

From: **Pippa Kearon** < >

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Subject: St Mary of the Angels and congregated living

To: <michael.moynihan@oireachtas.ie>, <disabilitymatters@oireachtas.ie>

Dear Deputy Moynihan

I am writing to add my own experiences to those presented to the Committee by Lynn Fitzpatrick in relation to government policy concerning congregated living for individuals who are differently abled and living with a wide range of disabilities and challenges.

I apologise in advance for the length of this email but I found my life and professional experience difficult to articulate without explanation and example. I understand that you are busy people but I feel that this is a complex issue with many angles that need to be addressed and examined.

My background and life experience has given me a wide range of living, working and community experiences with people from many different backgrounds and of differing abilities. I have experience of growing up in a family where we supported close relatives with schizophrenia, autism as well as challenges arising from childhood trauma such as addictions, depression and anxiety. In my adult life I have been a primary carer to a young person with moderate learning difficulties, autism and epilepsy for 12 years up until her death in 2002 at the age of 18. She often spent weekends on respite at St Mary of the Angels and we were profoundly grateful for the love, care and support she received when on holiday there. Prior to her death, we were in discussion with St Mary of the Angels as to a possibility that she would join one of the houses there and build an independent adult life within their community where her considerable and complex additional needs could be met whilst also affording her the opportunity to have plenty of choices of activity and life experiences. I have worked at pre-school, primary and secondary school level as a special education teacher and been proactive as a community development specialist both here in Ireland and in Sub-saharan Africa. Both here in Ireland and in Lesotho I have developed services for individuals who are differently abled and supported their families, the individuals and service providers to ensure that the aspirations and needs of those in receipt and those providing care and education are taken into consideration in finding solutions to meet the additional needs of those living with disabilities.

I have many friends and a large extended family with whom I have close relationships and I have learned to embrace diversity and respect and embrace difference. My family and friendship group includes many wonderful and treasured friends who between them have a range of additional needs and challenges including for example, mental health problems, psychiatric disorders, learning difficulties, cerebral palsy, hearing and sight impairment, autism, dementia, challenging illnesses, addictions and depression. In other words, I see these challenges as part of life and consider my life a rich one as I have learned to be open, flexible, compassionate and understanding and have learned to see and listen to others of all ability, remaining open to learn from and be guided by them. For some of these friends living in the wider community provides wonderful opportunities and a fulfilled life but for others, they find their fulfilment and happiness living amongst others who have complex additional needs with whom they can be themselves, feel safe and protected and where their preferences, personalities, strengths and weaknesses can be facilitated and, in turn, they

can feel a sense of belonging and self worth. My friendship group and family have taught me that one size does not fit all and that no matter what challenge an individual faces, their specific circumstances, preferences, personalities, cultural background, strengths and weaknesses need to be seen and heard by those who are in a position to facilitate for their particular needs and the needs of those who are their primary carers/support.

Individuals, who society perceive and describe as 'normal' (but who often have a myriad of hidden challenges), are afforded every opportunity to make choices, voice concerns and opinions, seek 'what they want', have access to education, medical care, recreation and leisure opportunities, make career choices, plan for the future and express themselves emotionally and physically. We watch endless programmes on TV about people's choices for living. Their houses, their food, their transport, their leisure activities, their hobbies, their holidays, their education, their careers and their relationships. They can, on the whole, make these choices because they are fully integrated members of society who understand the 'rules of engagement', have the ability to cope with success and failure, can negotiate and work in relationship with others in society, be flexible, problem solve, critically evaluate and speak up for themselves if necessary. To be integrated, we therefore need a wide range of skills and opportunities and a high level of understanding of 'how to' navigate the complex world in which we live. Integration does not arise from merely living alongside others.

My experience of congregated communities for people living with disabilities who do not have the independent, prerequisite skills and abilities to access all that open community living has to offer, is that they are able to provide many of the choices and opportunities that open community living can offer, but in a smaller, more intimate, compassionate, inclusive and accepting environment where diverse additional needs are understood and accommodated and where differently abled individuals feel seen, heard, safe and respected and therefore happy, content and free to be themselves. The support teams who live and work beside those living with disabilities are trained to see, hear and respect the individual and to empower, support, encourage, guide and facilitate their choices, strengths and weaknesses and advocate for their preferences and needs. In the case of St Mary of the Angels, my friends who live there are so well known to their community that both the staff and their housemates know their strengths, weaknesses, needs, personalities, preferences, choices and can spot when the individual requires additional support or is feeling challenged. The staff are highly trained to provide for the needs of the very diverse individuals who live at St Mary of the Angels. The dedicated team are in a position to provide individually tailored personal care, daily activities and outings, social, learning and recreational opportunities and ensure that specialised therapies and medical interventions take place. Each person living at St Mary of the Angels is regularly assessed to ensure that their living space is appropriate for their age, their preferences, their interests and their needs and that they have opportunities to develop new skills and try new activities. Where routine is essential for stability and well being, that is accommodated. The background of individuals is also taken into consideration and I have one friend living there who is regularly taken to GAA matches, music sessions and Irish dancing in Killorglin and Killarney as she grew up loving these activities. This is the level of care that is necessary for some people with additional needs to feel a sense of love and belonging where their well being is maintained and they can live fulfilled lives.

I have several friends in the UK who have complex additional needs. Two ladies, who I have become close friends with since I travelled to Lourdes with them, grew up in a residential congregated community run by Sisters in Brighton. When they became adults, these ladies who have moderate learning difficulties and other challenges, remained at the centre and, rather like at St Mary of the Angels, they were able to avail of a wide range of training, social

and recreational opportunities and try their hand at a wide range of activities and hobbies. They had an active social life and felt a great sense of belonging, acceptance, purpose and safety. In the 1990s the UK government made a policy to disband congregated living for those living with additional needs with only a few very specific exceptions. My friends were sent out to live independently in council flats and YMCAs where they found themselves vulnerable, isolated and lonely and they became depressed, overweight, had challenges with their health and little by little even their day support services dwindled away. With no-one to advocate for them, the local service providers targetted services for those with the least ability to speak up for themselves as a means of saving resources and reducing public expenditure. One of these ladies has learning difficulties and schizophrenia. She rings me nearly every day and has been so lonely and frustrated. Her physical and mental health became a life long problem. Her diet is dreadful and led to obesity and she developed diabetes. She was extremely lonely and spent her days in second hand shops and cafes seeking social interaction. Her friendships were priests and people like me who she can call on the phone and talk with but most of us cannot see her very often in person as we live too far away. Her brothers have found it very difficult to maintain harmony in their own marriages, families and work places as they are often called away from their commitments to attend to their sister's needs and financially there are many supports needed which their spouses do not always understand or appreciate. She often rang A&E for emergency help and sometimes it was just crying wolf for attention but other times there were real problems that she had difficulty convincing the paramedics of because of all the false alarms. I have advocated for my friend on several occasions in order to get the help that was needed. Recently she had a stroke and has had to go into an old age and additional care home. She is so happy and says she now feels safe and protected again and is enjoying making friends and even goes out in her wheelchair being pushed by others she lives with. She said it's fun to watch telly with others as you can talk about the programmes. These are the small things that help us to feel a sense of belonging and well being and are so important to our mental health and feeling of fulfilment in life.

On the other side, I have a friend of the same age who has severe cerebral palsy who fought hard to be provided with enough support that she could live independently in the open community. She had to fight through the courts to be allowed to live independently and to be granted a personal care assistant to help with daily care needs and facilitate access to activities and opportunities she wanted to be able to participate in. She is a wonderfully funny, articulate and intelligent lady who uses assistive technology for communication and is physically totally dependent on support for personal care. Since being awarded a personal assistant and living an independent life in a ground floor, specially converted flat in a large town, she has thrived. This was her preference and her choice. This is where respect for the individual is so crucial and remembering that one size does not fit all. For some independent wider community living is wonderful but for others it is a road to despair, unhappiness and, at worst, living without safety.

So, in writing this letter, I urge the Committee to immediately reconsider and overturn the policy to disband congregated living for children and adults with additional needs. It is my life experience and my professional stance that there are many individuals whose additional needs are best met in congregated living spaces such as St Mary of the Angels. There are so many children attending St Francis Special School who may choose to live or avail of respite as children, teenagers or as adults within such a community and this choice should remain open to them. I agree with Lynn Fitzpatrick and her family that St Mary of the Angels should not be targetted for closure but rather studies should be made to examine the care model and seek ways to improve and replicate this on the beautiful grounds where so many individuals with additional needs have thrived and found their sense of security and self worth over more than 6 decades. I urge the Committee to consider what it means to live in

compassionate communities and to take time to hear from families, advocates, support workers, friends, businesses and local service providers before closing the doors on valuable community assets. How many people living in Killorglin for example, would be trained or knowledgeable enough to live alongside a person with a sensory, physical or learning disability? Has anyone asked the community in Killorglin, Killarney and further afield if they are ready to support individuals with additional needs on a daily basis and provide a compassionate community where diversity is embraced as part of the norm. This is a daily commitment which needs to be sustained by everyone from paid home help to neighbours, businesses, local services, clubs, recreational and leisure facilities, schools, GPs, dentists etc.

I would urge the Committee to set up a working group to undertake a "Value Management Study" to assist all stakeholders to work together to come up with innovative and compassionate solutions to this challenge. As a recent First Class Honours graduate of an MSC in Programme and Project Management with University of Limerick, I am now also a qualified Value Management specialist and would be happy to discuss the possibility of facilitating a 40 hour Value Management workshop with your committee and other stakeholders if you would like to discuss this idea further. At the very least, please take time to hear the personal stories and advocacy from families and individuals who have personal, close associations with St Mary of the Angels for many years and also know the challenges that face young adults who remain with their families in open community living here in our rural community. My experience is that they are often lonely, depressed, unmotivated, vulnerable and highly dependent on their parents. They find it very challenging to make friends, develop interests, find social and recreational activities that they can independently access, integrate with their peers or find employment or purposeful daily activities. Individuals I know who live in community housing in Tralee are extremely vulnerable and I know of many cases where this community housing has been far from a positive experience.

I believe that more discussion and research is needed before you allow an ill thought out and grossly negligent and ignorant policy to irreversibly remove the fulfilled lives and future opportunities of those living now or in the future in St Mary of the Angels and other such living spaces, who are most in need of care.

Yours sincerely

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