

An Insight Into The Lives Of Young Carers In Essex

Information obtained via staff, service users and their families at Carers Choices and Carers First services for young carers.

What matters to young carers?

Typically, young carers place value on things which are in short supply to them. One of the most important things to a young carer is to have some time to themselves where they can be themselves. Although frequently young carers do not identify as such, they place great value on the time in which they do not have to be a young carer. This is the time when they can put themselves first, do things that they enjoy and relax without having to worry about their caring responsibilities. Put simply, they value pure 'me time'.

What are some of the challenges for young carers?

Low school attendance is a frequent issue for young carers, mainly due to their loved one's reliance upon them and their strong sense of duty to be with said loved ones. Bullying can also be an issue for young carers who remain within a school setting, often because they are not in attendance regularly enough to establish friendships or fall behind academically. Heather, Carers Choices Coordinator, talks of a young person who potentially could have remained in a school setting but left because of daily bullying as he is a carer. He has currently been out of education for two years. Young carers struggle with the expectations placed upon them by the school system as their young carer duties are usually their priority.

Families where there is a young carer are often on lower incomes. When the family is fined because of low school attendance they cannot afford to pay what is required. Increasingly, these families are choosing to home educate their children in order to avoid the fines, but do not have the capacity or resources to adequately home educate their child. Once the child or young person is no longer within an educational establishment, they have no access to external support networks, or often, education itself. Heather cites a particular young person who has experienced this scenario and is aged just 12.

What would young carers like to change?

Quite simply, they would like not to be a young carer. They want their loved one to be well and to have a 'normal life'. The cared for are often filled with guilt about the burden which they perceive they are placing on the young person. The young carer misses out on what other young people take for granted, such as going to the cinema or sleeping at a friend's. Many young carers do not identify as such; they do not give themselves a special status, instead they see what they are doing as normal and just what you do for your family. It is more often the case that an external party will make them

aware of their status. Many young carers are identified in school by issues with their attendance and sometimes behaviour.

What about services for young carers?

Counselling is very valuable, but the service is simply not there. Essex's Emotional Wellbeing & Mental Health Service has had an approximate 18 month waiting period for new referrals. This is in stark contrast to the high rate of mental health issues in young carers. Most do not access counselling, with many deterred by this lack of accessibility. Carers Choices offer low level interventions namely around anxiety, low self-confidence, stress, self-harm, low mood and anger. These are not counselling sessions per se, but they try to fill the gap by incorporating low level therapeutic work into activities such as arts and crafts workshops and sports coaching sessions.

A significant barrier in accessing groups is transport. There is no county wide transport scheme. Organisations such as Carers Choices and Carers First rely very much on volunteers and using their own personal vehicles to transport the young carers. Due to varied circumstances, many of the parents may be unable to drive and this is further compounded for those living in rural locations, or simply outside of the main towns. The most disadvantaged are able to access less due to their circumstances.

Generally, most interventions are not timely due to young carers not being identified until they are at crisis point. This lack of prevention leads to services being reactionary, but this is in contrast to long waiting times for new referrals.

Carers Choices believe that it is necessary, in fact vital, to work with the whole family inclusively. As much as the young carer needs their own time, the parents also need the opportunity to offload and be their own person. In a typical two hour session, the young carers groups will incorporate activities such as cooking, colouring, scrapbooking, bingo, board games and barbecues along with work on self-esteem. They also organise trips occasionally, but these are affected by the lack of available transport.

Action for Family Carers work in schools and provide referrals to Carers Choices along with Essex Young Carers, Social Services and Family Solutions. Some schools will refer directly and referrals direct from the family themselves have started to emerge. Schools differ greatly in the support offered to young carers. Some engage well, and some are very resistant. Interestingly, Ofsted removed young carers from their inspection checklist this year.

Most young carers are caring for either a parent or sibling. Mental health issues are a major factor for both the carer and the cared for. However,

young carers - when in a group together - show huge empathy for each other. Caring from a young age takes away the ability to build resilience. However, unlike adult carers, there are no respite breaks in place for young carers.

Carers Choices run the following groups:

- Basildon Juniors - group of 20 with 10 on the waiting list
- Basildon Seniors - group of 15
- Castlepoint Juniors - group of 12
- Castlepoint Seniors - group of 15

What do young carers miss out on?

Young carers miss out on many things; childhood, freedom, innocence and education among many others. These are basics which most young people - not in caring roles - enjoy and take for granted. The burden of their responsibilities means that they are unable to take opportunities that would enable them to succeed in life.

Many young carers are secretive about their status, as in society if you are different it can make you a target, resulting in judgmentalism, isolation and lack of inclusion. The school setting is particularly typical of this. The young carers and their families tend not to talk about their situation, the aim being to protect the family unit. For many adults, the fear of social services taking away their children is still very real and filters down to the children themselves.

Example 1

Fiona* (aged 8) has been attending a young carers group for twelve weeks now. Her mother, Kelly*, spent one year searching for some kind of sibling support for Fiona*, as her brother Dylan* (aged 9) has a diagnosis of autism. Kelly* searched online, including social media, for some kind of support for Fiona* but found nothing. Kelly* expressed that having to look for this kind of support made her 'feel crap' as she could see that Fiona* needed some help and felt bad about this. Kelly* stated that Dylan* is in mainstream education, and whilst the school had generally been fairly supportive, his teacher last year had not been so. She had insisted that Dylan* remove his ear defenders in class because he could not hear her, even after Kelly* had explained that he could not cope with the sensory overload in a classroom setting and removing them would cause him much distress. Kelly* also made a communication book for Dylan* and asked the teacher to write in it so that they could communicate via the book, but the teacher told her that she would not be doing this. Kelly* eventually sought help from the school leadership team, but the situation still made her feel that this year of education was effectively 'written off' for Dylan*.

Fiona* states that she doesn't really do anything for Dylan*, but Kelly* responds that she does a great deal; prompting him to get dressed, reminding him to put his shoes on and knowing how to soothe him when he is agitated. Kelly* states that Fiona* 'somehow knows to not hug him but sits behind him so he knows she is there, like a hug without touching'. She also keeps an eye on her brother when they are outside of the home, 'steering him in the right direction'.

It is difficult for the family to go out very much as Dylan* does not like leaving the house. This has impacted on Fiona* who was 'getting stuck in all the time'. Since joining the young carers group, Kelly* observes that Fiona* 'is like a new child', growing in confidence to the point where she has been able to join a dance class and participate in a public event.

Essex Young Carers (EYC) completed an assessment on Fiona* this summer and allocated her a keyworker, who will be going to see her at home and at school. Fiona* has already enjoyed a camping trip with EYC. Kelly* feels that the young carers group has been great, although she had to research and refer her daughter to the service herself as she was not identified via any other route. Kelly* feels that the pastoral care in school is 'spread too thin' and that information for families with young carers 'just isn't out there'. She also notes that from the point of Dylan's* diagnosis, the needs of his sibling were never identified or addressed by any professional agency or individual. Fiona* wants to be a teacher when she grows up and Kelly* is pleased with this ambition. Previously Fiona* had told her mother 'that she should not be alive and then Dylan* would be able to have all the attention'. Now Fiona* asks when the next young carers session is and has made friends of her own there.

Fiona* states that she enjoys having 'sweets and doughnuts' at young carers and that the staff there 'are really good'. She particularly enjoyed grass tobogganing on a trip to the activity centre recently and has grown her hair so she can donate it to make a wig for a child with cancer. Kelly* adds that the family days are very helpful as they include everyone. Fiona* attending regularly gives her time to concentrate on Dylan* and allows Fiona* her own time which is all about her.

Example Two

Teresa* (aged 9) attends the young carers group as she helps to look after her sister Matilda* (aged 7). However, Teresa* herself has been diagnosed with high anxiety, depression and expresses suicidal ideation. Their mother Julie* states that Teresa* 'talks about killing herself and others' over the past nine months. She says that Teresa* is an insular child with high levels of anger and is on the autistic spectrum.

Julie* feels that much improvement is needed with EWMHS. She states that three referrals were made for Teresa* and that she waited three years for an initial appointment with EWMHS after an assessment at school. When she chased up the appointment, she was told by EWMHS 'to go to A&E if she was really worried'. Eventually they informed Julie* that they 'would not be taking Teresa* on as there was nothing they could offer her'. Julie* remains unsure as to why this decision was made as it was not fully explained to her or her husband John*.

Teresa* did see a counsellor for six months and really enjoyed the sessions, but the counsellor terminated them because 'they were not getting anywhere'. She has now been to the young carers group three times. Julie* made a self-referral after hearing about the group from another mother at school. Teresa* states that she 'liked making a raft' with them recently. She is very worried that Matilda* will come to the group, despite Julie* reassuring her that this will not happen, as she wants to keep the time and space for herself.

Julie* states that the family have had no support apart from the young carers group, and she hopes to find something similar for Matilda* to attend.

Teresa* hates thinking that she is 'different' or being portrayed as so in any way. Julie* says that Teresa* will not allow herself to be called beautiful and that she believes her daughter 'hates herself'. She struggles socially and friendships she did have have broken down. Julie* suspects that Teresa* is bullied to some extent at school. She states 'you get a diagnosis and then are left wondering what the purpose was, because nothing happens or changes. It's so hard to find any support'.

This report contains the opinions and accounts of young carers, their families and professionals supporting them, and does not necessarily reflect or represent the views of Healthwatch Essex.

**names have been changed to protect the identity of individuals consulted*