

Joint Committee on Disability Matters, 1st July 2021

Opening Statement from Lynn Fitzpatrick St Mary of the Angels Parents and Relatives Association



I thank the Chairman and Committee members for the opportunity to give voice to my brother Bernard, who can't represent himself due to the profound nature of his disability. His 40 years' lived experience in residential care is a crucial consideration for today's discussions, but not for the reasons one might assume. Because Bernard has never lived in an institution or inappropriate setting. He has lived in St. Mary of the Angels.

Bernard lives a full, valued and meaningful life on a tranquil 30 acre campus in Beaufort; not far from our family home in Cahirciveen. When we were kids, 'Bubo' (as we've always known him) spent weekends, holidays and special occasions with us. During the week, he lived among his peers; who at the time were children with severe or profound physical and intellectual disabilities.

My mom recalled the impact on Bubo, after he moved to St. Mary of the Angels at the age of 5: *"Everything in his world changed for the better. His epileptic fits began to diminish...The immense heartbreak I [initially] felt...was soon replaced with... gratefulness that my son was in the best place, getting the best chance for a long and healthy life."*

Bubo and his friends grew up together in an environment that was **purposefully built for them**ⁱⁱ. From its founding in 1968, the campus was developed and upgraded with them specifically in mind. The onsite facilities include a heated hydrotherapy pool, a sensory room with heated water bed, a wheelchair swing, outdoor sensory equipment, occupational therapy, physiotherapy, music therapy, jacuzzi baths, psychology, psychiatry, massage, speech and language therapy, dentistry, GP visits, and a day centre for crafts and cookery. There's also a special school and a chapel which many individuals can walk or cycle to independently. Recently, the local community raised half a million euro used in part to improve walkways, landscaping and construct new bedrooms and sunrooms.

Today, Bubo's at home on holidays. But if he was in Beaufort, he'd be at a tea party with friends or spending time in the spectacular grounds. He might be planting flowers in a sensory box in the patio outside his private ensuite bedroom or chilling out in the hydro-pool. Maybe he wouldn't be there at all and instead be out on one of his regular day trips to the nearby towns of Killorglin or Killarney. All this with the help of the exceptional frontline staff who know him so well.

This is Bernard's life now. But his future is uncertain due to a government policy.

The 2011 Time to Move On reportⁱⁱⁱ identified St. Mary of the Angels as one of 72 residential settings to close within 7 years purely because it is campus-based. If Bubo could tell us where he wanted to live, we believe he would **choose his current place of residence**. But this policy **mandates** that he move out to live in **its preferred place of residence**: *'an ordinary neighbourhood'*^{iv} and sets out narrow parameters within which Bubo can make choices. In this way, the policy denies people like Bubo rights afforded to them under Article 19 of the UN Convention^v.

The policy ensures they will be forced to comply by issuing a **further mandate**: *that there be no new admissions to congregated settings^{vi}*. With an aging population, it's inevitable that the number of people living in St. Mary of the Angels will dwindle, making it economically unviable to maintain its facilities. Ultimately, numbers will fall to an extent that makes it impossible to stay open for the few who remain. Meanwhile, Bubo's vibrant community will diminish and he'll notice a change in his environment, it will feel lonely and isolated. His home could become an institution for the first time.

The policy removes Bubo's right to live on a campus and denies this right to all current and future 'Bubos' because its implicit aim is to *'eliminate congregated settings^{vii}* and its explicit aim is that there be *'no further need for congregated settings^{viii}*. This too violates a right under the Convention to make choices on an equal basis with others, since campus-living is an option open to other cohorts of society like students, older people and even some people with disabilities.

The policy insists Bubo won't live in a community until he's in an 'ordinary place' being an 'ordinary person'. But a community is, by definition, 'a group of people living in the same place or having a particular characteristic in common'. Bubo lives among people with whom he shares much in common. *'The government should not define 'community' for the individual, rather it is the individual who should define 'the communities' in which they wish to participate.'*^{ix} For Bubo, moving to 'the community' means losing lifelong friends and having nothing in common with his neighbours.

Research supporting the ideology that ordinary community living is best **for all people with disabilities** *'no matter how severe or complex'*^x must take into account the unique needs and real lives of the minority^{xi}: (14% of people with severe ID and 4% with profound ID) - for whom a dramatic change of setting and routine could have negative consequences. The essential facilities they need won't be available to them 'out there' in the community any more than they're available now to the families with disabled children who are crying out for them.

Decongregation has played out internationally with tragic consequences^{xii}. To date in Ireland, the only stories getting airtime are the successful ones. I can't ask you to take my word for it that so far this policy has badly failed some vulnerable people, but please consider the fact that since its launch, in the period 2012 to 2019, 278 people were admitted or readmitted into congregated settings^{xiii}. This happened despite the policy's aim to remove the need for such places. Where are these people supposed to go when the door to the last 'St. Mary of the Angels' has shut for good?

I put it to you that St. Mary of the Angels is a community in its own right with a proven track record of success spanning six decades. It is a residential care model that should be researched and replicated, not broken up and sold to fund community living. In closing I ask the Committee to support my request that St. Mary of the Angels be immediately exempted from the Time to Move On policy which should never have targeted it in the first place, let alone designated it a pilot and priority site^{xiv} for decongregation.

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- ⁱ <https://www.irishexaminer.com/business/arid-20455575.html>
- ⁱⁱ www.savestmaryoftheangels.com/resources/Historical_Press/The-Kerryman-1993-04-30--25-Years-of-caring.pdf
- ⁱⁱⁱ Time to Move on from Congregated Settings report (TTMO):
<https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings—a-strategy-for-community-inclusion.pdf>
- ^{iv} 'All housing arrangements for people moving from congregated settings should be in dispersed housing in ordinary neighbourhoods in the community' - TTMO page 101
- ^v <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- ^{vi} 'Recommendation 1: No new congregated settings will be developed and there will be no new admissions to congregated settings.' - TTMO page 15
- ^{vii} Finian McGrath, 11 December 2018, written answer to PQ 375,
https://www.oireachtas.ie/en/debates/question/2018-12-11/375/#pq_375
- ^{viii} 'Our proposals aim to ensure that there will be no further admissions and no further need for congregated settings.' - TTMO page 3
- ^{ix} <https://www.togetherforchoice.org/post/together-for-choice-policy-statement>
- ^x 'The policy should apply to all those living in congregated settings, no matter how severe or complex their disability.' - TTMO page 92
- ^{xi} [NASS 2020 - Intellectual Disability Infographic \(hrb.ie\)](http://NASS2020-IntellectualDisabilityInfographic(hrb.ie))
- ^{xii} [St Mary of the Angels Beaufort: International Resources \(savestmaryoftheangels.com\)](http://StMaryoftheAngelsBeaufort:InternationalResources(savestmaryoftheangels.com))
- ^{xiii} <https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/infographic-time-to-move-on-2012-2019.pdf>
- ^{xiv} Finian McGrath, 3rd November 2016, written answer to PQ 146,
https://www.oireachtas.ie/en/debates/question/2016-11-03/146/#pq_146