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A mother writes of her heartbreak over proposed move while HSE describes it as 'positive change'

PUBLISHED

08/10/2016 | 00:00

SHARE

My son, Bernard, now aged 40 years old, has been a resident in St. Mary of the Angels since 1981 at the age of 5. Bernard is profoundly mentally and physically handicapped and in need of 24 hour care. In many ways he is still very much a 'baby', loving to play with his activity centres but he cannot walk or talk, is spoon fed and wears nappies.

However, Bernard is very happy and content, his only independence being his ability to move around in his wheelchair. This he can do freely and safely in his unit St. Fidelis. He exercises his only freedom of choice by choosing whether to stay in the dayroom for activities e.g. a music

session, then deciding to roam the long corridors when he has had enough or feels like a change of scene.

Bernard has always been loved and cared for very well by the fantastic staff who themselves have been through difficult times due to lack of funding, staffing, the very long shifts recently introduced and a very demanding and physical workload.

The night that the appalling circumstances concerning Aras Attracta were highlighted on Prime Time, I initially panicked and became very upset at the potential that Bernard could be open to this kind of mistreatment also, especially as he would not be capable of telling me.

But in the cold light of day, my mind went back over all those years whenever I would call to St. Mary of the Angels, often unannounced, when each time I saw nothing but love and care for my son and all who share the campus with him. The morning after the Prime Time investigation aired, I rang the unit to thank the nurses and staff for their great work and dedication.

I received a telephone call recently by the head of the unit, saying that Bernard's name had been "put down" for a house in Milltown, in one of two sites purchased by HSE, the other being Tralee.

My concern is that Bernard's safety, security, freedom of movement, access to services e.g. GP, OT, Physio, Swimming pool etc., will all but cease. The removal of his familiar surroundings including the most beautiful grounds and location of St. Marys will be most distressing for him. Bernard is always happy to return there after his weekends and holidays at home.

The bustle of everyday life he has always known will be taken from him. And he will be isolated in a house, in a town, where he has no connections, friends or family. The familiar staff may also, in all likelihood, be gone - replaced by agency staff.

Bernard is thriving in a loving, caring and safe environment in St. Marys. He is surrounded by fellow companions and well known by their families and also the staff from other areas on the grounds.

I agree his present building could be modernised but apart

from that, Bernard has all he needs and more and is happy and content at St. Mary of the Angels.

On the Communication Plan for the HSE's 'Time to Move On' report, it is repeatedly stated that people like Bernard must be 'ordinary people living ordinary lives'. I would like to remind the HSE that people like Bernard are EXTRAORDINARY people. In this situation, as in life, it is not a case of 'one size fits all'.

What is so wrong with the idea of my son and people like him who have profound mental and physical disabilities, living extraordinary lives in a truly special group home like St. Mary of the Angels?

The reality is that my son already lives in a wonderful, warm, loving, friendly, safe community where people understand him and he can be himself.

The fact that the HSE are framing the relocation of Bernard and his friends - which will be a scattering of them into small houses around the county - as a 'move out into the community' raises serious questions as to how well the HSE and the Minister for Disability who supports this project actually understand people with disabilities at all.

Yours sincerely,
Ina O' Dwyer

The following statement was released by the HSE on the proposal last week:

"The HSE wishes to assure all residents of St John of Gods Services in Beaufort, and their families, that they will be consulted with and fully involved in any proposed changes to the residential services provided on the campus in Beaufort. No changes will proceed until this consultation process has been completed with all relevant parties. This consultation and engagement process is underway having commenced earlier this month.

"The proposed changes for the services at St John of Gods are in line with similar positive changes in residential services for people with an intellectual disability across the country and supporting the move to community living.

"As part of the implementation of the 'Transforming Lives' programme, the vision is to support people with disabilities to transition to community living with the appropriate supports; to live lives of their choosing, to decide where they live, who they live with and how they spend their time.

"The HSE is working with a number of partner disability organisations, including St John of God Services in Kerry, to implement this new model of residential support where people with disabilities are supported to live ordinary lives in ordinary places, with no more than four people with a disability living together in houses that are dispersed throughout the local community.

"In line with national policy, St. John of God Services campus in Beaufort has been identified as one of a small number of priority sites for de-congregation. A "congregated setting" is defined as one where ten or more people reside in a single living unit or are campus based. There are currently a total of 76 adults with intellectual disabilities residing on the Beaufort campus. 17 people are accommodated in old style ward facilities. This ward style accommodation is unsuitable as it does not meet HIQA residential standards for people with an intellectual disability and it is contrary to the HSE policy; Transforming Lives. The remaining 59 residents live in bungalow style accommodation on the campus.

"The HSE is committed to working with St John of God Services to start the transition to community living with the 17 residents currently living in the unsuitable ward style accommodation on campus to more appropriate settings in the local community. A consultation and engagement process has commenced with residents and their families/advocates to ensure everyone's voice is heard and their wishes and preferences in relation to where they live, who they live with and how they spend their time are taken account of and respected. Any proposed changes will happen on a phased basis and only following a thorough consultation process with all those affected...The proposed changes do not affect St Frances Special School and there are no plans to relocate the school..."

Kerryman