

Young Carers - Comments on TEC use

Healthwatch Bolton

October 2017

Young carers are one of the 2017 priority areas for Healthwatch Bolton. In this short* report Healthwatch Bolton is working with The Young Carers Partnership Group to better understand current experiences.

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)

*A full report is available separately.

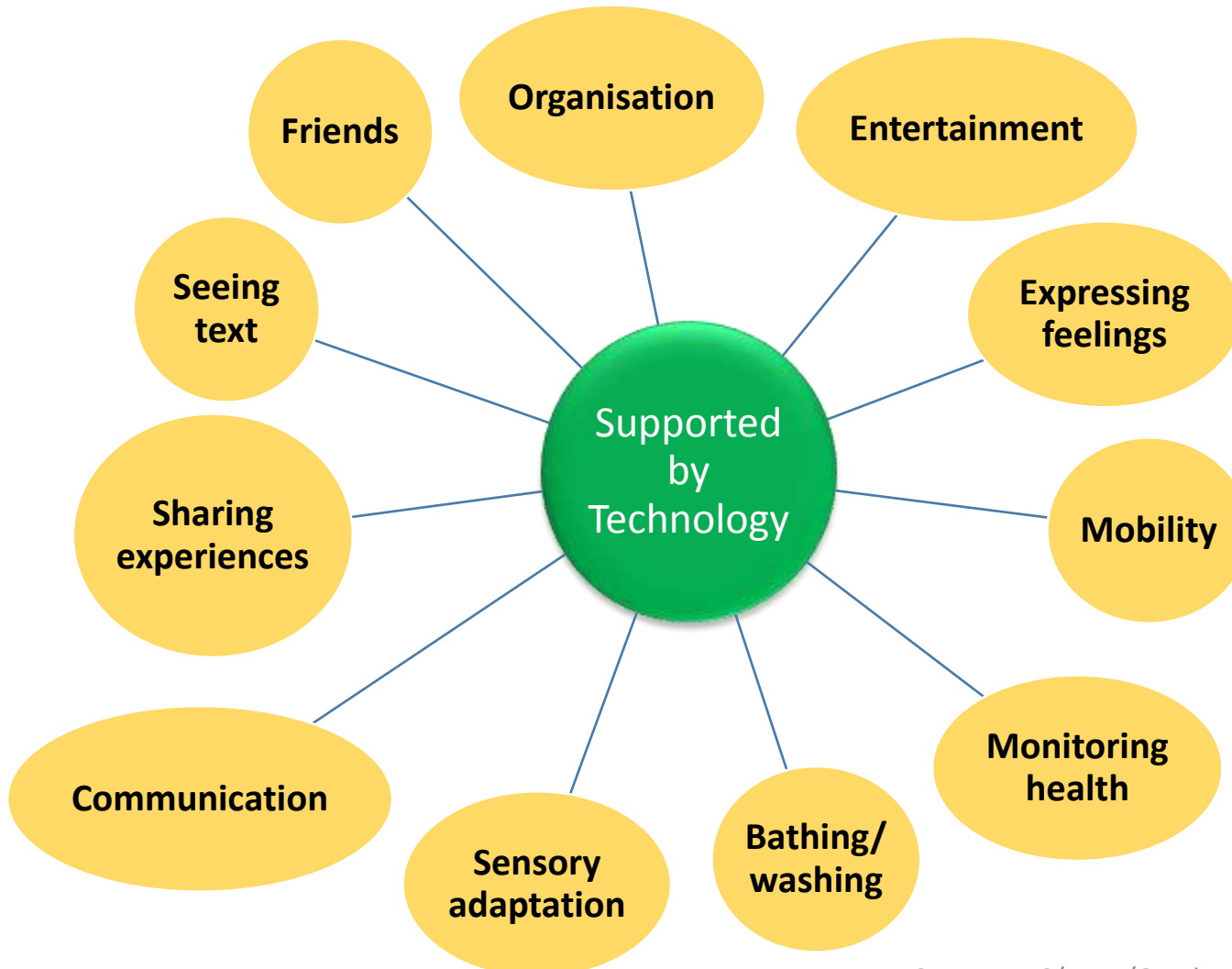
The Young Carers Partnership Group has identified four areas for improvement in their aims:

- 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 voicing the experiences of a sample of young carers in Bolton.

Technology and Caring

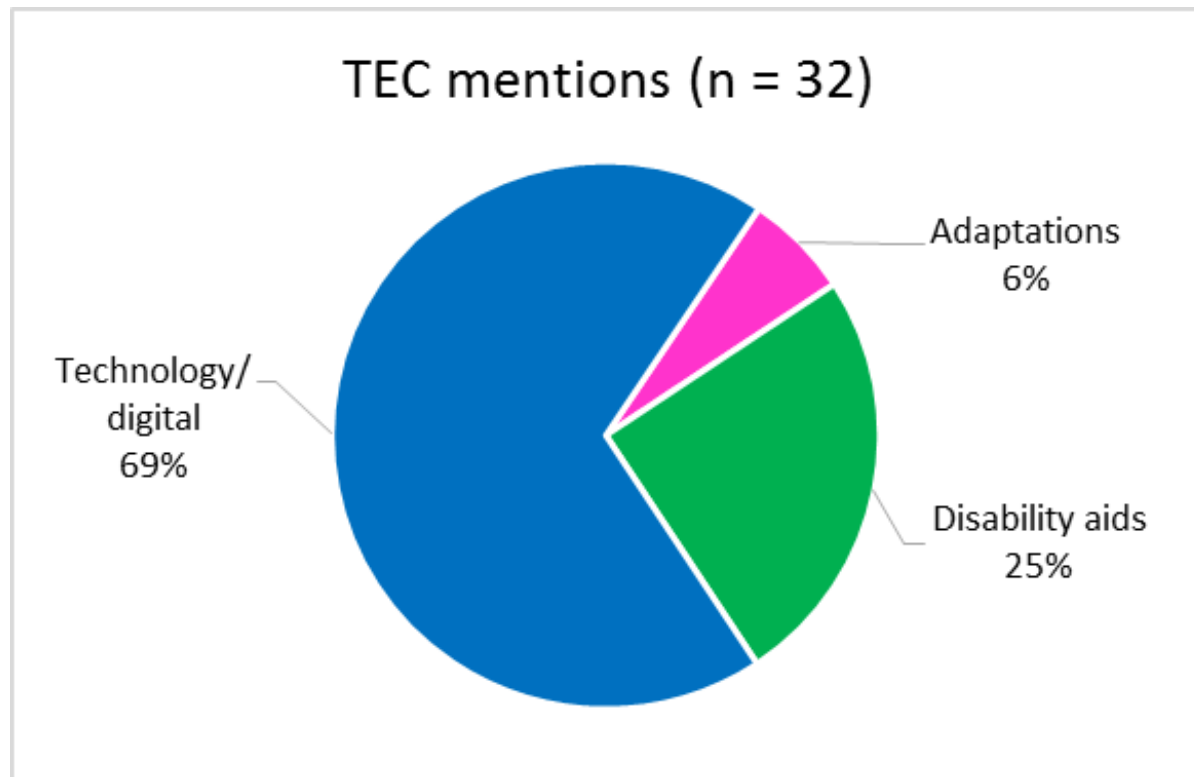
Technology was a part of everyday life and assisted in care.



Young Carers mentioned the ways technology was used to assist in care.

Examples of the technology include:

- Computer
- Smartphone
- Tablet
- Stair Lift
- Wheelchair
- Blood pressure monitor
- Hearing aid
- Amazon Echo
- Apps



Technology/digital	Total 22
Phone	11
Tablet	3
Facebook	2
Amazon echo	1
Computer	1
Instagram	1
Internet	1
PS4	1
WhatsApp	1
Disability aids	Total 8
Stair lift	2
Kitchen gadgets	1
Blood pressure monitor	1
Electric wheelchair	1
Hearing aid	1
Hospital bed	1
Wheelchair	1
Adaptations	Total 2
Extra lights in kitchen	1
Wet room	1
TOTAL	32

Young Carers – Technology

Connectivity

- *“Mum has a phone, she uses that a lot. Sometimes I have to help her because her MS means she can’t see. She tried to get a stair lift but they couldn’t fit one, it’s a shame because it would have helped.”*
- *“Phone. I use WhatsApp and Instagram to speak to my friends when I’m stressed out.”*
- *“I text my friends a lot about how I’m feeling about a situation I can’t deal with. Sometimes I don’t say anything and keep things to myself so my friends don’t have to deal with me.”*
- *“I have my phone and if I get stressed which happens quite often then I message my friends for support. One of them has a sister with Downs Syndrome and we support each other.”*

Practical support

- *“...she’s got an electric wheelchair, hospital bed, a stair lift and a wet room.”*
- *“...she’s bought a lot of her own stuff to help such as safe kitchen utensils.”*
- *“Mum has extra lights in the kitchen, chair lift, she has just got an Amazon Echo that’s from the blind society (loaned) it’s really good...”*

Three themes were identified that related to TEC: connectivity, practical support, the need for maintenance.

There is a need to define TEC in a broad way, with the clearest example here being importance of mobile phones.

Fragility and tech

- *“My brother likes to play on his computer but sometimes he shouts at the screen. When he’s shouting really loud I put my ear defenders on, they were my brothers but I use them now.”*
- *“He has a phone. He’s had loads of phones and tablets but he breaks them. He broke my PS4 only a few weeks after I got it. He’s stolen my phone twice and mum always has to keep buying me a new one.”*
- *“My brother has an iPhone and its brilliant to help him, he loves him Kindle too. He’s quite obsessive with it, he watches documentaries and films on it. It would be good to use outside but we don’t have the internet outside so we cant. He uses his phone for games but he’s so forgetful that he always loses it or breaks it.”*

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.

Access to tech/internet at home

“I do use some technology to help such as phone apps like meditation and sleep support. They were easy to get and are easy to use. I’m not sure what else would be beneficial.”

“With regards to technology I have a mobile phone and tablet. They are easy enough to use and I bought them myself but my daughter has to do it sometimes because my MS affects my sight. None of my family have any technology that help them with my needs; as far as I am aware.”

“The Amazon Alexa/Echo is brill. I can store my diary appointment on it. I can ask it what time it is and put music on. It also does audio books from Amazon. It’s been a life line, its loaned from the blind group. I asked about it and they said they were getting some and would put me on the waiting list as they only have a limited number. I hope they don’t take it back. There is other stuff available – they wanted me to have a panic alarm for when I fall; which is a lot but I just can’t afford it; there’s a cost to most things. My sister uses online banking and shopping – she has to screenshot everything to make it bigger to read though. But this will get harder as it progressive...”

“With regards to technology I have a mobile and have apps for a weight tracker, mindfulness and relaxation. I have only used them a little bit but they are good. I do use the relaxation app more; sometimes every day, sometimes every other day. They do help me but if I am really stressed I can’t concentrate. They are easy to get; just download them and they are free. I need a laptop and am looking into buying one but the cost of one and the cost of the internet is a barrier. My mum has one and she reads my emails for me because I can’t access them at home and I get a lot of social services stuff through emails.”

“Proloquo2go – it’s been brilliant, we had to fight to get it though, as he’s the only one at his school who’s got one , it’s really helped, it’s reduced his self-harming and explosive behaviour and it’s fantastic at helping him communicate with us because he’s non verbal.”

Different and varied uses of technology were found.

Many gadgets bought or borrowed; these require maintenance.

The need for a clear offer on TEC; this should be consistent, with an open view on what technology can do for health.

Care packages

“I don’t have a 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.

Technology was shown to be doing more, and have greater benefits; than just monitoring or being a purely medical device.

- **TEC and Young People** – There is increasing support for the use and development of healthcare related apps. However existing apps may not see young carers as a specific group. In this study young people were using apps simply to ease communication between themselves, those they cared for, and wider support networks.
- **The popularity of smartphones** – Smartphones are common and may present an affordable way to connect available support with young carers.
- **Fragility of technology when used as an aid** – Constant daily use may mean technology such as phones and tablets do not last as long.
- **Access** – The definition of technology used in supporting health was broad, extending to commercially available apps and items, as well as specific TEC such as communication apps. There is a need for recognition of this breadth in assessments for TEC funding.
- **Care Packages** – Many people did not have care packages which might support the purchasing of TEC aids.
- **Separation of care and personal life** – While promoting TEC may have benefits, there may also be increased pressure on young people to care ‘virtually’ and at a distance, as well as when physically present. This would be a topic worthy of further exploration.

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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Report: Alice Tligui, Alex Tan