

Young Carers - what I do is just 'normal'

Healthwatch Bolton

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“I know I’m a carer because I go to the young carers group...”

“Over the years I’ve learnt to accept this as my way of life. Personally I’d want to be known as a kid who helps more than a carer, because in that way I connect with the subject more.”

“No, it’s my brother, it’s just normal. My mum does most of the caring... We support each other. I worry a lot.”

“I don’t know what a carer is. It’s just normal what I do.”

Young carers are one of the 2017 priority areas for Healthwatch Bolton. In this report Healthwatch Bolton is working with The Young Carers Partnership Group to better understand current experiences of young carers in Bolton. The work comes in the context of Bolton Council refreshing its Carers Strategy (making it 'all age') and reconsidering its offer to young carers which has long been under scrutiny from partners and the voluntary sector.

As context this report refers to The Young Carers Partnership Group terms of reference document, which states:

“The term young carers should be taken to include children and young people under 18 who provide regular and ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances.

A young carer becomes vulnerable when the level of caregiving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well-being, or educational achievement and life-chances.”

(Association of Directors of Adult Social Services and the Children’s Society)

The Young Carers Partnership Group has identified four areas for improvement in their aims:

1. *Effective engagement with young carers to identify their needs.*
2. *Increased awareness around young carers, their needs and the support available to them.*
3. *Young carers are able to recognise themselves as carers and are supported to seek help.*
4. *Young carers are able to access opportunities that are open to their peers.*

This research aims to contribute to these broad aims by:

- *Finding and engaging with a sample of young carers in Bolton.*
- *Obtaining Young Carers views on self-identification, experiences and support needs.*

Two engagement officers from Healthwatch Bolton conducted interviews with local people for this study.

A digital 'poster' advertisement was used to make people aware of the research - this was shared by email with relevant local groups, through social media, and also combined with telephone outreach to local groups.

People's experiences were gathered using a questionnaire with four parts. Participants did not always complete all four parts; this depended on which experiences they wished to share:

- A semi-structured questionnaire to give detailed accounts.
- A short 'day in the life of' questionnaire, this allowed people to describe their daily experiences of caring, as well as express any feelings and concerns.
- Participants were asked if they wished to complete a 'support in school' questionnaire and 'barriers to learning' questionnaire.
- Case studies by parents.

Comments were recorded verbatim, otherwise individuals were free to fill in information themselves.

Analysis is based on five themes:

1. How young people feel about caring.
2. Impact of caring on daily life.
3. What support carers give.
4. What support people need.
5. TEC **presented separately*

Young Carers – The Questions/Who we Spoke to

Interview questionnaire section	Question themes
Young carers discussion questionnaire	<ul style="list-style-type: none"> • What role does the young person play in care? • What is the impact of performing this role? • Awareness of available help. • Attitudes to the impact of caring on life.
'A day in the life of'	<ul style="list-style-type: none"> • A normal weekday looks like this... • A normal evening looks like this...
Support in school	<ul style="list-style-type: none"> • Having access to various support at school. • Information about being a young carer. • Any other needs?
Barriers to learning	<ul style="list-style-type: none"> • School attendance and participation. • School work. • Fitting in and social effects of caring roles. • Emotional effects. • Material and financially related aspects. • Support in family and outside the family. • Future plans and impact.
Case study	<ul style="list-style-type: none"> • Understanding needs. • Care package. • Issues around technology to provide support. • Impact of care needs on family.

Research detail	Total
<i>Total participants</i>	13
<i>Total parents</i>	6
Gender breakdown	12 female 1 male
Questionnaires	11
Day in the life of	5
Barriers to learning/ Support in school	11
Case study: parents	6
Former carers	3

How do young people feel about caring

- Feelings of worry and stress are a common reaction. However, young people want to help and support the family.
- Some do not self identify as carers, which poses a challenge for contact by services.
- Parents and siblings most likely to be classed as those being cared for in this study.

What is the impact of caring on daily life

- A range of domestic tasks are being done as well as personal care.
- Young People have significant responsibilities over a long period.
- Young People do not always have much free time or ability to get to places – support would need to take this into account.

What support are young carers receiving?

- There is a lack of dedicated support for young carers.
- Young people relied on close family, school, and any support groups they are in contact with. In an absolute emergency people would dial 999.

What support do people need ?

- A need for awareness of the situation young carers are facing.
- Support could be available at places frequently used by young people e.g. schools or specialist services.
- Young carers expressed a need for support with practical life skills and resilience.

How do young people feel about caring?

Young people were taking on many different responsibilities - This could bring emotional stress.

Despite the challenges young people recognise the important role they play, many wanted to continue helping at home.

Reactions to caring role included a range of emotions:

- Guilty
- Stressed
- Frustrated
- Tired
- Upset
- Hard
- Sad
- Angry

Caring as a constant feature of daily life

“Since I was small, about 6/7yrs old. I help with cleaning, cooking and I sometimes help her go to the bathroom. I also have to help send texts and ring people because her vision sometimes goes...”

“Extra supervision because he struggles to be understood and cleaning up to help my mum.”

“I help with everything. I help with her medication mostly - everyday. My brother helps sometimes, like he had to help her cross the road yesterday because she couldn't see properly.”

“My brothers struggles to fall asleep and they can be disruptive.”

Can bring feelings of confusion and worry

“Sometimes I get frustrated because I feel like I'm the only one who helps out, but then when I think over the situation I start to feel guilty for not just doing it as asked in the first place.”

“It depends, sometimes it stressed me out and I get frustrated. I get tired sometimes, mainly on days when mum's having a really bad day.”

“It used to be very stressful because people didn't understand him. It's hard when he gets away with things that I wouldn't and night time is hard because he can keep me awake a lot.”

“I don't get stressed but I worry about my mum because I love her.”

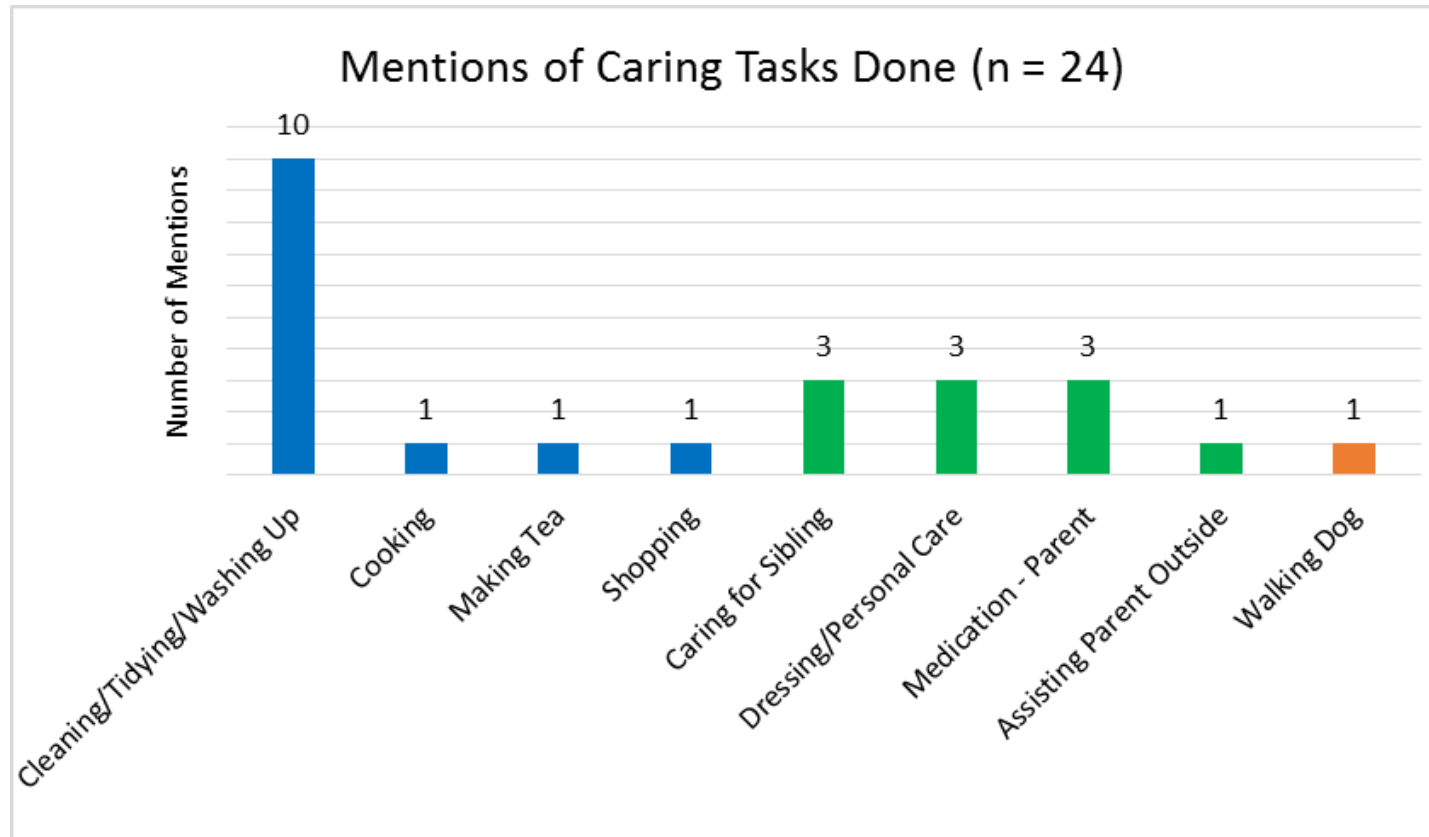
“My anxiety - I went to CAMHS once and they said I don't need their help but my anxiety is really bad...”

Impact on daily life

Carers identified a number of tasks associated with caring including domestic activities and personal care.

Carers identified a number of impacts relating to their health, wellbeing and personal lives.

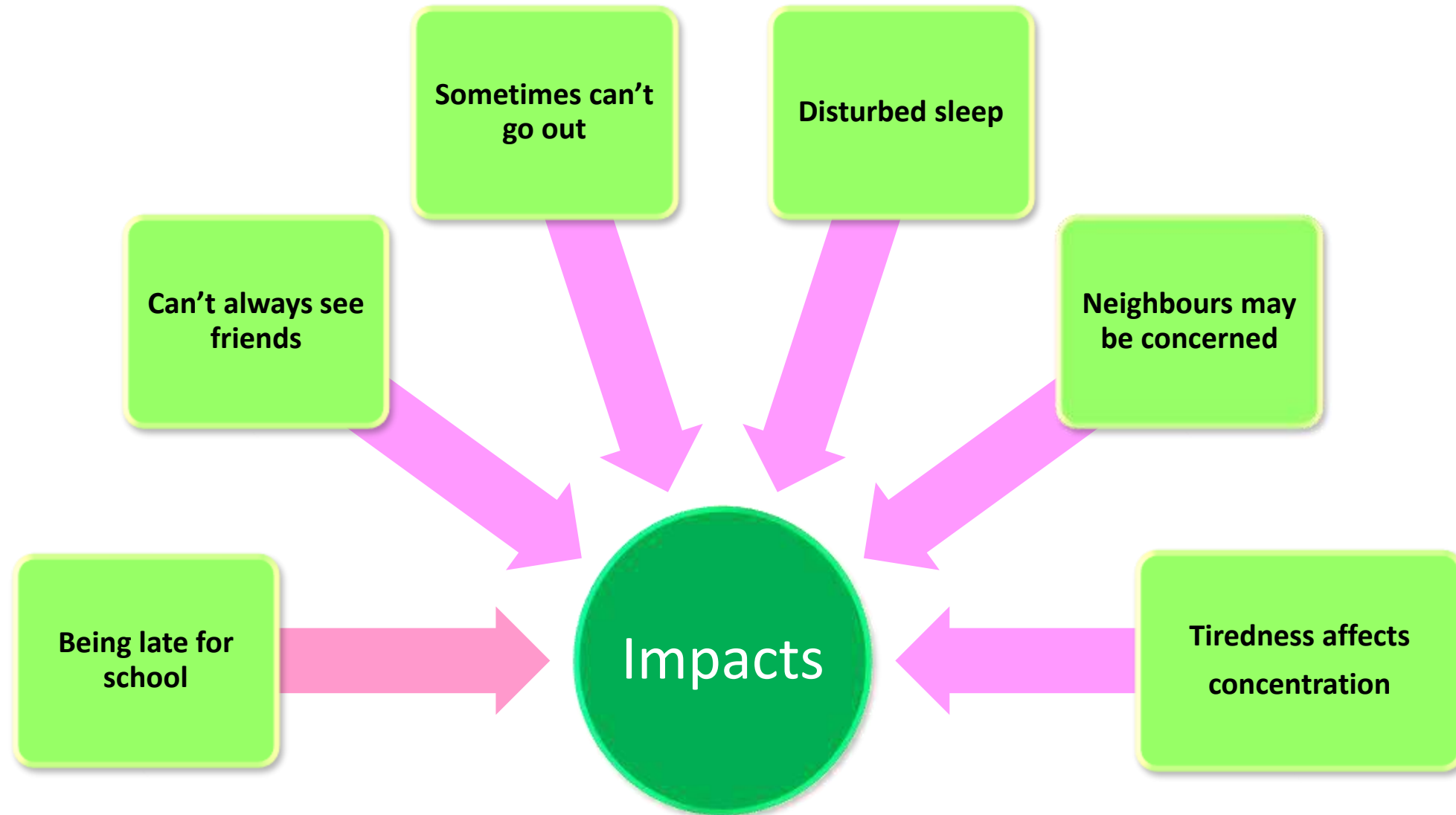
Caring can impact all day and respite is difficult to find. Some also anticipated this lasting beyond childhood.



The length of time individuals have been caring was between 18 months and 8 years.

When asked what tasks they helped with the majority were for tasks related to cleaning, tidying, and running the home, 54% (13).

There were significant mentions for the range of personal care tasks, 42% (10).



Impact on life now

“Personally I don’t miss school for those purposes but there have been times where my friends has asked me to go out and I’ve had to decline so I can look after my mum when she’s unwell.”

“Yeah, I’m tired sometimes. Sometimes I can’t go out because my mum has to deal with my brother which makes me really annoyed.”

“He doesn’t like to go out so that can really impact. Like the other day we was going to go to Blackpool but he refused to go and sometimes it’s just easier to miss out than deal with the repercussions. I couldn’t do after school club because my mum needed help with him at home.”

“Sometimes I couldn’t go to my swimming lesson because my brother is having a meltdown.”

Everyday tasks

“If I’m up early I make mum and dad a cuppa.”

“Get mum’s medication if she forgets it.”

“Help mum if she needs something.”

“Sometimes I do worry about my mum’s health. Sometimes I can’t concentrate but I still put my head down.”

“After school I go home and make me and my brother something to eat. I do some school work.”

The future

“I plan on helping out for as long as I can no matter what career path I take, I also plan on keeping a positive attitude even if I’m stressed.”

“I was thinking of doing medicine, I want to go to Uni, I don’t know if I will move away, I won’t go far away from mum.”

“I like maths so I might do that when I’m older. I don’t know where I will live.”

“I want to go to Uni and study to be a mental health nurse.”

What support are young carers getting?

Many families were not in receipt of a care package or a personal budget.

Some young people identified a wider support group including school and services, though it is noted that experiences of school were mixed.

Immediate family and friends were seen as essential support and in a crisis emergency services would be essential contacts.

As part of this research engagement officers also gathered experiences of 6 mothers. Parents accounts were taken at the same time as young people were being interviewed.

Case studies from 3 former carers were also taken.

These accounts covered the following topics:

- Family
- School/Home
- Complex needs
- Practical needs and effects of lacking/having help
- Uses of technology
- Emotional impacts
- Services involvement

We have chosen to highlight two issues from within these themes, whether families had access to the internet, and if they had a care assessment.

Care packages

“I don’t have care package but I’d like one. I acknowledge I need to look after myself better to help my children more.”

“My husband does virtually all the cooking and cleaning and my daughter helps a lot...I don’t have a care package but I want to do things more independently...”

“I don’t have a care package at all.”

“We don’t have a care package specifically for me, but we have a family one through social services, not that it’s worth the paper it’s written on. The social workers are always changing, I have to chase them up all the time,

“I don’t believe my sons support needs have been met by outside agencies, which has meant more and more pressure on us as a family. I constantly worry. I worry about my family being split up by social services. It’s a constant battle to get support and I’m exhausted. It’s one battle after another, after another.”

“I don’t have a care package anymore. I had carers when I was really bad but I couldn’t afford them...”

Many families were not on a care package or personal budget; this could be due to actual and perceived complexities in the system, and feeling that services could not offer what was needed.

There is need for support outside the current system.

Care assessments could take all kinds of technology into account when implementing TEC. Please see the accompanying report on young carers and TEC for more information.

Grandparent(s)

- *“I’d prob ring the ambulance or my grandma. When my mum was in hospital I wanted her to come home because I really missed her.”*
- *“Yes, if I couldn’t cope I would ring my gran and granddad or ring 999 if it really serious and dads not home.”*

Parents

- *“I know what to do, if I can’t get to them then I would ring an ambulance or my nana. I’d stay with my dad and brother. Mum had her gallbladder removed and ended up in intensive care and I really panicked when she was in hospital.”*

Emergency Services

- *“I would go to my bedroom and if it was really bad I would ring 999. Mum has had to ring 999 a lot because my brother is kicking off and sometimes he hurts mum.”*
- *“Yes, I would ring my mum or in a real emergency I would ring 999.”*

Immediate family and friends were seen as essential support and in a crisis emergency services would be essential contacts.

Some young people identified a wider support group including school and services, though it is noted that experiences of school were mixed.

Teacher

- *“I’ve got teachers at school. My mum got me some leaflets from the MS Society and I also looked online to find out more.”*
- *“I can speak to my teacher at school. I see her every week. She asks me about my brother and things at home. I tell her when it’s bad and when it’s good. She’s very nice.”*

Friends

- *“...I do moan to my friends sometimes, it can be really hard.”*
- *“I think my mum would like to get out more... lots of help and guidance from her friend will work and get her out more often to enjoy her time away from home not worrying about us.”*

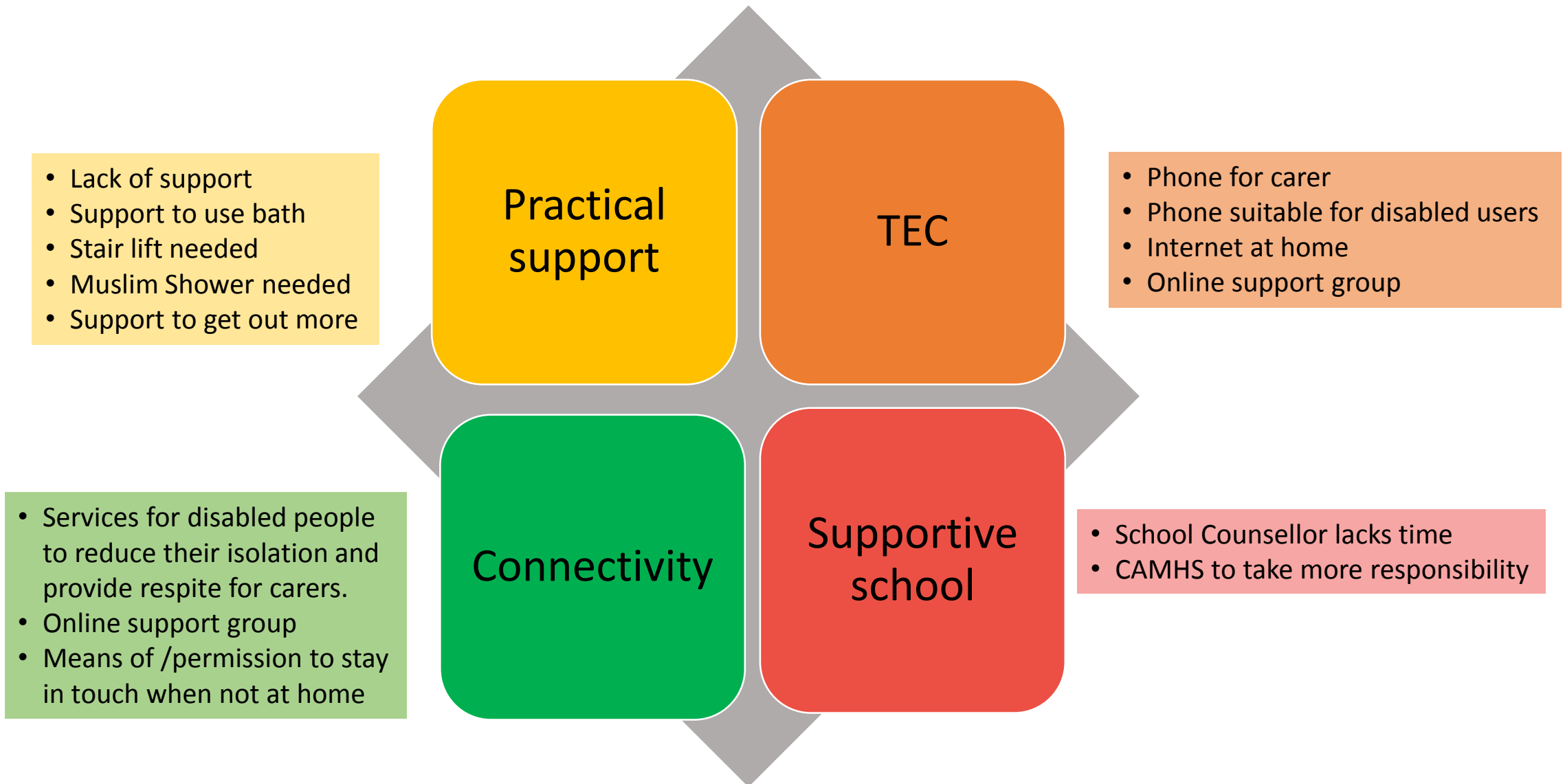
Other services

- *“I’ve got a counsellor at school but I haven’t spoken to them since May, he’s got too many people on his waiting list. I went to CAMHS once because I was so anxious but they only saw me once and said they couldn’t help and referred me to the school counsellor but my anxiety is still really bad.”*
- *“Yes, Young Carers group helps. School sorted it out. We go on Thursdays...”* *Attended the group in Manchester as not offered in Bolton.

What support do young people need?

Young people mentioned a variety of things that would support them these can be analysed under the headings of:

- Practical Support
- Connectivity
- TEC
- Supportive School



Young Carers – What Support Young People Need

"I don't know. My mummy keeps asking for some help but we don't seem to get any."

"Something to help mum get out of the bath, she has a bath as soon as she gets home (from work) it helps with her pain but she struggles to get out of the bath and I have to help her."

"A stair lift and Muslim shower."

"My brother won't use the services available. He doesn't think he's like other people with disabilities. This is hard because I don't get any time alone with my mum. The support needs to be better so he will go."

"Mum would go out more with her friends if she could. She's quite isolated. She has to take lots of tablets which make her tired."

"Young Carers group helps. School sorted it out. We go on Thursdays, we did a photoshoot, It was brill, it was fun dressing up and meeting other kids like me..."

**Attended the group in Manchester as not offered in Bolton.*

"I sometimes worry if its been a bad morning and I don't know until I come home if my mum's ok."

"I think my mum would like to get out more, and I like lots of help and guidance from her friend will work and get her out more often."

Practical
support

TEC

"Mum says I can have a phone when I'm older and I can play on the computer at home as well."

"Mum said phones could be better because she really struggles to see the screen...She has to screen shot things to enlarge them to be able to read."

"I've got a counsellor at school but I haven't spoken to them since May, he's got too many people on his waiting list. I went to CAMHS once because I was so anxious but they only saw me once and said they couldn't help and referred me to the school counsellor but my anxiety is still really bad."

"Sometimes I don't have enough time to get my homework done and I get a detention, some teachers think you make it up why you haven't done it."

One time at school I got in trouble off my teachers because I had messaged my mum saying I was anxious/stressed and I wouldn't tell the teacher myself because I was scared and don't like telling them..."

"There was pastoral support but not specifically for young carers. I was scared to speak to her though because she reports everything to social services."

"There wasn't anyone (at school), it would have been good if the teachers were trained to spot young carers."

Connectivity

Supportive
school

How do young people feel about caring?

- Caring is a constant feature of daily life, this can result in feelings of confusion and worry due to the pressure.

What is the impact of caring on daily life?

- As most of the people in this study were children, there was considerable impact on daily life for them. It might be harder to see friends, or go out if they had home responsibilities.
- The support young carers gave varied greatly depending on their circumstances, age, and ability.

What support are young carers getting?

- Family and close relatives were the main source of support.
- Many families did not have care packages. Technology was also assisting care in a variety of ways, but there was a blurred line between health technology and commercial technology, with both being used.
- A supportive school was a big boon but not all experienced this
- In a crisis young people would likely turn to their parents or trusted relatives. Otherwise they knew about emergency services and would dial 999 if there was no alternative.

What support do people need?

- Need for greater awareness around the responsibilities that young carers face; in particular schools need to know.
- Practical support / Connectivity / Supportive Schools / TEC.

Young Carers – Recommendations

Recommendations to Local Authority

1. Many families with young carers are not receiving any kind of care package, the Local Authority needs to understand why this is so and seek to address this reality.
2. All assessments for care packages should consider if there are young carers in the household.
3. A specific offer for young carers should revolve around Practical support , Connectivity , Supportive Schools, TEC activity.
4. An interactive web-site based support and information group might respond to young carers needs and help the Local Authority and other services to interact more effectively/provide relevant information to this group of people, who remain largely hidden within the community.

Recommendations to Schools

1. Schools need to take into account the home circumstances of young carers which can impact on their education.
2. Schools could do more to identify young carers and work with them in a destigmatising way.
3. School Support should consider help with homework and support to attend extra curricular activities, emotional and mental health support, specific pastoral support, general awareness raising activities among staff and should take this into account.

As part of this research a song was recorded including the experiences and views of young carers. This was seen as a good way to raise awareness of their experiences and of carers in general.

The single is now available to download on over 50 online stores including Amazon & iTunes. iTunes for example is: <http://itunes.apple.com/album/id/1327903143>

50% of any monies raised from the download will go to local charities in Bolton supporting young people. Please help support and raise awareness by downloading the single and sharing with friends and colleagues.

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