

The Ramblings of a Bockedy Man, Vol. 1:

an autoethnographic review of disability in
the context of reorienting a ‘spoiled identity.’



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‘... a man takes joy even in sorrows, one who has suffered very much
and wandered much.’

- From Homer’s *Odyssey*, (Finley, 1978, p.47).

Acknowledgements

My Grandad, Michael Dempsey, introduced me to a world of stories. His liquorice sweet, topped tales stretching from the dog-and-the-pipe to Thermopylae inculcated a love of reading and derring-do. This ensured that one day I would be carried to the crew of the Rasa; Tomás, Donal, Gordon, Sinead, Pete, and ‘Tony the Boat.’ I thank them all for initiating me into their lives of adventure and for teaching me the language of the sea. I am also grateful to Greet Dekker for the ‘voyage of memories’ and for the images of the Anne-Margaretha.

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Abstract

In this thesis, I am adopting an interpretivist position in that I scrutinise the world around me, my place in that world and the reality of this positioning. I, subjectively, examine this reality and positioning. As an inquiry into the congenitally disabled male experience, my thesis seeks to make honest and authentic contributory claims to knowledge by examining the interplay of disability with Goffman's studies regarding shame and 'the spoiled identity.' Approached through an autoethnographic lens, I examine 'identity' and its tentative reorientation through Freirean consciousness and Mezirow's Theory of Transformative Learning.

I set this work in the context of my experiences as a congenitally, disabled man taking part in the 2002 Cutty Sark Tall Ship's Race. It was a seminal episode in my life prior to which I had come to recognise that I was falling significantly behind my peers in terms of educational attainment, career opportunities and in my relationships. I was literally 'all at sea.'

Then I joined the ship!

The sea proved emancipatory. It was while in the middle of the Bay of Biscay that I began to consciously reflect on my life choices and the role disability played in the actualisation and determination of those choices. And it was at sea that I started to see myself for the first time in terms of capability rather than disability. Further, the exhilaration of witnessing up-close the majesty and power of the ocean effected a renewed zest for life and a desire to acquire the knowledge to best live that life. It was here that I started to question my foundational 'frames of reference,' and presuppositions regarding identity, ideals, desires, and expectations. It was aboard the Anne-Margaretha that I first began to realise that my own life experiences as a man with a disability were atypical and in that, had a value. It was here that I began to open up to tell my own story.

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CHAPTER 1



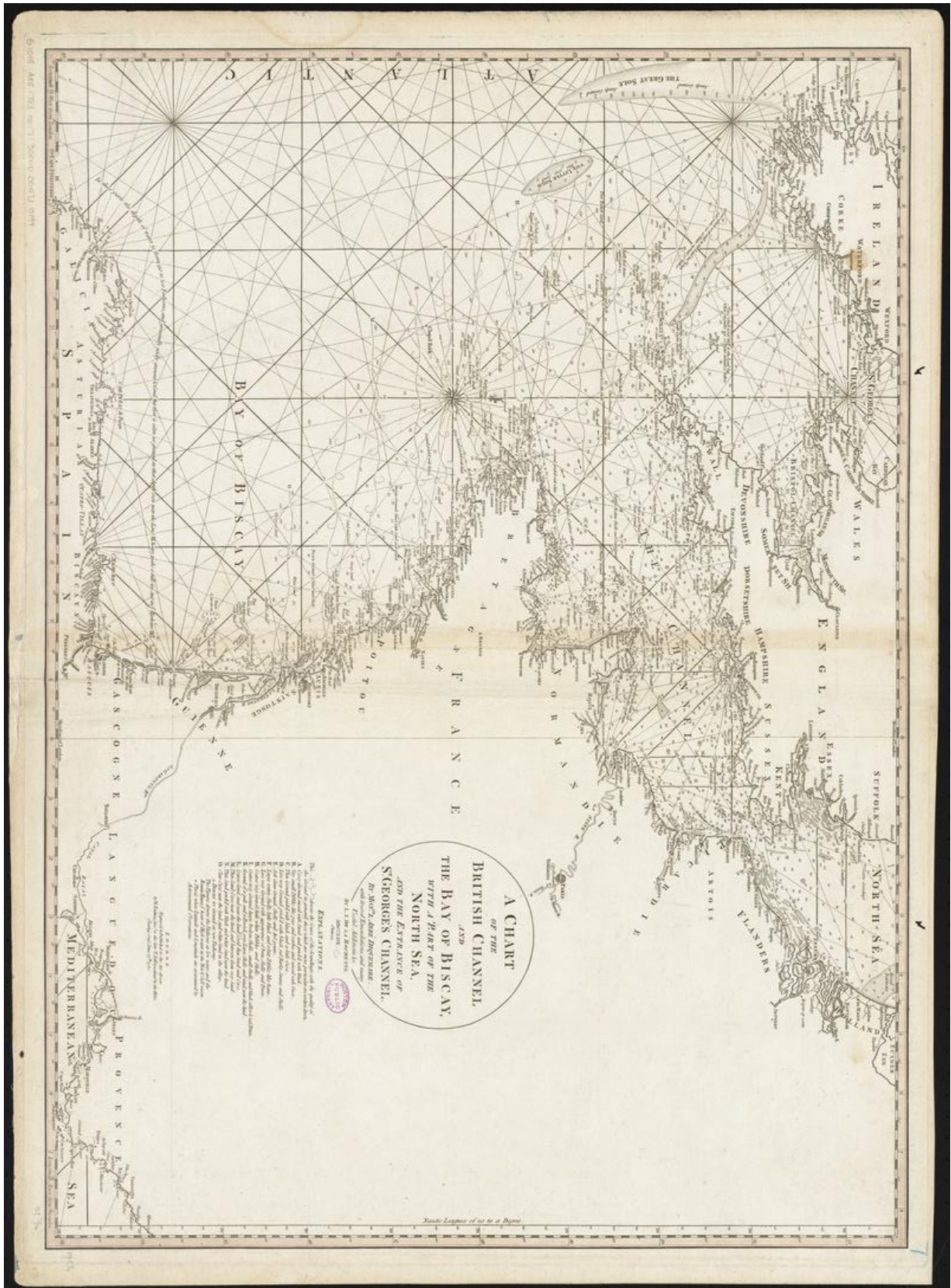


Plate 1.1: A chart of the British Channel and the Bay of Biscay, with a part of the North Sea, and the entrance of St. George's Channel - Norman B. Leventhal Map & Education Center; Source of image: J.F. Dicquemare, 1780

Casting off

*43°27'40.6" N, 3°48'06.0 W
Day 1, Ship's muster.*

Santander looked beautiful washed in morning's first light. A city of contrasts, the old and the new, rich, and poor, those who slept in beds and those like me who found themselves roughing it on bus station benches. 'Here for the race... let me sleep,' I pleaded with the cloth-eared security guard who had heard it all before. 'I know, I know...', he said shooing me onwards. Dishevelled and laden down with bags and crutches, I blinked my way towards the tall masts peeking out over red-tiled rooftops in the port town. Bells pealed from a church tower, heralding the day, while the aroma of coffee and churros impregnated the air as the city awoke around me.

With slow, careful steps, I found the berth and two similarly lost looking puppies, crewmates apparently. It was obvious that we, three, were no scurvy seadogs. Just the three of us, then. Bags thrown at our feet as we awaited the others. The longer haired dude smoked more than he spoke. The taller one spoke with a strong Spanish accent and a smile. I liked him instantly. After initial greetings, we retreated back into ourselves to harbour for an age in the unsure silence of strangers. Alone in my own thoughts, I looked down into the dirty, black water and beyond and wondered had I already revealed myself? Had they detected the extent of the difference between us? Of course not, I have spent a lifetime hiding in plain sight.

'What's this?' the smoker spoke up.

'Er, its my journal. I hesitated, I like to write poems... and shit,' I added the qualifier to make it more manly. Embarrassment notwithstanding, I continued, 'I like to lead a writing life. To recount my adventures. To make sense of all this.' I circled my arms and crutches around my body. I could feel myself reddening.

'I too write. In Spanish of course. Published twice.' He drew on a replacement cigarette. 'I am Miguel, a student of philosophy in the University of the Salamanca,' he said with discernible pride.

'And you?' I pointed my chin at the other.

'Soy Alonso. I study film here but am from Ferrol. This coastline, these are my waters. But you are not telling us everything. Why these ... er mulettas... como se dice?... Crutches.'

Realising he had prompted discomfiture, he changed tack. 'You said you are a writer,' he said, swiping my journal. Flicking through it he read aloud. My words punctured the air now sounding odd, foreign, and unfamiliar in his voice.

*'... Crippled and a warrior, this is my story.
Mine's no glory wrote in allegory,
Not wrought from palsy's purgatory.
Open me, see no brittle layers behind the hard.
I remain undiminished yet I am scarred.
Warriors, defined by scars someone said.
True, I wear scars, a decorated skin I cannot shed.
Ophidian, pink lines, ogham on the bark of my flesh.
A reminder of my resurrection and my tests.
Crippled and warrior I am, fully man, not less.'*

'You wrote this?' the one I now knew as Alonso said while turning towards the other offering translation. 'Tio!' replied Miguel the actual poet, 'Que pretencioso, este poema es muy horrible, ¿no?'

A poet-philosopher and a filmmaker! Always comparing myself to others I felt stung by my own inadequacies, my lack of accomplishment. What did I have? I left college with an average diploma in a subject I didn't love. No prospects. No ambition. No clue.

'What did he say?' I asked fishing for validation from these artistes.

'He said...'

A brief, interminable pause.

'... he said, is no bad, es muy bien!' Alonso smiled wanly, handing me back my battered notebook.

Mustered there on the quayside, two Spaniards and an Irishman, artists and a self-declared warrior preparing to do battle with rhyming couplets and the Atlantic Ocean! Each of us brought our own crutch. One Spaniard held onto cigarettes, the other a front of fearless resolve. I leant on my own actual crutches, keeping me upright, even though my legs were beginning to buckle. Nerves and a neuro muscular condition would do that to you. We heard their laughter before we saw them. All along the quayside it bounced like balls of derision aimed in our direction. The regular crew strode towards us with Teutonic confidence. Dutch elbows ribbed German sides, a gesture pointed towards us. And I for one couldn't begrudge them their loud guffaws for we three, the jonny-come-lasts, made for unconvincing shipmates. As the regulars drew closer, I tried to draw myself up to my full height in anticipation of another encounter with strangers who I would need to convince of my value.

My name is Niall Dempsey, and I am a disabled man. It has taken me over forty years to write those words. A form of denial, I have tried to hide and disown the full extent of my disabled identity from the wider world. Such self-repudiation involves fabrication and telling lies. These lies, told mostly to myself, impact on my relationships with people who matter. I have often preferred to let friendships and relationships slide rather than admitting who and what I am. Goffman (1968, p. 123) recognises this tendency amongst the stigmatised, which includes people with disabilities, to 'keep relationships distant... [reducing exposure to] unanticipated events that disclose secrets.' My secret is not even that dark.

I was born with a condition that means I am weak. My condition affects growth and development of the muscle fibres. I am a man without muscles. I have always felt ashamed of this. The shame is my own because I grew up loved and accepted by my family. I grew up in a 'House of Books' where my Grandad told me stories of 'heroes past.' I picked up cues from these stories about 'what it means to be a man,' – strong, brave, unflinching. My early years passed by immersed in books. I still read voraciously. Like the fairy tales I expect that I was waiting for the 'happy ever after.' The thing, I didn't learn from these stories is that this transformation doesn't happen overnight it is a continuous work in progress.

My own family name in Irish is *Ó Díomasaigh* meaning 'proud, arrogant, contemptuous.' I wondered, then and now, if these prideful traits were passed down from a named ancestor, *Díomasaigh*. I wonder who he was, if he was brave? If he was strong? I wonder if he had a

disability that defined him? My condition has always defined me. Even in its repudiation my disability contributes to the shaping of me and the experiences that have contributed to shaping me. Possessing an 'undesired differentness' (Goffman, 1968, p.15) meant that from a young age I had a heightened 'need' to conform to perceived societal masculine norms and a strong desire to simply fit in, to be liked. I tailored my personality accordingly for I learnt that society can often be slow to accept difference.

Looking through an autoethnographic lens, this thesis explores disabled identity and how this identity may interplay with shame, Freirean consciousness and Mezirow's Theory of Transformative Learning. In relating my experiences, I seek to highlight issues of relevance to congenitally disabled males. My aim is to make an authentic contribution to knowledge.

The '- ologies'

Bochner and Ellis (2016, p. 66) say, 'autoethnography inhabits a space between ... epistemology and ontology; between facts and meanings ... between a commitment to document the reality of what actually happened and a desire to make readers feel that truth.' I intend to offer 'sketched layers of experience' that 'provide a means of opening conversation about how to live.' (Bochner and Ellis, 2016, p. 211) I veer towards an impressionistic, evocative, autoethnographical methodology. In relating my lived-through stories, I invite 'readers to enter the text' (2016, p.211) as an insight into the congenital male disabled experience and how I sought to make sense of these experiences. I provide my stories and my understanding of my experiences as 'equipment for living.' (2016, p.211)

Phenomenology is the philosophy of experience where it is understood that the source of all meaning is in the lived experience of human beings. It is this *a posteriori* perspective that pushes me towards evocative autoethnography as a means of telling my own story. Autoethnography therefore is a shift from 'empirical methodologies, quantitative research studies and the objectification of human communication' which according to Bochner and Ellis (2016, p. 34), 'stripped context from life.' Evocative autoethnography can 'move audiences emotionally in order to engage questions of identity.' (2016, p. 61)

Bochner and Ellis (2016, p. 65) describe autoethnography as an 'autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural.' Epistemology is described as 'a branch of philosophy that investigates the

origin... and limits of human knowledge.’ Laible (2000, p. 686) Autoethnography, then, is an ongoing method of research which ‘moves between’ the epistemological and ontological trying to understand the meaning and experiences that shape one’s being. (Bochner and Ellis, 2016, p. 67).

From this, I glance at the critical theorists who promote the idea of critique. Habermas (1981) argues that knowledge grows with the ‘cognitive interests’ of social groups, one of which is emancipation. Emancipation overcomes distortions in knowledge and action, whereby an engagement with ‘critical-dialectal thought’ leads to liberation. This concept is important to my thinking on disability in terms of inclusion and acceptance. Freire (1970, p.19) asks who other than the oppressed can ‘better understand the necessity of liberation?’ Residual attitudes persist to ensure that a disabled man’s lived experience doesn’t equate to a ‘free’ life. For example, we are not ‘free’ to simply glide into a room without comment or scrutiny. As Foucault, asserts (1977, p.195), the oppressive, panopticon gaze is ‘alert everywhere.’

This gaze has an ontological impact. My ontological position derives from the conflict encompassing me - conflict with the self and societal perceptions of my ‘disabled self.’ It presages a shamed identity reflected in Goffman’s (1968, p.9) description of the individual who is ‘disqualified from full social acceptance.’ This emanates from society’s capability in creating a ‘social identity’ borne from a perception that ‘the person with a stigma is not quite human.’ (1968, p.15) As a disabled man, I am possessed of ‘abominations of the body – the various physical deformities.’ (1968, p. 14) and am subject to this perception. Naturally, I rail against this view. Goffman (1968, p.155) refers to this positioning as ‘stigma management’ whereby the individual ‘exerts strategic control over the image of himself.’ As Goffman (1968, p.111) astutely highlights, we have ‘many ingenious tricks’ to assist our disguises. Ontologically, this can often be detrimental to happiness, to our sense of being, ‘as we plot and plan and be wary, where others are merely having to be boys.’ (1968, p.110)

When I was sixteen and becoming self-conscious, a girl called Geri asked me, through her friends if I would like her phone number. She was from another school and wouldn’t have known ‘my history,’ the degree of my disability or that I wore callipers on my legs just the previous school term. Without considering her feelings, my response was ‘*nah, I have too many phone numbers.*’ I liked her and the strong possibility that she liked me. I believed that were she to find out about my shameful disability that she would have been repulsed. My defensive, ignorant response insured this in any case. I recall this as it is my form with friendships and

relationships. I struggle with this aspect of life. I know that relationships with others requires sometimes revealing vulnerabilities. But I cannot do this. Revealing the ‘terrible secret’ of my condition means admitting to literal weakness. Instead, in my head I hear the drums of an ancestral incantation. I hear the reminder; *‘Is mise an Díomasach. Is cumhactach mé.* I am the Dempsey. I am powerful.’

I am powerful.

I tell myself this lie often. Similarly, as it equated to admitting to myopathy, I wouldn’t in my youth wear t-shirts. Short sleeves revealed my weak, undeveloped arms. Shorts? Never! I also became a master of coming up with excuses, saying ‘no’ to fun if that activity risked amplifying my weakness. It became my ‘job’ to maintain the pretence of a relative normality.

Goffman (1968, p. 111) says ‘concealment often becomes cumbersome.’ I found the exertion all-consuming. Exhausting. Oppressive. And wondered why I was unhappy. It was from this nadir that I sought an epistemological and ontological reorientation of my points of reference. Freire (1970) indicates that liberation from an adversity is achievable. But how? Mezirow’s Transformative Learning Theory assists in examining ‘frames of reference.’ Transformation Theory allows me to ‘learn what we seek to learn as the result of transforming our frame of reference (Mezirow, 2007, p.10).’ Transformation occurs when we discover that our old frames of reference are ‘no longer working for us.’ (2007, p.11) As I reflected on my own early distorted frames of reference, I recalled an assertion by Habermas (1981) that all knowledge is subjected to criticism and I came to recognise that all that I knew about myself, my positioning and disability was flawed, erroneous to a degree and restrictive.

Ethical Considerations

Bochner and Ellis suggest (2016, p. 138) that ‘... all approaches to studying human behaviour present ethical dilemmas...’ Ethics are an important consideration in qualitative research. I am informed by McLeod’s (1996) directive to ‘avoid harm,’ as cited in Ricken (2015, p.19). Bochner and Ellis (2016) indicate that the narrative process is projected through a strong ‘I’ voice. This in itself caused me concern as I reveal ‘the hidden me,’ and the thoughts and words that emerge from this. Conscious of the ‘auto’ aspect of autoethnography I have a duty of care to myself. I became alert to this through the advice of my supervisors, Dr. David McCormack and Dr. Jerry O’Neill.

Bochner and Ellis, (2016, p.151) suggest ‘writing autoethnography inevitably makes the author vulnerable... re-experiencing a traumatic situation might mean you relive the trauma.’ In January 1998, cycling down the quays towards Heuston Station, I was run over by a lorry. My injuries were immense coalescing with an underlying condition to ensure that I haven’t, yet, recovered from them. I can remember the white burst of impact, a brief ‘coming to’ on the roadside and a jagged femur protruding through my red soaked jeans. I remember laughing through my delirium on my way into hospital and when asked why, replying ‘my mother always said ‘make sure to change your underpants every day. You never know when you will be run over by a lorry.’

The Irish mammy’s standard imploration.

I recall these details with clarity and this study causes them, and more, to well up inside me again. To this day, when traversing that part of Dublin, I avert my eyes from ‘the spot.’ Critical reflection, however, remains at the crux of transformative learning theory and this study is *causing*, not *forcing* me to remember and reflect. I make this differentiation because I am a willing participant offering full consent to ‘me’ to delve deeper. I embrace this writing life fully and know it is beneficial.

Medford (2006) outlines the writing process as one that could cause personal or professional difficulties to arise. Authenticity, however, required that I leant into Maynooth University’s ethics policy for social research carried out involving human participants. My narrative is based on actual events and features real people who live today. Maynooth University’s ethical guidelines (2020, p.12) state that ‘researchers have a primary responsibility to protect

participants from harm, physical or otherwise, during the investigation.’ I ensured that ‘due care’ was exercised to consider ‘the wider context and how any individual’s participation in the research may lead to repercussions for that participant or for others.’ (2020, p.12)

Bochner and Ellis (2016, p.152) outline methods to protect the identities of those whose role have an influence on the narrative, ‘autoethnographers write in ways that take the focus of the specific identity of who they are writing about.’ Personality is at the centre of my inquiry and ‘identity collapse’ and ‘blurring the storyline’ could confuse the narrative. ‘Ezbecca Kaselmay,’ for example, is a pseudonym. Conscious of the Maynooth University Ethics Policy (2020, pp.12-13) concerning, the right of confidentiality, I am confident that such pseudonymisation fulfils this requirement.

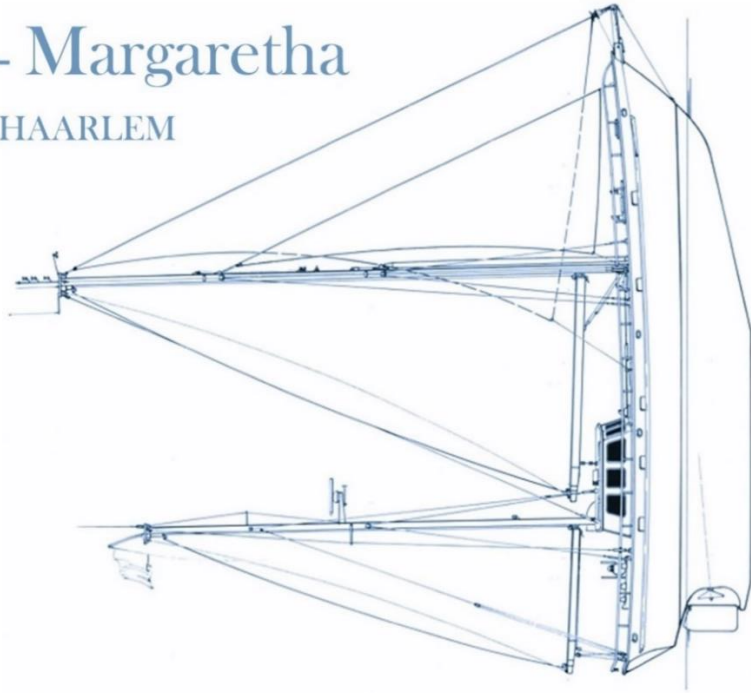
Grue (2021) makes me conscious of the effects that my story may have on others as it touches on dark, personal themes. At times, I hate seeing my refracted image. And other times I hate myself for hating myself. This image, however, is now reflected back to me as I ‘become’ my story. I am conscious of the ethics of inviting people into that story. I also have a duty of care to the reader that this narrative is authentic, informative, academic and entertaining.

CHAPTER 2



Anne - Margaretha

HAARLEM



Technical details

Mat. haul:	Steel
Length:	22 meter
Breadth:	5,5 meter
Draught:	2,8 meter
Displacement:	49 ton
Sails:	240 m ² – 515 m ²
Engine Daf 825	160 hp
1st Generator:	16 Kw
2nd Generator:	13 Kw
Guest berths:	10/11
Life rafts:	2 x 16 people
Life jackets:	16
Sailing area:	World wide
Mat. haul:	Steel

Owner: Anne-Margaretha Charters, (Heinz Wurschke & Greet Dekker) The Netherlands. Built to meet all official Dutch maritime regulations.

Inside

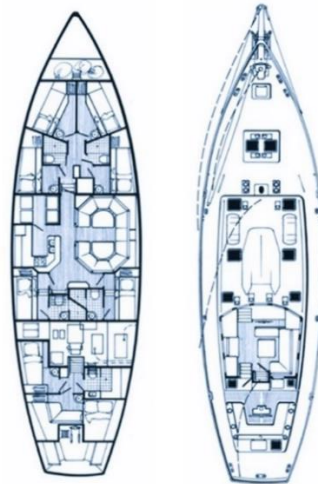


Plate 2.1: Anne-Margaretha, (2021), Source of Image: Greet Dekker (2021).

'I am what I am'

43°50'54.4" N, 4°24'45.0" W

Day 1, Ship's 'dining-in.'

We spent time getting familiar with the boat and each other while we grappled with the final leg of the Cutty Sark Tall Ships Race from Santander to Portsmouth. Our voyage would take us six hundred sea miles across the most treacherous, body of water in the world, the Bay of Biscay. The Atlantic's nasty backyard. The captain estimated with good weather we would 'need seven, maybe eight days.' Good weather, according to the captain meant high winds. Very different from the expectation of us habitual 'landlubbers' dreaming of sun-loungers and cocktails aboard a pleasure cruise to England. Later that first evening round the dinner table, we formally introduced ourselves. We were eleven, Captain Greet and her partner, Captain Heinz, their two elderly friends, Jan and Anja, permanent crew members Ari and Julius, his less robust brother, Haraald, a posh German called Schneider, the two Spanish dudes and myself. I was last to introduce myself. Alonso, however, interrupted my flow; 'Him? He is a warrior and a poet!'

'A warrior?' Captain Heinz exclaimed. I felt, maybe unfairly, that he wasn't a fan. But Captain Greet explained later with Dutch candour, 'No, he was just concerned that your crutches would mark his woodwork. You know, he built this himself.' I liked Captain Greet. Her innate, quiet leadership qualities made me think that we would have followed her anywhere, not least through a storm. This boat, the Anne-Margaretha was called after her

'A warrior, yes....,' I toyed with my food awaiting the red flush of embarrassment to wash over me. '...when I was a boy, I was very weak. My Grandad told stories urging me to be resilient, that I was a warrior and that my illness was my enemy. He told me about our ancestors, the Fine Ua Díomasaigh, fighting the invading armies of Strongbow who had conquered half of Ireland for their English king. With our battle cry, 'An Díomasach Abú,' we roared into war. We bate them! Their humiliation was so great that when they went back to their king, heads hung low, they said 'before our very eyes, they turned into wolves.' Grandad said this explains why, even today all Dempsey men have hairy backs, a reminder of our strength.'

'An Irish werewolf, huh?' said Schneider incredulously.

Maybe it was the wine that made me react. Low and laconic, I growled, baring my teeth.

Around home, there is a man nicknamed 'Bill the Beast,' and then there is 'Horse' (and his son, naturally called 'Horsheen' or 'Little Horse'). These nicknames celebrate agricultural and athletic vigour. The presentation of strength can often be seen as important to many males from my background. It can also be perceived as vital, integral, and essential. I was reminded of this in our lecture on Gender, 31st January 2022, when asked 'what constitutes a man?' a classmate replied, 'men tend to be stronger!' Another added, 'more muscle mass.' This is the norm, as Butler (2004, p. 52) advises that is 'actively conferring reality.' Societal reality differs from my own reality and as such 'this muscled norm' feeds my sense of shame. Foucault (2020, p. 184) describes the power of the norm in 'imposing homogeneity' which 'is established as a principle of coercion.' This explicates why I chose to cover up my arms, to hide my condition. As I couldn't fully disguise my physical appearance, I opted instead for the performance of a 'strong' masculinity. I adopted a mask of bravado, 'smartassery' and scholastic underperformance.

This aligns with Morgenrath and Ryan (2018, p. 5) who in considering the consequences for those, that do not meet the descriptions of their gender role, such as disabled males, cite Bosson et al, (2013) to suggest that men must continuously prove their masculinity to avoid 'negative consequences.' In a way, disability renders my masculinity 'precarious' and caused me to adopt a rigid sense of gender identity. I become the wolf and show my teeth in response to perceived slights regarding my condition. I concede that this is line with Butler's (1990) ideas around the 'performativity' of gender as I seek to portray a semblance of a strong masculinity. In always biting back, I assert my masculinity perhaps at the expense of my humanity, I promote 'pride' over humility. In owning up to this error, I concede that it is hard to be different. Everyone wants to belong, to fit in. Even non-conformists look for their tribe.

I think about this often.

Shame

Shakespeare (1996, p. 103) decries the ‘major obstacles to developing a positive and strong disabled identity.’ Indeed, I elected denial to live feeling shame. Goffman (1968, p. 18) describes shame as ‘... arising from the individual’s perception of his own attributes as being a defiling thing to possess.’ Society is slow to accept differentness especially when one possesses ‘an undesired differentness’ (1968, p.15) such as a disability. This instils a belief that the person is ‘reduced in our minds from a whole and usual person to a tainted discounted one ... especially when its discrediting effect is very extensive... a failing, a shortcoming, a handicap.’ (1968, p. 15)

Quin and Redmond (2003, p. 174) remind us of Mary Ellen Synon’s infamous Sunday Independent article, dated 22nd October 2000, she stated, ‘... these so-called Paralympics ... are, well, one hesitates to say 'grotesque.' One will only say 'perverse' ... It is not about finding someone who can wobble his way around a track in a wheelchair, or who can swim from one end of a pool to the other by Braille.’ Synon’s words remain reductive and humiliating. The intervening years haven’t softened her waspishness. Realising that the then editor of the Sunday Independent, a popular Irish broadsheet, saw nothing wrong with Synon’s vitriol, I began to examine their import. How many more were complicit in shaming we who ‘wobble?’ How many more found disability ‘grotesque’ and ‘perverse?’

I wondered were her views representative of society. That marginalising article remains emblematic of those occasional ‘assaults’ that come out of seemingly nowhere to hurt.

Growing up with my Grandad’s tales of ancient Greece, I was excited to go to see the film, ‘300,’ the story of the Spartan force who defended the Pass of Thermopylae against ‘a million Persians.’ I was saddened, however, by the portrayal, in the movie, of the traitorous Ephialtes, as profoundly disabled. Rejected by Spartan King Leonidas due to physical impairment he betrays his countrymen leading to their slaughter. In the original Greek telling of the story Ephialtes though ‘flawed in character’ was not disabled. Instead, Hollywood deploys disability as a crude shorthand indicating that the flaws in his body equate to his weak character and weak morals.

I reflect on these media portrayals.

Appropriately, Goffman (1968, p. 11) describes how ‘... the Greeks originated the term stigma to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier.’ He equates this to our modern-day conception of shame in that it ‘is applied more to the disgrace itself than to the bodily evidence of it.’ (1968, p. 11) I sense the origins of my sense of shame and my lack of self-acceptance in these vignettes which align with Goffman’s (1968, p.17) assertion that ‘the stigmatized individual tends to hold the same beliefs about identity,’ and even with his sense of being ‘a normal person he may perceive, usually quite correctly, that whatever others profess, they do not really ‘accept’ him and are not ready to make contact with him on ‘equal grounds.’ (1968, p. 17 – 18)

Questions linger within me. Are my experiences of disability defining? If so, have I *allowed* myself to blame my lack of success (however you may describe it), precarious employment status and relative poverty on my disability? Goffman (1968, p. 21) is alert to this, describing the ‘hook’ on which the stigmatised hang ‘all inadequacies, all dissatisfactions, all procrastinationsas a reasonable escape from competition but as a protection from social responsibility.’ I note this to allow my thoughts to hop to the Marxist origins of critical theory and its exhortations to the working class to land on the disabled, my identity group, who are in modern Ireland, the not-allowed-to-working class. I think, then, of my own struggles to get a full-time, properly paid, job and an ESRI report (Kelly, E. & Maître, B., 2021) which describes Ireland as ‘no country for disabled people who want to work.’ This report (2021) reveals that only 36 per cent of working-age disabled people are in employment, compared with two-thirds of those who are not disabled. I find myself intrigued with the assertion that ‘autonomy and self-determination’ are the ‘ultimate goal’ of Marxist thinking. (Fulcher & Scott, 2003, p.60) How do I achieve autonomy and self-determination without a job? Would a proper, secure, decently waged job allow me to take my place in society? Would it bring me societal and self-acceptance?

I tarry here to recall Goffman’s (1968, p.19) assertion that ‘the central feature of the stigmatised individual’s situation can be stated as one of the pursuits of ‘acceptance.’ Such acceptance is, however, not obtainable if I am to live in a bitter world of ‘small violins,’ collaborating with the negative perceptions of disability. Instead, I must look to the positives. Indeed, reflection allows me to recall a more gracious world where my disability has been met with wonderful acts of kindness, and acceptance. It is here I interact with the positive power of humanity and strive towards, ‘the vocation of becoming more fully human.’ (Freire, 1970, p.18) When I was very young, my mother couldn’t find trousers that would fit over the bulk of my callipers. I

remember the kindness of Tom Tuohy, manager of Farah Clothing, Galway. Mr. Tuohy kindly deployed his team of tailors and designers to ensure that if I couldn't fit in that at least 'I would stand out in style.'

Mr. Tuohy never charged.

I also recall my secondary school History teacher, Mr. Michael Shaughnessy who recognising that my disability meant that I was the only boy left behind, insisted, instead, that I travel to all the school rugby matches with him and the squad. He wanted me to belong, he wanted me to feel part of things. 'Shaugh's' remains my favourite teacher. Or years later living in Egypt, struggling in the heat on crutches, the many stools that came flying out from behind shop-stalls with implorations to 'SIT!' On asking why, the response could vary from 'because you are my brother' to 'you and I are thirsty.' With reflection, I know that the ugliness of Mary Ellen Synon is the exception rather than the rule. I know, on reflection, that people are inherently good.

Travelling slower than almost everyone facilitates seeing things with different pace and perspective. Hill (1990, p.23) informs in this regard, 'every adversity has the seed of a greater benefit.' I see things that a 'fast-strider' may miss. In seeing more, my disability makes me aware of the need to be kind. Reflection makes me ask, in turn, have I always been kind? Have I made a positive difference? I reflect on the responsibilities we, as a society and community, owe to one another. My disability doesn't absolve me from this responsibility rather it ensures that I aspire to it. I am inspired by Hill (1990, p.24) who reminds me that 'the greatest value in life... is loving people and serving them.'

A disabled identity

*44°20'36.5" N, 4°24'45.0" W
Day 2, Afternoon watch.*

'So, what do I call you? Cripple?'

'No.'

'Hop-a-long? Yes, that's it. It has ... familiarity.'

'Asshole.'

'Or, we go with Handicap?'

'Get lost.'

'I know, Quasimodo. Or some other famous handicap. Hmmm, I know Long John Silver, Its topical, ja? Aber, you are not 'exotic' enough for Long John Silver... I have got to call you something. What do I call you?'

'How about Niall?'

'Hey Irish,' the captain bellowed from the wheel. 'Bowsprit. Go.'

A shot to the arm. 'Hey, he gets to call you something?'

'Really, you can't see the difference?' With, a gesture resembling a smile I attempted to hide the coldness I was beginning to feel towards this person.

'I said, go! Now!' the captain loudly interjected.

I must have looked bemused. What was I supposed to do?

'Scan the horizon for any whale blow, expelled columns of moist air, indicate to me where... like the hands of a clock and I will steer our passage around....'

'I think, that's the most he has ever spoken in his life,' said Schneider.

'No, we had big excitement after midnight. I was at the wheel while you were snoring. Next thing, a pod of dolphins appeared, streaming alongside like torpedoes. Keeping pace. clicking nervously, scared of something. Julius didn't know what was happening so he went down to get the captain.

'... Just as the captain arrived on deck, we all heard it.' I paused for dramatic effect.

'Was zur hölle... Tell me.'

'We heard these explosive bursts of air... puh-wah, puh-wah,' I mimicked from memory. 'The dolphins suddenly disappeared just as this great big grey mass broke water to surface alongside us. So close. He may have been touching off our sides at times. And the coolest thing happened, he rolled over on to one side, almost as if he wanted to get a better view and I swear he looked me right in the eye. It was wonderful.'

Seeing that I had failed to find registry, I sought to clarify matters.

'It was a whale, Schneider, a huge, solitary, sperm-whale!'

'Doch! Irishman, schon. You eyeballed an actual whale? I know now what I am going to call you. I will call you Ahab. Captain freaking Ahab.'

Focusing on physical difference, Shakespeare (1996, p. 95) says, that 'disabled people are defined as that group of people whose bodies do not work; or look different or act differently; or who cannot do productive work.' It is useful to record Swain and Cameron's (1999, p. 71) observation that impairment is 'something we have while disability is a social construction based on the exclusion of those who have impairments.' Shakespeare (1996, p. 96) expands to say 'disability has been conceived as an outcome of social processes ...' In this way, differentness is stressed in terms of inability to perform tasks and an inability to conform to standards.

Reflecting on his own disabled childhood, Grue (2021, p. 88) ponders the response of 'a child who is not deviant' to the question 'what is the normal child?' His words whisper in my ear as I return to my own feelings of shame and embarrassment growing up, 'the shame over not being like the others, the shame of standing out, the shame of being a nuisance.' (2021, p. 88) This echoes a commonality of experience. Growing up, I recognised that being disabled meant ascribing to certain tropes. We are either noble in the stoic acceptance of our pain, a Tiny Tim-like 'brave little soldier,' unbalanced in our obsessions, 'Captain Hook,' or deviant, undesirables, like 'Quasimodo.' We were never the hero riding off into the sunset and glory.

Hacking (1986, p.236) suggests that in 'making up people' society attempts to assume agency in determining the path towards personhood. He continues to discuss identity formation created the term 'dynamic nominalism' which illustrates that 'numerous kinds of human beings and human acts come into being hand in hand with our invention of the categories labelling them.' I

am complicit in this where Grue (2021, p. 211) says, 'it's necessary that both the person who is stigmatized and the society around that person – the normal people – are in agreement that this person is not how they ought to be.' I recognise that in creating an inauthentic self that it was a retaliatory response to an unwanted societally constructed perception of disability. In my focus on the perception, I became subject to it.

This agrees with Foucault's (2020) assertions regarding subjection, that is the coercive, restricting act of losing control to the will of another. Reflexively, I can accept Shakespeare's (1996, p.100) warning that in 'accepting external disempowering agendas' in order to deny my disabled self in preference for a pretence or the performative version of non-disabled masculinity was 'not psychologically or socially healthy or progressive.' (1996, p.100) I become invested in myth, in history and a Dempsey clan identity as this identification allowed me to become a warrior fighting my condition. A role that made sense in the context of self-identity, defined by Giddens as (1991, p.53) 'the self as reflexively understood by the person in terms of her or his biography.'

However, in becoming invested in my history I began to recognise the extent 'of denial.' Shakespeare (1996, p.100) touches on familiar ground when he describes the 'considerable tensions and difficulties of managing information and interaction' that are expended when a person tries to 'minimise the importance of impairment in their lives, perhaps by concealment.' Denial is a tool to support claims of being 'really normal.' (1996, p. 100) Interestingly, Shakespeare (1996, p. 95) addresses the 'limited range of narrative devices and themes' that are available to people living with disability, to say that 'new stories are being told.' It is of importance, he says that 'we are creating ourselves for ourselves, rather than relying on the traditional narratives of biomedical intervention or rehabilitation, of misery, decline and death.' (1996, p. 95) According to Giddens, (1991, p.53) 'self-identity is not a distinctive trait, or even a collection of traits, possessed by the individual. It is the self as reflexively understood by the person in terms of her or his biography.'

Identity is complex. Shakespeare (1996, p. 95), likens identity to storytelling whereby identity 'is an aspect of the stories we tell ourselves, and to others.' In this way, I want the reader to know I am disabled, and I want it to be known that I have had extraordinary adventures – the two are not mutually exclusive. In writing my own story new layers of understanding are beginning to emerge.

Identity and badges

45°22'38.0" N, 4°39'34.9" W

Day 2, First dog watch.

'Of course, you weren't really werewolves. It was a story your enemy told to dehumanise you and to hide their shame in being humiliated, in their minds, by an unworthy foe. And it was a story you told yourselves to cope with centuries of loss, and defeat. A reminder that once you were more than mere men, you were strong in the face of danger and invincible in the face of your own mortality.'

'Wow Miguel, I couldn't have put it better myself,' I said surprised with his command of the language. He is a poet! 'And of course,' I added sarcastically, 'I was annoyed that Schneider couldn't see that too!' Alonso chipped in, '...and he made fun of my shirt.' He referred to his soft, baby pink with thin blue stripes Breton jersey. 'It wasn't always pink,' he said conceding that he had washed it with an errant pair of red socks. 'I won't discard it. My grandmama bought this for me as a gift. For this sailing. I care more for her love and kindness than the words of a snide, over-privileged, aristo-kraut.'

It seems we weren't too fond of Herr Schneider.

We laughed at our high words which seemed absurd given our present surroundings. Our first full day out at sea and one of the 'Northmen' had had an 'accident' destroying the boat's bathroom, 'the head.' Miguel exclaimed. 'This guy must be some kind of abstract artist or political prisoner doing the dirty protest.' We suspected Haraald. He had already looked delicate at the dinner last night while still in sight of shore. He had disappeared several times during the Parade of Sail, that marked the start of the race. As Miguel said, 'who could miss such a unique spectacle!'

'Of course, the northerners would give this dirty job to the Spanish,' protested Alonso, '...and Irishman, you are one of us. Everyone knows that the Irish are los Latinos del Norte.' Recalling Hercules in the Augean Stables, I welcomed the obvious acceptance of my 'compañeros.' I knew then that Captain Heinz in assigning this onerous task had separated, in his mind at least, the men, that is those who were capable, resilient, and strong, from the boys who were not! Strength grows from strength and belief grows from belief.

And I grew from this.

Many men tend to hide behind shields, symbols, and stories. I include myself in this regard. In ancient times, before literacy, people adopted symbols to convey messages, to communicate. The lion is one such pan-cultural symbol. Gaelic tribes adopted it as it relates a particular narrative. In tradition, a tribal shield featuring a lion denoted your people were of the royal Milesian race, the ancient rulers of Ireland. The Dempsey coat-of-arms features a lion and two swords, proclaiming our prowess in battle. We show the lion in favour of another clan favourite, albeit a less expedient one, the wolf. I prefer the wolf; before extinction in the 1770s it was native to this place. The lycanthropic wolf is also part of my myth, both clan and the personal, symbolising one who 'is' but has the potential 'to be something else.'



Plate 2.2: O'Dempsey's GFC Crest, (2022), Source of Image: Anon (c2022).

To the head of the clan, is bestowed the title, An Díomasach, or 'the Dempsey.' The coat of arms of 'The Dempsey' of Clanmalier, Fine Ua Díomasaigh, consists of a lion rampant, armed between two swords points upwards, one in bend dexter the other in bend sinister.

It is human, however, to hide from the monstrous, to hide from perceived difference. Similarly, I used to hide behind these myths.

They offered me comfort and consolation from the unpalatable and a false, foolish hope that I would be ‘cured’ of my disabilities. Reflection changes all this. Warriors only know war. I want more. I want to reconcile my identities. Working towards acceptance means that I do not hide anymore. Acceptance recognises that I have a new shield now.

It bestows upon me ‘privilege’ and it symbolises my right to park, to access, to be included.



Plate 2.3: ‘The blue badge,’ (2022), Source of Image: Niall Dempsey (2022).

To the ‘core’

When you have a neuro-muscular disorder no major movement is automatic – you have to think things out, and contemplate on the consequence of that action. You become conscious of the finite nature of your energy, that your ‘battery’ could run out without notice. Will I be able to make it back if I move too far? Will I fall? Where can I rest? What if there are stairs? Before wheelchairs and crutches when I was trying to perform ‘normally’ stairs provided the greatest risk of exposure. I was never able to climb stairs properly, I used my upper body to pull the rest of me along. A slow procedure which to my burning shame created human traffic jams in its wake. Ireland is a country of steps, stairs, obstacles, and barriers.

Grue (2021) resonates with me when he describes measuring his movements in millimetres. Similarly, I could estimate in the tens of metres how far I have walked in my life without assistance. It seems anomalous but I can cycle a bike and when I was at my strongest, I was able to cycle to college and back home after lectures a roundtrip of twenty-six miles. Not anymore, though my condition is described as ‘only mildly progressive.’ Prof. Tommie McCarthy, Biochemistry Department, UCC explained in a personal conversation that my condition is most probably, ‘Central Core Disease’ where fault lies in the ryanodine receptor gene which prevents muscle fibres from processing calcium. The condition is distinguished by the hollow cores present in the muscle fibres. These ‘central cores’ create instability and also have an impact on the mitochondria which generate cellular energy.

I assess my condition in terms of my ability to perform household tasks, for example, I can’t one-handed lift a full kettle of water. Because of the muscle weakness my legs do not fully support me nor allow me to stand up straight. I remind me of an old, ‘bockedy’ chair that we had in the kitchen. Bockedy comes from the Irish, *bacach*, meaning lame, unsteady, unstable. Similarly, I am a ‘bockedy’ man. I wobble, though I can’t stand for long. When I do, after a minute the gluteus maximus, my ‘posterior’ muscles, begin to sting. A burning sensation moves down the back of my legs. Trying to compensate the muscles above my knees, the quadriceps, attempt to kick in. ‘Oops,’ they announce quickly realising their over-eager error. They forget their instability which causes distress throughout my body. I may start to perspire heavily. Unstable, I look around for something to lean against. If nothing is available, I look for an out, a funny story or an apology so I may exit the situation. In this regard, I had a wry smile in reading Freire’s words (1970, p. 37), ‘self-depreciation is another characteristic of the oppressed which derives from their internalization of the opinion of the oppressors hold of

them.’ My mind then works on overdrive to find the least humiliating extrication. Like the duck swimming on a pond, there’s a lot going on below the surface!

Further, my back muscles lack the power to maintain my spinal skeletal system causing curvature. This is called scoliosis and it gives me discomfort. It also means that I have never stood at any approximate of my full height. Using the principles of the Vitruvian man, doctors measure my height from right hand fingertip to left hand and estimate my height to be 187 cm. My ‘little’ brother, Maurice, is 194 cm while my cousins Des and Michael exceed the 200 cm mark. In my wheelchair I feel as tall as them.

Paradoxically, despite it being the most obvious of disability and ergo ‘shame symbols’ (Goffman, 1968, p. 59), I feel less disabled in my wheelchair than without it. The wheelchair offers whole new worlds of freedom. I can ‘pop to the shop’ and stroll (correction, roll) to see what is around the corner. I don’t have to think about falling or an inability to complete simple journeys or tasks previously these were often beyond me. I love the freedom of being able to perambulate, to travel further using the residual power in my limbs.

I regret now that my earliest reactions to disability were negative distinguished by ‘denial’ to create what Goffman (1968, p. 31) alludes to as a ‘spoiled identity.’ Shakespeare (1996, p.99) rounds this out asking that we consider ‘the concept of identity as narrative, which focuses on the stories we tell about ourselves... which encompass plot, causality, and conflict.’ In this way, I recognise that I did what almost every child would do I [mentally] ran away from the thing that frightened me. And in itself that is normal. I now know that disability as it occurs in nature is a natural thing. Yet I was ashamed of this natural state of being. It was my ignorant shame regarding this ‘true’ nature of things that caused my suffering. The great Buddha refers to this suffering as *dukkha*, ‘a defining unease.’ I seek absolution from my *dukkha*.

My truth is that I had always chosen denial as my primary strategy in ‘overcoming’ impairment. Shakespeare (1996, p. 100) perfectly outlines the strategy of denial as often ‘associated with masculine expectations, it involves a refusal to submit to reality, and an attempt to regain a normal identity through superhuman activity and endurance, for example in the case of many sporting activities.’ And this is how I found myself and my stupid sense of arrogance, in the middle of the Bay of Biscay, on two crutches and with uncommonly weak limbs all under threat from an impending, thunderous, treacherous storm.

CHAPTER 3



All at sea with the methodology

*46°10'33.7" N, 5°41'52.4" W
Day 3, Forenoon Watch.*

Something novel, 'whale watch duty' entailed shimmying out onto the bowsprit, the very foremost point of the boat. You rose with the boat into every crest and skimmed every trough. Splash! It felt precarious even with the knowledge that a strong netting protected you from falling into the deep. It felt precarious because I don't have much power in my legs and limbs! It felt precarious because I am resolute in hiding this fact from the world. This balancing act risked exposure. 'Focus Niall!' I am supposed to indicate back to the wheel the sign of whales ahead. The whales themselves are not aggressive, Captain Heinz said, 'but they are inquisitive and if we encounter one there may be damage.'

Time passed slowly alone out on the bow. It gave me the opportunity to think about where I am and what I am doing. Out here, I feel like I am in charge. Feeling comfortable under the late morning sun I discard my shirt. Lost in my thoughts, I never heard Alonso coming up behind me, despite his burden of heavy waterbottles.

'You must drink.' he said before adding 'Que mono!' Immediately, I went to cover up and as I did so mulled over his expression which meant 'how cute' when addressing a child. Its literal meaning however is 'what a monkey?' I understood his intent with the next question.

'Are you the missing link?' he broadcasted. I am sure they heard him in France forty sea miles eastwards. 'I have never seen a person as hairy as you. And I am Spanish!' He threw his head back and laughed.

'Yes, I am hairy. I remember when I was a small kid sitting on my Grandad's lap for him to say, 'Niall, I hope when you grow up, you have a hairy back. I guess he wouldn't have been disappointed.'

'What a strange wish... you Irish, very strange!'

'Like I told you all at dinner, he said it was because it is a sign of strength in a man.'

'Well, then, you must be very, very strong.' Water delivered. He turned back towards the galley and his duties.

Eyes ostensibly fixed on the horizon ahead scanning for whales, I tried to refocus on my task. Instead, I found myself contemplating. Exposed, I had passed this test. My unmuscled, abnormal arms didn't even raise a flicker, he didn't notice and if he did, he didn't care. It began to sink in 'people don't care about my disorder.' In the great scheme of things it doesn't matter! With nothing around me but the 'big blue,' I thought of the smallness of my thinking and its outsized impact on my life. I contrasted this to the immanent majesty of the whales hiding somewhere ahead, the wonder of them.

Then I saw it, the tell-tale waterspout as a leviathan rose to skim the surface and to breathe.

Whale ahead. two o'clock, two o'clock, I roar back to the wheel, and with great exuberance wave my bare, useful arms indicating a new direction.

According to Bochner and Ellis, (2016, p.196) '... the goal of the story is to resonate with the lived experiences of readers, inviting them to use the depiction of one's person's experience to explore and understand their own.' However, when you have lived in shame it is hard to suddenly broadcast that which shames you. You are reluctant to shout 'disability, disability, disability,' when you spent a lifetime, hiding from it, denying it, the shameful creature locked up in the attic of your identity.

Yet, here I am.

Spilling the beans.

Autoethnography is the storyteller's research methodology, and I am drawn to it. Hesse-Biber and Leavy (2006, pp 189-190) describe autoethnography as a method that connects 'the autobiographical and personal to the cultural, social and political.' Autoethnography is 'an approach to social science which emphasizes the utility of narratives and vocabularies rather than the objectivity of laws and theories.' (Rorty 1982, p. 195) An autoethnographic practise is outlined by Bochner and Ellis (2016, p. 164) as examining and analysing 'context, culture, and self-other interactions in reflexive and introspective stories as we describe our thought, feelings, bodies, motives and experiences.' Bochner and Ellis, (2016, p164) continue that it involves observing and writing about 'others as we observe and write ourselves and we observe and write ourselves as we observe and write others.'

Coffey (1999) implies that autoethnographers are narcissistic and self-indulgent. But is it self-indulgence to describe an atypical life experience, one that is under-represented in the library? One that describes the disability lottery of being born with a neuro-muscular condition only to be later run over by a lorry. What are the odds? I have found it redemptive and restorative to write about my feelings in ways that could reach out and communicate to others about their own human experiences and expressions of living, their own subjection and struggles. My 'lived through,' experience of life as seen through the lens of disability has the potential, per Bochner and Ellis, (2016 p.30) to offer meaning to, and evoke meaning in, others.' This echoes Denzin, (1997, 2014) and Van Maanen, (1988), who describe the desire to tell an evocative story as writing from the closeness of experience in a way that connects with readers. I like the idea of connection however quiet fear rises in me that, ironically, destructs those allegations of narcissism. I realise to be evocative I must expose my vulnerabilities. I must strip myself bare to reveal and admit my weaknesses. All my life, I promulgated an inauthentic self-image to hide my core weakness. Now I am asked to 'be' vulnerable? It feels like a violation to suddenly invalidate my curated identity. I realise, on reflection, that a failure to do so leaves me as I am, in stasis, that is, not progressing, not making a contribution. I recognise that 'immobility represents a fatal threat' (Freire, 1970, p. 57) and to progress I must move forward. I must do this!

Bochner and Ellis outline (2016, p. 80) the role of vulnerabilities when describing the work of poet Audre Lorde (1984) to say she is 'afraid, because hers is an act of self-revelation fraught with the danger of vulnerability introduced when what has been silenced is put into language.'

And, with my discomfort an inner examination and negotiation returns.

The nightmare came back last night. Trapped, naked in a glass cube, Exposed. I was placed at the top of Eyre Square, Galway, unable to hide from scrutiny. Multitudes pass by as I cower and try to cover myself up. I am afraid, lonely and ashamed. The throng keeps coming, aware, staring blankly, judging, assessing. Cold, unblinking, appraisals.

Measured in milliseconds.

No one stops to ask if I am alright. Nobody offers me the protection of a coat or reassurance. Nobody even lingers as I am not worth the second glance. No one smiles.

I don't know if this dream had any meaning but I find myself stripping off layers, weak and vulnerable exposed under a harsh white light, my secrets splayed out on the surgical table of

scrutiny. It is a difficult position and lies in great contrast to my life of covering up. A life hiding. Is it appropriate to extricate this life from the shadows, to cast off those superfluous layers to reveal the truths behind ‘my spoiled identity?’ This dream is recalled on reading Grue (2021, p. 50) who describes the gaze as ‘... sharp and penetrating, but simultaneously dull and disinterested, that separates things that should not be separated and at the same time mistakes one thing for something very different.’

I struggle with my difference, not wanting to be ‘the other’ but I am not aligned, either, with the ‘dull and disinterested’ gaze impervious to the narrative of struggle, my own and the struggle of others.

Like Grue (2021, p. 50) I cannot be ‘the normality that stares at difference.’

Evocative autoethnography

Phenomenology is the philosophy of experience where it is understood that the source of all meaning is in the lived experience of human beings. It is this phenomenological perspective that pushes me to cast aside other forms of autoethnography to move towards the evocative as a means of telling my own story. Bochner and Ellis (2016, p.239) assert ‘it is no secret that autoethnography has a wide appeal to people on the margins.... [those who have been] silenced, objectified, left out or oppressed by value-free, disembodied social science.’ Autoethnography offers those like me a chance to say listen to us, in so doing we reach out to autoethnography’s ‘capacity to heal, change, validate and engage others through self-reflexive and self-critical accounts of experience’ (2016, p.239) For those of us who feel we don’t have a voice and/or when we do speak up are quickly hushed we can place a value on evocative autoethnography where the experiential stories offer analysis through inference whereby ‘ the story itself should always occupy a prominent position.’ (2016, p.186)

The stories are our voice.

This has the added value found in Roberts (2015) suggestion that engaging in an autoethnographic exercise is healing. In presenting myself as the storyteller, I seek to ‘connect and communicate’ with readers,’ to represent ‘reality in order to develop theory and reach generalizations.’ (Bochner & Ellis, 2016, p.185) In this way an evocative story well presented,

is in itself ‘theoretical,’ allowing the reader to experience the story as impactful and ‘to find in that experience a truth about your life.’ (2016, p.186)

Theory can’t always fully address the disparate ifs and ands that constitute the messiness of life, in friendship, in relationships and conversation between intimates. I am conscious that I write in a fashion that would test the traditional boundaries of academic writing when I portray friendship, and intimacy in Chapter 5. Bochner and Ellis, (2016, p.51) suggested this slant which ‘emphasized and underscored subjectivity, self-reflexivity, emotionality where story-telling is placed at the center of our project which meant some of the conventions of academic reporting would have to change.’

A standard approach wouldn’t have worked.

Throughout this thesis I set the reader a big task. I ask the reader to simultaneously remember and forget that I am disabled. This is particularly so in Chapter 5 as I describe ‘a day in the life’ experience with somebody I greatly care for and the implications of that as we negotiate a relationship from platonic to romantic and back again. I set the reader the task to formulate their own questions. Autoethnographical passages, as Bochner and Ellis (2016, p. 225) reminds us can appear as ‘a conversation’ but can be read as ‘a meditation,’ whereby internal dialogue comes to resolve issues. In this way Chapter 5 uses ‘autoethnography as a form of meditative consciousness.’ (2016, p. 225)

In presenting the narrative, ‘as is’ I am reminded by my supervisor, Dr. Jerry O Neill of my role as ‘the curator’ of my own story,’ that is, I present stories in a way to highlight certain issues. I think of my experiences navigating life and relationships from childhood callipers, to crutches and an adult embrace of the wheelchair. The stories selected have a purpose. They assist me towards an understanding of these experiences and allow me to offer my stories as an avenue to help others reach their own understandings. I think of how all these experiences have shaped and still shape me. Nonetheless, I should be cognisant that ‘telling stories has a double meaning: our stories should have force and produce a strong effect, and we as authors should be aware of how we are telling them and how form affects content.’ (2016, p. 194)

Truth

46°10'38.0" N, 5°42'01.2" W

Day 4, Middle watch.

We huddle close together, back-to-back for warmth. It's frightening how like a flick of a switch the warm days turn to accusatory cold nights. Especially so out at sea where the damp seeps through to deposit layers of wet onto your skin. I could hear his teeth chattering despite the wind. The gusts of wind meant our whispered replies found expression in loud bellows. Still, I didn't know how to answer when he asked, 'So, Captain Ahab you have a woman?' I noticed that they were all calling me this now.

'Is that a proposition, dude?'

'No! I mean stupid of me to ask, like how can a cripple like you have the love of a woman' he guffawed.

I went silent and my mind went to a warmer, kinder place. I thought of back there and then.

I remembered my ability to hold your gaze. Your interesting, interested gaze.

'You are not a man,' you said... It was edge of the sofa stuff.

'Not a man?' I protested. 'No man from your country could endure what I have endured. And hold down a job and buy a house and....'

'... and you interrupted, 'Niall, you should leave.'

I pulled my crutches together and pushed myself up. At the door you touched my arm and said, 'Just so you know for the next time, if there is ever a next time, when a woman from my country says you are not a man. It is not an admonishment. It is an invitation.

I clip-clopped down the stairs, post eviction, smiling the words to myself, 'You think I am a man! You think I am a man!'

My inquisitor reminded me of his presence with a sharp elbow into the side, impatient for the answer that perhaps I was reluctant to provide.

'Yeah?' I said into the storm.

'Exactly, your silence says it all! What woman would want you?'

'It's... its...' I stammered trying to recover that warmth.

'As I thought, who could want you? Seriously, even if they did, do you have a special device or something for, like, 'doing it.''

'Yeah, I do. Your momma!' I replied, lowering myself to allow the crude to match rude.

The exchange as detailed, above, didn't take place on the *Anne-Margaretha*. I don't ascribe the words to anyone aboard. A criticism of autoethnography is that it has been called a 'fabrication,' a flight of the imagination, that the stories 'aren't true.' Bochner and Ellis addresses this (2016, p. 231) in saying evocative autoethnography is construed as 'a hybrid form of expression and inquiry that sits between social science and humanities, between facts and values. The primary focus is on meanings, subjectivities and feelings' I understand that autoethnographies work between these foci to depict experiences 'as believable, life-like, and possible staying close to the facts as we recall them.' (2016, p. 172)

The preceding dialogue or variations of it, have consistently pockmarked my adult life. It is not my aim, however, to document actual events, as they occurred, but rather to indicate the meaning in them. This work seeks to look to the meaning behind why I am unable to cast off such experiences. Yin (2011, p. 93) stresses the focus 'on the meaning of real-life events, not just the occurrence of the events.' This vignette or versions of it, play on loop in the actuality of my life. I include it also because it does not just reside in my past it is also part of my present and will feature in my future. It is little consolation then that Goffman (1968, p. 31) states, 'since the stigmatised person is likely to be more often faced with these situations... he is likely to become more adept at managing them.' A prurient society will always question me, a disabled man, and my intimate, the able-bodied companion of a disabled man, as to the practise and intimation of our affections, the mechanics of that relationship. Our private intimate lives are public property, subject like all aspects of a disabled life, 'to comment and scrutiny.' She will be asked and has been asked, 'how can you be with him?' The prurient manner this question is asked has a meaning, as does the feeling of freedom and regularity by which the always ever-changing, non-disabled interrogator holds to ask it. Shame. And yet, it is I who feel ashamed? 'Adeptly,' I just smile.

Writing autoethnographically requires bravery as I reveal my inner thoughts and feelings, the ‘the hidden me.’ I am conscious of Grue’s (2021, p. 61) admonition that ‘... to cloak something in words is to adapt it to the expectations of one’s listeners and readers to their world.’ I see this as a reminder that my own words must be representative and authentic. I am aware of Bochner and Ellis (2016, p.170) contention that it is common for ‘humans to control and manage their instinctive reactions. And fit into whatever is deemed appropriate or civil in the society in which they live.’ Further, I am mindful of Goffman’s (1968) suggestion that we all become self-censorious to ensure what is acceptable is portrayed, offering a version of the truth that is more palatable. I shocked myself on re-reading my disrespectful, ‘your momma,’ comment. My instinct was to delete it. To do so, however, would equate to a betrayal of the reader. Not an excuse for my response, it was said to sting in response to the provocation. It is ugly and it makes me look ugly. However, this is my truth, as presented. I have never outwardly shared these thoughts before. I kept them in like a choke in the throat so letting them out is liberating. Autoethnographic writing helps me to understand my situation as these stories ‘attempt to bring vivid and resonant frames of understanding to one’s anguish and pain.’ (Bochner & Ellis, 2016 p. 69)

I recount this conversation to show that sometimes, when you are disabled, it seems like non-disabled people ‘have no filter’ when talking to you. The things they say! ‘They’ can land their ignorant curious blows in a manner that they wouldn’t countenance with other sections of society. At weak moments you find yourself responding in like-manner. Goffman (1968, p. 16) warns against this as self-defeating proclaiming that ‘his defensive response to his situation [provides] a justification of the way we treat him.’ The best response therefore is exemplified in Michelle Obama’s words (2016) ‘when they go low, we go high.’ She infers, therein, that we are better than that and in responding tit-for-tat, that I lower myself, I denigrate my education. In lowering myself I lose.

According to Bochner and Ellis (2006, p. 111) autoethnographers aim to show ‘people in the process of figuring out what to do, how to live, and the meaning of their struggles.’ In this way, my thesis aspires to be ‘an artful illusion of the real.’ Singer (2013, p.242) In curating my life-story into a compact narrative, I have had to include and exclude events, ‘characters,’ thoughts, feelings and ideas, however I have maintained the narrative truth which means ‘that the story is truthful to life as it is lived.’ (Bochner & Ellis, 2016 p.232) In line with an adherence to narrative honesty I adopted the writing strategy of a realist ethnographer with ‘...collapsed events, changed the time-line, left out events to protect [myself and others] and... reordered

the events into scenes that had a particular focus, were not repetitious, described a particular activity.’ (2016, p.172) This is continued by Poulos (2021, p. 5) who says autoethnographers ‘often rely on various methods... including narrative analysis, artifact analysis... journaling, thematic analysis description ... context, interpretation and storytelling.’

These events and people are real:

The actual race occurred in 2002. Anne-Margaretha still sails the seven seas with Captains Greet and Heinz at the wheel. Whereas their names have been changed both ‘Miguel’ and ‘Alonso’ are, warm-hearted, funny, and personable artists and documentary film makers. They live in Spain.

‘Ezbecca Kaselmay’ was and is an important agent of positive change in my life. She remains a close friend. Once upon a time we went, every day, to a café whose name translates as ‘home’ for shisha and tea, and in long conversations under a distant sun we discussed everything under that sun. Freire (1970, p.62) describes the transformational importance of dialogue ‘as a means of changing the world.’ Through, our daily discourse, collaboration, and imploration she made me see ‘a better way.’ She taught me her language, and how to laugh at my own po-faced pomposities to become ‘a softer,’ more relatable person. It was she who taught me without irony that a disabled man should consider Nietzsche’s words (1911, p. 64) ‘... one must first be firmly set in oneself, one must stand securely on one’s own two legs, otherwise one cannot love at all.’

And it was these words that prompted nascent acceptance.

Literary style & language

I like language, linking words to other words, and piecing together a body of text like a giant jigsaw puzzle, every word in the right place. I see language as art in line with Bochner and Ellis, (2016, p.54) who maintain ‘language reveals and conceals... we do things with words: and the things words do to, and evoke in, us.’ I am, however, used to ambiguity in language. It reflects the speech patterns of my native place, where the answer is never, ‘yes.’ This also reflects my disabled childhood where I never spoke the truth preferring to speak in the language of opposites, ‘it doesn’t really hurt,’ ‘I am ok,’ ‘it is fine.’

I like language when spoken as a code, with subtexts almost reflecting the macaronic, to be taken as a riddle to solve, a language imbued with semiotics, metaphor, and signifiers. I want my ideas to reflect Bochner and Ellis’s (2016, p. 34) desire to present the writing as ‘tantalizingly suggestive and generative.’ I describe threatening waves as ‘cowled’ to reflect the curve of a monk’s hood, that is what they looked like to me, and to suggest the exaggerated, version of our ‘aysht Galway’ accent that we, my friends, and I, accentuate to pronounce ‘cold.’

In this way, a theoretical interpretation of my approach suggests a tendency towards formalism that is placing an objective emphasis on the techniques, and other functions that comprise the literary work. I find expression in those qualities that renders the text artistic rather than functional. I like to think that the narrative is the hero, and the hero is the narrative who relays my meaning subjectively, objectively, overtly and covertly. In trying to find my voice I paid attention to the formalist approach favoured by Shklovsky (1925) who wants us to ‘feel’ objects. By witnessing the sensation in small things art is created. Shklovsky (1925) suggests that literary language, in emphasising the expressiveness, attempts to make the reader perceive the mundane and routine in a new and fresh light. It draws the reader into appreciating the meaning and possibility in the small thing.

Shklovsky’s ‘defamiliarization’ (1925) highlights the difference between literary language and ordinary, communicative language to describe our experiences in a strange and new way to permit the reader to interpret their experience of the world with new eyes.

I like this form and as an example would describe a kiss as ‘she placed on my lips the sensation of song’ (Dempsey, 2019, p.132) where the alliterative ‘s’ sound is suggestive of the action.

In this manner, I choose my words.

Art is creative thought in tangible form. Even words brush the lips. A kiss is not just a kiss. It can be a million things to a million people.

For me, this line of thinking shows the importance of context, which Bochner and Ellis (2016, p. 219), believe starts by ‘giving priority to the stance of the storyteller.’ In aligning yourself thus it allows you to find refuge in a story, using it for reflection, to think ‘with’ rather than ‘about’ the story. (Frank, 1995)

Metaphor

I chose this period of my life and this nautical experience for its personal transformational properties and for its metaphorical impact as the setting for this thesis. I recognised early on that I would be difficult to tell my story without metaphor as I feel a residual resistance to disclose my vulnerabilities. Metaphor could be the feint that helps me to open up. Reflection on my disabled life reveals that I have never spoken directly and frankly. I speak to entertain, to obfuscate and to hide. Metaphor assists in overriding this inability to talk directly about my feelings regarding my disability, weak muscles, callipers, crutches and scoliosis, the things that shame me. Metaphor allows me to reveal albeit in an oblique manner. Metaphor also allows us to ‘think aesthetically’ and assists in focusing on meanings ‘that can take readers into the heart of lived experience.’ (Bochner and Ellis, 2016, p.34)

As I was telling, retelling, reading and rereading this story to myself, I became mesmerised by the notion of the ‘sea’ itself. I came to consider similarities between its depths, vast below the surface, and the mystery hidden in all of us. Like most things hidden in the depths, the secrets I didn’t want to share about my disability were not, ever, supposed to see the light of day. In ‘running’ with this idea, I came to see that my encounter with the whale had a huge, personal significance. Like the whale, my disabled identity, my spoiled identity, belonging to those depths seem, now to have found their way to the surface.

Further ethical considerations

*46°10'44.0" N, 5°41'57.2" W
Day 4, Afternoon Watch.*

Following a sudden squall, a sticky, briny guck washed over the foredeck. After a close inspection, the captain ordered me to clean it up lamenting that it wasn't 'whale vomit.' Detecting my revulsion, he added, 'it's as valuable as gold, they use it in the perfume industry,' Not knowing whether to believe him I settled down to the task, I quickly found something comforting in the mindless repetition as I pushed the hand-brush hard along the line of the wood removing the mess. I began to admire nature's artistry in following whorls and knots of the woodwork. Lost in the task, the repetitiousness of it all proved hypnotic and transportive. I forget my burning neck, the ache in my arms, I forget the sea, the boat. I forget to remember. I remember the hardwood court back home.... Back home, the lads and the hurling.

'...best of three!'

The thwack of the ball. I drive it long, down into the middle of the tussle twirling between Pat and Stephen, They spin and turn trying to outfox each other, wheels whirling hurls wielded, wristily and loose, to manipulate the ball away from the other and into space. Stephen emerges from the rut, deftly switching the ball behind his rear wheel into the path of Shane who angling forward despatches the ball in a flurried blur. 'GOOOOAAALLL.'

More 'solid than speed,' I roar a load 'yesssss!' from the rear-guard, a fly goalie, and wonder then to myself why interrupt the flowing sense of all this, this contest, as young and not so young lads play ball, the joyful, lightness of it all with my inquiry and inquisitiveness. I want to ask a million questions. About shame. About disability and exclusion. Heavy stuff. Not appropriate today. So, I park my curiosity as Gabe 'snakes' to my left anticipating the long high pass. Bearing down on me I wonder if he will slide the ball back across to Pat on the other wing in a nice one - two. I hold off as he strikes, my reaction slower than my eye as I watch the ball fly past me to rocket off the back wall. He scores and I am deflated momentarily until I see the joy on his face. We were in national school together, way back before our respective injuries and I had invited him here tonight for his first tilt at wheelchair hurling. And his first goal. Against me! Blast-it!

'Next goal wins!'

Dr. Jerry O'Neill advised me against making 'claims that are difficult to support.' I extrapolate from this that without support a claim is just a hunch. My biggest hunch is that mine is the 'everyman voice' of the congenitally disabled male experience. Collison et al (2016) indicate that only one to three percent of the disabled community are congenitally disabled, that is born with a disability, and that our experience is very different to those who acquire disability in later life. I deduce that this is due to the effects of othering, low esteem and exclusion on the child's development as opposed to acquired disability in later life when the personality is developed. I wanted to 'chat to' a small sample of congenitally disabled people who might corroborate my voice. I thought of my Connacht Wheelchair Hurling teammates, however, the coronavirus had curtailed sport and contact.

I found the lonely pandemic had a major impact on my research in that in my deep dive into the reflective I found myself in dark places. I found that I often returned to those seemingly long-resolved standard, disabled questions involving 'why?' and 'why me?' Grue (2021, p. 140) again resonates, 'it isn't my fault that my body is the way it is; it isn't anyone's fault. It's no secret that my body is the way it is. I am allowed to feel sad that this is so.' It became restorative to be told that it was allowed to express my loss to myself and to mourn.

The process of mourning is important as a 'first step' in moving on.

I must move on.

I realised that I didn't want to subject my teammates to a mental self-investigation on our return to training. It occurred to me that I would have to ask them to reveal their 'vulnerabilities,' just as I am working through my own. Why subject them to this? Struggling with this idea from an ethical perspective, I found myself reverting to my oldest friends.

– Books.

I always found comfort, and companionship in books. In looking for corroborative voices, I found myself enthralled by the voices in the wonderfully written; '*My left foot*' by Christy Brown and Jan Grue's '*I live a life like yours*'. Not alone were they great reads by great writers but these writers were also congenitally disabled with mobility impairments. It is no wonder then that I kept finding resonance and recognition in a myriad of common experiences.

Disparate similarities that kept cropping up. Words and ideas that struck a chord. These commonalities became the basis for the material and topics that I could write about. For example, Christy Brown (1972, p. 42) describes the aftermath of his first swim; *'I gasped as I felt the cold, icy water rush over me. My brain became confused; everything melted into a watery blur.*

I was beneath the water for a second, rose, went under again, rose once more ... Jim hauled me ashore.

I lay there, panting but triumphant.'

Grue (2021 p.170) also explores the emancipatory potential of swimming; *'My legs were swallowed up by the sunlit water. Yet another layer of anxious expectation and disappointment was washed away.*

I swam in the cool water beneath the warm sun. The distance between thought and action was gone.'

Even though, like those men, I too cannot walk properly, I am a swimmer. And in the water, my worries and anxieties are also washed away.



Warriors wear helmets ...

Plate 3.1: 'Warriors wear helmets' (2022), Source of Image: Niall Dempsey (2022).

CHAPTER 4



Conscientização & reflexivity

*47°56'21.0" N, 9°21'41.7" W
Day 5, Forenoon.*

I look in the mirror and don't necessarily hate what is reflected back to me anymore. I like the 'salt and pepper' on my face but wonder should I shave it off or not. Captain Greet got word over the shortwave that BBC Portsmouth want to interview me when we hit land, a few days hence. She didn't say if it was radio or TV, but I am hoping the former. I have a great face for radio, boom, boom. Despite joking to myself, I am nervous and question their "freakshow" interest in 'a disabled sailor.' I question labels. These past few days, I don't 'feel' my disability, but I don't have the 'sea-legs' to earn the title, 'sailor' either.

I pick up the razor and hesitate as I look at the beard that looks back at me. I like the way it frames my face hiding a right hemisphere weakness. Is this why I grew it in the first place or was it laziness? True, you can hide behind a beard. Am I still in hiding? I look from my brine-burnt nose to my right eye and the slight tell-tale droop. I notice my hair has grown long since I left Ireland months ago. I run my fingers through it knowing that, like all my Mam's brothers and Egan cousins, that one day, possibly soon, I will have none. I like my hair even though the mirror now confirms that I am growing forehead and think of another from long ago. Samson lost all his strength when Delilah had his hair shorn off. I think how I never had physical strength and in losing my hair wonder what the parable is in that.

I begin to wonder what if science found cures for my neuro-muscular disorder and male pattern baldness, but I could only choose one. The dilemma! Which would I choose? My youthful hair was ballad black and equate it to my sense of self and my confidence. I reflect on my life thus far and realize I have travelled far to be bothered by these trifling things. I have travelled well! Was it inner belief that got me this far, on callipers and crutches and for a time, a wheelchair? Has that belief and confidence stalled? Not at sea. Not out here. I am competent and capable. I am moving forward. I see that I am beginning to recognise my achievements and to revel in them. I am beginning to find acceptance even though in my reflection I see the flaws.

Freire's (1970) concept of conscientização inspired Mezirow to investigate the importance of critical reflection in an adult's learning process. Indeed, Mezirow overtly acknowledges (2007, p. 12) this in developing Transformation Theory stating 'Freire pointed out a crucial missing dimension' from which derives an 'empowering learning process' encompassing 'awareness,' and 'action' whereby 'traditional frames of reference' may be changed. (2007, p. 12)

This crucial dimension is conscientização. It is useful to note Freire's (1970, p.10) concept of 'conscientização' as 'learning to perceive social, political and economic contradictions, and to take action against the oppressive elements of reality.' Freire (1970, p. 82) outlines his position to say 'humankind emerges from their submersion and acquire the ability to intervene in reality as it is unveiled... conscientização is the deepening of the attitude of awareness characteristic of all emergence.' I understand from this that consciousness is necessary to change lived reality. Freire (1970, p.10) cites Hegel's Phenomenology of Mind, 'it is solely through risking your life to achieve freedom that you can attain it...' It is in this struggle that we achieve consciousness. In my case, the struggle was literal. Freire's belief (1970) is that this life risking struggle is hewn from two competing ideas, one trying to dominate the other. It was a case of 'do I accept my disability?' (peace) or 'do I continue to fight it?' (war).

Looking back, like Pinocchio, I felt that I wasn't a real boy! Pinocchio was made of wood while I was made of spindly limbs, metal rods and straps. Shameful denial led to the development of an inauthentic personality. Denial is antagonistic to the Freirean concept of reflection. Freire, (1970, p. 77) says 'when people lack a critical understanding of their reality, apprehending it in fragments which they do not perceive as interacting constituent elements of the whole, they cannot truly know their starting reality.' Freire (1970, p. 82) contends that human beings *are* 'because they are in a situation.' It would have been helpful, had I from an early age, begun to reflect on my own 'situationality' to the extent that I was 'challenged by it to act upon it.' (1970, p. 82) To understand my situation, I must reflect on this sense of shame as 'my starting reality.' Critical reflection helps people to recognise their situations as neither 'a dense, enveloping reality or a tormenting blind alley' but as an objective-problematic situation' (1970, p.82) that is something that can be solved or resolved through praxis. Freire, (1970 p. 82), says humans can improve when 'they not only critically reflect upon their existence but critically *act* upon it.' Mezirow (1990, p.1) explores this in saying 'critical reflection involves a critique of the presuppositions on which our beliefs have been built. Further, Mezirow (2007, p. 12)

contends that critical reflection changes ‘the way we see the content of a problem or see our see our process of problem solving.’

Etherington (2004, p.19) supports this describing reflexivity as ‘an ability to notice our responses to the world around us ... and to use that knowledge to inform our ... understandings.’ A new understanding allowed me to counter an undercurrent of shame and appreciate the interesting aspects of differentness that form character. Shame resembles the stranglehold of creeping ivy. Control is emancipatory. Mezirow (1990, p.1) assists claiming ‘critical reflection involves a critique of the presuppositions on which our beliefs have been built.’ He says reflection allows us to rectify ‘distortions in our beliefs and errors in problem solving.’ Reflection retracts the creeping ‘ivy’ of shame.

I began to play with the idea that maybe I was ‘meant’ to be disabled. Exploring this, disability seemed more palatable on discovering disabled sports, supports in purchasing a car, assistance at the airport - all new and emancipatory possibilities. I came to realise that in accepting my disability, crutches, and a wheelchair that I was traveling further than my previously curated identity had allowed.

Before a semblance of acceptance, I had always said ‘no’ to hide the secrets of ‘my spoiled identity.’ Then, one day, out of the blue, my phone rang. It was my friend, Tomas Thompson. He continued, ‘There’s this adventure, a great big sailing race from Spain. The Cutty Sa-....’ I could not have foreseen what was to come but I interrupted him to say, ‘Yes!’ This ‘yes’ prompted an odyssey, and a subsequent life that encompasses Spain, Egypt, Oman, Wales and home again. I have found that in saying ‘yes’ and making myself open to new experiences and adventures that I wasn’t just meant to be disabled.

I was only meant to be me.

Whoever that ‘me’ may be.

Journaling & memory

My primary method of collecting data involves a deep dive into the self to trowel through the rich treasure trove of knowledge that lives in us all. I dug out dusty boxes of my old notebooks to see what I had written before with only minor degrees of embarrassment! Strangely, it felt reassuring to read those old words recovered from a rich seam of old emails, replies and stories greeting me again like an almost forgotten, nerdy, traveling companion. I sourced data from memory prompted through mediative practise and introspection. Today, I record my ideas, and contemplations in a daily journal. This has proved beneficial in corralling my thoughts, putting them in order and creating a space for reflection. I was aided by direction from Bochner and Ellis, (2016, p. 171) who reminded me that the ‘goal was to turn these chronological notes – this happened, and then this – into an evocative tale that had the elements of a good story...’ Further, I realised that this process allowed me ‘to stay true to the experience as I had recalled and recorded in my notes.’ (2016, p.171) As I traversed meanings and feelings, this ‘back and forth’ between journaling and memory offered me ‘the greatest possibility of deep understanding.’ (2016, p.171)

Further, I used the resources of the Maynooth University Library, to read and research autoethnographic methodologies. I was also introduced to the research of DACE alumni, Keith Ricken (2015) and Sharon Conlon (2019) which I found helpful. I found their methodological layouts hugely instructive as I sought to acquaint myself to this non-traditional approach to research. I was very moved by Sharon Conlon’s powerful and evocative writing.

Throughout, the year, I reacquainted myself with the pleasure of reading. Everything, I came across that mentioned Goffman, Mezirow, Freire, and Foucault met with a neon highlighter. I became friendly with the voice on the other end of the phone at Charlie Byrne’s Bookshop, Galway. They recognised my joy, when such a title was in stock and my despair when another title was unavailable. They were most helpful in their recommendations. Indeed, my ‘library,’ is growing as I embrace ‘this writing life’ and, amongst others, I was able to source, Christy Brown’s and then, Haraldur Thorleifsson’s life-stories. They led into the work of Jan Grue. Parallel lives, almost! When Grue (2021, p. 139) wrote these words they could have been my own; ‘I had expected long psychoanalytic work, digging down through tightly packed layers of history in order to understand myself. But I had already done this work ... I had been working through these thoughts for several years. I had simply neglected to acknowledge to myself that I was doing so.’

Grue and Thorleifsson! Who are these men? They wear many hats - creatives, thinkers, speakers, and thought-provokers. They too share myopathic diagnoses, conditions of weakness. Their accounts make me realise that I am not alone. Further, it seems 'my kind' tend towards the creative and artistic. It is, also, of great interest to me that these men are contemporary Vikings from Norway and Iceland respectively. I laugh at this because the Ua Díomasaigh fought with the Norse at the Battle of Clontarf against the then High King of Ireland, Brian Boru (Mathews, 1903). It seems we, a Gaelic-Norse alliance, continue to share adversity today. I find this noteworthy because my autoethnographic inquiry is not just the study of self, it investigates ancestral memory, the stories my Grandad, Michael Dempsey, told me which I retained and utilised to makes sense of my condition and its implications.

Naming things

*49°24'16.3" N, 9°48'03.8" W
Day 5, First dog watch.*

The Anne-Margaretha is 90 foot long and he seemed half that. That's big! The whale had returned and in swimming alongside us. He has turned over to one side to facilitate, one eyed, an investigation and observation. The whale was studying us! As I looked into 'the beast's' eye, I saw sentience and I saw a soul. I spoke to him.

'Forgive me, Whale for calling you 'beast.' It's reductive. It's just that in Irish, we call you, an Míol Mór Mara, the big sea beast. It's strange but here, in the natural world, I find myself feeling things as Gaeilge, in Irish, in terms of words and emotion. I am not even strong in Irish. Still, I believe there's a connection in there somewhere. It is lovely to meet you. I feel I can trust you with some of my secrets. May I tell you them, tell you who I am?

My name is Niall Dempsey. My dad was Sean and his dad, my grandad, was Michael whose own father was named Patrick Dempsey. From them, it is only a hop, skip and a jump back to 1690 and a Jacobite soldier, who injured in the Battle of Aughrim, (Each Dhroim, 'Horseback Ridge') pulled into the side of the road at Knockatogher (Cnoc an Tochair, Hill of the Causeway) near Athenry (Ath 'n Ri, The Ford of the King). We have been thereabouts ever since. That man was part of Patrick Sarsfield's cavalry. Sarsfield was a great hero back home and his granny was Eileanór Ní Dhíomasaigh, 'sure, wasn't she one of our own people.'

Around home, our wider family were once called 'the black Dempseys.' Dad wasn't sure if this referred to our hair colouring or the intent in our hearts. He meant this as a joke.

I live through my ancestors. I know through them I am supposed to be a fighter. I have always fought. I was born with a neuro-muscular condition that leaves me weak and then I was in a serious accident. With all your power you can't imagine what it means to be powerless. Me, as a man I find it shameful. I fight this too. I have undergone many tests but they didn't really propose a diagnosis. When the results finally came in, I was called to a clinical meeting with a geneticist to discuss the implications of my condition. She told me that 'the mutation occurred at conception, so you are the first in your family with this' and that the results indicated that the condition was 'autosomal dominant.' The dominant aspect implies that a single copy of the disease-causing mutation present within me is enough to cause the disease in future generations. I could pass 'the-thing' onto my children! So, at the age of twenty-seven, I decided as 'the first' that I would be 'the last.' No other Dempsey boy would bear this condition no Dempsey girl would pass it on.

Niall, Sean, Michael, and Patrick Dempsey. We are descended from Gaelic kings. Derived from Díomasach, our name has a meaning, coming from the Irish for 'proud, and arrogant.' As nomenclature goes, these are redundant traits in someone with a humbling neuro-muscular condition, most probably, central core disease. I say, most probably, because the clinicians can't give me a diagnosis without using non-committal terms such as 'most probably,' and 'largely undiagnosed.' As a result, I can't say, precisely, what it is that afflicts me, just that it is part of me and unlike my stories, these stories, it will die with me. But of all my stories, meeting with you and your kind makes for the best and fills me with great joy. Thank you for that. Now swim off and in the deep keep safe and keep my stories with you to tell them to your friends. Because it is only in the telling that these stories may live on.

It wasn't easy deciding not to have children. In not having children, I have marked myself out as 'different' and in this differentness I lost sight of myself. I once saw, wrongly, a societal perception that is not true, that of a disconnected, barren, and unsexed, 'handicapped' man. Still, I made this decision and yet in making it, I recognise that I became damaged as a result, marking, in some cases destroying, my relationships and my attitudes towards relationships. Often, I am painfully reminded that no small voice would call me 'Dad.' I am mindful to what

Goffman (1968, p. 14) calls the ‘plight of the discredited’ which acknowledges that ‘stigma is transmitted through lineages and... family.’

‘... Disabled Dempsey, bockedy man.

Walking, rolling, toolbox man.

Sticks and spokes,

Wheelchair squeaks

to speak,

Disabled Dempsey, bockedy man.

Disability carries a weight and a mark. In not wanting this for my own children, (I speak of them as if they are not figments of my imagination!) I feel that I have disavowed my ‘responsibility’ towards the continuance of the Dempsey name into the future. There is a pressure knowing that the name originates from an 11th century prince of the Royal House of *Ua Conchobair Failghe* (Mathews, 1903). Sometimes, I feel alone and lonely in separating from ‘my people,’ that is those who came before me and those who could have come after me. This loneliness is, I feel, all part of my condition. It will anonymise me if I let it. Instead, I must look for names and record these names. It is my contribution! Writing and recording is a form of preservation. Naming things facilitate the construction of the worlds we inhabit, naming things create connection within those worlds.

However, without consciousness you can’t fully identify that thing, the baseline matter that ails you. You must name a thing to make it almost tangible. As Freire (1970, p. 61) contends, ‘...it is in speaking their word, that people, by naming the world, transform it,’ Bochner and Ellis (2016, p. 54) concur saying, ‘naming brings things and ideas into existence, making them real and lasting.’ If I am to, in Freirean parlance ‘exist, humanly,’ it would require praxis, that is ‘to name the world, to change it.’ (1970, p.61) Once named, the world in its turn reappears to the namers as a problem and requires of them a new naming.’ Freire asserts (1970, p. 61, 62) the importance of naming things in so doing creating form, a form that can be altered and transformed. He expands (1970, p.64) on this to suggest that naming is essential to dialogue even if that dialogue is with the self. Dialogue (1970, p. 61) is ‘the way to achieve significance as a human being.’ A raised awareness allows me to acknowledge a problem; that I was born with a neuro-muscular disorder that leaves me weak in a localised ‘world’ that not only seems to lionise masculine strength, but seems to expect it. I can acknowledge that I was not always

strong enough to rise above this problem embarrassed by my condition. In this acknowledgement I can begin to name the ‘problem’ that I inhabit and rename it. It is in this naming process that my transformational journey accelerates. In naming my ‘problem,’ I can know it and it is only in knowing your ‘enemy’ you can defeat it.

Who or what is my enemy? I ask, it seems, couched still in this ‘warrior language.’ My enemy is not my condition, my ‘largely undiagnosed,’ neuro-muscular disorder. My enemy is the negative attitudes towards disability, my own included, which encompasses shame, stigma, and exclusion. I came across Callus (2017, p. 603) critique of Greenstein’s (2015) *Radical inclusive education: disability, teaching, and struggles for liberation* in which she identifies the call, ‘... for a rhizomatic view of embodiment in which bodily differences are seen as just that – differences – rather than as impairments.’ I had to look up the meaning of rhizomatic, which apparently suggests that when learners adopt a fluid approach to changing circumstances, adapting their understanding of a task or problem to explore more organic paths towards resolution that learning becomes more effective. I liked this instantly. This approach bending and growing with events and consequences implied a greater flexibility to life and learning than I had been experiencing. It meant discarding a rigid set of beliefs. Instead of being formulaic, life was a freewheel rather than a tram ride set according to fixed lines. It meant that I could separate my identity from my impairment which I name, ‘the-thing-that-is-wrong-with-me.’ A mouthful, I have shortened this to ‘the-thing.’ I recognise that ‘the-thing’ springs from my condition but is really the attitudinal response to it i.e. shame, low-esteem and a lack of confidence. In naming it, I can address and correct it.

In line with Mezirow’s (2007) outline of his transformation theory this proved ‘emancipatory’ and ‘transformative’ in that it freed me from the ‘constraints and distortions’ in my frames of reference, i.e. ‘the structure of assumptions’ through which I created meaning. Mezirow (2007, p.11) describes this as ‘one that is more inclusive, differentiating, more open to alternative perspectives and more integrative of experience.’ Reflection was the impetus to this process whereby I transformed an outdated frame of reference, my negative feelings towards my disability for a more developed and nuanced one.

It is important to reacknowledge the humanising power of reflection. Freire (1970, p. 78) calls the act of reflection ‘a dialectical movement of thought’ that can resolve false perceptions of reality. My condition ‘most probably’ has a proper name, but we don’t know it yet. As it transpires, my uncertainty in this regard doesn’t really matter. I am not my condition, and it is

not me. We are separate entities with separate identities. I am certain that my own name, however, is Niall Dempsey. My friends and family also call me Nialler, Mary-Niall, Demps, Díomasach, ‘the Master of Disaster,’ and Sticks. I like all of these names. They reflect ‘me,’ and the people who have made ‘me.’ They reflect the evolution of my frames of reference, an appreciation of the experiences and adventures that contribute towards the layers that form the composite of self. They reflect an acceptance of self. This is congruent to Hacking’s ideas (1986, p. 236) which state ‘numerous kinds of human beings and human acts come into being hand in hand with our invention of the categories labelling them.’

Collison et al (2021, p 61) discusses the meaning of the word ‘able,’ in the context of *disability* versus *able-bodied*. They quote Judy Heumann (2021, p.61) who describes the term ‘non-disabled’ as more neutral serving as a reminder that many people ‘at some point in their lives.... may have a temporary or permanent disability. It is assumed that names are just words. Collison et al (2021, p. 61), again quoting Heumann, point out that ‘words matter’ and that with nuance, naming words become an important conduit towards a societal acceptance of physical differentness. Our preferred words, labels and names reconcile language with the world we choose to inhabit. In choosing and discarding labels, that is in naming and renaming, the self-acceptance that emerges opens up new and exciting possibilities.

Disorientation

*49°24'18.4" N, 9°47'54.8" W
Day 6, Afternoon watch.*

*In the absence of security
I made my way into the night*

Really! The thoughts that strike at the point of peril. Focus... wait, what's the next line? At that, wind and wave strike knocking me sideways. I am compelled to ask, what am I doing? I like to test myself but singing 'fast love' in the middle of the Bay of Biscay, in a storm...

The wind accelerates.

'I need help.'

Hostile, white-crested, seawater slaps the deck washing over the bow. Brine skitters and slops out the gunnels. Listing heavily to port we bob precariously amidst charging seas and howling wind, I have never felt so insignificant.

Since I was a kid wearing hip-high callipers to cry help was anathema to my sense of being. Back then, I would walk home from school by the railway to avoid offers of a lift home from well-meaning neighbours. Stubborn, I wanted to make my own way. With leaden legs, every odd step a victory, I made it! Yes, 'help' was always a dirty four-letter word. Men don't ask for help. I am as capable as any man.

A loud snarl. The cowled sea looms over me.

'Help,' I force myself to roar, 'Help... Captain ...Captain Heinz...'

He steps into the deluge as I slump over the wheel in distress.

'It's alright. Go.'

Before descending to my bunk, I roared an obscenity into the night. But the stars and all the elements knew I was defeated so the gesture was empty. It was then I reflected and thought of the alternative, of the ten others aboard whose lives at one point were in my hands. No, I did the right thing. The sea makes us honest. Then, through intercession comes change, I realise that weakness is relative, and it is in admitting weaknesses that we become strong.

The realisation that I had no option but to ask for assistance was, in Mezirowian terms a ‘disorienting dilemma.’ It runs contrary to my sense of self to request assistance as it seems to confirm my disability. However, disorientation prompted something in me, a constituent of Transformation Theory which according to Mezirow (2007, p.10) occurs ‘when we find that our old ways of understanding are no longer working.’ Mezirow (2007, p.11) describes Transformation Theory as ‘an explanation of how our frames of reference influence the way we make meaning’ and how ‘transforming’ old frames of reference may create empowerment.

According to Mezirow, (2007, p.11) frames of reference have two dimensions. The first aligns to our ‘abstract habits of expectation,’ or our ‘meaning perspectives.’ These ‘shape, delimit and often distort our experience.’ (2007, p.11) These meaning perspectives are subject to ‘three sets of filtering or constraining codes’ that affect our ‘understanding of reality.’ (2007, p.11)

- Socio-linguistic – ‘ideologies, norms, language codes.’
- Psychological – our innate characteristics and early experiences that are personality forming.
- Epistemic – our application of knowledge, ‘learning styles’ and ‘sensory preferences.’

The second dimension refers (2007, p.11) to the accumulated ‘beliefs, feelings ... and attitudes’ that formulate ‘meaning schemes’ or ‘our points of view.’ This second dimension assists as I examine impressions and representations of disability in the context of the self and wider society, in terms of shame, stigma, accomplishment and achievement.

Transformative Learning, the altering of our frames of reference, requires ‘critical reflection.’ Mezirow describes (2007, p.12) this as ‘assessing one’s assumptions and presuppositions’ to change meaning perspectives or ‘habits of mind.’ Critical reflection presents itself in different forms. Mezirow (2007, p.13) describes objective reframing as ‘a pause in the instrumental action of problem solving to identify a new metaphor that redefines the problem.’ From an autoethnographic research perspective my interest lies in that other dimension, ‘subjective reframing’ which Mezirow (2007, p.13) states ‘pertains to critical self-reflection and involves the examining the reasons why we have acquired distorted or dysfunctional frames of reference.’ For me, the key word is ‘critical,’ which differentiates *reflection* from *memory* and gives the concept the potency and agency to enact transformation. Subjective reframing, Mezirow (2007, p.13) asserts ‘is involved in the most significant transformative learning experiences.’

Mezirow (2007, p.14) states that there are two kinds of learning:

- *Instrumental* – ‘task orientated ... useful in controlling and manipulating environments’
- Communicative – ‘involves intentions, values, feelings and moral decisions’ assisting learners in their expression.

Transformative Learning values the communicative as a greater agent of personal change in that it is centred Mezirow (2007, p.14) around ‘assisting learners to negotiate their own meanings and values rather than to passively accept social reality as defined by others.’

Dr. David McCormack impresses upon me his ‘profound belief in the power of conversation.’ Discourse (2007, p.14) is an important method of ‘establishing the validity or justification of a problematic belief.’ I recognise in Mezirow’s (2007, p. 14) words that discourse is helpful in that it is analytical in ‘weighing up evidence or reasons in support of or opposition to a deeply held point of view.’ Discourse works best according to Habermas (1988) when participants who trust each other and are equally conversant in the subject matter work towards achieving harmony through mutual understanding. According to Habermas (1988) the conditions inherent in good human communication are those that promote clear, unbroken and rational discourse namely, an equal of exchange of ideas and information partook in abundant trust, respect, and empathy without coercion.

Kitchenham (2008) conflates Transformative Learning with deep, underlying changes in the fundamental ways we think, feel and act which invariably result in alterations in perspectives and in our meaning schemes. The basic frame of reference that dominated my formative thinking was that my disability was ‘shameful.’ As such, ‘help’ was an ugly concept tied to an uglier reality. ‘Help’ confirmed my weakness, my piteous and dependent state. Strong men do not ask for help. Evidently, this was not a safe frame of reference in the middle of an Atlantic storm, requiring urgent reassessment, reformulation, and change. My experience at sea illustrates Mezirow’s belief that Transformative Learning involves disassembling those deeply held convictions formulated in childhood and allowing critical reflection to facilitate transformation with a more appropriate revaluation and understanding.

Mezirow (2007, p. 11) suggests learning occurs ‘as the result of transforming our frame of reference.’ defining a frame of reference as ‘the structure of assumptions with which we interpret our sense perceptions and by doing so, create our experiences’ (2007, p. 11) in the process. Transformative Learning is the rational methodology of altering frames of reference through critically reflecting on these, perhaps outdated or faulty, ‘beliefs’ and ‘consciously’ acting to implement change to address new experiences. This is an important brick in the epistemological and ontological wall towards self-actualisation, not just in the academic realm, and a completion of thesis but in the practicable achievement of life goals.

I am interested at an ontological level on what it means to be free because as a disabled man I feel shackled by my condition, not just in body but in mind, by my presuppositions and the attitudes of wider society. I see links between the disabled experience and the enabling power of Transformative Learning as described by Mezirow, (2007, p. 11) ‘as emancipatory in that they free learners from the constraints and distortions of their own frames of reference.’ He continues to say (2007, p. 11) that a ‘fully developed and dependable frame of reference is one that is more inclusive, differentiating, more open to alternative perspectives and more integrative of experience.’ That is, Transformative Learning allows me, through critical reflection to recognise the pivotal role my past has played in shaping my present, yet in so saying how certain beliefs and presuppositions have limited the actualisation of my full capabilities.

I would argue from a disabled viewpoint, that the disorienting dilemmata we encounter, namely, an attitude that sees us as incapable, ‘burdensome,’ undesirable and ‘unemployable’ warrants further scrutiny. Transformation in the personal or wider societal sphere is necessary while societal perceptions and beliefs regarding disability remain damaging. As Goffman (1968, p.17) asserts we ‘believe that of us, which society holds to be true.’ Morris (1991, p.28) expands on this saying, ‘the messages we receive are very strong and clear and we have little access to different values which may place a more positive value on our bodies.... Our self-image is thus dominated by the non-disabled world’s reaction to us,’ These views filter through to inform our frames of reference. Accordingly, I value Mezirow’s ideas as it allows us to disregard those attitudes in favour of a better, more affirmative sense of self. This is congruent with Goffman’s (1968, p. 146) outline of the ‘nature of good adjustment’ which requires that ‘the stigmatised individual cheerfully and unself-consciously accepts himself as essentially the same’ as everybody else.

Mezirow (2007, p.22) states that the following phases of meaning may assist transformation.

- i. A disorienting dilemma
- ii. Self-examination with feelings of fear, anger, guilt, or shame
- iii. A critical assessment of assumptions
- iv. Recognition that one's discontent and the process of transformation are shared
- v. Exploration of options for new roles, relationships and action
- vi. Planning a course of action
- vii. Acquiring knowledge and skills for implementing one's role
- viii. Provisional trying of new roles
- ix. Building competence and self confidence in new roles and relationships
- x. A reintegration into one's life based on conditions dictated by one's new perspective

Choosing my personal *abhorrence of assistance* as confirmation of my unwanted disabled status I relate the impact of Mezirow's (2007, p. 22) phases of meaning to my own sense of shame arising from that disability:

My initial 'disorienting dilemma' was (i) in realising that I had a neuromuscular disorder and nothing would change that on an incremental level. Feelings of guilt and shame (ii) seeped in to formulate an alternate, inauthentic persona who looked to the warrior myth, to impersonate what I was not, namely, strong. This necessitated (iii) a 'critical assessment of assumptions' as to what it means to be a boy with congenital weakness, the antithesis of the localised masculine ideal, lionised in agricultural and athletic endeavours. It became performative in that I was always 'grand' and never admitted to pain.

Later, I recognised (iv) that my 'discontent,' i.e. faulty frame of reference was not psychologically sound, as it rejected the authentic self and those 'identifiers' such as a wheelchair, potentially beneficial but perceived as 'stigma symbols,' Goffman (1968, p.59). I came to realise that my proud pretence was isolating, exhausting, and unsustainable, accordingly a change was required. I had to (v) explore options regarding my attitude towards assistance, that is when, who and how to ask for it, an example includes my early attempts to assemble my wheelchair as a situation that may incur offers of assistance, I (vi) used my pride as a guide i.e., what would be least shameful to identify participants who I could allow 'into my story,' who I could ask for assistance.

My course of action (vii) involved attempting the task myself and if unable to complete same, I was hypocritically happy that any struggle would invite an offer of assistance. This (xiii) maintained my masculine masquerade in that I was not outrightly requesting help but may 'deign' to accept your assistance should you offer. Social interaction (ix) involves a level of skill in negotiating language, etiquette, and societal norms. I likened my position to that of birds in a mating ritual, that is the offer and acceptance/rejection of assistance involves relinquishing power by one of the parties. Dismissing this on reflection, it became transformative realising that an offer of assistance is neither dehumanising nor a sinister power-play but a necessary social interaction. With this acceptance (x) came a willingness to seek reintegration into society, through the normalisation of a previously misconstrued social identity now permitted 'based on conditions dictated by fresher, and a more nuanced perspective.'

Aboard the Anne-Margaretha, I realised that my pride and shame were dangerous in the face of a raging force ten storm. I could have stuck to my principles refusing to countenance assistance, battling with the boats steering and the tempest and jeopardised the lives of everyone on board in the process. Seemingly engulfed by mountainous waves, it became obvious as we listed heavily to one side that I was literally 'out of my depth.' It was while faced with this manifestation of real power that I questioned that frailty inherent in all humanity. I came to know that true strength resides elsewhere beyond the meat and flesh of musculature, it is found in the mind, in character and in integrity.

I recently read Humphreys' (2022) Irish Times interview with Michael Schur who in discussing contractualism described morality as where everything we know is derived through relationships with other humans. I understand this to mean that through contact with other humans that we become human. Accepting assistance is social in nature ergo, I become fully human in asking for and receiving help. This agrees with Vygotsky's (1978) theories defining the importance of social interaction in the formation of meaning. Accepting assistance, it would seem, is the intelligent thing to do!

An awareness of Mezirow's (1991) Transformation Theory has given something nebulous, my shame, a form and shape. It is now something I can call out, address, and accept. It is in this tacit acceptance even in the face of 'labelled deviations' (Goffman, 1968, p. 149) that I can find liberation.

However, the cynic in me asks if Mezirow's theory is mere placebo, the educational version of a snake-oil salesman offering faux-remedy and quack-redemption. Do I believe because I want to believe? Questioning things refocuses on the centrality of reflection. Yet, I wonder if this is a good thing. Is it not bringing me back to dark places? Does reflection not threaten those slivers of hope, my masquerade, that allows me to stand, no pun intended, my ground. To stand firm, to stand here. To stand still?

But I do not want to stand still. I desire what lies beyond.

This desire is at the crux of the human condition. Lear (1988, p. 1) quotes Aristotle who says, 'all men, by nature, desire to know.' I want to *KNOW* how I can realise my potential. Reflection turns my own gaze inwards, to examine my feelings of shame, which I can see now is my true disabler, not some murky, myopathic diagnosis. Shame holds you back from higher achievement and self-actualisation per Maslow's (1943) hierarchy of needs. Reflection encourages me to celebrate accomplishment. I am a published 'writer,' I own my own home, I can swear in four languages and bless myself in three. Life? I have done ok. So why, still, do I feel shame?

Illeris (2014) says that it is 'implied' that if meaning perspectives and frames of reference have been established that they must have an origin. If my governing frame of reference is negative i.e., a shameful regard towards my disability, I must ask where this comes from. I had a happy, 'typical' childhood, yet I developed negative attitudes to my disabled condition at a young age. I reflect on this and recall a set of encyclopedia that were a childhood steadfast. In addition to a 'bank of knowledge,' it also gave me my first negative, character-forming, impression of disability! Culpability lies in, Volume H (for '*Handicapped, rehabilitation of the* ') which read (1976): '... were often cruel to persons with handicaps. Someone who was unable to hunt or fish was no help to the tribe in getting food. If his physical condition made him look strange to the others, they often felt he was involved with devils or evil spirits. Handicapped persons, even small children were often cast out from the home...'

Significantly, I read this as I was being bullied at school. It reinforced the bully's message. 'They' were older boys, third years, who taunted me with a modified cartoon theme tune, 'He-man, he-man, you are nothing but a walking toolbox man!' referencing the clank of my metal callipers. They were skilled at this, chanting the song when they found me alone, emphasising

‘nothing!’ When it became obvious that I was familiar with the words, they would just whistle the tune. I hated my first year in secondary school and these feelings seeped into how I viewed education. Feelings magnified by my own self-hatred and shame. As a result, I became a people-pleaser. I wanted to be an insider and popularity was more important than academic performance. I feel Mezirow’s (2007, p. 14) gentle reproachment when he reminds us that ‘learners must negotiate their own meanings and values rather than to passively accept social reality as defined by others.’

I linger on Mezirow’s (2007, p.16) highlighting of the ‘devastating distortions created by inequalities’ when I recall subsequent adult trauma. In the aftermath of a serious accident these distortions allowed me to align my shame with a previously unidentified societal attitude which allowed me to further bury my disabled identity. In the wake of this trauma, I was now no longer ‘merely disabled,’ I was ‘in an accident.’ It was a subtle shift, a sleight of words but it facilitated ‘passing.’ (Goffman, 1968, p. 58) I see this as a suitable point to ponder my shame regarding congenital disability in that society offered ‘the accident survivor persona’ acceptance as opposed to the sometimes, colder shoulder I received as a person with congenital disability.

Bochner and Ellis (2016, p. 69) facilitate the question why do autoethnographies ‘focus on tragedies or personal trauma?’ I recall this on reading Newman (2014, p.347) who dismisses Transformative Learning for its ‘narrow concern for me, my and mine.’ That I should speak of my own set of circumstances draws Newman’s criticism upon me. His denunciation ‘diminishes’ the strong ‘I’ voice in autoethnographic research. As a largely ignored epistemological community, we, people with disabilities, learn from each other, from our lived experiences and from narrative inquiry. Deeper reflection on this point suggests a strong fit between autoethnography and transformation learning. Then, Bochner and Ellis (2016, p. 70) present a ‘mike-drop’ in saying ‘every autoethnographic narrative of suffering refuses to be an end in itself; it anticipates and seeks something beyond suffering... an appeal for social justice.’

I ponder my journey of transformation and remember that ‘they’ called me ‘He-man,’ I laud their ingenious use of irony, using a hyper-masculine, caricature of strength, to signpost my myopathic weakness. Later, I channelled this, drawing on my own strengths, my own capability to endure and to withstand pain when in the aftermath of being run over by a lorry after being knocked off my bike. Why was a man with a neuro-muscular condition on a bike in the first place? It was a more mechanically efficient method of transport than walking and it also served

as a mask. I realise that this was part of the performativity of my disability - you don't expect that the person cycling a bike is unable to walk properly. I awoke in the Intensive Care Unit of St James Hospital in a critical condition. My injuries were extensive to the extent that I have never fully recovered from them.

Despite this, I realised that survival itself was a victory and I developed a 'superman complex.'

This 'superman' questioned why I should suffer shame for a flaw in the ryanodine receptor gene, a millions to one chance that this mutation would find expression. Why should I feel shame for just 'being,' for myopathy and 'perambulatory difference.' This 'superman' informs me that only a strong man could endure eleven hours of surgery, three cardiac arrests, compound leg fractures, a severed femoral artery, and a near fatal allergic reaction to anaesthesia. A member of the medical team later told me that my exercise regimen over the years in an effort to overcome my underlying condition meant I had developed a 'superior cardio-vascular system.' Paradoxically, I only survived this accident because, despite my condition of weakness, I am, apparently, strong. This thought agrees with Nietzsche (1886, p. 199) who states, 'a species comes to be ... in the long fight against essentially constant adverse conditions.' This is recognisable in the paraphrase 'that which doesn't kill you, only makes you stronger.'

Reflection. Understanding.

Acceptance.

And with this I can now assert that my weakness is my strength.

This is revolutionary for a boy cowed by shame. In thus 'proving' to myself and accepting that I am strong I can allow my rigid set of beliefs masking my condition of weakness to bend. I can now relax because Vohs et al. (2005) has shown that the capability to alter behaviour to meet specific circumstances is important in the attaining of life goals such as maintaining career paths, forming identities, and in building, and sustaining relationships.

CHAPTER 5



Reorientation

*49°54'10.7" N, 3°01'51.6" W
Day 6, Between watches.*

I still felt rattled from the storm. Whiskey had helped but that artificial euphoria reverted to melancholia. Tomorrow, we would hit land and there were mixed feelings. Deeply pensive, reflection on our voyage set in. My mind is unclear in the fog and I speak, unsure if on my own or in company.

'... My life there revolved around the beach...

White sand. Pristine.

... and the water was warm like a bath. Most importantly no one went there in the middle of the day. And it got hot! The locals preferring sleep to the early afternoon sun. Once, melting under the forty-degree sun, Ezbecca stood up announcing that she was going for pepsi cola. Ice cold bottles. Nice. In a wrap-around of beach towels, she drove off, leaving me alone with my thoughts and my contentedness. Soon after, I heard a car slowing down on the compact sand behind me to allow a local male voice to roar out before it too sped off.

When Ezbecca arrived back a few minutes later, I babbled that a local dude tried, 'y'know, to proposition me,' a joked about irritant here in a stifled society.

'Why what did he say?' she asked passing me a cold bottle.

'Hey handsome or something like that,' I replied, feigning modesty.

'Ya hayawan, maybe?' She said smiling.

'Yeah, that's it.'

'... I believe in Arabic that it means 'you animal.'

'Animal?' We laughed, because it was funny, but it was a reminder deep down that here on land, I wasn't always regarded as fully-human.

I preferred the water.

Drifting.

Just me and her and the little orange inflatable boat.



Plate 5.1: 'Waves and palms,' (2017), Source of Image: Niall Dempsey (2017).

The seawater offered solace from the sun-roasted sand. She, fully aboard, 'making bronzage,' her favourite sport, and me, half submerged, my legs trailing, in the water, giving a surprisingly strong, frog-like kick when required, the half-powered engine running operations.

Looking back it was the perfect arrangement. She loved to tan, and my body needed exercise. And in the weightlessness of the water, I could push and swim for hours and hours. And that's what we did.

In the water, I had the exhilarating pleasure-pain feeling of the body being used and useful. I was unshackled from that what restricted me to stretch and splash and scissor-kick. The pull on my abdominals seemed to unfurl my back and I felt tall and long and a man. There, I didn't feel different. That residual 'thing' still lurked in the depths but in the shallows it was a non-issue. There, I felt my disability was incidental to my life. Incidental to hers. A part of me like freckles, blue eyes, or the bump on my nose. Just part of the soup. There, I was just me.

In the water.

And she was accepting. When we talked if it came up, it came up innocuously, and I would say 'maybe my legs DO hurt a little.' No big deal. But mostly, we would just chat when it was time to chat, and we would be silent when it was the time for silence. Sometimes, we would hold hands and another time, under a peach-skinned moon she jumped in and we skinny-dipped, the phosphorescence giving her body an aqueous, animatronic appearance. It all felt deliciously illicit in that conservative, conformative and codified place. There alongside our almost deserted, Occidental beach. Bobbing in the water, I just felt like any other 'fella,' splashing about, having fun in the company of a beautiful woman, my friend Ezbecca Kaselmay.

Sometimes, she would run her hand, lightly, softly up and down my wet arm. Up and down, softly, lightly and she would look at me, her big brown eyes, heavy lidded, locked on mine, her lips parting only slightly. And I could feel her touch, soft and light, up and down, up and down until her free hand would crook behind my neck and my back where her fingers would splay out, I imagined, like those of a dance partner. Her grip on me and on my shoulder tightening as she leant closer to reel me in perceptively closer, closer. And, in the warm sea, I could think only of the now, this, the most important thing ...'

'Hombre!' Alonso interrupted; his voice punctured my reverie.

'Suddenly - aarrrrgh - she would grab hold with all her might, she was small but mighty, and pull the hair on my shoulders and upper back. I fell for this every single time.

All I could do was laugh because it was comedy and life is comedy and comedy always resides in the predictably unexpected. But mostly I laughed because I was happy.

She used to say that I was like a butterfly flitting around from one thing to another, flimsy, blown easily this way and that by the winds. Light and no substance. She said qualifications would give me substance. Qualifications she said would ensure that I wasn't always beholden to my past and would allow me to prepare for the future. The future ...' – I trailed off.

'... And you know I used to laugh at her but now meeting you guys and seeing you live out your interests makes me think on her words and remonstrations. Like, I mean, you are clearly doing something you love. Something that gives you a purpose and passion. Miguel never stops jotting down his thoughts and you are always playing around with that camera, lining up shots. God, I hope you haven't filmed me...'

'Yes, Irishman I will make you a movie star. It will be a horror movie of course... OK so you see me and Miguel and that our studies are more than a pass time, they consume our time, they are our passions. What topics invigorate you, what would you study? What are your passions?'

'Whiskey, Girls...'

'Seriously!'

'I dunno,' I said, '... I think I would like to use my experiences to reach out to other disabled men, men who, like me, in a post rehabilitative setting, feel wayward and a bit lost. I would like to be immersed, somehow in a world of books, and words, writing, in adult literacy, helping these men express themselves, their thoughts. I think if I had a second chance that I would like to become a teacher.'

'That's very interesting Irishman. Then go do it.'

'I will think about it ...'

'And this woman? You will think about her too, no? Where is she now? You dumped her body out at sea and ...'

'And you have a dark imagination.'

'But now you are a single, que pasa?'

'I asked her to marry me, she said yes and a week later she said no.'

'I don't understand.'

'I asked her to marry me. But her family raised objections, some of which related to my disability. Khalaas! Its ok. We talked it out. Ultimately it was her decision. I just didn't tick enough boxes.'

'Joder!'

'To be honest, she didn't care that I was disabled. And I mean this in a good way. My disability, per se, wasn't the issue. True, she wanted, eventually, to live in her own country near her family. My condition and my disability dictated that I couldn't live there. Also, she wanted to have kids of her own and if she chose me, well, its complicated... again dictated by my condition. It is what it is. We talked everything through. This helped me to progress. We are

still friends; she is my best friend. Our friendship is based on this, on conversation, the laughs and respect – she is like that. Smart. Fun. Respectful.’

‘Pendigo! Que incomprehensible. Which ‘respect?’ she rejected you.’

‘Rejection? Don’t you see that she accepted me as fully human, that I wasn’t some half-man, monstrous thing. Perhaps that is what I craved the most. Acceptance. She created a space for me where it was ok to be me, to talk and cry about bockedy legs and pain and myopathy. She created this space when, perhaps, I had been unwilling or unable to! I came to learn, thanks to her, that in talking things out, that problems become smaller, manageable... er... less problematic even! Instead of leaving them to simmer inside, in letting them out, and in speaking of my feelings about my disability she taught me how to accept myself, that me being disabled was just another slice in the cake of life.

‘Wow, she said that ... ‘Cake of life?’ That’s so corny.’

‘Shaddup,’ I laughed, ‘English is not her first language.’

‘But, do you not resent her for not sticking with you?’

‘... Wouldn’t it be worse if she stayed with me out of misplaced pity? Imagine, trapped in a relationship because she felt sorry for me. No, she chose rationally and not from ableist prejudice. In our softer moments, she always told me that she chose to be with me over the others precisely because I was disabled. Ironically, it was those traits, related to my disability that made me different and interesting. Attractive almost.’

‘Ironically?’

‘Yeah, because ironically, all this warrior guff, I come out with. Well, its only interesting to a point. It creates obfuscation. She didn’t reject me because I am disabled, she rejected me, if you like, because of my attitude towards my disability. My negativity, my cold suppression of my secrets, my shame, all underscored the fact that I saw myself as less than equal, why should anyone love me when I didn’t even love myself. In the end, she said my walls were too high and impenetrable, making me cold when she was only used to heat.’

‘Dog, what you saying?’

‘Tch, not what you are thinking. Besides the captain is calling you. What’s up now?’

'No, he can wait. It's worth a mutiny. She is beautiful? If so, why would she chose an incapacitado like you. You look like one created in a monster factory, but they ran out of the parts.'

'Her beauty is not for discussion. I was attracted to her because of the way she made me think, because she is funny, engaging and intelligent – she speaks three languages. You know what I realised? If I could be THIS attracted to her brain, maybe somebody could love me for mine, limited as it is!'

Alonso blinked rapidly; his jaw dropped open. No words escaped though I could see them forming. He missed his chance to protest so I continued.

'The brain, man, think about it. It's the control panel of erogeneity. Every touch is more scintillating when you ignore the body for what it is, or in my case, not, and accept what it can do, not instinctively but when it is ruled by the brain and a libidinous imagination. Sherlock Holmes, said, 'Watson, I am a brain, the rest of me is a mere appendage.'

'First, I don't speak English and I don't understand any of those words and second you are an idiota. Do you not feel that you missed your opportunity? OK this crazy mujer was kind enough to hold your hand. Who else would want you? Look at yourself, it's like Quasimodo married Godzilla and you were the result. Come on man!'

'Oh my feelings,' I joked, glad that he found his voice, 'She taught me that I have a value that my disability doesn't limit me or my choices. And not to settle for just anyone that shows me attention. She taught me that I am not my condition and that my condition is not me. As a result, I don't have to keep fighting it, hiding it even, that I can lower my walls and when I am willing, that I can be discerning as to the person I let in.'

'Mechago en la leche de puta que te pario! I have heard it all now. A disabled guy, he cannot walk, thinks he is Sherlock Holmes and that he can be discerning. What is it you say in English? Beggars and choosers?'

'Yeah, but that's the thing, because of her I know that I don't have to beg. For anything.'

CHAPTER 6



Disembarkation

*50°41'19.4" N, 1°37'26.2" W
Day 7, 'Above board.'*

'Land ho!'

As we entered the Solent for a straight run into Portsmouth Harbour, Captain Heinz called us all on deck. It was the first time all eleven onboard assembled at the same time since we left Santander, seven days and 622 nautical miles back. It was still only first light, so our voices were cold and subdued as we crossed the set of coordinates that signified the finishing line. We crossed that line together. The crackled static of shortwave suggested we were not alone. 'Race result,' someone whispered. We fell silent as a plummy, emotionless voice announced 'Anne-Margaretha, registered in Haarlem, The Netherlands, first in class....' Our resultant cheers confused the gaggle of trailing gulls and Captain Greet popped open a bottle of champagne. 'I was going to do it anyway,' she laughed. Amidst, 'bubbles,' breakfast, and backslaps, we cast anchor awaiting the other boats in our class to catch up for a glorious 'parade of sail' into Portsmouth Harbour.

A boisterous, flag-waving crowd was gathering along the quayside as we finally came in. 'Look, look' Alonso roared 'over there your TV crew, Captain Ahab.'

He asks me what I will do next.

I point over towards the L.E. Asgard, distinguished by the figurehead of Grainne Ní Mhaille at the prow. My eyes well as they follow the wind unfurling her green, white, and orange ensign. Sand or something. Maybe.

'I sail to St. Malo in France and then back to Ireland. And then? Well, I have decided to go back to college in September. To finish my degree. I will see where that brings me... maybe, it will bring me to teaching. What ya think?'

Before he answers, Miguel joins in and with loud slaps throws his arms around us as we come within touching distance of Portsmouth and England.

'Amigos,' he said, 'we did it. We are sailor-men.'

I don't correct him.

Alonso asks, '... this Asgard, is there room for two Spaniards with you?'

'I don't know,' I smile, 'we can ask.'

'... because I have this traditional Galician story, how Irlanda gets her name. It is from my Grandmama, it is long and the telling needs some time.'

I look incredulously at him, a Spanish guy wants to tell me how my country was named. This I got to hear. 'Yeah,' I replied, 'I would love to catch that.'

'Look you mythmakers and storytellers,' Miguel intercedes, 'there are girls, lots of pretty girls and they are waving at me ... us! Grab a rope, pretend to look importante, like we are captains of the high-seas.'

We laugh at his earnest lustfulness and just like pirates and conquistadores contemplating what was left behind and what has yet to come, we felt assured that the sea has transformed and emboldened us.

My supervisors, Dr. Dave McCormack and Dr. Jerry O'Neill were influential in guiding me towards autoethnography which according to Bochner and Ellis (2016, p.239) has a 'capacity for self-reflexive and self-critical accounts of experience that can heal, change, validate and engage others.' I saw beyond the academic, a life-affirming and therapeutic methodology. Now I am fully immersed in 'the writing life' giving presentations in colleges on the disabled experience, my disabled experience! My presentations start with the words "My name is Niall Dempsey and I am a disabled man." This admission equates to self-acceptance. Autoethnography serves this process allowing disabled people like me the opportunity '... to heal, change, validate and engage others through self-reflexive and self-critical accounts of experience' (2016, p.239). My time aboard the Anne-Margaretha initiated an awareness that I needed to change my worldview. The sense of shame that bound me to underperformance and negativity became loosened to open up the possibilities of achievement, self-realisation and happiness. The self-acceptance inculcated at sea led me to a sense of, to paraphrase Popeye, 'I am what I am.'

As aboard the Anne-Margaretha, I have on occasion been the first congenitally disabled person in a given situation. How I present and conduct myself may have a consequence for the disabled person that follows me. As pompous as it may sound this makes me 'an ambassador.' This is a role, I neither looked for nor aspired towards. Goffman (1968, p. 39) describes this as the 'moral career' ensuring that I present myself as representative of those with my condition with a positive face. Disability is a performance, in any case - one where you are always on display.

To recap Foucault's (1975, p.195) presentation of the panopticon whereby 'one is the subject of the omnipresent gaze.' It takes strength to deal with constant scrutiny and comment. It takes strength to rise above the ritualistic comments of 'what's wrong with ya?' I know my weakness has made me strong. This is how I perceive myself in the context of my world.

Over the course of this work, I witnessed the youthful version of myself, peeking curiously over my shoulder. That early iteration of myself, full of shame and rejecting his disability was blasé about education. 'Sure, it doesn't matter,' I once, stupidly, broadcasted, '...it won't help me walk.' Experience tells me otherwise. Returning to education in adulthood, allowed me to do more than walk, it allowed me to travel! Education offsets many negatives. Today, I find myself looking at a letter received from the President of Maynooth University offering her 'personal and heartfelt congratulations' on achieving the Taught Masters Scholarship award. This feels significant. I wish my younger version knew this! I would like him to know that the only limiting thing is low self-expectation.

As I type, I am, happily, interrupted by implorations from my hounds, Jojo and Sowdee. Their increasing racket can only mean one thing; Mam is at the door. I will go to let her in but not before I acknowledge the greatest strength and support, I have had in my life is her love, and that for all my, what my brother calls, '*Dempseyisms*' that through her I am also an Egan. It is from my Egan side, passed down from my granny Mary Egan to my mother Therese, from whence I derive the thirst for education and educational attainment. It is through education that this disabled man learned to accept and become. I value education now. The hope further and higher education engenders has seen me through tough times. As Aristotle said, 'Education is an ornament in prosperity and a refuge in adversity.'

I thought it would be fitting if I finished this whole work with the ancient war cry of *Fine Ua Díomasaigh*, '*An Díomasach abú*', but fundamentally and consciously know that 'I am an Egan too.' Instead, I will close with the appropriate words of educationalist, Paulo Freire (1970, p. 57) who said, '*... Looking at the past must only be a means of understanding who and what you are – so you can more wisely build the future.*'

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