DOES THIS DEFINE ME?

Eleanor is an 18 year old young woman. She is also a daughter, granddaughter, sister, cousin, friend, University student, Rover Scout and is our CMT Australia National Office Assistant. Eleanor has Charcot Marie Tooth. She recently completed her final year in High School, submitting a Personal Interest Project (PIP) for her final assessment in 'Society & Culture' entitled 'An Investigation into the Process of Identity Development in Physically Disabled Individuals'.

Eleanor explains: 'I had always known I wanted to do my PIP on disability. It's my thing, the 'niche' feature that sets me apart as different from everyone else'.

The formulation of my PIP topic came after a conversation with my Dad who lives the same disability as me. My Dad shared and continues to share, into his adult life, the same struggles that I experience with the representation of disabled persons in the media.

Eleanor described how 'quite ironically, I feel I have discovered a deeper understanding of my identity through this PIP, my research challenged me in my beliefs and throughout my discovery of all this information I found myself changing my behaviour'. She continues; 'It was one of my biggest struggles during my research that theorists and journals used often referred to disability as something that happened as a result of an action such as an injury. It is not to invalidate the experiences of those who become disabled at a later stage in life, they are as much valid in their disability status as I am, however, it was frustrating to read about disability so commonly as something which happened to someone, often in their adult life. It is on the contrary to my experience of growing up with a disability and around people who have not known a life outside of their current status. It also furthers both stigmas that young people cannot be disabled and that disability is the blame of the disabled individual.'

The Impact of the media on forming disability identity.

As a disabled person growing up in the 21st-century with the rise of highly accessible media, I noticed that there was a limited representation of disabled people within the media and furthermore, if there was some representation, individuals were portrayed as unfortunate or treated with a sensitivity that made them vulnerable or even tokenistic. Research suggests that societies understanding of disability is largely derived from the available media but very few positive representations exist in this domain creating a subconscious reinforced view that people with disabilities are lesser in society. This representation forms constraints on opportunities for building a disabled identity.

In the 'Industry versus Inferiority' stage, Ericsson maintains that "children begin to make comparisons between themselves and others" in order to assess "where they stand". This is followed by Ericsson's next stage 'Identity versus Role Confusion' where adolescents search for a sense of self and identity. As author Nathalya Cuba's outlines in her 'Self Concept' work; "some challenges for adolescents, then, may come from feeling different due to gender, sexuality, ethnicity, class, or ability." This is reinforced in an interview from the point of view of my millennial's sister who declared she felt there was "definitely a certain distance between me and others, especially at school, because of CMT."

It is at this point in adolescence where disabled individuals discover a feeling of difference, often as a result of the common isolation of having a disability, this process is delayed and often leads to 'role confusion.' Role confusion involves a lack of personal cohesion resulting from conflicting identities being sampled in an endeavour to fit in or achieve an identity, this is reflected in a quote from my Gen X father when musing on his adolescence that he "never really felt like I fitted in anywhere specifically, I was both too disabled and not disabled enough".

Much of our identity is built from the media we consume; the films, advertisements, social media posts and other media all have an impact on us as individuals and as a collective. Yet still in our society, the way our media portrays disability is fraught with ableism, if disability is depicted at all, which creates issues for the development of the disabled identity and culture.

The media maintains a crucial role in the construction of identity and can have nuanced effects on the individual. The characterisation or portrayal of how 'inspirational' people with disabilities are for completing tasks or simply just living is one example of this. This can be further connected to the common reaction to focus on the goodness of the able-bodied person performing a charitable act towards a disabled individual, that, in many cases, invalidates the agency of the disabled person to some degree. My research therefore suggests that persons with disability are seen much more today in terms of media and pop culture representations, but that 'being seen' does not necessarily equate with being understood.

This was exemplified in the case of Stephen Hawking. Hawking was a strong disability advocate and scholar well known for his contributions to scientific knowledge. He asserted throughout his career that it was his wheelchair and assistive devices that allowed him to engage, not be restricted, in his work. This was ignited further in an article by the guardian featuring a cartoon, which has now been removed, of Hawking walking away from his wheelchair. The representation of Hawking in this way demonstrates the common ableist perception shown in the media where mobility aids are shown as restricting and disabled individuals are perceived as not being able to achieve academically. The illustration of such plays on ablest narratives that present people with disabilities as inferior to able-bodied people, as defective or as having a worthless status. This reinforces that there is no attempt made by the media to portray physical disability in a way that is integral to the wider understanding and acceptance possible in the future.

Microworld and the Acceptance of Disability

In my personal microworld, I have always been proud of my identity as a disabled individual. I identify strongly with the disabled community, I have always surrounded myself with disabled peers, media intended for disabled people and groups who are affected by disability, which made me wonder why there is such a big contrast between myself and my cousin. We are much alike, she is five months younger than me, we go to the same school in the same year and have spent the

majority of our lives known as the 'troublesome two', we have the same disability; so why, in our near adult life, does she still not talk about and reveal her disability?

Although we share a disability, one inherited from our twin fathers, our symptoms are quite different. As such, in contrast to her, I have had invasive surgery and spent long periods using assistive devices such as wheelchairs or AFO's. These were definitive signs of disability or at the least difference and although I do not rely on these mobility aids anymore, their effect on the development of identity and my acceptance of my disability was   profound, especially due to their prevalence in my adolescence when much of the identity development processing happens.

Personally, and for some other people with disabilities, disability identity entails growing up with a positive sense of self, and a feeling of connection to and affinity or solidarity with other members of the disability   community. My immediate family, of which three quarters are disabled, have maintained an open view on our disability as a part of me and have continued to encourage this through my adolescence.

This view is promoted by Nas Campanella. Campanella is an outspoken media commentator on disability affairs, previously a Triple J newsreader and now ABC's Disability Affairs Reporter. Campanella is blind and suffers from CMT, and she talks about how "being blind is a big part of me, but it's not who I am." She commented about how her disability affected her adolescence; "I already felt different and I thought the cane made me look different" adding "especially as a young girl you just want to fit in". The confidence she found later on allowing her to "embrace that part of me and love it", demonstrating an important part of identifying with a disability.

Early in my research process, I made the naive assumption that changing media depictions of disabled people is key to better including persons with a physical disability in society. However further research has demonstrated that the more substantial and lasting impact exists in the meso world interactions and relationships that physically disabled persons have with able-bodied members of the community. It should, however, not be up to physically disabled persons to create the social change needed to bring about inclusion. This would be an unfair expectation and a double standard, rather, what is needed in society is a culture of seeing persons with physical disabilities for who they are first and foremost and seeing their disability as just one component in the overall make up of their identity.

Driving Societal and Personal Change

"Able-bodiedness is undeniably and unquestioned, unremarked upon state which only becomes notable in its absence, the difference of disability can never be raised and as such disability will never be accepted without a shift in the environment of disability within society."

Historically, disabled people lived in institutional homes, either alongside the elderly or other disabled individuals. From the freedom movement of the 1970s and at the turn of the 21st-century, disabled people were increasingly included within the community and their families, allowing for increasing independence. The connotations of physical disability as curses or disease has created a wider social view or stigma of dependence and helplessness. However this stigma has created issues which were described by my millennial sister as she felt "locked out of society at times, the doors aren't open to me," she further describes how this made her feel often isolated. This alludes to the conclusion that the prejudice and discrimination that often accompany illness can be as limiting as the condition itself, which is further supported by the statement that "it has been a vital step in the development of political consciousness to recognise that disability is something imposed on top of

our impairments by the way we are unnecessarily isolated and excluded from full participation in society."

One of the biggest conclusions I drew during my PIP journey was that for wider acceptance and disability literacy within the society to be achieved there needs to be change on all three levels, macro, meso and micro. Interactions in the meso and microworld with disabled individuals are crucial to creating lasting change that fosters wider acceptance. It is the collaboration of exposure in education in schools and institutions in the meso world, and macro world representation in the media that allows for a future where the stigma surrounding disability is reduced and the normalisation of disability is achieved. This leads to the ultimate positive conclusion that as proud disabled individuals, by just being, we bring awareness and become disability activists within ourselves.

Eleanor is a University Student studying a double degree in Law and Psychology at the University of Wollongong, NSW. She is pictured at the summit of Mt Kosciusko, the highest peak in Australia.