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No respite for family whose sons have autism

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By Claire O'Sullivan

Irish Examiner Reporter

Little Michael regularly wakes up at three o'clock in the morning. He'll jump out of his bed and race, shouting, into the rooms of his brother and sister, dragging them from their beds, pulling off their pyjamas.



The family knows once Michael is up, there will be no going back to sleep for him, or, by extension, for his family.

Michael is five and can't speak. He gets enormously angry and "lashes out a lot", says mum Jean.

"He's black-and-blue all over from pinching and hurting himself. He self-harms out of frustration."

Such is his frustration that he spends much of the day trying to soothe himself by "moaning", making a constant, low, plaintive cry that "torments his 14-year-old brother, Ciarán".

While Jean can cope with the consequences of Michael's moaning, it's when he gets overly excited and starts high-pitch screaming that she has to run from child to child trying to calm each down. Once Michael screams, teenager Ciarán goes into a meltdown, starting to shout and act out.

Both of Jean's sons have autism.

"To be honest, Ciarán's autism is manageable. It's Michael who was the real wake-up call," she says.

As well as autism, Ciarán also has a mild-to-moderate learning disability and dyspraxia, while Michael, the younger, has global developmental delay, and suffers from muscular seizures. Michael can't dress himself and shows no awareness of needing to use the toilet and so can't be toilet trained.

"We're all wrecked; it's hard going, but you just have to get on with it. They are our kids and we love them," says Jean.

She and her husband, Ted live in Dromoughty, outside Kenmare in Co Kerry. Ciarán attends the autism unit at Pobalscoil Inbhear Scéine, while Michael's more profound needs means he goes by bus to St Francis Special School in Beaufort, 45km away.

However, since he started school last September, Jean and Ted were told they wouldn't be getting any more HSE-funded respite. They were to manage on their own.

"We manage during the week, as Michael is gone from 7.20am until 4pm. It's the school holidays that are the most difficult. He doesn't understand the concept of holidays, so he is sitting by the window looking for the bus, getting more and more frustrated," says Jean. "The Christmas holidays were not easy. If we even had a bit of respite during the school holidays, it would just allow me to get a few jobs done at home or even just to sleep."

The HSE's Community Health Organisation (CHO) spokeswoman last night acknowledged the "the current level of [respite] provision does not meet the need".

"There has been difficulty in meeting increased level of need for respite for adults and children. The CHO continue to make a case for additional resources for the region for respite care, and we hope to be in a position to do more in 2017," she said.

Last week wasn't a good week for Jean. She was exhausted after the Christmas holidays and then Minister for Disability, Finian McGrath visited St Mary of the Angels in Beaufort, where he confirmed that the centre for people with physical and intellectual disabilities would be closing to new admissions.

"I always saw Michael living there when we die, as it's a lovely place. The minister told me they will properly resource the community [instead], but I know that's only words, as I've seen how they just remove services when the money isn't there," said Jean.

The Save St Mary of the Angels committee is asking parents with respite difficulties in Kerry to contact Donie O'Sullivan at 086 780 7871

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