What are the qualifying criteria to have such an assessment?
11. Do you know what support is available for young adult carers?
12. What do you think are the barriers to young carers and young adult carers being identified? Is there a lack of professional confidence / willingness to proactively identify carers / refer carers? Lack of awareness of safeguarding. Lack of awareness of statutory duty to assess young carers.
13. What is your opinion of Kingston adopting a Memorandum of Understanding between Children and Adults Social Care of the [ADCS/ADASS Memorandum of Understanding](#)¹ for use with carers up to the age of 24 in order to better identify young carers and enable transition?

¹ Association of Directors of Adult Social Services (ADASS) and Association of Directors of Children's Services (ADCS) (2009), 'Working Together To Support Young Carers – A Model Local Memorandum of Understanding between Statutory Directors for Children's Services and Adult Social Services'. ADASS and ADCS.

Questionnaire Survey with Young Carers Leads in Schools

Kingston Council is currently undertaking a Needs Assessment on the health and social care needs of young carers and young adult carers in Kingston. As part of this, young carers, young adult carers, parents, and relevant professionals will be asked questions relating to identifying and supporting young carers and young adult carers. The information gathered will help inform strategic and funding decisions in Kingston Council so that young carers and young adult carers can be better identified and supported in the future.

Any time taken to answer these questions is greatly appreciated. Please return completed questionnaires to me at julia.waters@kingston.gov.uk by **Friday 24th March, 2018.**

1. Please state the name of your school

2. Please state your name and contact details if you are happy to be contacted.

3. Please tell us about how young carers are identified in your school?

4. How many young carers have you identified in your school?

5. How many children do you have in total in your school?

6. How does your school raise awareness about young carers?

7. Are all children systematically asked if they are a young carer? (Please mark with an 'X' in the appropriate box)

Yes	
No	

8. What do you think the barriers are to young carers accessing support for young carers within your school?

9. How many young carers do you have at your school who do not access any support (e.g. that the school provides or the Young Carers Project, YCP)?

10. Are you aware of any young carers at your school with disability, with additional needs, with reasonable adjustments?

Yes – please state number, if known.
None known

11. Are you aware of any young carers who are caring for someone because they misuse substances / alcohol?

Yes – please state number if known.	
No	

12. Are you aware of young carers who are caring for someone with mental ill health?

Yes – please state number if known.	
No	

13. Does your school reach out to hidden carers (those who do not self-identify as a young carer due for example to their socio-cultural, religious background or because of stigma eg mental health problems, and drug and alcohol problems)?

No	
Yes – please state how your school reaches out to hidden carers.	

14. Do you utilise the Early Help Assessment in your school? (Please mark with an 'X' in the appropriate box)

Yes	
No	
I don't know	

15. If yes, what are the qualifying criteria for a young carer to have an Early Help Assessment?

16. Who (what is their role) undertakes Early Help Assessments?

17. How confident is your school to undertake an Early Help Assessment for young carers? (Please mark on the line).

Not confident at all

Completely confident



18. How confident is your school to refer young carers for a young carers assessment by children social services? (Please mark on the line).

Not confident at all

Completely confident



19. Are all parents systematically asked if they would like their young carers to be offered support in school?

Yes	
No	

20. What support for young carers does your school provide at the moment?

21. What plans if any, does your school have for young carers in the future?

22. Does your school offer support for young carers regarding

	Yes	No
Physical activity		
Healthy eating		
Emotional Health and Wellbeing		
Substance misuse and alcohol		
Relationships and sexual health (including personal hygiene and puberty)		
First Aid Training (including calling 111 for non-emergency and 999 for emergency events)		

23. This question is for **secondary schools only**:

Does your school offer support with transition from the age of 14 for young carers regarding (please put a cross in the appropriate box(es):

Family relationships: including the potential and capacity of their family network, parents, siblings, other relatives and friends, to help and encourage the young person to make a positive transition;	
Social support: including the young person's relationship with friends and involvement in support networks – e.g. groups for young carers/ young adult carers;	
Education, training and employment: arrangements for young people to complete their secondary education and move on to higher education, training or employment;	
Accommodation and independent living: including the young person's future plans and any intentions they may have to live independently. These plans may link to their ambitions to go to university or seek employment away from their home area;	
Health, development and general wellbeing: including recognition of the young person's physical emotional and mental health needs and an evaluation of their capacity to obtain access to health care in the same way as other young people who do not have care responsibilities;	
"Financial literacy" and skills in financial management: including information about how it is expected a young person will support themselves financially in future.	

24. Are all young carers referred to the Young Carers Project?

Yes	
No –	

please comment why this is the case.	
--------------------------------------	--

25. Does your school have a Young Carers Policy?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
I don't know	<input type="checkbox"/>

26. Does your school's bullying policy include Young Carers?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
I don't know	<input type="checkbox"/>

27. Does your school have a Young Carers Lead?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
I don't know	<input type="checkbox"/>

28. Are reasonable adjustments made for Young Carers?

No	
Yes – please describe what.	

29. Is there an 'open door' policy for young carers to access support at your school?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
I don't know	<input type="checkbox"/>

MANY THANKS FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

PLEASE RETURN YOUR COMPLETED QUESTIONNAIRE TO julia.waters@kingston.gov.uk or if preferred, a hard copy to:
Julia Waters, Public Health Department, 2nd Floor, Guildhall One, High Street, Kingston KT1 1EU.

Appendix Three: Consent Forms

Under 16s Consent Form



Dear Parent/Guardian/Carer,

Kingston Council is currently undertaking a Needs Assessment on the health and social care needs of young carers and young adult carers in Kingston. As part of this, young carers, young adult carers, parents, and relevant professionals will be asked questions relating to identifying and supporting young carers and young adult carers. The information gathered will help inform strategic and funding decisions in Kingston Council so that young carers and young adult carers can be better identified and supported in the future.

Names will not be collected and information provided will not be traceable back to the young person providing the information. Young Carers have the right to refuse to answer any questions or to stop taking part at any time.

Any time taken to answer these questions is greatly appreciated.

By receiving and keeping this information, you are showing that you are happy for the young person in your care to be included in focus group and questionnaires as part of this Kingston Council's Young Carers Needs Assessment.

16s and over Consent Form



Consent to take part in Research for Young Carers aged 16 & over

Public Health (from Kingston Council) is talking with young people and their families to understand how young carers feel and think about their caring role. We are not asking for your name or personal details and there will be no way of tracing anything that you say back to you. The reason we are asking these questions is to show where Kingston Council and other services could work harder to know and support your needs better.

By reading this information and keeping it as a reminder, you are showing that you:

- understand what the research is about
- give permission to record what you say so the researchers have an accurate record of our conversation
- understand that your details will not be shared with anyone and that your name will not be used in any reports
- understand that you do not have to take part
- Understand that you can refuse to answer any question or to stop taking part.

Appendix Four: Full Responses from Young Carers, Young Adult Carers, Parents, and Professionals including from Schools Leads

Young Carers Focus Groups Analysis

Experience of Types of support offered by Schools for young carers

Common types of support offered by schools included:

- monthly lunchtime sessions dedicated for young carers or for children with additional needs
- Time-out where parents and teachers agree that *some children need time away from class at certain times.*
- Extra time to hand in homework or allowed to attend late
- Being unsure if there was any support
- No support offered.

Experience of support received

Response to this question was not forthcoming or ambivalent. One carer remarked:

It helps to have a safe place to go if you are feeling anxious or to get help.

Views on needing more support during key transition times

For those who received support, lunchtime support was viewed positively but many young carers felt that there was not enough support offered by schools:

Well I didn't get much help at primary school. I only found out about it [YCP] at secondary school.

Views on why some young carers don't get any help

Generally the young carers felt that this may be because:

- The young carer may not be aware that they are a young carer,
- Not everyone wants to be known as a young carer,
- They do not want the school and consequently their friends (or vice versa) to know they are a carer.
- Unaware of support due to inadequate promotion of help offered e.g. YCP.
- Lack of time.
- The school would not understand the roles and responsibilities of being a carer:
I might be late to school and hand in homework late and be too embarrassed to say why because I didn't think they would understand.

Types of formal and informal support accessed outside Young Carers Project

The majority response was that support was only from YCP which was viewed very positively. A few responses included school, their parents, CAMHS and art therapy, and Social Worker who:
made me feel better about going to school.

I get help from my mum but not as much as I need as my brother can't be left unsupervised.

Someone did come in but she was really old and was unable to look after my brother properly or, you know, safely.

I have a social worker but that's like a different thing. It's really complicated. We have someone who tries to bring families together who comes to our home.

Perception of Value of support services

The majority could not comment as they had not received any additional support (apart from YCP). For the very few who had received support, social services support was seen as not improving the situation or of being unclear in what their aims were:

Not really as it didn't make things easier, didn't make any difference. It was a bit slow. Slow process. They didn't get straight to the point enough, made it confusing, not making it clear what they want to do.

Conversely, YCP's support was very highly valued. Initiating and maintaining friendships at YCP was easier than doing this at school where there was a lack of understanding.
Without YCP, a lot of us would crumble, be stressed. You get really good friends though. You just click because they [other young carers] understand.

Impact of caring on friendships

Those who spend less time caring (e.g. two days a week or less) remarked on their friendships being unaffected but for the majority of carers, time constraints, embarrassment, and lack of understanding by their peers featured strongly as barriers to initiating and maintaining friendships particularly amongst the older young carers:

I find it really hard making friends. A lot of people don't understand.

They don't understand that I can't spend time with them because I am busy – I am with my brother or with my mum.

When they come over, if they see what's going on they don't understand, friends get annoyed.

They didn't understand young carers or the disabilities my brother had and kinda judged me for that.

Friends think it's funny. I do have time to have friends over – it's more the embarrassment. If mum goes out I can't - I have to entertain him if mum goes to the shop.

[I cannot go to my friend's house] if my mum needs me back, for example if she is really tired. It's 24/7. Sometimes he wakes up in the night, and I have to go to school the next day which is pretty bad.

I have some friends at school but have better friends here [at YCP].

Bullying featured as negatively impacting friendships:

I was being bullied because I had to help my family a lot and when friends came around they were asking: 'why do you have to look after your family?' and take the mick and stuff.

It's just annoying, pretty much all the people in my class haven't been through the things we've been through. It's hard being the only one. There is bullying in my class.

I've been bullied for 3 years.

My schools anti-bullying, but it's not. I have been bullied.

There was evidence of careful selection of which friends the young carers let know that they are carers:

It's OK with friends. Most of my friends don't know. I've never seen others being bullied, I haven't been bullied. I think there's an element of respect in it when people find out. It's not a big thing.

It depends on your group of friends.

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

A girl went to primary school with my brother – she understands, she's seen what he's like"

Impact of caring on free time

Generally the older young carers felt that caring had significantly reduced their free time.

What's free time? We work [paid work] as well so we don't get free time at weekends.

Because of her [mother's] anxiety we live at my nan's so don't free time.

So maybe at breaks at college or school.

Confidence contacting emergency services by dialling 999 to get help

Overall the older young carers felt that could if they needed to and some already had. The younger groups (aged 8-13) did not know how to call emergency services.

Involvement of young carer in care when the person being cared for is hospitalised and help received during this time.

Young carers expressed perceptions of not being included in discussions about the person they cared for and about having to rely on other family members despite these members being unwell themselves.

They [the healthcare staff] thought I was just there to comfort them [the person they care for]. They say 'we are not allowed to disclose to you'. One [member of staff] did inform me of progress that he was making but I think that was just one [member of staff] who was used to older and younger siblings caring.

At the time the only help I had was at the time my dad left and mum stayed in hospital with my brother so I had to go to nan – she is quite old and has health problems. I was nine and that was the only help I got.

Experience of Young Carers Needs Assessment from Kingston Council

Last year I had one (response of 17 year old young carer who had been caring since he was 11).

About one year ago – I was happy with the assessment but nothing happened afterwards - nothing changed. Well I got referred to [a service] to plan if I get too stressed, like for example, could I go to a friend's house or something like that.

Situations that made caring more difficult.

There were strong themes of reports of 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 mum feels like she is burdening us.

My brother takes his anger out on me. He has ADHD and is getting tested for Apsergers.

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.

Mornings are most difficult for me as it takes time for the medication to work – my brother is in the mode of throwing pillows on the floor – it takes about 30 minutes for him to calm down.

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.

Sometimes [the person I care for] wants me to do something for him and I am already doing something else; but if you don't come immediately, he will get up and hurt you.

My brother gets angry when he doesn't want to do something.

There were also themes of needing more support:

If mum gets more ill and is in bed all the time and I wouldn't have someone to guide me.

Young carers voiced the educational and financial impacts of caring for the 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.

My mum can't work full-time so we lose out on money, stuff like that.

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.

Sometimes if you are late you get a detention and then they [the school] stop you having it [the detention] once they know you are a carer. It would better not to be given a detention in the first place.

What was least enjoyed about the caring

Young carers expressed 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.

We miss out quite a bit.

We can't go out. We can't go for long days out.

Watching mum go through (physical) health problems.

People used to make fun of me.....they used to....but they don't anymore.

What was most enjoyed about caring

A very common theme was praise for the YCP because it is informal, its drop-in nature, provides activities and the opportunity to talk with friends who understand:

And all for free and it gives us a break. You can come whenever you want.

I like the YCP because you get to have fun and you get to interact with new people.

Other carers noted they most enjoyed seeing the person they cared for not needing their care so much or enjoying time with them:

Seeing my mum happy and not in pain.

Sometimes I can have fun with my brother when he is calm and he is not going to hurt me – it can be good.

Recommendations suggested

More promotion of YCP and its mentoring programme and having more male staff at YCP featured as themes as did raising awareness about young carers and more support for the people they care for so that the young carer can have more free time:

Make more people aware of what we do and how tough it is.

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

Interview Themes for Five Parents of Young Carers

Description of the family situation and what the young carer does

When the person being cared for is another parent, there is a sense of feeling like a single parent and having another child to care for.

Young carers have to:

- Be more independent than other children of their age,
- Support the parent who is not being cared for
- act as an intermediary:

Q has to learn to call for help in case there is danger or he has to finish things off if I have to tend to A. Also Q emotionally supports me and is more concerned about me being OK rather than himself.

There was recognition that Kingston Young Carers Project (YCP):
gives a safe space for D to be a child.

Young carers of siblings with Autism, Aspergers – are described as having to ‘tolerate’ their sibling’s *argumentative, aggressive, or violent* behaviour. This is corroborated by the young carers focus groups which exposed how young carers adapt their behaviour to manage this type of behaviour in their siblings.

Type of helpful support to look after your children that prevents a crisis

Themes included:

Reliance of parents on their own parents during term time.

A limited number of other parents and YCP are the only source of support.

No other support network in terms of crisis prevention and intervention.

Less support available during extra-curricular times e.g. holidays and the child (being cared for) cannot attend after school clubs as these clubs cannot cater for their needs; this impacts on the parents capacity to work and the family’s income.

Do you receive helpful support to look after your children that helps you in times of crisis?

The carer is used to violent relationships only as his sibling was violent as part of his [condition]. This impacted on his relationships at school and led to him being bullied:

He (Q) has trouble in schools because of bullying because he hasn’t learnt how to interact with ‘normal children’ as he is used to a violent relationship. I have had some dealings with social workers because I was screaming out for help.

Support networks were more established with other parents specifically of children of similar age and similar needs as any other parents do not understand the family dynamic, the needs of the cared for child, and the role that the young carer has in the family.

Other Peoples’ Understanding about the role of young carers among others

Parents voiced that it is more difficult for people to understand when the condition/illness is not visually obvious as to why the member of the family needs additional support and why there is a young carer in the family e.g. mental health, Autistic Spectrum Disorder.

Other comments underlined the importance of the need to consider the true impact on children who are carers and the different types of caring:

It is important to highlight the different aspects, different categories of young carer – an 11 year old boy might not be concentrating at school because he is worried about his

mother taking her meds. He could phone her to check so that he can concentrate at school. Then there are those with parents with mental health, alcohol, drugs, learning disabilities, lack of mental capacity – those young carers are different to young carers of parents with physical disabilities. It is so important that different needs are represented as they might not be able to come to these [YCP support sessions] kind of things.

Outside population have little awareness and have fixed ideas about what constitutes young caring.

Not everyone understands 'young carers' when there is no-one who is physically disabled.

[The parent who is cared for] has stress, anxiety, depression; he does hold down a job but crashes at home which permeates into the family. People can't see that as [the parent who is cared for] holds down a job – why children need support.

Parent support groups and the Role of Kingston Young Carers Project.

Generally, YCP was depended on more for support than other organisations and there was a variable level of awareness of other relevant local agencies e.g. Express CIC, SEND Family Voices.

A desire was expressed for YCP to provide emotional support for young carers:

My children love YCP but we need an organisation to talk to my children about their anxieties and YCP don't seem to provide that.

Freedom from fear of removal.

Perhaps unsurprisingly, parents interviewed expressed no anxiety about telling Social Workers or healthcare professionals about the level of caring that they provide and had no fear of not being able to continue to live under the care of their parents. In order to find out more about this risk, a much higher sample of parents of young carers who are caring for people with a much wider range needs would have to be sampled with assurances regarding confidentiality. This would include those areas where there may be a perceived higher risk of children being removed into care e.g. parents misusing substances, alcohol.

Health concerns for the child who is a young carer

Parents expressed more concerns over young carers' mental health (lack of confidence, anxiety, feeling isolated at school) and becoming overweight as a result of comfort eating and lack of physical activity:

He only wants to go into his bedroom and play on his PS.

Q is very inactive and a bit overweight – he turns to comfort food.

I am worried about their emotional mental health – they lack confidence. My son is struggling to deal with stress. They don't talk about caring at school – their friends are not aware that they are carers.

Need to have YCP attending to psychological wellbeing rather than their other needs. Not worried about physical health.

Concerns over the safety of the young carer

This group of parents expressed a level of anxiety which had improved now that the child(ren) (the young carer and the cared for) is/are older and that despite the stresses that caring creates, there were also very strong bonds between the young carer and the cared for child:

I suppose you always do worry that sometimes T will act something out and can't stop the impulse. They [the young carer and 'T' the cared for] have disagreements but they have a 'deep care' for each other.

Key worker support

The response generally was that no assessment or support had been offered and any support that had been offered was inappropriate:

We had a Family Support Worker 5-6 years ago for a couple of months to help manage (D's brothers) behaviour but their suggestions were not helpful. We have not received any assessment.

Preparation for transition (starting school, starting a new school, child to adult services) Do you or your child (who is carer) have any anxieties about becoming 18 and linking into the relevant support and benefits?

None of the parents interviewed had yet thought about transition for the young carer in their family. Reliance on the young carer when the parents had died was suggested by one parent:

We imagine T will continue on the same trajectory and A (the young carer) will stay with us; later in life they might live together and still have this circle of care.

Experience of awareness, identification, assessment, and support from:

- Social services (children and adults) – experience of Young Carers Assessment
None of the parents believed a young carers assessment has been undertaken and there was exasperation expressed about the disjointed pathway in which ASD was diagnosed and the resultant lack of support for the young carer involved:

Not had Young Carers Needs Assessment nor a family Needs Assessment. You go through social services for the diagnosis. So first of all you go through SWL St Georges Hospital from the SPA and then get referred to Tier 3 CAMHS who send you a letter, so parents think it is a mental health diagnosis and you are then dropped from social services. You then have to go back through SPA or through an EHCP to get back into the system (in order to access any social services support). Although SGH [St Georges Hospital] knew about siblings, their needs are not assessed. They did not tell you about YCP [Kingston Young Carers Project] for siblings. P has mild ASD [Autistic Spectrum Disorder] without learning disabilities.

- School – potential and actual barriers to informing school.
Parents demonstrated an expectation that school would know that the child is a young carer and therefore would not need to tell the school themselves because:
 - YCP had visited the school or
 - their child is accessing emotional help at the school or
 - the child may or may not go to the lunchtime (some schools lunchtime clubs are not specific for young carers and can be for children with a variety of needs)

- The school know the child has a sibling with needs.
- School Nurse
Parents expressed no awareness of the role of the School Nurse in supporting their young carer.
- GPs had not been actively supporting young carers and there was a lack of awareness by one parent of the need to involve the GP and another that the system didn't enable the GP to be involved with supporting the young carer:
All letters were cc'd to the GP but didn't need to involve them to get into the system.
There doesn't seem to be any way that the GP would recognise A as a young carer.
This group of parents were not aware of the rights for their young carers to access vaccinations (eg flu vaccine for main carer).
- Community Pharmacy
The parents did not access Community Pharmacies and did not envisage the role of community pharmacies in supporting the young carers. This may be because the young carers did not have to access the community pharmacies as either the parents did this or the conditions of the cared for family member did not require medication.
- Hospital
Similarly the involvement of young carers in care and discharge planning in hospital was not deemed relevant for these parents as the condition of the cared for did not require them to attend hospital on a regular basis.
- CAMHS
The parents experience of CAMHS was portrayed negatively as the young carer or the cared for fell below the threshold for continued provision:
We has negative experiences from CAMHS for my older son. Q had 2-3 sessions with CAMHS but the counsellor said it was pointless as he would not talk.
Son was referred to CAMHs – only offered 6 month course of CBT as he was still functioning and they said they had to focus on children with autism, those not functioning at school, that was affecting their academic performance.
- Voluntary and Community Groups.
Parents mentioned YCP as most helpful but also Express CIC which offered social support for parents of children with an Autistic Spectrum Condition (not for young carers).
- Youth services.
There was a low level of access by the young carers of youth services but this service had not been told that they were a young carer.
- Family and Friends.
This was limited to very close family or to parents with similar situations:
[I get support from] *my mum and my sister.*

I would say that I have lost a lot of friends probably because of their lack of understanding; but I don't think my autistic son needs more support now. When things were bad, what I needed was something to help [the young carer in my family] – everything was focused around [the sibling being cared for]. There

needs to be something to support siblings of autistic children and when there is violence in the family and to teach them that that is abnormal.

What I would like is to meet people with similar family situations.

Close family know and provide emotional support.

We have no families in the area. Tend to have friends who have a similar situation to us - have children with similar conditions because of the lack of understanding and having to explain again to friends who do not have the same situation.

Surveys with Schools

IDENTIFICATION

How are young carers identified in Kingston Schools?

There was no consistent way that these schools identify young carers. One school stated the visits by Kingston Young Carers Project (YCP) to schools to raise awareness of young carers helped *children often speak about having to care for family members which is then followed up on.*

Another school described a more systematic approach:

1. *Through working with Kingston Young Carers Network.*
2. *Through identification of family members with illness / disability on our admission forms.*
3. *Through teacher training and awareness raising for all staff & pupil assemblies*
4. *Through information in our newsletter.*

Other schools had a less proactive approach, relying on information passed from the pupils' previous school, or relying on the young carer or the parent to inform them.

Systematic asking if children are young carers

Generally schools did not systematically ask children if they are young carers:
We encourage children to speak about it and occasionally they tell us.

We do in a roundabout way, we ask if there is a family member who has an illness or disability. We also put info in our newsletter about YC [young carers] periodically and ask parents to contact us if their child is a young carer.

Number of young carers identified.

There was a wide variation in proportions of young carers identified in schools of between 1.0% and 2.2% with 4.2% identified in a special school. Each school will have at least 3% of its total number on roll who are young carers, consequently it appears for this small number of schools at least, a substantial number of young carers are not being identified.

How school raises awareness of Young Carers

Schools generally felt that they could do more to raise the profile of young carers e.g. with Young Carers Project coming into their PSHE lessons. Teacher training and YCP were also mentioned in their assembly work that they do with some schools.

Schools perceived barriers to support within school for Young Carers:

These schools identified that parents deny that their child is a young carer, the young carer does not understand that they are a young carer (this is particularly pronounced for those with learning disabilities) or does not wish to be identified as a young carer.

More recent reduced staff capacity was also cited as a result of their constrained financial situation:
We used to run a young carers group but now no one has the time due to reduced staffing.

Number of Young Carers not accessing support in or outside school

All schools were unsure about any of their Young Carers not accessing support in or outside school – reasons offered for this were that some do not want support or that *parents do not want to consent to referral to YCP or they have strong family network and support already in place.*

Awareness of any young carers with disability, additional needs, reasonable adjustments or who care for someone with mental ill health.

Apart from the special school, all schools had various levels of awareness of their young carers having any additional needs. However all were aware of young carers who cared for someone with mental ill health.

How the school reaches out to hidden young carers (those who do not self-identify as a young carer due for e.g. to their socio-cultural, religious background or because of stigma e.g. mental health problems, drug and alcohol problems)

All three schools who responded to this question attempted to reach hidden carers but they also underlined the difficulties involved:

We are aware that one little boy is a carer for his Mum who has both emotional and physical needs, we have invited Mum in for meetings with both us and young carers [Young Carers Project], we have got an interpreter to help, I have phoned Mum to remind her and I receive a copy of YC's [Young Carers Project] holiday activities to go through with him and help him choose the activities, unfortunately this little boy still does not attend.

We have someone at the moment that we are struggling to get them to come forward as a young carer as we don't want to make the situation worse for them but we are closely monitoring them.

ASSESSMENT

Utilising the Early Help Assessment in school

Overall the Early Help Assessment was not being used with young carers in these schools.

Awareness by schools of the qualifying criteria for a young carer to have an Early Help Assessment

There was a lack of response from all schools on this question except for one which stated:
If when working with the family it is identified that they need it and the support is not just referral to YCP. If the young person is struggling and parents' consent to us trying to identify what extra support is available.

The role of the member of school staff undertaking Early Help Assessments for young carers

Two schools recognised this role as the Inclusion Leader, Designated Safeguarding Lead, and Young Carers Lead.

Level of confidence of the school to undertake an Early Help Assessment for young carers (where 0 is no confidence and 10 is complete confidence)

Three schools scored an average 2.3 out of 10. Another school who scored this as 7 stated that there was a lack of confidence engaging adult social care and actual support following assessment was also questioned:

I am confident to complete EH [Early Help] assessment but not sure if I identified support needed, say from adult services for example, how this would work with us getting a service from this team or professional attending a meeting. I could assess that a family need support but if they get that support is another matter.

Level of confidence of the school to refer young carers for a young carers assessment by children social services

Four schools scored an average score of 2 out of 10; whilst the school that did not give a score, stated that (s)he:

Would rather speak directly to the family and young carers myself.

This implies a lack of confidence and knowledge of the pathway involved in engaging children's social care in the assessment of Kingston's young carers.

SUPPORT

Systematically asking parents if they would like their young carers to be offered support in school

This produced a very mixed response and implies that schools are not consistently asking parents if they would like their young carers to be offered support in school.

Types of support schools offer young carers

Overall there was a focus on the attainment, attendance, and emotional health needs of young carers, with no mention of their physical health needs.

Examples included:

- increasing teachers awareness regarding the impact of caring on attendance and lateness, lack of focus due to tiredness, completing homework on time,
- Regular support groups for young carers
- Access to calls home if needed
- Young Carers policy in place with Head teacher with buy-in as young carer Strategic lead.
- Suggesting *referral to parents for Young Carers Project, sibling groups etc.* and *very close links with Young Carers Project*
- Emotional support for a range of needs.

However one school replied that they offer no support and had very limited plans in place in order to do so. The exact issues this school was having might well become apparent during interviewing.

Plans for young carers in the future

All schools replied that they intended to carry on as they were, with one school wishing to improve advertising of Young Carers Project and another to work toward their Bronze (young carers in schools) award.

Support for physical and emotional health

The extent to which schools support physical activity and healthy eating was very variable. However all of the schools believed that they supported young carers' emotional health and wellbeing. Only one school believed that it supported young carers regarding substance misuse and alcohol and only two schools supported young carers with regarding relationships and sexual health (including personal hygiene and puberty). Again further questioning through interviewing would possibly expose whether the support that schools provide was specific for young carers or whether they received this support through the general curriculum.

Concerningly, none of the young carers received any First Aid Training (including calling 111 for non-emergency and 999 for emergency events).

Referrals to the Young Carers Project (YCP)

Not all schools referred all young carers to Young Carers Project:

Not always - some parents are happy for us to support in school but do not want referral to YCP. This happens mainly when we identify that a child is YC [young carer] rather than the family. Most of these parents do have MH [mental health] issues / other complicating issues – such as DV [domestic violence] issues.

Schools with a Young Carers Policy

This was a very mixed picture. Further research would be useful to inform the picture of which schools have a policy, which are using them, and how they can be supported to develop and use policies.

Inclusion of young carers in schools' bullying policy

Again this was a very mixed picture. Further research would be useful to inform the picture of which schools include young carers in their bullying policy, which are using them, and how they can be supported to develop and use these policies.

Presence of a Young Carers lead, reasonable adjustments and open door policy to support

All except one of the five schools had a Young Carers lead and an 'open door' policy for young carers to access support at their school.

All of the schools make reasonable adjustments for young carers.

Responses regarding preparation for transition were not considered for this report as response rate was very low. Exploration regarding the following areas would have to be asked

of secondary schools utilising a method that would better engage with schools eg electronically and through interview:

- Family relationships: including the potential and capacity of their family network, parents, siblings, other relatives and friends, to help and encourage the young person to make a positive transition;
- Social support: including the young person's relationship with friends and involvement in support networks – e.g. groups for young carers/ young adult carers;
- Education, training and employment: arrangements for young people to complete their secondary education and move on to higher education, training or employment;
- Accommodation and independent living: including the young person's future plans and any intentions they may have to live independently. These plans may link to their ambitions to go to university or seek employment away from their home area;
- Health, development and general wellbeing: including recognition of the young person's physical emotional and mental health needs and an evaluation of their capacity to obtain access to health care in the same way as other young people who do not have care responsibilities;
- “Financial literacy” and skills in financial management: including information about how it is expected a young person will support themselves financially in future.

Young Adult Carers Survey

A 10-question electronic survey was sent to all 96 young adult carers registered at Kingston Carers Network (KCN) of whom 33 received the email, and eight people opened the email. This survey was also sent to 33 young adult carers registered at Kingston University carers support service. Only 2 questionnaires were completed in total and returned (one from each setting). Reasons for this may be that the survey went to the university carers just before Easter when exams were imminent and that the university carers are already sent a substantial number of surveys. Furthermore, engagement with young adult carers at KCN has been challenging for Kingston Young Carers Project (YCP) themselves despite numerous attempts to contact them.

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*). 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.

Recommendation would be to improve engagement with young adult carers by working with the 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, and educational).

Survey of 23 9-18 Year Old Young Carers

Relationship of the Young Carers to the People they care for

The most commonly cared for person was a parent (50%, n=12) with equal numbers of mothers and fathers being cared for. Brothers (43%, n=10) were the second most commonly cared for person. Nearly a quarter (22%, n=5) of the 23 young carers aged 9-18 had more than one person to care for. Fewer than five cared for a sister or a grandparent. Only family members were cared for by this group of young carers.

The Age of the People cared for by the young carers were aged under 18.

The most common age group (of under 18s, 18 to 34 years, 35 to 64 years, 65 to 74 years, 75 to 84 years, 85+) of the person cared for was under 18, with 10 (43%) of these 23 young carers caring for 12 other young people and half of the 12-18 year olds caring for a sibling under 18 years. Eight people being cared for by this age group of young carers were aged 35-64 (second most common age group).

The Main Illness or Disability of the Person(s) cared for

The majority of reasons that the 9-18s young carers were caring for someone was because they had a physical disability (43%, n=10) or ADHD or Autistic Spectrum Disorder (35%, n=8). Caring for someone due to mental ill health and learning disability represented 35% (n=8) of the reasons for being cared for by these 23 young carers.

Types of Care given

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).
- 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.

When looking at the 12-18 year old carers only:

- 53%, (n=9) stated that they undertake *Additional childcare (looking after brothers or sisters)*.
- Fewer than five young carers stated that they worked to bring money in and also stated that they *lent money to mum*.

Person identified by young Carers as helping them with their caring

96% (n=22) had someone else to help them perform their caring responsibilities.

The most commonly-stated person to help the young carers perform their caring responsibilities was their mother (65%, n=15), with sisters being the second most relied on source of help (44%, n=10). Fewer than five grandparents also helped a young carer to perform their caring role.

All of the young carers lived with the person they cared for.

Impact of Caring on Family Relationships

The average score of the state of family relationships due to caring was 6.5, ranging from 3 to 10 (where 0 is 'argue a lot, relationships are difficult' and 10 is 'Good, warm, stable relationships'). This suggests a negative impact perceived by the young carers of their caring responsibilities on their family relationships. This score and range was the same for 9-13s and the 13-18s group.

Eleven (69%) of 16 12-18s young carers and six (100%) of the 9-13s young carers thought that there was adequate support for the person they cared for. 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.*

Six (29%) out of the 21 responding young carers stated that they were always involved in discussions and talks about the person they cared for whilst 14 (67%) stated that this was true sometimes.

Nine (43%) of the 21 young carers who responded described themselves as having 'additional needs'. This exceeds the national proportion of just over a quarter as described in [Young Carers: The Support provided to Young Carers in England \(Children's Commissioner 2016\)](#)

Perception of own Health

The 9-13 year olds scored an average of 8 for their perception of how healthy they were (where 0 is very bad and 10 is very good), (range 2 to 10). Overall 9-13s perceived their health as good although there was a wide range of responses.

The 12-18s scored an average of 6.5 for their perception of their own health, ranging from 0 to 9. There was also a wide range in the perception of their own health among the 12-18 year old young carers.

Emotional Health

All of the 9-13s young carers responded that they sometimes felt happy or good about themselves, or able to have a laugh.

The majority of 12-18s young carers (82%, n=13) sometimes or always felt happy, good about themselves and able to have a laugh.

However, all of the 9-13s respondents (n=5) said that caring had made them sometimes or always feel stressed, anxious, or isolated and lonely.

Fewer than five young carers stated that caring had sometimes or always given them back or joint pain, made them feel tired, angry, sleep deprived, down / sad, upset, have interrupted sleep, hurt themselves, miss meals and avoid eating, worry they have lost control over how much they eat, or believed they were fat but others say they are too thin.

Unfortunately half of the 9-13s did not respond to the questions regarding back or joint pain, and to 'Make yourself sick because you feel uncomfortably full?', 'Worry you have lost control over how much you eat?', 'Believe you are fat but others say you are too thin?', 'Believe you are fat but others say you are too thin?', and 'Feel that food rules your life?'. The lack of response to these last questions would require further more sensitive investigation using other methods eg interview with the researcher (again external to the Young Carers Project and outside a YCP setting).

Caring resulted in 12 (75%) of the 12s-18s young carer responders sometimes or always feeling tired or upset, 11 (69%) young carers sometimes or always feeling down/sad, 10 (63%) young carers sometimes or always feeling angry, 9 (56%) sometimes or always feeling stressed, anxious, sleep-deprived and 8 (50%) sometimes or always feeling lonely and isolated, 6 (38%) sometimes or always having back pain, and 5 (31%) sometimes or always missing meals and avoiding eating.

Fewer than five 12-18s stated that caring had sometimes or always caused them to:

- Have joint pain
- Hurt themselves
- Make themselves sick because they felt uncomfortably full
- Worry they have lost control over how much you eat
- Believe they are fat but others say you are too thin
- Feel that food rules their life.

Caring causing this group of young carers to feel stressed, anxious, lonely, and isolated was common for both the 9-13s and the 12-18s.

Utilisation of Health Services

During the previous year, all of the 9-13 year old respondents had visited their doctor and nearly all had visited their dentist, whilst half had visited their school nurse in the past year. This implies potentially good linking in with early health intervention and underlines the opportunities for GPs, dentists, and school nurses to utilise opportunities for identifying young carers and linking them into support. Community Pharmacist had only been visited by the minority of young carers (<5).

During the previous year, the majority (75%, n=12) of the 12-18 year old carers had seen a doctor and 3 other practitioners at the GP surgery. The majority had visited their dentist (44%, n=7) or a School Nurse. This implies potentially good linking in with early health intervention and underlines the opportunities for GPs and dentists to utilise opportunities for identifying young carers and linking them into support. Community Pharmacist had only been visited once.

Fewer than five young carers in the 9-13 and the 12-18s groups had hurt themselves whilst caring but they had also had equipment or aids to help move the person they cared for. Overall six young carers had equipment or aids to help move the people they cared for.

Healthy Lifestyles

Take-away Food Consumption

Generally the 9-13s show relatively low levels of take-away food consumption with one-third taking away food once a week.

Of the 14 12-18 year old respondents, six (43%) had takeaway food once a month and five (36%) had takeaway food once a week, with two young carers doing this once every 2 weeks.

The increasing consumption of out-of-home meals – that are often cheap and readily available at all times of the day - has been identified as an important factors contributing to rising levels of obesity. Nationally, more than one quarter (27.1%) of adults and one fifth of children eat food from out-of-home food outlets at least once a week. These meals tend to be associated with higher energy intake; higher levels of fat, saturated fats, sugar, and salt, and lower levels of micronutrients. Targeted support with healthy and cost-effective food preparation for this group should be considered.

Physical Activity

Only half of the 9-13s were undertaking physical activity to the level needed 3 or more times a week to maintain a basic level of health.

However only five of the 12-18 year old respondents (36%) stated that they undertook adequate physical activity.

For the 12-18s, lack of time was the seen as the biggest barrier to accessing activities, clubs, hobbies (43%, n=6) for the 12-18s. Lack of confidence was the second biggest reason (36%, n=5).

To maintain a basic level of health, children and young people aged 5 to 18 need to do (*Physical Activity for Children and Young People, February 2014. BHF National Centre for physical activity and Health.*):

- at least 60 minutes of physical activity every day – this should range from moderate activity, such as cycling and playground activities, to vigorous activity, such as running and tennis
- on three days a week, these activities should involve exercises for strong muscles, such as push-ups, and exercises for strong bones, such as jumping and running

Physical inactivity directly contributes to one in six deaths in the UK⁶ and the link between physical activity, ill-health and obesity is well established (Effect of physical inactivity on major non-communicable diseases worldwide: an analysis of burden of disease and life expectancy; (July 2012); Lee I-M, et al; The Lancet 380:219-29.)

Smoking and Substance Misuse

None of the young carers aged 9-13 smoked cigarettes / tobacco, drank alcohol or took drugs. Less than five of the 12-18s reported that they:

- vaped once a month,
- smoked cigarettes / tobacco more than once a day
- smoked cannabis once a month
- Drank alcohol once a week or once a month.

None of the 12-18s reported that they took drugs e.g. Xanax.

Awareness of GP Practices and Schools of their Young Carers' status

Only a third of 9-13s confirmed that their GP surgery knew that they were a young carer, with two-thirds not being sure.

71% (n=10) 12-18s young carers had not told their GP surgery that they were a young carer. Six (43%) young carers stated that they 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.

Five out of six young carers stated that their schools were aware that they were young carers. As there was no response to the barriers perceived as stopping 9-13s informing their school of their young carer status, this would need further investigation e.g. focus group or interview.

Fewer than five (31%) of the 16 12-18s young carers had not told their school or college that they were a young carer and 67% of these carers stated that the school does not need to know. Two young carers stated that the school does not need to know.

Support from Schools

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 – helping them to feel happier.

64% (n=7) of the 12-18 year old young carers felt that having lunch clubs helped support them as a young carer. Fewer than five young carers felt that their school /college was supportive in other ways (School/college has allowed them to start later or finish earlier, allowed them to have my mobile phone switched on during lessons, Emotional Support, homework deadlines).

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, with a range of 4-6 (where 0 is not helpful at all and 10 is very helpful). The middle score for all 9-13s suggest that there could be improvements in how much support schools offer young carers in Years 5 to 8.

Thirteen 12-18s young carers rated the extent to which they felt their school / college helped them as a young carer a low average score of 3, range was 0 to 6 (where 0 is the school didn't help at all and 10 is that the school helped very much), suggesting even more need for schools to support secondary aged carers.

Impact of Caring on School, Social Life/Interests, Friends and Family Relationships, and Free Time

All of the 9-13s young carers felt that caring sometimes affected their free time but never affected their relationships with friends. It is unclear whether this relates to friends outside of the Young Carers Project or within it or both. Five (83%) young carers felt that caring sometimes or always affected their concentration and two-thirds felt that caring sometimes or always affected their social life and interests. Five out of six felt that caring never affected their attendance at school and never affected their relationships with family. This latter response belies the scale response scoring which implied a perceived negative impact of caring on family relationships. This suggests that this sensitive question would require further investigation through another method e.g. interviewing.

The majority of 12-18s young carers felt that caring sometimes or always negatively affected their:

- homework (71%, n=10),
- concentration and their free time (64%, n=9),
- Social life and interests (50%, n=7).

Bullying

The majority (five out of six) stated that they had never been bullied due to being a young carer. Of the 14 12-18 year old respondents, 9 (64%) said that they had never been bullied due to being a carer, whilst fewer than five had *a few times* (although this was when they were at primary school) and fewer than five had more than once a week.

This information contradicts that given by young carers as part of the focus groups with them.

Experience of Young Carers Needs Assessment

Fewer than five of the 9-12 year old young carers responded to each of the questions regarding Young Carers Assessments and whether they felt it improved their outcomes, or were not sure or stated that they thought they had had a needs assessment, and that they were unhappy about how they were assessed. There were no other responses when asked why the needs assessment had not made things easier for them.

Seven of the 14 12-18 year old respondents stated that they had received a Young Carers Assessment. However, this contradicts the information from Young Carers Project and from AfC at the time which implied that almost no young carers had had a formal assessment.

Consequently interpretation of responses to this question and the following related questions is limited, suffice to state that it is significant that half of 12-18 year old young carer respondents believed that they had a young carers assessment when it is highly unlikely that they did as almost no young carers assessment have happened in Kingston up to the time of this survey being undertaken.

Responses from 12-18 Year Olds Young Carers Group only

Transition Support

Five out of the eight (63%) respondents aged 14 or older had not received support regarding *Education – learning new skills, additional qualifications, colleges, careers advice, funding options.*

Seven (88%) 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.'*

Half of the eight respondents had 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.'*

Eleven (85%) of the respondents 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.

The average score was 5 for the 13 12-18 year old respondents experiencing anxiety about accessing support when they left the Young Carers Project at 18, ranging from 3 to 10 (where 0 is *not anxious at all* and 10 is *extremely anxious*). This indicates a need to better identify and address these anxieties for those aged 14 – 18.

Thirteen of the 14 young carers were full-time students.

Employers Awareness of Young Carers Rights

Fewer than five young carers replied to the question asking whether their employer knew about their rights, e.g. flexible hours and having time off in an emergency. But half of those who did responded that their employer was not aware or were not sure whether their employer was aware. This implies that young carers may not themselves be aware of their employee rights as carers.

Increased Caring Responsibilities with Age

Nine of the 14 (64%) respondents believed that more had been expected of them in their caring role as they have become older (they have taken on more responsibilities).

All of the 12-18 year old young carers had between one to four other children living at home with them. Six out of fifteen (40%) had three or more other children living respondents none of the young carers had children of their own.

Of the 12 respondents, six (50%) were not sure if *there 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.

General Support accessed

Other than the Young Carer Project (100%), the School Nurse (50%, n=6), GP (<5), and National Carers Service' for 13-19s - information, advice, guidance to help decisions on learning, training, work <5), none of the 12 respondents 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'.

Suggestions to improve Young Carer's Health and Lives

The majority of the 12-18 year old young carers stated that the following would improve their life including their health:

Going on holiday (71%, n=10), evenings out, meeting with other young carers or more time for social / sports / activities (64%, n=9).

Suggestions by the 12-18s young carers to an open question about what would improve the lives of other Young Carers were:

- *To think about yourself now and again and your health.*
- *More awareness so people can realise they are carers.*
- *For there to be more things in school and outside of school.*
- *School should know.*
- *Help with travel for the under 16-18s age group.*
- *To help the young carers have clearer way to find access to emotional and physical health. Also to provide more chances to be alone / not care.*

Professionals Interviews

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

1. What do you know about how young carers are identified in Kingston?

AfC recognised that there is a £40,000 budget (through Troubled Families) for Kingston Young Care Project (YCP) but no service specification and the contract is 4/5^{ths} completed. 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.

It was highlighted that:

Community Mental Health Trusts (CMHT) ...did not identify young carers well. A third of young carers known to the KCN young carers project care for an adult with mental ill health. However there were no referrals from CMHTs. It would seem that young carers are not picked up in routine assessment. Young Carers have some publicity when I circulated KCN material but there needs to be more, potentially KCN going into team meetings etc. During the past 3 years there has been an increase in profile of young carers but but this did not result in greater referrals from the mental health system.

There were calls for a voluntary register of young carers as there is for children with disabilities so that families can be kept regularly updated on all the services and support.

Few adult services refer young carers to YCP, and not many from health services, very few referrals from substance misuse and mental health services (adults teams). Social Housing are well placed to identify more young carers as there is often a healthcare issue and young carer present. There should be a 'no wrong door' approach to a formal identification process.

Voluntary organisations expressed that they were not involved with identifying young carers but do refer to the Young Carers Project. *There probably needs to be more work to identify young carers and from schools. 70% of children on the autistic spectrum are in mainstream schools so siblings are not always identified.* Express CIC could possibly link young carers into a needs assessment but would lack the capacity to intervene more.

One professional encapsulated the themes running across all professional's interview responses - that young carers are not identified in routine assessments:

.....we always ask about family members – usually will make a referral to SPA. Questions we ask are not about young carers as such and our assessment process definitely needs to be looked at [to ask whether there is a young carer in the family].

2. What do you know about the young carers assessment and how young carers are linked into having an assessment? What are the qualifying criteria to have such an assessment? Who undertakes the assessment?

AfC state that:

There are a large number of Young Carers referred for an assessment from Young Carers Project, we then assess them and refer them back to YCP because they do not meet the threshold for more service intervention.

Issues were underlined with assessments being adequately completed and with leading to adequate support:

I do not have an issue with the content but I don't think they [the assessments] are sufficiently done – they are not sufficiently completed. However the primary issue is whether they [young carers] are provided with adequate support.

SPA are also looking into increasing awareness of the Early Help Assessment as this is not being used consistently and:

Agencies provide support without wanting to do a formal assessment.

There was differing opinion even within the same organisation as to whether the Early Help Assessment would be adequate in identifying young carers.

AfC staff felt that there should not be an actual specific young carer needs assessment:

.....so it's about working with that and possibly having a one pager to supplement the Early Help Assessment. The actual assessment tool would have to be trialled with young carers. We have 600 already so they would have to be assessed as well as the new referrals. At least with AfC, if not schools in the outset using this assessment (the number of assessments would be much improved).

If CMHT and statutory services are not aware of what is available in the community, when assessing an adult or young carer we cannot assess the young carers properly and refer / signpost to the most effective resources.

The Kingston Young Carers Project recognised that only recently childrens social care were showing signs of acknowledging a need for assessing young carers. YCP are also discussing training and what assessment should look like with Family Support Workers.

A lack of awareness by childrens services of what adult services offer and vice versa.

Yorda, Express CIC, RAK – not aware.

There is a common misconception among professionals that YCP undertake full young carer assessments.

Some adult services describe themselves as neither commissioned, nor equipped, nor confident to undertake children's assessments - that their IT systems do not interface with children services, and that they lack the capability and capacity to assess for young caring roles. There was also concern particularly from adults substance misuse and alcohol services that although their services *wish to keep families together and to enable parents and young people to engage with [them] and get support*, that there is a reluctance for families to make their children and their caring roles known because of fear that that the children will be removed into care.

Some service expressed that they have so many other assessments to undertake that they would need a tool / aide memoire to remember to also consider the young carer questions.

3. Which organisation(s) / agency(ies) is/are best placed to undertake a young carers needs assessment? – including for young carers with complex needs.

There was a mixed response to this question:

Depends on case and type of young carer. It [the assessment] can be a bit subjective as to whether a young carers needs assessment would be needed to ensure there are no underlying issues.

However overall, AfC staff viewed that assessment are *best contributed to by the professional who knows the child best e.g. the school, or health, or voluntary organisation or the church*, with the voluntary organisation (YCP) and SPA particularly recognised as key.

However some members of staff in AfC felt that some organisations are not placed to undertake a full needs assessment and 3rd sector organisations might instead use a screening tool to ascertain whether the young person needs a fuller young carers/whole family assessment by a statutory organisation.

This needs to be done by a specialist, not just as an add-on to the initial social worker assessment. There could be more done with screening.

Other members of staff believed that the assessment should be undertaken by *Any children and young people's service eg children social care, schools, and youth clubs.*

AfC advocate the use of one assessment and not developing and using another assessment:

Having a separate assessment is against the ethos of AfC. All AfC staff work under one assessment.....whether it is Early Help Assessment, Children in Need, Asset Plus Work needs to

be done to tighten up the specification and to work with YCP to develop this screening tool which can be used alongside the existing assessment.

However another member of AfC staff stated that there was more than one type of assessment used already:

There are still 3 separate assessments: Asset Plus, ILLY (case management system - Health and Wellbeing) and the ICS assessment; there is still way to go before we have one assessment and one plan....we should have a screening tool.

We would need to streamline MACA and PANOC tools which are very helpful but also too detailed. These would be developed with young carers who would also have a part to play in developing pathways and protocols.

AfC suggest that there should be an on-line tool for practitioners to increase awareness of young carers and face-to-face training in those staff who have yet to be identified who would be best placed to undertake assessments.

AfC have set up a protocol group to look at developing these tools to raise awareness and assessments.

Improvements to the strategic forum for young carers was also suggested e.g. *young carers steering group*, which would improve the link to Adult Social Care*Part of the Adult Social Care budget could be used to get young carers to school for example.*

KCN.....using a partnership approach.....are in the best position to undertake constructive Carers Assessments because of their knowledge of resources, welfare benefits etc

YCP felt that they would not have the staff capacity to undertake full assessments, but that they could use a pre-assessment tool. Currently YCP use MACA and PANOC tools and these would be improved upon. It was considered that the SPA should be the gateway to the appropriate member of staff within AfC who would undertake the needs assessment. *The actual assessment tool would have to be trialled with young carers. We have 600 already so they would have to be assessed as well as the new referrals. At least with AfC, if not schools in the outset using this assessment (the number of assessments would be much improved).*

If it is fairly simple, it should be the Family Support Worker or the Social Worker of the person with the care needs. It should be whoever is supporting the person with the care needs if it is the case that by providing a bit of extra care to the person with the care needs the young carer's needs will also be met eg if the young carer has to do shopping every day causing stress, by providing a personal assistant for the parent, the young carer's need to shop would disappear and so would the additional stress. Same with adults services, if child cannot get to school, adult teams should arrange transport. If it is a complex young carer, Early Help or Social Work teams needs to be involved.

Whole Family work has never been demonstrated. They are going to have complex needs for some time and I know of families where there are so many services involved but no co-ordination as a whole.

We have used the MACA and PANOC tools before - they are a good starting point and are well evidenced but I think that Surrey ICare tool is more thorough, asks more open questions and gives opportunities more for the young carers voice to be heard.

4. Do you think that there are adequate levels of Young Carers identified in schools? (If not, why not – what are the barriers?)

AfC showed an awareness of the potential scale of unidentified young carers in Kingston.

YCP work with 600 young carers and there are meant to be up to 2000 young carers in Kingston – so a huge number remain unidentified.

There was recognition of the limitation of schools in identifying young carers due to not being equipped to identify carers and because of the different types of care that remain hidden:

Schools undertake work that we are not aware of. But not sure schools are equipped to identify young carers. There are young carers who are the core group and there are those young carers who dip in and out of caring so are more difficult to identify.

Young carers of adults or siblings with physical disabilities are better identified.

AfC highlighted that schools identification of young carers is patchy and that the *onus is on schools* to systematically identify early those young carers not accessing other services and those who provide care on an ad hoc or temporary basis.

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:

You would hope that Adult Social Care are identifying them but this is not happening – it is not just about looking at the adult's needs – need to look at the package. If ASC are working with vulnerable adults, this may impact on their parenting capacity and may be a safeguarding risk when AfC would be liaised with. The relationship with ASC could be improved....and referral by ASC to AfC.

AfC stressed the importance of workforce training in improving awareness in schools of young carers particularly among independent schools:

RBK should offer training to all organisations working with children and young people. There needs to be good governance arrangements... ..Take up of training is an issue particularly among Independent schools.

Young Carers Project viewed that schools were highly variable in how well they identify schools, this is despite the amount of support that the project offer to schools. It was particularly challenging to engage with Independent schools to take up the offer from YCP:

Some schools are particularly good and some are particularly weak. We offer the same service to them all but not actively with Independents schools – although they also receive the letter we send out to all schools every September. One of our workers went into an (independent school) and did 2 assemblies last term because a young carer attends their school.

In relation to refugee communities, there are no adequate levels of Young Carers identified in schools. The main barrier is lack of understanding about how much young refugees involved in caring for their parents, relatives and members of community.

5. What do you know about how young carers are supported after they have an assessment?

AfC responded that:

AfC develop a care plan which would be delivered to meet all needs and would be reviewed if there were special measures.

Those [children with a safeguarding concern - not just those with a Child Protection Plan - but where there is risk of family breakdown –are well supported.....If they are missing education, there is a statutory CME panel and we work with the school. Effective co-ordination between services is needed instead of services so readily referring to YCP only.

However there were varying levels of awareness of what YCP provides and what other support might be available:

I haven't seen any recent publicity [for YCP] so I wouldn't know.

Not sure what there is for teenagers.

YCP stated that none of their young carers had had an assessment historically and that schools support was highly variable.

There is discrimination against parents with mental health issues.....Parents with physical health needs may have services provided such as transport to school for primary school aged children – parents with mental health needs eg depression would just be pressured/expected to take their children to school themselves.

School and Express CIC (support for siblings of children with autism).

There is an Early Help system but the Early Help assessment does not focus sufficiently on the caring role. If they are children in need or child protection plan again the social care assessments (but this) does not always involve a focus on their caring role.

Young Carers are not supported with information about the health condition of the person they care for – they need to know more about the health condition of the person they care for. Also young carers are not involved in any planning for an emergency / crisis and young cares needs

more emotional support. They need outside positive role models. Young carers in lone parent families without extended family support get very isolated.

Services felt that there were *blurred boundaries between children in need / young adult carer. Organisations are specific for children in need or young carers. Secondary school X had a session once a month which was good but not enough. All are very impressed with YCP.*

6. Are you aware of any assessment that would systematically identify and assess young carers in order to support their transition needs?
Generally there was a lack of awareness of this area. AfC acknowledged that 14-16 year olds young carers were under-identified and underrepresented in Kingston.

AfC admitted to historically lacking awareness of the voice of young carers and the detail of what YCP provide in order to work more effectively with them:
There has been a gap in AfC's knowledge of what YCP provide. There needs to be more awareness regarding YCP's offer – have this information on on the Local Offer website. Young Carers voice needs to be better tapped into about how better to promote supportive services.

YCP and NHS were unaware of any transition assessments.

7. Are you aware of any young carers who are caring for someone because they misuse substances / alcohol or have mental ill health?
Response from AfC was that *All of our assessments do that* although there was also recognition that this population remain unsupported.
We would want the same outcomes framework [in Kingston] as there is in Richmond. There is insufficient joint working between AfC and YCP and there needs to be more integration. I used the COBIC outcomes that the CCG is using as best fit for the Richmond young carers voluntary organisation provision.

ASC - Yes – *they are under-identified nationally. Serious Case Reviews demonstrate a disproportionate amount of incidents / fatalities families where there are mental health issues, substance misuse, domestic violence. This is a potential area for investment i.e. Strengthening Families.*

YCP recognised the significant prevalence of mental ill-health among its service users:
One-third of our young carers have this as the primary reason for being a young carer but once you get to know them, it is about two-thirds of families have mental ill health It is really hard to engage families where there is alcohol and substance misuse so there are low numbers..... I am not sure that families where there is mental ill health is more difficult to engage but they are possibly more hidden and young carers in families with mental ill health access YCP services more inconsistently.

There was also the perception that social services will simply refer any young carers to YCP instead of carrying out a full whole family assessment or undertaking any joint working. This situation is potentially exacerbated if there is an (invisible) mental health issue within the family:
we are referred to by social workers and family support workers. Sometimes it seems that it is part of the plan that young carers are referred to YCP instead of any joint working. There was a comment from a social worker that the young carer cannot be a young carer as their parents did not look disabled – so there is some lack of awareness of mental health and the role of young carers with that. Family Support Workers or Social Workers working with the family with limited capacity, view it as an easy win to refer to us as they can say they have arranged support for the child. Sometimes this is sufficient, other times more family support is needed.

NHS

Services state that the lack of communication skills of families affected by mental health and substance misuse can exacerbate the difficulties services have identifying needs of young carers in these families:

There is a reluctance and a difficulty to talk...an emotional immaturity.... lack of emotional language which the parents show and which is part of why they use substances – this is passed onto their children who then cannot express their emotional needs.

8. Does your service routinely ask whether a young carer is involved in caring for the person receiving the service?

None of the services directly asked young people accessing their service whether they were young carers/ had young carer 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: No – unless the child had a specific set of needs, unless they had an EHCP or statement, no formal need other than young carer. This area needs further work.

RAK: We do ask this question because sometime refugee parents bring their children with them to advice sessions to interpret for them, and young refugees play an important part in helping their parents at hospitals, GP surgeries and other statutory services.

NHS – no.

9. What do you know about how young adult carers are identified in Kingston?

Lack of awareness by AfC of the need to improve identification of young adult carers (or those who are soon to become adult carers):

We are currently reviewing our case management system for new cases but we are not in a position to do that retrospectively (identify young carers and young adult carers) from our existing caseload.

YCP said that they had worked with the college and the university but there are low numbers being referred to them.

10. What do you know about how young adult carers are assessed? What are the qualifying criteria to have such an assessment?

There was awareness by AfC of the need to have a whole family approach to the assessment of the young adult carer:

Should be a holistic assessment, not just in isolation, but in the context of the family, siblings, and extended family.

Adult Social Care: *Referrals from CMHT to KCN need to be improved. Under the Care Act, they should be assessed like any other carer.*

YCP felt that they 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

Nothing. Provision sometimes lacking even if a young adult carer is identified.

11. Do you know what support is available for young adult carers?

Overall, AfC had a knowledge gap of what support is offered to carers once they reach 18.

Nothing specific, nothing targeted to their age group. Access anything at KCN. YCP are about to start a fortnightly support group sessions for 18-24 year olds.

12. What do you think are the barriers to young carers and young adult carers being identified?

AfC acknowledge the barriers to identification of young carers and young adult carers as: lack of staff awareness of these carers - *level, type, and frequency of care; this applies across the professional network. The lack of joined up working and co-ordination between Adults Social Care (including Adults Healthcare services) and Childrens' Social Care. E.g. a nurse visits the home of an adult and doesn't identify the needs of the child who is there. [Serious Case Reviews] tell us that this is not happening.*

- young carers not identifying as young carers
- young carers not wishing to identify as carers due to fears of being bullied

- lack of awareness of supportive services.

Adult Social Care: *The questions being asked are not identifying young carers and they do not necessarily identify themselves as young carers. They may label themselves as a daughter or son but not as a carer. Also caring is usually linked with physical health. Caring role isn't associated with mental health – being depressed or psychotic.*

YCP highlighted that there is

fear that they will be removed if they disclose that they are young carers

- negative experiences of previous assessments where nothing changed has reduced young carers disclosing.
- Caring for someone with mental ill-health is not recognised as a caring role.

RAK: With regard to our client group (refugees) the main barrier is understanding definition of carers, recognising caring in this community is different because very often young carers and young adults act as interpreters/adviser to their parents and members of community because of language barrier and cultural differences.

NHS

Professionals voiced the challenges of remembering all of the necessary referral pathways and constrained by having to consider a number of assessments, whilst dealing with the lack of joined up working between children and adults services:

Need to build relationships and trust and always feel rushed with the formality of assessments – there is a need for a more informal way of giving support. There is a split between child and adult services and each not being mutually aware of what both offer. There are so many referral pathways, just knowing all the services available for your own clients is hard enough. There is a difficulty keeping expertise in all areas....

Young carers will often have a strong loyalty to their parents and will not necessarily communicate their needs because of fear of the consequences of disclosure.

What do they get out of an assessment if nothing changes following an assessment?

13. What is your opinion of Kingston adopting a Memorandum of Understanding between Children and Adults Social Care of the [ADCS/ADASS Memorandum of Understanding](#)¹ for use with carers up to the age of 24 in order to better identify and support young carers and enable transition?

AfC were generally supportive of the introduction of a Memorandum of Understanding between Children and Adults Social Care as long as it is not tokenistic and has comprehensive stakeholder engagement including the family.

However other existing policies and protocols were also highlighted as important:

There are already the 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.

AfC also suggested the importance of having a local young carers strategy and of using a whole family approach, particularly when there are adults with mental health and/or problem use of substances or alcohol.

The buy-in is there but the formalisation has drifted over the past few years.

There is an impact of adult's behaviour on the child. There should be a whole family approach with a focus on the child, particularly the case with young carers of adults with mental health issues - and so also likely alcohol and substance and alcohol misuse.

ASC: *Joint protocols are laden with risk as services constantly re-configure - they almost need updating before they are finalised. An MoU is worth a discussion but it would need to be integrated. We are due for an updated carers strategy [national and locally] – we are awaiting central government. What about the interface between Adult Social Care and mental health? Does the Thrive Strategy cover young carers? Is it useful to have another protocol? So this MoU would have to be embedded in the other strategies: Thrive, Carers, Autism, Dementia, in order to have any accountability.*

I am not sure there would be the resource to have a separate young carers steering group. There needs to be a consideration of stopping the AfC costs relating to young carers migrating to Adult Social Care.

YCP supported the introduction of an MoU quite strongly and felt it should be part of all relevant staff's (including housing) induction. Lack of a signed MoU has meant that YCP have not been able to apply for funding..... The MoU template lacks the child's voice for Kingston – it needs to be clear why we are having an MoU..... I have left a task with (a member of AfC staff) to develop pathways for the young carers needs assessment. The importance of making Adult Social Care funding for young carers needs to be realised. YCP would like to be involved with developing training for AfC from the start.

For complex cases there are families find there are too many assessments and not enough support.

Big gaps in the services eg no one supporting with underlying issues such as finance/benefits exacerbating mental health problems.

It would be good to have a framework that we can all tap into in order to know what other agencies there are.

Also, mental health and wellbeing and transition from CAMHS to adult mental health services need to be aligned. For example, community and district nursing teams visiting into people's own homes where a young carer maybe present, but even if the carer is not present because they are visiting during school hours, the District Nurse should know a young carer is involved. As the primary care team expands those working within and across primary and community services who are often familiar with those with chronic and long-term conditions – it would be appropriate if all were aware of young carers.

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.

In supporting young carers, it would appropriate to know who they would talk to in case of a crisis and or if they felt they needed more support and were unsure what to do in caring for another.

¹ Association of Directors of Adult Social Services (ADASS) and Association of Directors of Children's Services (ADCS) (2009), 'Working Together To Support Young Carers – A Model Local Memorandum of Understanding between Statutory Directors for Children's Services and Adult Social Services'. ADASS and ADCS.

Other Information provided at End of Interview

The Family Services Directory fulfils part of the information duty on the LA and this sits with AfC on their AfC info website It used to be on the RBK website and now is on the AfC website which people may not know about or use as much. It is a constant task to raise and maintain awareness of AfC services and the website across the borough and to work with RBK colleagues to signpost from the council site. There is not a particularly structured or coordinated approach to working with and networking with agencies outside of RBK.