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Mum's open letter to Minister on closure of residential care centres

Tuesday, July 25, 2017

After reeling from recent comments by Disability Minister Finian McGrath suggesting parents were 'dumping' their children in institutions, **Ina O'Dwyer** says his crusade to close residential centres caring for people with profound disability is not in their interests.



Minister McGrath, I write this letter in response to the recent article in the Irish Times titled: 'Finian McGrath pledges to ratify convention on people with disabilities', with the sub-headline: "'Dumping' of relatives in institutions a key matter of concern in Government strategy." (July 14, 2017)

The article has left me reeling in shock, disbelief, and horror. I feel so upset, so hurt, so angry, and appalled that you, Minister Finian McGrath, would accuse me of "dumping" my son in "an institution" and accuse me of abandoning him there. I feel sickened to the very core of my being.

Minister, you have no concept of the overwhelming grief suffered by me, a once 19-year-old mother whose baby boy, born in 1976, endured a most horrific birth which left her baby son, Bernard, brutally brain damaged.

Minister, you have no concept of the harrowing years that followed as we watched my son suffering endlessly. The constant pain, the constant crying, the numerous doctors, consultants, and hospitals trying to find the answers, trying to find the cure. But there was no cure to be found. Lourdes didn't work either.

My baby, soon to be 41 years old, is still just that, a baby. He can neither walk nor talk. He cannot feed himself, in fact, his food must be softened and mashed. He cannot clean his nose and no matter how bad it gets, he must wait for someone to notice and then do it for him. He likes to play with activity centres from his childhood. He wears nappies and always will. Minister, have you ever had the experience of changing the nappy of a 40-year-old, even once? How would you feel about 40 years of constant nappy changing? This is the reality.

My son was blessed when, at five years of age, he was welcomed into the wonderful care of the Franciscan Sisters, to whom we are eternally grateful, at St Mary of the Angels, in Beaufort, Co Kerry. Everything in his world changed for the better. His epileptic fits began to diminish, and with all the care, support, and on-site facilities (too numerous to mention), he has thrived in his safe, beautiful and peaceful home away from home.

I take huge offence that you, Mr McGrath, would endorse the notion that people like my son are being deprived of liberty or being "kidnapped" and in fact take it as an insult to us as a family. Thirty-five years on, my son continues to enjoy the freedom of coming home for long and short stays. We can visit at any time, often unannounced, to take a walk or a drive or to attend family occasions.

My son enjoys the best of both worlds. He is happy to be home with me and he is happy to be in his second home, St Mary of the Angels. He has taught us the meaning of unconditional love. The immense heartbreak I felt at the initial stages was soon replaced with a sense of acceptance and gratefulness that my son was in the best place, getting the best chance for a long and healthy life.

In the early years, I grieved each milestone he would never achieve. At five, he should have started school. At seven, he should have made his First Holy Communion, and so on. It was heartbreaking. One weekend on his visit home I had a realisation as I looked at his beaming smile. My son was completely happy in his own world, it was I who wished that he would be 'normal', it was I who was the unhappy one wishing he would be like everyone else. And

suddenly it became very clear to me that it doesn't matter what we become in this life, whether we are ministers, doctors, airline pilots, or bankers, it doesn't matter in the end... we will all leave this earth the same way. What matters most is that we find happiness, and my son, through all his pain and suffering, has discovered this beautiful gift and shares it with the rest of us.

So, Minister, I have neither dumped, abandoned, nor kidnapped my beautiful and precious son. I have always been there with him and for him and always will be. How can you judge me when you don't know me? Reading your remarks in the article, I was reminded of the Tin Man in The Wizard of Oz: He was hollow inside, and without a heart. But that was only a story; are you, Minister McGrath, the real Tin Man?

Last year, when asked about St Mary of the Angels in Dáil Éireann, you vowed to "eliminate all congregated settings" on the grounds that "there will be no institutions in this country under my watch". That you would write-off and see no value in a place that has given my son and others like him every opportunity in life, gave me cause then to question your suitability as Minister with special responsibilities for disability. Based on your latest comments in the article, I seriously question once again your suitability for such an important ministerial role.

Yours in disgust,
Ina O'Dwyer
Cahersiveen,
Co Kerry