

Joint Oireachtas - Disability Matters 02.02.2023

Opening statement – Catherine Gallagher

Awareness raising has consistently been a topic and ever-present focus in discourse regarding disability. While I understand it can come from the best of intentions – I have to ask what do we need to be aware about? Do we need to be aware that disabled people exist? Do people have to be reminded that I am worth including or being on board in a team or a part of the community? If that is the starting point, I am not sure if that is a feat I can personally take on. For decades in Ireland, disabled people have tried to speak their truth to power as individuals, community groups, and DPOs (Disabled Persons Organisations). Nothing I am sharing today is inherently new or unique thinking; I have listened to and have been informed by my community against the backdrop of my own lived experience.

The social model looks at how society is structured and how it disables people. It isn't based on a person's impairment, it is about what barriers that exist in terms of attitudes, policy development, access, or lack of supports that prevent people from participating in society as equals, with choice and control over their own lives. In this model it is society that disables people from achieving their hopes and dreams, not a person's impairment.

The medical / charity model individualises disability and promotes the idea that people are disabled by their impairments or differences. The medical model always focuses on people's impairments from a medical perspective. In some ways it still looks at what is 'wrong' with the person and not what the person needs. It creates low expectations and leads to people losing independence, choice, and control in their own lives. This model also assumes that disabled people need to be 'looked after' or 'cared for'.

Words can hurt, and words can heal. Consider how we describe activities. Exercise and going to the gym for non-disabled people is described as 'physio' and 'rehabilitation' for disabled people. Swimming lessons for non-disabled children is 'hydrotherapy' for disabled children. Music lessons for one child is 'music therapy' for another. You might feel included or a part of your community, but for someone else, they are 'rehabilitated' into theirs. I never had 'special needs.' My needs have always been specific and when/if they are facilitated, it allows me to have autonomy over my life. If I have autonomy and genuine liberty, it will allow me to make certain decisions that may be of great benefit to those I work with, work for, and society at large. Language around activities and how we live our lives is medicalised and pathologised when referring to disabled people.

As I shared in my last attendance to the Joint Committee on Disability Matters (29 September 2022), being able to live with privacy, dignity, and discretion is a privilege. Due to the lack of direct investment in disabled people's lives to give us choice and control, many disabled people and their families are often left to self-advocate for basic services. In the absence of investment in autonomous collective spaces such as DPOs to campaign for systems and structures to be overhauled, it is left to individuals and families to advocate for change.

Some disabled people or families who have disabled children feel that the systems are so unresponsive that they must go public to highlight these issues. Often when media take up

this issue, it is done through the lens of a medical / charity narrative of disability, which individualises the story based on a person's impairment and the 'tragedy of disability' as opposed to the need for investment in systems that give us our rights. You will see these stories as human-interest articles and segments and at times they lack in information-rich context which outlines the root of an issue.

This is not to find fault with any disabled person or families who have disabled children for using any means they have to secure the supports that they need but to recognise that in not investing in collective critical voices led by disabled people, we are continually forcing people to share intimate details of their lives to secure supports that should be given as a right. We need to think of the implications of publicly sharing intimate details of our lives.

I have had time to reflect on this personally within the last two years, following the introduction of Catherine's Law. I regard myself as someone who has been mentally resilient – which is not necessarily related to my experience of being a disabled person. With that said, the implications of this period – coupled with simultaneously emerging out of almost two years of strict cocooning – resulted in what I can only describe as feeling as though my 'spark' has been chipped. The fun and creative sides to my personality and personhood took a backseat for quite a time. I am actively, and very consciously, prioritising my time this year to bring this back to fore again. If we lived in a society where we moved beyond awareness, to taking constructive action to realise the vision held by disabled people, there is a very good chance that this is something I would not have to do.