

# Our brother can't care can he just be sent out

**M**ICEAL McMANUS cannot say a single word. At 54 years of age, he struggles to co-ordinate movement. He has no real concept of night and day. He does not understand the need to eat or drink.

His days, spent in a shared bungalow in Saint Mary's residential care home in Drumcar, Co Louth, are filled with simple and familiar joys. The gardens there have toys and a swing for him to play on. He loves music and has an audio system in his bedroom. His favourite books and stacking blocks are kept close to his bed.

Although he has no idea, his way of life — the only one he has known for the past 25 years — is under threat of changing forever. As part of the HSE's national strategy to move people with disabilities from so-called 'congregated settings' to a community-based model of care, Miceal is facing the prospect of leaving his home and relocating to a nearby town or village.

He does not know how to speak, yet the HSE states that his discharge 'will be discussed, planned for and agreed' with him before it takes place.

He has the mental capacity of a two-year-old, yet he is expected to 'participate and consent', with supports where necessary, to decisions about his care.

Miceal is not alone. Across the country, homes and communities for severely disabled adults with learning disabilities are being closed. Admissions to such places have ceased and government policy is to 'eliminate' them entirely. These are places that have been proper homes to some of the residents for 20 to 30 years.

According to the HSE, the policy — outlined in a 2011 report titled *Time to Move on from Congregated Settings* — is a new model for residential support in the mainstream community, where people with disabilities are supported to 'live ordinary lives in ordinary places'.

Yes, there are many intellectually disabled adults who can choose to live lives which are very 'ordinary', to use the report's word. Others, like Miceal, can't because they are simply too disabled.

Left without a voice, their relatives are fighting to preserve their quality of life, one that they feel can only be maintained at the Drumcar campus.

'Miceal is our brother,' Patricia Gilheany told the Mail this week. 'He cannot speak so we will speak for him and fight on his behalf.'

'We have nothing against people moving out into the community if that is their wish and they can express that.'

'We had Miceal at home for years, he had as much love and care as we could give him and it just didn't work. Drumcar is his home, a home he loves. Why take that away from him?'

Miceal McManus was a 'perfect' baby boy when he was born in October 1962. His father Peter was a local postman and his mother Maura, who already had two young daughters, was a proud housewife. The family lived in a modest house in the rural village of Swanlinbar, Co Cavan.

Aged just 2, after their only son became gravely ill, a doctor told Miceal's parents 'not to bother' taking him to hospital because he wouldn't live. Alive, but severely brain damaged, they took him home from Crumlin Children's Hospital ten months later. Maura,



by **Catherine Fegan**

CHIEF CORRESPONDENT

a devoted mother and wife, became his sole carer.

'We never really found out what happened. It was suggested, many decades later, that it could be Reye's syndrome,' says Patricia of the rare condition that causes swelling in the liver and brain. 'That was never confirmed.'

'My parents brought him home delighted. I remember my father used to say, "Ah he will come normal". He had no speech and he walked to one side but my parents were just so relieved he was alive.'

'We had kind of had the trauma of thinking he wasn't going to live. He came home and we started into

**'We will speak for him and fight on his behalf'**

life again as before. He looked fine, but as he got older we noticed the differences.'

Miceal's early years were difficult. He spent his childhood being vilified, laughed at and shunned by society.

Friends told his beloved mother, his sole carer for 32 years, that he was 'simply spoilt' and that she should 'put him to work'.

Instead, Maura dedicated her life to caring for her son. She fought to get him into a special needs school in Cootehill, even considering moving into a caravan beside it so he didn't have far to travel.

She made nappies for him by hand, her daughters recall, unaware that she was entitled to get them free from the State.

'Mummy was his full-time carer until she drew her last breath,' says Patricia. 'She was in a wheelchair for the last few months of her life and she was still insisting on

Miceal McManus has never spoken and has the mental capacity of a two-year-old. Yet as his care home faces closure by the HSE, his two sisters have been told his discharge will be 'discussed, planned for and agreed' with him... not them



Worried: Miceal's sisters Patricia and Ann

being pushed down to the bathroom to take him to the toilet. That was her responsibility. She wasn't entitled to carers' allowance because my father owned so many acres of bogland. She never took a penny off the State.'

After she got married, Patricia built a house next to her family home so she could help her parents with Miceal.

Ann got married in July 1984 and their father passed away suddenly four months later.

'From that day on, my mother and Miceal lived with us,' says Patricia. 'The following year, myself and Ann had our first children. Miceal regressed a lot because he felt so jealous.'

'Even before our mother got cancer he had developed an awful lot of behavioural problems. He was in competition with the children. He would spit out his food. He would

get into terrible fits when the children were getting something.'

Over time and without the support of suitable services near the home, Miceal's behaviour became more challenging. Increasingly, his

**'Drumcar is his home, a home he loves'**

sisters could not cope. When their mother's health began to deteriorate due to cancer, they attempted to broach the subject of Miceal's future care.

'She didn't want to talk about it,' says Patricia. 'We just hit a brick

wall. There was no talk about Miceal, it was just assumed we would look after him.'

Ann took charge of visiting prospective residential care homes while Patricia cared for their dying mother and their brother. She visited Cregg House in Co Sligo and returned to Cavan believing that Miceal could go there, or if he didn't, that he would be placed in a similar care centre.

'A few days before mummy died the HSE came out and said they had a place for him to go,' says Patricia. 'They said if he didn't go the day mummy died, he wouldn't get a place, so we agreed to it. We had no idea what we were letting ourselves in for.'

On the day Maura died, Miceal was taken to Clogher House in Co Monaghan, a unit that has since been de-designated as a centre for people with intellectual disabili-

# for himself. So how 'into the community'?



Vulnerable: Miceal McManus lives in a residential care home

ties. 'It was such a traumatic time,' says Patricia. 'I remember seeing Miceal going off and thinking, are we doing the right thing?' Several days after the death of her mother, Ann and her husband Martin went to visit Miceal. 'The horror of where he was hit us immediately,' she recalls. 'What we didn't know was that Clogher House was attached to St Davnet's. It was like the worst horror film you could imagine. It was around the time the scandal

about the children in the orphanages in Romania had broken, the pictures of children in cots chewing on bones. I remember we came out that day and my husband said, 'The only difference with Miceal and what we are after seeing on the TV yesterday is that he hasn't a chicken bone in his hand.' It was 1984. Miceal, who was 32 at the time, was in a dormitory wing of the psychiatric hospital. 'The beds were filthy with urine and excrement,' says Ann. 'Half of

them were walking around naked, they were left to it. On another visit, they were doing a supposed paint class and they were all jammed together, criss-crossed all over the room and there was a man lying dying in a bed in the middle of all this. No one was near him. 'There was another girl in a strait jacket. She went into the kitchen and the leftovers were lying around the sink on the plates. She put her head down and started to eat.' After a lengthy battle to have him



Childhood: Miceal with his two sisters and, top, with his father

removed, Ann and Patricia secured a place for Miceal in Saint Mary's in Drumcar. By that stage, according to his sisters, Miceal's behaviour had deteriorated.

'I remember the first time I went in to Drumcar,' says Ann. 'It was Christmas. We walked in and there was Christmas music playing and a beautiful big tree. The first place we walked into, because we didn't know where we were going, happened to be the sick unit.

'They were the bad cases, and the love and care and the sense of compassion we saw was just unbelievable.'

Saint Mary's residential disability centre in Drumcar, Co Louth, opened in 1945 and presently the Saint John of God North East Services has 102 residents on campus and is providing respite to 54 children and adults.

This is where Miceal, who turns 55 this year, continues to live, no longer on a ward, but in a house with about eight others.

'First of all, it's not an institu-

tion,' says Ann. 'Miceal is happy there. It's the little things.

'When they go to Mass, the residents walk around the church — we used to take him to the back row and try to keep him in. There they said no, this is their community, let the outside community fit in with them.

'This is the whole point, this is the whole ethos of Drumcar. They aren't being forced to try to fit in to a community that they aren't compatible with.'

Miceal's sisters are in their late 50s and are exhausted after a lifetime of battling to get the necessary support.

Their latest fight is the hardest — and the most heartbreaking.

They agree that people with a physical disability should have maximum control over their lives, with all the support that they require. However, they argue that people with severe learning disabilities are more vulnerable.

'If Miceal was in a small area and he was with new people he would be frustrated,' says Patricia. 'He would start screaming and roaring. He would end up having to be locked in. It wouldn't work and he would be moved — and where to?'

## 'We're back where we were 25 years ago'

Our big fear is that he would be sent to somewhere like Clogher House. We are effectively back where we were 25 years ago.'

There are others with the same fears. Kathleen Cusack's son Martin has been in Saint Mary's for 37 years. He's now 41 years old and Kathleen is adamant that he needs to remain where he is.

Amanda Fitzsimons' uncle Charlie, 60, has been in Drumcar for 48 years. He is highly dependent and his loved ones need Saint Mary's to be kept open.

Further afield, families of adults with special needs living at Beaufort's Saint Mary of the Angels in Kerry are facing a similar battle. Like Drumcar, it is owned by the Saint John of God's service. Like Drumcar, plans are afoot to move more and more residents into the 'community' — essentially single unit housing in towns and villages across the county.

Again, like Drumcar, many relatives are deeply critical of this model in respect of Saint Mary's. They describe the centre as a wonderful facility staffed by deeply caring workers in what they believe is a 'community' setting already, rather than a congregated setting of the traditional institutional kind.

Despite this opposition, plans to bring an end to congregated living are gathering pace. There are

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currently about 2,725 people living in congregated settings throughout Ireland. The HSE's objective is to reduce this figure by a third by 2021, and ultimately to eliminate all congregated settings.

To date, a significant reduction has already been achieved on the 2008 figures, when 4,000 individuals with disabilities lived in congregated settings.

The HSE's 2011 report into 'congregated settings' states that 'the community' can mean many things, including sharing a house with a small number of others; living alone, independently; or staying with family.

As far as the document goes, disabled adults should be 'able to exercise meaningful choice, equal to that of other citizens when choosing where and with whom they will live'.

However, many argue this implies that all people with learning disabilities are able to understand their 'rights and responsibilities'. This is often not the case, and this blanket form of assumed capacity is the cause of great unhappiness among the loved ones affected. Many feel relentlessly sidelined and are often denied any part in the discussion about

where their adult children or relatives with learning disabilities should live.

'We feel like we are being kept in the dark,' says Patricia. 'There is very little information available and few answers to our many questions.'

In response to queries from the Mail this week, a spokesperson for Saint John of God Community Services (SJOG) confirmed that they are planning for 30 individuals to transition into community-based services this year.

'We fully understand and respect the views of family members when discussions about transitioning people currently living on campus at Drumcar into our community-based service,' he says.

'As new homes are identified, we will begin the more formal discussions with family members.'

Since 2011, 55 residents have moved off-campus at Drumcar. They have been relocated in houses in Louth, Monaghan and Meath. In February, HIQA issued notices of proposal to close the four units at the Saint John of Gods campus, deeming them not fit for purpose. Staff were praised in inspection reports, but not the physical facilities at the campus.

Ann and Patricia, like many other fami-

lies, argue that instead of spending money buying and adapting homes in the community, funds should be used to upgrade the present facility. 'Our argument is that if HIQA want modern buildings they have the space there to build them and it would cost far less,' says Patricia.

In response to this, SJOG says that funding for such improvements is not available. 'The improvement of the physical facilities at Drumcar would certainly address many of the issues identified by HIQA in recent reports,' says a spokesman. 'Like many other services, our annual budgets have been directed towards service delivery, more especially as the funding allocations from the HSE have not kept pace with the cost of those services, accordingly, maintenance and capital works budgets have been minimised at Drumcar.'

He adds: 'SJOG has funded a number of operational budget deficits over the last four years, ie the difference between the funding provided by the HSE to use as a Section 38 provider and what it actually costs to run the services. That figure is in excess of €13million.'

The question of what will happen to the campus after all the current residents

leave is also a cause for concern. Many families avail of respite services at the facility and fear the impact its ultimate closure will have on their lives. According to Saint John of God Community Services, the future of the site will be a 'decision for the board to make if/when all residents have transitioned off-campus'.

Meanwhile, people like Miceal, who SJOG say is not on the list of 30 earmarked to leave this year, face an uncertain future. Through his sisters, he will argue that those without mental capacity or the ability to look after themselves cannot simply told that they want to be independent. He will say that the assumption that everyone has the same desire for 'independence' — and that everyone wants to exercise a 'human right' to live as if they did not require 24-hour care — is deeply misguided.

People with severe learning disabilities deserve to live with a peer-group, in intentional communities, where they can be looked after with kindness and compassion and long-term continuity of care. 'Tearing that away from people like Miceal is just cruel,' says Patricia. 'They need security, they need the familiar and they need each other. They have a right to that.'