

Factual – Measured - Critical

On the Frontline: Young Carers

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The recent Census (2011) suggests that around 178,000 children aged under eighteen in England and Wales are responsible for caring for members of their family. That is around 1.5% of the child population. A large survey conducted by the BBC in partnership with the University of Nottingham suggests that the figure is very much higher – around 8%. These children are known as ‘Young Carers’. Their average age is 12 years, but many between 5 and 7 year also provide care. Often the older ones have been caring from a very young age. When asked “How long have you been caring?” a typical reply is, “Ever since I can remember”.

This is the experience of a young woman, let us call her Sheila, who has been caring for her disabled mother since she was a toddler: “I first started picking things up off the floor for my mum before I could talk. She made it into a little game. But as the years have gone on, her condition has deteriorated greatly and now [she] nearly always using her crutches except in the house and needs a wheelchair for moderate to long distances.”

What started as a game has now turned into a full time occupation. But she is lucky inasmuch as she is able to share the caring with her brother: “Both me and my brother look after our mum together so that both of us can get some respite. I take care of her on Saturdays and he does so on Sundays.”

Young carers carry out a whole range of tasks from domestic chores such as cleaning the house and going shopping, through to dealing with family finances, and nursing and intimate personal care. For many young carers, carrying out personal care is particularly upsetting as it emphasises the helplessness of the person being cared for, and the loss of dignity and pride on both sides of the relationship. This is the task that Sheila dislikes the most: “Taking her to the toilet and washing her. My mother is obese and can get quite sweaty in the summer months and so the smell can be quite overpowering sometimes.” Another young carer, Jill, also finds taking her disabled younger sister to the shower and toilet a difficult experience “because we are siblings I do not believe it is right because of their dignity and relationship status.”

Whilst intimate personal care can be upsetting, other tasks can be difficult because of their nature and the fact that young carers are children and so not have the physical strength of adults: “I absolutely hate lifting heavy stuff, I get back problems occasionally and it doesn't help”.

Over half of young carers live in lone parent families. Money can be tight and this can lead to a whole range of difficulties. Tasks are not made any easier in the conditions that some young carers have to live and work in, for example: “[I dislike] putting the washing in the dryer at my nans. The room that the dryer is in is falling apart and used as a storage room. So you have to tread really carefully. also there are snail trails everywhere and the cat flap

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broke so there is a hole in the door as well as the light not working. So when I need to put drying on at night you have to guess where you are going mainly”

Whilst the tasks that young carers have to perform may be unpleasant and distressing in themselves, their involvement in the process of caring often leads them to confront the reality of the condition of the person they care for. At an early age they are forced to understand how serious the condition is, and how poor the prognosis may be: “Watching my mother all the time, it upsets me the most because I can watch her falling further away, and how worse she is as the days go by.”

Another young carer said, “as a scientific type I know what each of the medication does and knowing that some of the medication are either a last resort or are to prolong life is really upsetting”

One might expect people in general to be supportive of children and young people who have to carry out such a difficult role, but surprisingly this often not the case. Around a quarter of young people still at school reported that they were bullied because of their caring role and for some, the bullying and abuse still continues after they leave the school gates. This is the experience of a young woman who looks after her mother who has multiple disabilities and mental health problems: “[I dislike] Taking my mother for walks, we get stared at sneered at and she gets comments shouted at her.”

Many children have to cope on their own with limited services available from local authorities and often their caring roles going unrecognised by their schools, social services, and health professionals. In a recent, and as yet unpublished, study of young carers (which also included young people up to the age of 24 – Young Adult Carers) we found that only a fifth had had a formal assessment of their own needs; and less than half considered that they and their family were receiving good services.

It is not surprising therefore that many young carers experience a range of negative outcomes as a result of caring. These can include both physical and emotional problems; educational difficulties; restricted opportunities for social networking, making friends and taking part in leisure activities; and many others that lead to significant challenges in making a successful transition from childhood to adulthood.(1) In our recent work, we found that only a quarter of those at school who responded to the survey considered their own health to be ‘Very Good’, whilst almost a third felt it to be ‘Just OK’; and over a third reported that they had a problem with their mental health.

In spite of all of the difficulties facing young carers, some are still able to find something positive in all of the adversity. Research shows that for some there are also some positive outcomes. These can include the development of knowledge and understanding; a sense of responsibility and maturity; and a range of life, social, care-related and other skills. Children may feel ‘included’ in the processes of the family, and the experience of caring can actually bring children and parents closer together. (2)

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Take the example of a seventeen year old boy who looks after his father: “ [I enjoy] taking him out in his wheelchair or looking after him on my own because I get to spend some alone time with him and bond a bit more and also makes me feel like a better person and more mature.”

Young carers are now recognised by government and social services who acknowledge that they should be providing services. But in times of economic hardship it is easy to see how priorities for service provision can slip. Many young carers (and young adult carers) are supported by local projects, and nationally the Carers Trust speaks on their behalf. But there are very many more who do not contact local services. They do not know that they exist. Many young people who care will not be familiar with the term ‘young carer’ and will simply get on with the job of looking after their mothers, fathers, brothers and sisters, to the detriment of their schooling and their health. They themselves need to be cared for. But who will care for the children who care?

References:

- (1) Becker, S. and Becker, F. Service Needs and Delivery Following the Onset of Caring Amongst Children and Young Adults: Evidenced Based Review (Cheltenham: Commission for Rural Communities, 2008); Becker, F. and Becker, S. Young Adult Carers in the UK: Experiences, Needs and Services for Carers Aged 16-24 (London: The Princess Royal Trust for Carers, 2008).
- (2) Aldridge, J. and Becker, S. Children Caring for Parents with Mental Illness (Bristol: Policy Press, 2003); Becker, F. and Becker, S. Young Adult Carers in the UK: Experiences, Needs and Services for Carers Aged 16-24 (London: The Princess Royal Trust for Carers, 2008); Evans, R. and Becker, S. Children Caring for Parents with HIV and AIDS (Bristol: Policy Press, 2009).

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Information on the Young Carers project at the University of Nottingham is available at:
<http://nottingham.ac.uk/impactcampaign/campaignpriorities/healthandwell-being/young-carers-and-young-adult-carers/youngcarers.aspx>.

Footage from a Young Carers Open Day at the University of Nottingham is available at:
http://www.youtube.com/watch?v=3NAE_y2BQtk