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# Trailing my journey into disability insights

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## ABSTRACT

The following short article traces my journey towards a better understanding of disability in my personal and professional life. I argue that context, professional cultures and changing theories of disability have all intersected in my journey to this fuller understanding. In turn this provides me with a better theoretical and professional tool kit with which to grasp disability and the lives of Maltese disabled people.

When I wonder how my standpoint on disability has developed so far, I find myself following a trail of events in my life that made me discover a different viewing platform with each new experience. In a phenomenological sense, I embarked on a phenomenal journey through which I gained new understandings. Living in Malta for the past 30 years has placed me in a very particular context with respect to insights on disability. As depicted by Camilleri and Callus (2001), the way Maltese society has traditionally looked at disability has been highly influenced by the historical past, the Catholic Church, the family and the recent establishment of non-governmental organisations. Disabled people have traditionally been associated with burden, sin and punishment and were meant to be kept unnoticed. In the past 60 years, disabled people have been brought out of hidden places and there has been a huge shift in attitudes. Yet they still remain indirectly segregated through special schooling, lack of independent living accommodation and limited employment opportunities (Camilleri and Callus 2001).

I have been involved in some way or another within the disability sector throughout my life. As a child, I used to pay frequent visits to a residential home for disabled persons, where my relatives were employed. Despite exposure to the experience of disability from a very young age, I describe my position at that time as a spectator from a distance, in an environment where disabled persons were perceived as 'angels' and 'special people'. Disability was depicted as suffering (French and Swain 2004), associated with dependence and abnormality (Oliver 1993).

As I entered my adolescent years, I wanted to move away from the passive onlooker. I started offering my time and energy in charity events, as I believed that the disability sector was in great need of financial resources. Little did I realise that being presented as objects of charity effectively robbed disabled persons of the claim to individuality and full human status (Barnes 1997). I started questioning my views on disability when I started working with disabled persons as an ability promoter about 14 years ago. I began challenging the paternalistic environment as I was learning that disabled persons have feelings, thoughts, dreams and aspirations. For the first time I attempted to make the voice of disabled persons themselves heard within their own home, even though I was unaware that this was part of the emancipatory framework which disabled persons were fighting for at that time.

Entering into physiotherapy had a huge impact on my insights about disability. I was thrown into a culture of middle-class values and professionalism (Albrecht 2003 as quoted in Devlieger and Balcazar 2010), a culture in which the medical model of disability is glorified. Within the medical world, the disability experience is an individual problem. Also, the notion of independence is linked with function, even though disabled persons usually perceive independence in terms of autonomy. As healthcare professionals, we empower clients to achieve their maximal potential, but disabled persons frequently criticise us that this is done on behalf of the dominant ideology of normality (Oliver 1990). Despite not being able to fully escape from the power of the medical model, my past exposure to disabled persons helped me not to get completely carried away by it. From my early days of practice, I perceived the client as the expert knower and promoted the view that healthcare professionals can be

enablers in the lives of disabled persons. Whilst clients and their relatives felt empowered by such principles, this was not always the case with colleagues who felt that professional expertise was being threatened by such an approach.

Eventually, I found myself applying for a master's degree in Disability Studies. Coming from the medical sphere, I admit that initially I felt out of place as I came to know that healthcare professionals are not perceived by disabled persons as their ideal allies. The first year of studies was a continuous battle to examine my preconceptions of disability and to bring forward what I believed in, even if it was not compliant with the dominant discourse. This was no easy task, especially since the social model of disability kept cropping up in every discussion and was used as the main defence to fight against the medical world.

In the last decades, there has been a great push towards the establishment of the social model of disability to challenge the grand narrative of the medicalisation of disability. Nevertheless, this process led the social model of disability to become a grand narrative in itself. Pinder (1996, 137 as quoted in Watson 2004) claims that it has become relativistic and reductionist, and omits 'a much more complex multi-layered picture' that portrays the experience of disability. My main concern with the social model was always its struggle to stress commonality at the expense of difference (Priestley 1998; Shakespeare 1999). As a result, the diverse narratives of disabled persons were continually being put aside. Disability scholars do not consider autobiography as a satisfactory vehicle to document the disability experience. They argue that it is individualistic, reinforces the cultural dominant discourse and is incompatible with the values of disability rights (Barnes 2003; Bérubé 2005; Coogan 2007; Kleege 2005; Mitchell 2000).

This conflict calmed down by the end of the year as we were presented with different disability models, such as the affirmative model, which follows my line of thought. Additionally, I became more familiar with prominent disabled activists, such as Jenny Morris, Tom Shakespeare, Susan Wendell and Liz Crow, who talk beyond the social model of disability. These authors provided me with new insights, most of which were solid arguments which I now use to support my reasoning.

At the start of my second year, I felt a breath of fresh air as we were given the task of reading narratives. Since my professional work involves being part of the daily lived experience of disabled people, I felt I could relate much more to the narratives than the models. As I read, I realised that I was identifying myself with different aspects of the narratives. I could see myself when authors talked about youth and relationships, and could appreciate their opinions about the healthcare system since I work within it. Along the past 50 years, narratives written by disabled persons have become more prominent in published literature.

The expanding market is challenging the prevalent discourse and indicating that disability is a diverse, fluid concept that involves experiences which contest the truth of grand narratives and models (Couser 2005; Mintz 2006). According to Couser (1997 as quoted in Coogan 2007) and Engel and Munger (2007, 85), narratives have their significance in disability studies because they can be helpful in breaching 'the barriers of detachment, doctrinal technicality, scepticism, and even irony that often separate legal scholars from the actual life experiences'. Through being the subject of the narrative, disabled persons are showing initiative in representing themselves, proving that they have valuable lives and that they have a significant position within society (Couser 2005).

My academic journey led me to a life-changing project: my dissertation. Getting myself to read phenomenology for the first time was one of the many achievements that formed this exciting experience. Further to this is the blending of such philosophy with emancipatory principles. Exploring the lived experiences of youth who acquired a physical impairment resulted in realising how life is one huge rollercoaster ride with significant life events within. I became aware how the sense of continuity can act as a stabiliser among the inevitable changes that might occur. Above all, my research confirmed that the expert knower is no one but the person experiencing the phenomenon and non-disabled people should also see themselves as collaborators within the disability field.

Where do I stand after all this? Within the past year since I concluded my studies, I have noticed how the new gained knowledge has become ingrained in my thoughts and actions within my personal, professional and academic life. Since then, I have noticed a shift in my approach to my lived experiences – a move from the tragedy approach to the affirmative approach. I have also become more assertive regarding my principles about disabled people within my professional work and have tried to be influential on others with significant success.

Although I am still at crossroads with regards to my career pathways, and with so many unanswered questions, and even more unexplored areas, my focus is clear; it is solely directed towards the needs and empowerment of disabled people. My search thus continues for new knowledge from the expert knowers, that is from disabled people. Only this can enrich my understanding and make me a better collaborator with disabled persons.

### **Disclosure statement**

No potential conflict of interest was reported by the author.

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