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UNDER THE RADAR

Why young carers miss out on the support they need

By Elaine Cole [@prideinnursing](#)

One evening, nurses at Whittington Health NHS Trust in London noticed an 11-year-old girl sitting with a patient – her mother – on an adult ward late at night. ‘She had been there all day and nobody had noticed,’ says Colette Datt. ‘She had no idea how to get home.’

After hearing about the case from the safeguarding team, the trust’s nurse consultant for children and young people investigated what carer policies Whittington Health had, and discovered there wasn’t one for carers, whether child or adult.

With band 6 nurse Sandra Frimpong, medical student Naheeda Rahman and a group of young carers, Ms Datt began a project to empower young carers by teaching them their rights and co-creating an identity

card encouraging healthcare professionals to recognise the caring role.

A largely hidden population

Ms Datt, who was undertaking a Florence Nightingale Foundation scholarship, says: ‘Young carers are looking after a relative or friend who is ill, disabled or misuses drugs or alcohol.’

‘Despite their integral role in society, they remain a largely hidden population and initiatives specific to them in healthcare are absent. We wanted to hear from the young people themselves but young carers are traditionally difficult to engage – the whole

problem is that they are so under the radar.’

She contacted Tottenham Early Health and Prevention Centre, which had a drop-in centre, and Islington and Camden Family

‘We had an “outstanding” care rating but you wouldn’t think so if you had heard what these young people had experienced’

Colette Datt, nurse consultant for children and young people, Whittington Health NHS Trust



➤ Action, which had a young carers' group. Because the latter was commissioned to provide services for young carers, it was able to bring 15 young carers to Whittington for an engagement session.

'We wanted to find out what they would find helpful but their stories were very difficult to hear,' recalls Ms Datt. 'I was shocked – we had an "outstanding" rating for caring but you wouldn't think so if you heard what these young people had experienced.'

'It was very upsetting,' adds Ms Frimpong. 'The vast majority had experience of not being listened to.'

'These accounts included healthcare professionals not including them in the cared-for person's care. They were not being taught when and what medication to give. They were seen as children

➤ A young carer takes part in a workshop exercise



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with no rights, rather than carers, and were not informed when appointments were cancelled even when they were missing school to attend.'

The team offered the young carers a session designed to help them assert their rights to the support to which they were entitled.

Quality improvement project

They registered their work as a quality improvement project to identify barriers for young carers in the trust and to create with them a policy to address their needs.

There was a rights workshop, which used the UN Convention on the Rights of the Child to frame discussions about the rights young carers felt most important.

'This time we went to them, rather than bringing them into the hospital,' recalls Ms Datt. 'It was much better in their own environment as they were more open and relaxed.'

Afterwards, the young people reported a 48% increase in knowledge, and a 56% increase in confidence to assert their rights.

Naheeda Rahman conducted semi-structured interviews with ten children's healthcare professionals, eight adult healthcare professionals and two young carers. The interviews revealed themes of lack of awareness, poor identification, young carers' voices, family dynamics and the impact of caring.

Identity cards

Lack of awareness or recognition of young carers were found to be the foundation of poor healthcare experience, says Ms Datt. 'The young carers wanted an identity

card to address this. They wanted an NHS logo on it – something official so they would be believed. And they wanted their rights on the back.'

The Healthy London Partnership, a local government/NHS collaboration, funded the prototype card with £1,120, and a design agency, Together Creative, helped the team and carers co-design the identity cards.

The six workshops held by the team were crucial, allowing them to hear the difficulties experienced by the young carers and develop the policy in a collaborative way.

'We enabled them to co-design everything on the card, which helped us to understand what was most important to the young carers,' says Ms Datt. 'The words "we matter too" is a direct quote from one of them.'

Feedback

The team collected feedback from 12 of the 21 young carers piloting the card every three months. This was used to create a carers' policy for Whittington Health as well as in the prototype of a second card.

Feedback from the young carers shows the difference the card has made to their experiences. Several have presented the card when picking up parents' prescriptions – previously they had not been allowed to do so. One young person used the card to get a free flu jab. Another reported a better level of respect: 'I showed the card to a consultant and he let me sit in my mum's appointment and explained things to me'.

'While these may seem like small steps, they alleviate certain

In their own words: what carers and hospital staff say

'We'll never be acknowledged or appreciated because it's like the only person who really appreciates that is the person you're caring for'

– Young carer

'The card... helps because it makes young carers feel like they are actually worth something. That they're not just someone who's being ignored'

– Young carer

'Some parents probably don't perceive... their children as being carers. They just think they're being their children'

– Healthcare professional

'Sometimes when we first meet them we don't know they are young carers. It takes us weeks and months to establish a relationship'

– Healthcare professional



