

FOCUS ON HSE'S 'TIME TO MOVE ON'

When jargon fails the vulnerable

LYNN FITZPATRICK ARGUES THE HSE'S 'TIME TO MOVE ON' POLICY FAILS PEOPLE LIKE HER BROTHER BERNARD WHO COMPRISE A VOICELESS MINORITY OF THE SEVERELY DISABLED FOR WHOM THE POSSIBILITY OF INDEPENDENT LIVING IN A COMMUNITY SETTING IS A NONSENSE



WHEN I was growing up, my brother was handicapped. Today he is physically and intellectually disabled. Though his condition has not changed, the label used to describe him has.

Despite the fact that the term handicapped is now considered politically incorrect, the word has survived in English dictionaries, albeit with a disclaimer that it is 'old fashioned' (Cambridge) and 'offensive' (Oxford). I looked it up because I was curious as to why a term that, at least for me as a child, carried connotations like 'love' and 'special', was dispelled from my brother's narrative.

In Cambridge, handicapped means "a condition in which

part of your body or mind has been permanently damaged or does not work normally". In Oxford, it means "Having a condition that markedly restricts one's ability to function physically, mentally, or socially".

My brother was permanently brain damaged at birth and as a result he got meningitis and suffered from severe epilepsy. Today he can't walk, talk, wash, feed or dress himself - he requires nappies and bibs. To me, there is nothing offensive about the term as defined in the dictionary - it is an accurate description of my brother's condition and gets across its severity.

Nevertheless, handicapped is a term I am afraid to use, not because I think it in any way

demeans or would upset my brother, but because I fear the wrath of the politically correct and the high-horse brigade. I fear that it would be the stick that Inclusion Ireland, St John of God management and advocates use to beat me with when I try to oppose the Time to Move On from Congregated Settings policy. I play ball and use their language because if I don't, they can say that I am 'backward', 'ignorant', 'out of touch' - they can discredit and point at me and say "See, we told you, the families don't know what's best." This could strengthen the argument of self-appointed 'independent' advocates that they are better placed to speak for my brother, than his own family. That is a risk I cannot take, when my brother's home, community, health and wellbeing are at stake.


And so I use their language and their labels to refer to my own brother, even though I think that doing so is misrepresentative of his condition and has serious consequences. Let me explain.

The term 'physical and intellectual disability' is exceptionally broad and non-specific. Disability can refer to and mean so many things, for example, arthritis, mobility challenges, loss of sight, MS, Alzheimer's, Parkinson's, acquired brain injury, etc. An elderly person with arthritis could live independently, a person without sight or mobility could be able to communicate; skills and abilities like these would set them apart from my brother. Some people referred to as 'intellectually disabled' have Down syndrome or Autism, many of them can compete in the Special Olympics and this too sets them dramatically apart from my brother.


Of the 27,000 people in Ireland registered on the National Intellectual Disability Database, 41% have a mild intellectual disability while 36% have a moder-



Lynn on one of her regular visits to brother Bernard in the place he calls home: St Mary of the Angels.



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ate disability. This means that 77% of the people who share the category of 'intellectually disabled' with my brother are vastly more abled than him. My brother and people like him make up only a tiny proportion of this group - 4%. There is also a 15% group, said to be severely intellectually disabled (4% are unverified). So what happens when you have such a disproportionate number of severe and profoundly disabled people sharing a category with mild to moderately disabled people? What happens when the majority can speak and decide for themselves and the minority cannot?

Well, what has happened up to now is that the majority have spoken and decided for the whole group. There is now a societal and political assumption that the majority and their advocates are best placed to advocate for the minority. It is accepted that the majority speak for and advocate for the minority, because after all, aren't they all people with disabilities? This is why a lady born with cerebral palsy, who works as an advocate, was able to appear on an RTE programme this month and make sweeping statements about the lives of people like my brother

in 'institutions'. Despite the fact that these claims were certainly untrue for St. Mary of the Angels, they went unchallenged and I think that is wrong. What other group of people can have a home they love and are proud of misrepresented in such a manner? I find it very hurtful and am glad my brother is not aware of it.


One way that the HSE justify the 'Time to Move On' policy, is to remind you that "people with disabilities have been campaigning for this for years." And it is true. Many people with disabilities have long advocated independent living and for some, who are able to live independently, this is great. But their campaigning has been for independent living for all and this has resulted in a policy requirement being placed on my brother to be 'an ordinary person, living an ordinary life, in an ordinary place'; a policy that removes his right to be an extraordinary person and live in an extraordinary place, where he is very happy.

Recently an Inclusion Ireland officer published an article that was highly critical of our campaign to save St Mary of the Angels. The article repeatedly used the term 'people with intellectual disabilities' in references


to residents (it never mentioned physical disabilities). I couldn't help but wonder, who is it that comes to the mind of a person reading that article; is it the 77% or is it the 4%? If it is the 77% then my brother is rendered invisible.

The article is critical that "the voices of the men and women who actually live in the institution have been noticeably absent from this debate". When I read this, I was overcome with the urge to pick up my phone and record a video of me talking to my brother about this debate and asking for his take on it. Of course, I would be talking at and not with my brother and he would most likely laugh, try to grab my phone, or wheel rapidly away from me. I thought that maybe I could upload this video, in response to this article and prove what a stupid and ill-informed statement that was to make. But I wouldn't like to take the chance that my brother might understand what I was saying, I would not want to burden him or risk upsetting him when he cannot reply and speak his mind. The best indication for where my brother wants to live is his happiness.

The article also states "independent advocacy is needed now more than ever to ensure that the voice, the will and preference of the men and women who live in such institutions is articulated and respected". I feel that Inclusion Ireland simply do not trust the family members' judgement in relation to our loved ones. They appear to believe it is more appropriate to have my brother assessed by an independent expert, than to leave any decision to those who know and love him best. I would like to know what the advocates' personal choice would be, if, God forbid, they were about to be rendered as dependant as my brother. Who would they want to decide for them about where to live? A person they



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have never met or their parents/
siblings/friends?

This is the vulnerable position in which my brother now finds himself. People who do not know him and have never met him but who assume he is the same as them are speaking for him and against his family. Policies are being drafted on the basis of giving choice, but they remove his choice because they already assume to know what is best for him. I think he and the 4%, possibly the 15% too, are in this position because they have been mislabelled. They've been lobbied into a group that they don't belong to and maybe, if my brother had been permitted to keep his original label, he would now be far better off. Maybe we would have a Minister for Disabilities and a Minister for the Handicapped, and the families struggling to care for profoundly disabled loved ones at home would have the services and the residential facilities that they so desperately need.

Disability scholar Jack A. Nelson has said "the main problem with [the term] handicapped... was simply that it had not been chosen by the people it was supposed to describe". Well here's the thing. My brother, and people like him, will never be able to choose their label. That's

not a controversial statement, it is the truth. They simply do not have the intellectual capacity, or the language or even the inclination. My brother has no concept of labels.

It is true that he didn't choose to be called handicapped, but he didn't choose to be called disabled either! At least the former label was a truer, narrower representation of his condition; at least there was a term for the forgotten 4%. And fair enough if that label was inappropriate for more able people with disabilities, they were right to shirk it off - but why did it have to be banished completely? Just because it was the wrong label for them, did it have to become an offensive word?

The sad truth is that the activists who themselves rejected having a label imposed on them, have imposed a label of their choosing on my brother. Unlike them, he cannot take a stand, reject it or point out that it doesn't fit. This means that he is completely at the mercy of their ideas, their aspirations, their campaigns and their policies. It means that when advocates like Inclusion Ireland and people who have disabilities advocate for change, they are advocating for the needs of the majority and ignoring the needs of the minority. Or worse, they

are assuming the needs and wants of the minority are the same as their own, when they absolutely are not.

There is a difference between 'believing something' and 'believing in' something. I believe in St Mary of the Angels. This is rooted in my experience growing up, seeing first-hand what a special place it is and how happy my brother has always been there, how he has thrived. Belief itself is different. It can operate on assumption alone and it is the human condition to unconsciously seek out information that reinforces what we believe. Advocates and Minister McGrath have a belief that all residential care facilities for 'people with disabilities' are institutions. And nothing I say and no evidence to the contrary, will ever convince them otherwise.

So maybe then, the best thing I can do is something that should have been done long ago. Maybe I can advocate for the 4% and perhaps the 15% to be re-categorised, to get them out from under this gigantic umbrella of 'disability'. That way everybody wins - advocates can continue to advocate for those who would benefit from their advocacy. Families who put their loved ones in residential care, can stop being regarded by disability advocates as the backward, ignorant, unloving, regressive people who threw their loved ones into institutions and forgot about them. And most importantly, my brother can be advocated for by people who actually understand him and love him and 'get' him.

I don't know if this is a question for the Minister for Health Simon Harris, or for the general public, or for the advocates but I know that I need to put it out into the world, so here it is:

If the term 'handicapped' has been banished for all eternity, please can I have a new label for my brother?