

SPECIAL INVESTIGATION: Hell of the carers driven to breaking point: As a

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SECTION: Observer News Pages, Pg. 10**LENGTH:** 1549 words**HEADLINE:** SPECIAL INVESTIGATION: Hell of the carers driven to breaking point: As a loving mother is spared jail after killing her Down's son, a study says even the meagre help now offered to such parents is to be cut**BYLINE:** Anushka Asthana**BODY:**

'THE LACK of sleep was crippling. It felt like torture.' In the first six years of her son's life Gail Hanrahan never slept for more than two hours.

The boy, Guy, who is now 15, has Angelman syndrome, a severe learning disability that means he has the mental abilities of a toddler. Gail, 42, changes her son's nappies as he is doubly incontinent, washes him, dresses him and feeds him. He rarely sleeps.

'You just can't keep it up physically or emotionally. It was affecting my relationship with my husband and impacting on the way I was parenting my other children. I was depressed.'

When her son was five his mother reached breaking point and called social services in tears. 'I remember saying "if you don't do something I am going to be a single parent or you will have to take him". I had to ask for help and I felt like a failure.'

What Gail desperately needed was a break but it was support she did not receive until she was ready to crack.

She is not alone. Tens of thousands of carers across Britain are at 'breaking point', begging the authorities for help but to no avail.

Many are depressed, stressed and exhausted from years of sleepless nights. Only one in five ever gets a break.

But instead of finding more money to help families such as these, local authorities are preparing to cut services, The Observer can reveal. A new report by the Association of Directors of Social Services warns that, if things don't change, local authorities could have to close down care centres, raise eligibility barriers, divert money from other areas or raise council taxes.

Struggling to cope with the lack of funds, councils overspent their budgets by £ 44 million last year, and the study's author predicts it will rise this year closer to £ 90m. By next year, some will have no choice but to cut back.

It is something that infuriates Hanrahan, who has seen services close down around her. In her county of Oxfordshire she has seen six respite care centres cut back to two.

Just down the road, in Buckinghamshire, a tragic case has spelt out what can happen if people are left without support. For 36 years, Wendolyn Markcrow had devoted every hour she had to her son, Patrick, who had Down's syndrome. But her life as his sole carer worsened seriously when he reached his twenties and developed autism.

Patrick began repeatedly hitting himself in the face. In July 2003, he blinded himself in his right eye. He would hit his mother when she tried to control him and regularly threatened to kill her.

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Chronic insomnia kept him awake for most of each night and he would scream and shout, having the 'tantrums of a three-year-old'. His mother repeatedly pleaded with the authorities for help, but little was done.

Last Easter Monday - after Patrick had spent the day shouting 'Elton' and playing the same Elton John song over and over - Mrs Markcrow snapped. She gave her son 14 sleeping pills and suffocated him.

She then swallowed pills herself and tried to take her own life. 'I snapped. I went crazy - I didn't know what I was doing,' she told police.

Despite her crime, the overwhelming response to 67-year-old Mrs Markcrow's case has been sympathy. Her oldest son, Martin, described her devotion to Patrick as 'saintly'. Even the prosecution at her trial called for her to be spared prison.

Last week Mr Justice Gross showed Markcrow mercy and kept her out of jail for the manslaughter of 36-year-old Patrick, calling her case a 'real tragedy'.

Her story is extreme, but her situation was, and is, in no way unique. If her council had found the resources to give Markcrow more support, her son might still be alive, campaigners say.

But instead services are being cut back across the country, as the ADSS report, Pressures on Learning Disability Services, shows. 'We are between a rock and a hard place,' said Anne Williams, chair of the association's resources committee and the author of the report.

'More children (with learning disabilities) are surviving into adulthood and more people are living longer. These demographic pressures are the rock. The hard place is that this is not a priority for the NHS.' Her study predicts that, by 2011, the government should be spending £ 800m extra each year to meet the needs of 21,000 extra adults with learning disabilities. But it says the Department of Health has frozen spending.

Giving the carer the occasional break by taking their son or daughter into a care centre is crucial in helping to prevent a repeat of a case such as Markcrow's. Parents often have to look after their offspring 24 hours a day, seven days a week.

Seventy-six per cent of parents caring for sons or daughters with learning disabilities suffer depression, 72 per cent lose sleep, 51 per cent have financial difficulties, 32 per cent trouble at work, 22 per cent housing problems and 10 per cent domestic violence. The study of 2,000 parents says nearly a quarter suffer four or more of the problems.

'That is a powerful combination,' said Jill Harrison of the charity Contact a Family, which did the research. 'It is very difficult to have a planned short break from the local authority. It should be a preventative measure. Often it is a crisis response.'

Angela Browning, Tory MP for Tiverton and Honiton in Devon, only received support for her son, now 33, who has Asperger's syndrome, when she was desperate. 'If you don't give them a break, they themselves will break,' she said. 'When that happens it is not only crisis for the carer but for social services.'

The charity Mencap wants councils to give carers a minimum of 52 nights off a year. David Congdon, its head of campaigns and policy, said: 'Some (of the people cared for) are fed through tubes, or by a spoon, or need to have their nappy changed. They may have epileptic fits. There may not be adult changing facilities. Most of your waking time can be spent caring.'

IN OXFORDSHIRE Mrs Hanrahan has been fighting for more than a decade to get support for people in her position. The mother of three from Chalgrove knows how bad it can get. 'People experience sleepless nights with a newborn baby. Imagine that for 12 years,' she said.

Bringing up a disabled child was an 'extraordinary parenting experience' where her two daughters, Tilly and Olivia, grew out of things that her son never did. 'Going to the dentist is a nightmare because he won't open his mouth or stay still, so he needs a general anaesthetic every time. He won't wait in queues. I can't take him to friends because he will go through cupboards.'

After calling social services Mrs Hanrahan managed to get a carer for one night a month, allowing her time to do things 'other people take for granted' such as having a bath or reading to her daughters. After

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years of more fighting she got Guy into a respite centre for four nights a month. 'That is considered a large package.'

That help kept her off Prozac and saved her marriage, she said. Mrs Hanrahan has since been campaigning for other parents, and said she was shocked by the numbers who were on antidepressants.

She is furious about the cuts: 'You can't cut something that has already been torn back to the bone. Every time there are cuts they take from vulnerable people - we're the ones who don't have time or energy to fight. Our kids don't have a voice. My son is lovely, he has a smile that lights up the room. He is not the problem.'

'It feels like if you aren't fighting to get a service you are fighting to keep one. There are no government targets in this area because we aren't vote catchers.'

Government reports said the right things but failed to deliver. 'Things have got worse,' she said. 'The only time people turn to us is when there is a tragedy. When a mother reaches the point that she kills her son.'

Mrs Hanrahan has been following Mrs Markcrow's case. 'When they say they offered respite care to her, when was it offered?' she said. 'Was it when it was already a crisis? Crisis management is bad management.'

Such parents have to battle for every little thing they get. One mother with a seven-year-old daughter with a learning disability and a two-year-old son kept a diary of how many appointments she had with professionals. There were 774 for her daughter compared to just 29 for her son. She had spent 4,942 hours in appointments and driven for 11,004 hours.

Despite all the calls for more money, campaigners say the government is moving in the opposite direction. Providing breaks for carers is not a statutory right so there is a postcode lottery as to whether a council will do it.

The government has removed ring-fencing from the carers' grant given to authorities. 'We have no way of knowing how much money intended for carers is being spent on mending roads,' said Olivia Belle from the Princess Royal Trust for Carers. 'Carers save the nation £ 57 billion a year - how much is spent on supporting them?'

The answer appears to be too little, and soon it will be even less. Yet campaigners believe a little money for preventative support could stop carers suffering from stress and depression. Pushing this up the priority list, they say, could prevent a repeat of what happened to Wendolyn Markcrow and Patrick.