

Sisterly love

Lynn Fitzpatrick believes her brother Bernard is happiest when he's living in a familiar community setting. However, she tells **Joy Orpen**, she is worried this won't be possible as policy on the care of people with disabilities evolves

Bernard Fitzpatrick is a valuable member of society who brings love and happiness into the lives of the many people who come into contact with him.

Nonetheless, this 41-year-old has very few life skills. He cannot walk, talk or dress himself and, crucially, he is unable to make decisions. Fortunately, his sister Lynn Fitzpatrick, 33, is fighting his corner for him. She's campaigning to ensure that Bernard, or Bubo as he is affectionately known, continues to be allowed to live in St Mary of the Angels, his "second home" in Co Kerry.

As things stand, his future is in question, as the HSE appears to have committed to moving people living with disabilities out of residential care, and into the broader community. This is an aspect of the 2011 policy, *Time to Move On From Congregated Settings*.

Dublin-based Lynn, who has a master's degree in e-learning, develops school books and online educational programmes. She, her brother and three sisters grew up in Cahirciveen in Co Kerry. "Bernard was a complicated breech birth," explains Lynn. "He suffered brain damage, and then got meningitis. My poor mother was only 19 at the time — it was very, very hard on both my parents."

When he was five years old, Bernard was offered a place at St Mary's of the Angels in Beaufort, Co Kerry. "The Doyle family donated the land to the Franciscan Sisters to be used for children with disabilities," explains Lynn. "They ran it until 2005, when St John of God, which provides a number of services in Kerry, took over."

Lynn says Bernard thrived under the care of the nuns and lay staff. "He really came on in leaps and bounds," she

volunteers. "Their ethos was driven by pure love, and that is still strongly in evidence. The staff worked hard, and were innovative in their approach.

"For example, they commissioned a sizeable hydrotherapy pool which is of great benefit to Bernard, who has spasticity in all four of his limbs. The physiotherapist said one hour of that was like a week in the gym for someone like him. There's also on-site physio, weekly visits by a GP, a chef to ensure dietary needs are met, a sensory room, an arts and crafts centre, and even a community bus."

Another positive factor is the building in which Bernard resides. "It's big and airy and he can roam about at will," says Lynn. "He pushes himself along in his wheelchair using his feet, and that gives him a sense of independence. He's also tuned into sound. So he loves being near the kitchen. The staff have known him for years, so there's plenty of banter. That makes him feel he really belongs, and doesn't everyone need to feel they belong to something?"

But Lynn is worried that all the things that root Bernard in this familiar world of his could come crashing down. The aforementioned 2011 report by the HSE proposes that all those living in residential settings move into the community. It also recommends that accommodation for the disabled be dispersed throughout "ordinary communities" and that any "clustering of properties be avoided". It also requires service providers to supply individuals with the supports they require to "enable them to live self-directed lives in the community".

"I looked up the word 'community'," says Lynn. "It said people living in the same space or who share a characteristic. And that's exactly where Bernard is right now. He is in a special community within



'There's plenty of banter, That makes him feel he really belongs and doesn't everyone need to feel they belong to something?'

the larger community of Killarney, Beaufort and Killorglin.

"To use the term physical and intellectual disability is to be exceptionally non-specific," she continues. "Disability can mean many things. A person without sight or mobility might be able to communicate well. Some people with an intellectual disability are well able to compete in the Special Olympics. All of these things set them totally apart from my brother."

Lynn says that 77pc of people who are registered on the National Intellectual Disability database have a mild to moderate disability. However, Bernard falls into a smaller group whose members are severely to profoundly disabled. So she and her family are very concerned about what may be in store for Bernard.

"The first we heard of this was when mom got a call out of the blue to say Bernard's name was on a list for housing in Milltown. She got an awful fright, as we all did. When he was professionally

assessed, he was found to have the intellectual capacity of a six-month-old baby. And they want to send him away to lead an 'ordinary life in an ordinary community?'" Lynn says.

"They say he will live in a state-of-the-art house. That means absolutely nothing to Bubo. The perception that he'd be more 'included' doesn't apply to him. For example, when we asked where he would go for hydrotherapy, we were told to take him to the local aqua centre. For starters, the lower water temperature would be a shock for him. He would hate the noise of screaming children, while he would be at risk from exposure to germs.

"There are many people with mild to moderate disabilities who will thrive living on their own, and they should be given every opportunity to do so," Lynn says. "However, this policy is advocating that people with disabilities, whatever that disability, be treated the same as everyone else."



A spokesman for the HSE said: "Assisting residents to move from large congregated settings to homes in the community is based on giving those residents choices and opportunities. In relation to St Mary of the Angels, it is not correct to say that any resident will be forced out. Planning is based on consultation with the resident and their family on the basis that it will enhance their life."

When asked how many residents from St Mary's were likely to be moved into the community, a spokesman said that depended on a review of each individual case.

Lynn is not convinced that her brother's future is secure. "According to the policy, everyone is the same. But Bubo is not the same. I don't want him to be treated like me. I want much, much better for him," she says.

"I want every possible service to be available to him in a completely loving and inclusive environment," Lynn says. "And that is what he is getting right now." ■

For more information on St Mary of the Angels, see savestmaryoftheangels.com