ABILITY, NOT DISABILITY: A TRANSFORMATIVE EXPLORATION OF STUDENT EXPERIENCES IN HIGHER EDUCATION

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Declaration

This Thesis is submitted in partial fulfilment of the requirements of the Master in Adult, Community, and Further Education of the National University of Ireland Maynooth and has not been submitted for any academic assessment to any other University. I confirm that this thesis is my own work. Assistance received has been acknowledged. Permission is given to the National University of Ireland Maynooth to lend this thesis.

Signed: ______________________

Date: _______________________

Acknowledgments

I am extremely grateful to so many people for helping me throughout the last year. I wish to extend my sincere gratitude to the participants in this study who took time out of their busy lives to tell me of their heartfelt experiences.

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Finally, people have come into my life recently and have contributed to the completion of this project in more ways than they know. To those, you know who you are, I am eternally grateful.

List of Abbreviations

Abbreviation	Meaning
HE	Higher Education
HEI	Higher Education Institute
DEIS	Delivering Equality of Opportunity in Schools
AHEAD	Association of Higher Education Access and Disability
NDA	National Disability Authority
ADA	Americans with Disabilities Act
IHREC	Irish Human Rights and Equality Commission
WALK	Walkinstown Association for People with an Intellectual Disability Limited.
UN	United Nations
DES	Department of Education and Science
DARE	Disability Access Route to Education
DAWN	Disability Advisors Working Network
ESF	European Social Fund
DES	Department of Education and Skills/Science
HEA	Higher Education Authority
NCSE	National Council for Special Education
PLC	Post-Leaving Certificate
PIP	Personal Independent Payments
UPIAS	Union of Physically Impaired Against Segregation
CAP	Creative Analytical Practice
QQI	Quality and Qualifications Ireland
UDL	Universal Design for Learning

Abstract

This study aims to explore why there are such low numbers of people with (dis)abilities in attendance at Irish Higher Education (AHEAD, 2017), The study explores the experiences of people with (dis)abilities as told to the researcher. These findings are reviewed within the context of the literature on Irish HE and (dis)ability, as well as the medical and social models of (dis)ability. Researching from the constructivist approach, qualitative, conversational interviews with participants are completed. Analysing findings in traditional qualitative format of transcripts becomes a barrier to accurate representation of the emotional resonance of the conversation, so a narrative approach to present findings using the creative method of 'found' poetry emerges (Richardson, 1990). The analysis also examines alternative methods of assessment adapting the Universal Design of Learning Technique and explores experiences of stigma as experienced by people in HE with (dis)abilities. Issues of funding policy for part-time students are also acknowledged.

Although there have been significant strides in improving the quality of the lives for people with (dis)abilities, due to the efforts of (dis)ability advocates and the development of the Social Model of (Dis)ability, it would seem apparent that significant changes in attitudes and a reduction in the neo-liberal ethos would contribute to a more positive and inclusive experience for *all* learners in HE.

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A Narrative of My Own

You are welcome to my research. I hope you enjoy where's, what's and why's..
The information, the policy, the methods, and stories that arise
Of HE for people whose experiences are often more lows than highs.
Instilling motivation, sadness, empathy, and stories telling a tale
To spark the depth of emotion for students, I hope I will not fail.

At nineteen, I apply to college, ready, but feeling quite coy.
One day the postman arrives with an accepting letter of joy.
Oh what worry this brings when I remember I'm carrying a baby boy.
With the help of my family I take off even though I'm just a girl,
With fear and anxiety within me, my thoughts are in a swirl.

I happily go in to college usually feeling upbeat.
The course, the staff, and the people I meet
Provide friendships and care and a smile to greet.
After three years I leave contented but with my mind in a daze
I count my blessings I have been lucky with my experience, in lots of different ways.

After time in society I realise my journey is not complete
I work with so many people who have not been as lucky as me
How can I change this I ask, this really can not be
So I embark on this Masters journey to place the world at others' feet
Now the end is in sight, the future looks bright and this project I will defeat

Chapter One - Introduction to the Research

1.1 - Introduction

This chapter provides a short introduction to this research project. Firstly however, I feel it is important to inform the reader about the language throughout the text so a short section follows.

The research aims to inform readers about the experiences of people with (dis)abilities in HE and I introduce this further in my statement of the problem. A brief introduction to the methodology is also included in this chapter as well as a description of the thesis structure and conclusion.

1.2 - Key Terms Throughout

Throughout the ages the people of the world have used many different terms, phrases and words to describe or define the word disability. These words range from 'freak' in the very early days to 'retardation', 'impairment', 'special needs', 'disabled', the list goes on. Many of these words are replaced over the years and include, 'confined', 'condition', 'illness', and again the list goes on. Today society tries to use the "person first" approach which identifies the person first and the disability second but there is still much difficulty in phasing this in. This is due to the Social Model of (Dis)ability, which uses the term 'disabled person', but this is discussed in more detail later. (Hall, 2007; Crotty, 1998) outlines that the use of language creates an image that then becomes our truth. We build a perception in our minds that may not fully express the complexity and diversity of human life.

The purpose of this section is not to re-define the term disability but to advise readers that I acknowledge that the use of language is an important aspect in writing and conducting research. As I write and try to name this research thesis I am confronted with a dilemma of using correct and inoffensive language but also connecting with my readers. To me, constantly using the term 'person with disability' takes away from the person's identity. However, I'd like the messages of this thesis to be read by those who want to make a difference in society and HE for people similar to those that I work with in my research. And so, because of this I have chosen to use the term people or person with (dis)abilities or (dis)ability throughout even when discussing models of (dis)ability but not when naming legislation, although it is only *my* chosen term and not the worldview. It is not to be confused with the terminology associated with the Medical Model, which exclusively uses the term disability. I feel that by enclosing 'dis' in brackets I am acknowledging that while we focus far too much on what people can't do, the phrase is needed to please the search engines in our libraries. I also realise that there is some use of out-dated words and terms but are used to encapsulate the derogatory words which once acceptable, are not my chosen vocabulary.

The (dis)ability access office is usually the term used in Ireland for the support office that works with (dis)ability groups in HEIs. I use the term access office or access officer as oppose to '(dis)ability access office' or officer to reduce the use of the term (dis)ability in the text.

In order to protect identity of the HE used I have given it a pseudonym throughout the thesis to further protect the identity of participants to people who know me *and* my story. The name it holds throughout is "Colaiste Eolas" an Irish term translated as "College of Knowledge".

1.3 - Statement of the (two) Problem (s)

There are 88,000 students in attendance in Higher Education as found in the 2014/2015 academic years. This includes both undergraduate and post-graduate courses (HEA, 2017). However only 10,773 students are identified as having (dis)abilities in the same year (AHEAD, 2016). Why are numbers so few? I want to explore their experiences in higher education. Why? Because having being part of HE myself as a young and pregnant student lucky enough to have enjoyed a supportive environment, I become overwhelmed by the encounters of people I meet in my work who cannot recall enjoying a similar system of support. And so I am met with my research question. What are the experiences in HE of people with (dis)abilities? As the research continues a second question materialises, 'How do I convey diverse elements of the findings of these experiences which include the practical, emotional and cognitive aspects of their responses?'

1.4 - Introducing Methodology

Methodology is "the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcome" (Crotty, 1998: 3). Using this definition to consider the most suitable methodology for my research I feel that qualitative research is the most befitting (Mason, 2002). Qualitative research is described as a ‘thick interpretation’ (Denzin: 2001: 162) and uses observations, documents and interview data to collect information (Creswell, 2003). Researchers will begin with an idea of what and how they will learn during the process of research and often leads to stating ‘knowledge claims’(Creswell, 2003).These claims might be referred to as ‘ontology’s’ (what is knowledge) and ‘epistemologies’ (how we know it) (Crotty, 1998).

This research adopts a social constructivist point of view, a school of thought about knowledge (Berger & Luckmann, 1966) that implies that individuals seek understanding of the world around them. Subjective meanings of experiences are developed and the researcher looks for a complexity of views rather than categorising them. Using this approach, questions are often open ended and the meanings are formed through interaction with others, ie, social constructivism. (Creswell, 2003). Narrative research is a useful method in creating unstructured and open ended questions providing the researcher with a discussion about experience and life stories and is told or retold by the researcher using the narratives of the interviewees as well as the researcher (Claundinin & Connelly, 1990). This also leads me to participatory research approaches, which I don’t anticipate at the outset but I embrace as a necessary part of this type of research. The process of interviewing is far more emotional than I expect, but so I become concerned that these experiences get lost in transcribing. Butler-Kisber (2002) encounters a similar experience in research she completes. She meets a lady whose experience resonates with her after conducting qualitative research on a graduate course she was teaching. When reviewing the transcripts she finds them flat and the resonance she encounters is lost. This is the experience that resonates with me.

> Resonance is a process of dynamic, complex, metaphorical relations. It is not confined to one single strand of connections. It is a complex relationship among many aspects of a story ... Associations can be made through its images, its mood, its moral associations, and more ... The resonance process is complex and covers a wide range of cognitive and non-cognitive elements (Conle, 1996: 313).

Using this concept, resonance, I begin to use participatory research characteristics in my analysis and presentation (Lincoln et al. 2011). Applying these characteristics, I explore a number of different approaches and decide to form a number of narrative poems known as ‘found’ poetry (Richardson, 1990) to better express how it feels to be a student in HE with a (dis)ability using their own words and in consultation with participants. Although I did not start out on this path it is influenced first by a lecture from Sarah Meaney on arts based research (Meaney, 2017) and then further inspired by the work of Laurel Richardson, Susan Walsh and Jerry O'Neill (Richardson, 1990; Walsh, 2004; O'Neill, 2015).

When I begin to use the narrative style of writing there is a slight change in my writing register and literary genre and although majority of my thesis follows the academic structure suggested in the course handbook (Maynooth University, 2016) elements of my participation and conversational reflexivity are interwoven throughout the text as appropriate.

1.5 - Structure of Thesis

Chapter one has introduced you to the research project and draws on where it comes from, how I formulate my ideas and what I am about to unveil in this research. The literature review is contained in chapter two, a large section discussing history, policy, models of (dis)ability and the work of Michel Foucault on education and power (Ball, 2013). It also acquaints readers with my approach, the constructivist approach to the literature. Chapter three provides a detailed methodology of my research where qualitative narrative interviews and ethics are central. It also provides a clearer understanding of the process of narrative interviewing and analysing through found poetry. In chapter four I reveal my findings in a series of poems. These consist of terms and phrases used by interviewees and extracts from transcripts by the researcher and formed into poems. This method is used to portray findings in a creative manner (Claundinin & Connelly, 1990). The following chapter, chapter five explores the results of my findings from a social constructionist point of view while chapter six draws conclusions which suggest that although people with disabilities are experiencing a much more inclusive society, HE efforts to improve educational experiences is often confined to structures in place which are adopted to meet the needs of traditional learners.

1.6 - Conclusion

This chapter provides a brief introduction to this research piece. It includes the rationale for this study and a brief synopsis of the language, methodology and presentation styles I adopt. I also outline the structure of the thesis providing a brief oversight of the layout of subsequent chapters.

Chapter Two - Literature Review

2.1 - Introduction: A Transformative Moment

Half way through the academic year, as the research begins to unfold, I am introduced to Jerry O'Neill. Jerry delivers a lecture on, what is to me, an unfamiliar style of research, the Narrative Inquiry (O'Neill, 2017; Claundinin & Connelly, 1990). I fall instantly in love with it. Although this method resonates with me, I did not set out on the narrative journey so I make a decision, after much reflection to adapt it where I can, my interviews and findings. This is discussed in more detail in chapter three. In light of this lecture, after meeting what I feel is a unique and beautiful style of writing, forming the literature review in an academic style proves especially difficult for me. O'Neill (2017) describes being disappointed with the linear writing in narrative research he encounters. Although writers claim to realise that interviewee's messages are lost, O'Neill feels that the linear style (Introduction, Literature Review, Findings, etc) still does no justice to capture the quality of their inquiry and I am confronted with a similar feeling when I begin to write my literature review. I would like to remind you that the decision which leads to narrative writing emerges late in the academic year and so this decision is evident in my literature review in particular, which follows the linear academic model with facts and figures and headings. Nonetheless, having been exposed to the narrative, writing in an academic style worries me that it might present as inconsistent with the following chapters due to the sporadic nature of my reflexivity throughout the text. To ease my mind and satisfy my creative writing streak and draw in the reader, I refer to some films to spark a lived experience of the history of (dis)ability. The text also includes some images and videos, which complement messages to the reader adding audio-visual elements and sentiment to the literature. I also want to identify with what has been depicted in the literature and so for each of the themes which emerge I begin with some quotes from my all time favourite books, Harry Potter. Now there's a narrative if ever there was one. I hope this adds character and depth to the literature review.

2.2 - Preface of Chapter

This chapter begins with a contextual history of (dis)ability from the early 1900s until recently. Writing a brief history is not easy as the experiences of people with (dis)abilities throughout are disturbing and complex. Reading through the horrific conditions to which many people spent there lives, isolated and ridiculed by society stirs many emotions for me. The history I provide is the only the tip of the iceberg. Also included in this chapter are the implications of the (dis)ability movement on policy in Ireland, which explores much of the legislation in place today.

Following from this I conceptualise three key areas, which I identify as reoccurring themes or issues for people with (dis)abilities in the literature. Although these themes re-emerge in chapter four they provide a baseline for the experiences people encounter.

Social constructivism and models of (dis)ability are key in developing a theoretical framework in my research, so I follow with an analysis of the Social Model and Medical Model of (Dis)ability incorporating Foucault and his work on power and education. This work is then outlined in more detail. Finally, there is a conclusion, which draws the literature together.

2.3 - A Brief History of (Dis)ability

People with (dis)abilities have long been campaigning for the recognition of (dis)ability as part of people's identity that influences experiences and is not just a sole defining feature of that person. Vaughn (2003) provides us with some information about the horrific treatment of people with (dis)abilities historically. People with (dis)abilities were stigmatized, which resulted in economic and social marginalisation leading to people living in desperate and impoverished states. This practice occurred for centuries. In the 1800s, history tells us that people with (dis)abilities were vastly ridiculed by the public and often only considered useful for the purpose of entertainment in circuses and exhibitions often entitled freak shows. You will see this captured in figure 2.1.

Figure 2.1 (Miller, 2013)

Considered abnormal and feeble-minded they were forced to undergo sterilisation and compelled to enter institutions and asylums to live out their lives, which only served to keep them hidden away from the fearful and biased attitudes of society (Switzer, 2003).

The films Shutter Island (Scorsese, 2010) and Awakenings (Marshall, 1990) show good examples of institutionalisation. Trent (1995) discusses institutionalisation in the past and tells us institutions for people with intellectual (dis)abilities and mental illnesses were seen to grow rapidly in the mid 1800s. Although training for employment was successful for some residents, recessionary eras saw the decline in the release of such residents as it was seen as free labour if the residents stayed and worked in the institution unpaid, thus reducing its costs. This became particularly useful during the Great Depression (Bartlett, 1964). In the 1920s, despite rapid expansion of (dis)ability institutional poor farms became dumping grounds for so-called “undesirables” and this included people with (dis)abilities. This is a decision which led to free labour for appalling living conditions and individuals took part in jobs such as breaking stones for the use of farming or harvesting duties so the supervisor and his wife could sell produce to make money. This may be seen as the early privatisation of institutes. These farmhouses were also viewed as an opportunity to sustain the wider community at a low cost by paying little or no wages (Wagner, 2005). Rothman (1990) argues that this action took place in order to remove those who were viewed as undesirables or deviants from society and thus maintain social order. This response was similar in England in the nineteenth century.

England in 1886 saw the introduction of what was termed the ‘passage of the idiots act’ for people who they called ‘mentally defective’. The purpose of this act clarified the difference between idiots and lunatics (Gladstone, 1996). ‘Idiots’ we deemed as permanent where lack of understanding was present at birth and could not be removed where lunacy referred to a short period of madness that can be overcome with the correct medical intervention (Wright & Digby, 1996). This resulted in the strength of social negativity and distancing of individuals from communities and society into institutions. Much interest in lunacy prevailed by practicing doctors and followed the Medical Model for treatment (Wright & Digby, 1996). If you have ever watched Girl, Interrupted (Mangold, 1999) this exercise is highly portrayed. Care for children referred to as ‘idiots’ fell primarily on the family and this saw an increase in special schools.

Specific advocacy movement within (dis)ability communities began to emerge in the late nineteenth century with the deaf movement. This movement began with the deaf community advocating for the use of sign language and eventually led to (dis)ability political action groups coming together. The continued strive for equality resulted in twenty-nine schools in the USA having published thirty-five newspapers and a strong commitment to keeping the language alive in a repressive society (Haller, 1993). This movement called for independence including universalising sign language however these positions were opposed by important figures such as Alexander Graham Bell (Bell, 1883, 1969).

The Medical Model at the time was the accepted model of intervention as these institutions spread throughout Europe and America. I describe the Medical Model in more detail later in this chapter. Professionals began developing schemes and interventions, which focused on specific impairments. However, by grouping individuals together, this created an opportunity for people with similar conditions to communicate with each other and become activists for their own rights, something possibly unforeseen by professionals (Albrecht et al. 2001).

By the 1920s, the label “socially deviant” was applied to many varied conditions and poor farms continued to be dumping grounds for many so-called “undesirables”. Haines (1925) refers to a study of the poor houses and thirty five percent were found to be ‘feeble minded, borderline defective, psychopathic, psychoneurotic, epileptic or suffering from mental disease’, conditions which today are completely treatable.

The 1930s to the 1950s saw countries sterilising people with these conditions with the rise of medical surgery approaches. Psychosurgery and other procedures also became treatments but instead cause further problems for the treated individuals. Such treatments listed above refer to treating people from the Medical Model approach to (dis)ability, which is described by (Arehart, 2008). This model relies on what can be agreed are the normative categories of ‘disabled’ and ‘non-disabled’. It believes that a person’s (dis)ability is a medical problem that requires an individualised medical solution. People with (dis)abilities do not face problems caused by society and social policy should not be responsible for making it better, rather the condition itself is positioned as the problem with solutions sought within medical interventions.

These practices continued until World War I where veterans, in exchange for their service, expect the US government to provide rehabilitation. In the 1930s new advancements in technology and improvements in government assistance contributed to greater self-sufficiency of people with (dis)abilities.

Although President Roosevelt, who had a (dis)ability, was a great advocate he still operated from the normative Medical Model opinion, that (dis)ability needed to be cured. World War II veterans began to advocate harder and citizens became more aware and thankful of the people who had fought for their country (Switzer, 2003). By the 1960s, the civil rights movement began to take shape and (dis)ability advocates join other minority groups to demand equal treatment challenging negative attitudes and stereotypes. Advocates became active on a local level addressing the social and physical barriers while parents began advocating to have family members removed from asylums.

2.4 - Policy Implications for Ireland

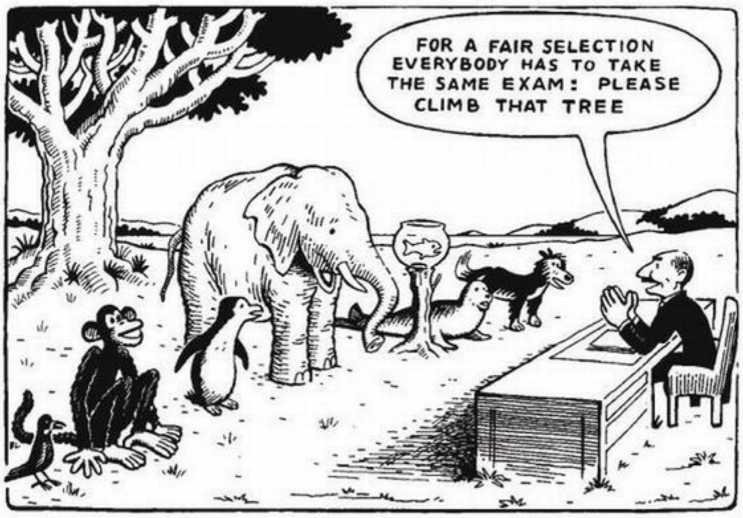

Figure 2.2

I now move to more recent events to discuss how this advocacy movement influences the rest of the western world and Ireland in particular. After much campaigning and a tiresome fight of advocates, the Americans with Disabilities Act (ADA) finally passes in 1990. Quin & Redmond (2003) discuss this in more detail and describe how it influences Ireland. A European Directive on non-discrimination is introduced in 2000 and its terms borrow quite heavily from the ADA Act of 1990. It comes into effect in Ireland in 2003 and prohibits discrimination against people on grounds of religion, sexual orientation, age and (dis)ability. The directive, as in America refers to 'reasonable accommodation' for people with (dis)abilities. A reasonable accommodation is any act that helps to alleviate a substantial disadvantage due to an impairment or medical condition (AHEAD, 2017). It involves providing facilities or adjustments, which ensure the person has a full access to services. However the term 'reasonable' is yet to be accurately defined. It is individually defined and varies from case to case. It takes into account the wider context in terms of the effect on other students, the availability of resources and how useful the accommodation is. It also takes into account cost and therefore institutions are not obliged to provide accommodations if it is more than a 'nominal cost' to the institution. 'Nominal cost' also remains undefined and depends on the size of the business (IHRED, 2017). This highlights some of the problems with the implication of this policy directive.

The right to education is further protected by Irish legislation such as Article 42 of the Constitution, The Education of Persons with Special Educational Needs Act 2004, The Disability Act 2005 and the Equal Status Act 2000-2011 (WALK, 2015). Although not yet ratified but signed, the UN Convention on the Rights of People with Disabilities 2006 also provides protection. It outlines the following:

- Persons with (dis)abilities are not excluded from the general education system on the basis of (dis)ability.
- Reasonable accommodation of the individual's requirements is provided.
- Persons with (dis)abilities receive the support required, within the general education system, to facilitate their effective education.
- Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion (WALK, 2015).

In addition to this, as a member of the Council of Europe, Ireland has a commitment to the mainstreaming of participation for people with (dis)abilities in all forms of education and training (WALK, 2015).

In 2000 the National Disability Authority (NDA) is established under the National Disability Authority Act 1999. It is established to replace the National Rehabilitation Board and acts as an independent body in order to 'support the achievement of good standards and quality in the provision of programmes and services provided or to be provided to people with (dis)abilities' (NDA, n.d). Their duties include research and development of statistics, development of codes of practice and monitoring their implementation and promoting ease of access to goods and services through built environment and technologies for people with (dis)abilities (NDA, n.d.).

In 1998 the Department of Education & Science (1998) develops the Green Paper on Education addressing education and training among many disadvantaged groups including people with (dis)abilities. In the area of HE it outlines the physical equipment or alterations that should be implemented in HEIs after a needs assessment for people with (dis)abilities that inadequately meets their needs (DES, 1998). This results in a significant improvement in access services across Irish HEIs as explored later. The White Paper in 2000 addresses the needs of people with (dis)abilities in HE by referring to the NDA (DES, 2000). It uses terms like 'supports' and 'working with people with (dis)abilities' but remains vague throughout the paper. It does however state the following but this was not implemented.

> Fees will no longer apply to third-level part-time students who are means-tested social Family Income Supplement holders or dependants and who are pursing first time under-graduate, nationally certified distance learning, or nationally certified certificate or diploma programmes (including university) or access programmes which guarantee entry (DES, 2000).

Failure to supply funding to part-time students acts as a real barrier to people with (dis)abilities in HE as it is a more adequate and accessible means of mainstreaming for such individuals (WALK, 2015).

2.5 - A Governmental Response

Gavira & Morina (2014) identify in their research a continuing theme of dissatisfaction with the exam process. Students outline that lecturers often race through a syllabus, the information is regurgitated in exams but it suggests there is no real learning from such a method (Gavira & Morina, 2014). Riddell (2016) encounter individuals who had been offered alternative methods of assessment, which reach the module outcomes but more importantly, meet the needs of the individuals. Based on this it may be fair to suggest that such practices need to be implemented around the globe.

Attendance of students with (dis)abilities in HE remains low (HEA, 2016). Initiatives are introduced to tackle this. The primary initiative is the national DARE scheme.

2.5.1 - Benefits of DARE

This is an alternative admissions scheme for people who encounter a negative experience in secondary school because of their (dis)ability. It offers HEI places on reduced examination points to school leavers and is an example of an "affirmative action" (Ryan, 2013, cited in HEA, 2013: 209). It is a scheme, which responds to the needs of individuals who experience educational and/or emotional difficulties as a result of their condition (DARE, 2017). Thirteen HEIs, including the seven Irish universities, currently participate in the DARE scheme. The scheme is identified as securing positive outcomes in progressing to higher education, including more awareness of opportunities of access (HEA, 2013). The figures utilising this scheme are briefly outlined below.

Type of educational background	Number of Schools	DARE Applications 2010	2011
Fee Paying Schools	55	22.1%	21.4%
DEIS[1]	195	12%	12.2%
Special Schools	140	6.4%	8.5%

Table 2.1

These figures suggest that a large proportion of private and fee paying schools are making applications to HE through the DARE schemes while only a small amount of applications come from DEIS schools, schools which are specifically recognised as schools in marginalised areas (HEA, 2013).

> The DARE scheme was established on the premise that applicants with disabilities are a homogenous group and are equally disadvantaged in the context of progression to higher education. This study suggests that while students with disabilities are a key target group in the context of improving access to higher education; students with disabilities who are also socioeconomically disadvantaged, particularly if they are attending a DEIS school, need to be considered as a separate and specific target group. Students from special schools are also striking in the context of how few are accessing this scheme (Ryan, 2013, cited in HEA, 2013: 112).

The following link describes the DARE scheme and how it works for individuals who have accessed HE through the scheme.

https://www.youtube.com/watch?v=YU1MtCjbZtA&t=192s

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[1] Schools which are identified as disadvantaged under the Delivering Equality of Opportunity in Schools (DEIS) programme

DARE and HEAR Promotional video (2015) Fig 2.3

2.5.2 - The Role of DAWN

DAWN is an organisation whose primary responsibility consists of supporting learners in HEIs with (dis)abilities. It works towards developing professional standards of best practice and collaborates on developing policies and procedures for inclusive education for learners in HEIs. They provide a forum for sharing expertise and developing knowledge and skills in this area. Responsible for monitoring and setting standards for alternative assessment procedures for people with (dis)abilities, DAWN also grants reasonable accommodations in examinations for students with (dis)abilities (DAWN, 2012).

2.5.3 - Student Fund for (Dis)abilities

In 1994 the government introduce the Fund for Students with (Dis)abilities which is underpinned by education policy and legislation designed to ensure equal participation in higher education for such students. It is linked with Europe-wide efforts to increase inclusion and receives funding from the (ESF). This funding contributes to reasonable accommodations required in education institutes and places of employment. It also focuses on supplying key resources and supports, which contribute to mainstreaming of higher education (HEA, 2017). The services are underpinned by the following key principles:

- **Independent learning** Funded services will support the development of independent learning and transferable skills, having regard to the importance for the student of labour market readiness and access to opportunities for further study.
- **Inclusive education** Funded services will, where possible, be provided within and will promote an inclusive educational environment.

- **Commitment to evaluation** Funded services will be subject to continuous improvement, drawing on periodic review and evaluation and student feedback.
- **Complementary Funded** services will complement the delivery of academic support for students with (dis)abilities through the mainstream.
- **Local, responsive approach** The funding process will enable those working directly with students to deliver effective, best-practice support at the appropriate time.

(HEA, 2017)

2.5.4 - National Plan for Equity of Access to Higher Education 2015-2019

These national policies are enacted through a series of the national access plans. The most recent National Plan for Equity of Access to Higher Education 2015-2019 aims to facilitate access to higher education and targets many disadvantaged groups. It outlines that higher education should be accessible to all regardless of (dis)ability (Higher Education Authority, 2015).

The plan is underpinned by many principles, one of which includes a 'whole of education' approach for people with (dis)abilities. The plan suggests that resources should be made as early as possible for students to smoothly integrate into higher education. During the process of suggesting this plan the need for part-time funding is acknowledged as an ongoing issue and the report suggests that this needs to be examined further. It also identifies targets of entry for people with (dis)abilities (HEA, 2015). These include an increase in entry among three under represented groups (physical, sensory and multiple (dis)abilities), an increase from 390 students to 570 students who have physical (dis)abilities, 210 to 280 for individuals who are hearing impaired and for visually impaired, an increase from 140 to 200 individuals. Despite targets being (dis)ability specific the HEA remains committed to increasing entry to higher education (Fleming, Loxley & Finnegan, 2017).

Despite these policies and legislation people with (dis)abilities are still among the most disadvantaged in our education system, as recent figures suggest. In February 2017 AHEAD releases figures for the year 2015/2016 of those with (dis)abilities in attendance to Irish higher education institutes and find that although figures are rising, students with (dis)abilities make up merely 5.2 per cent of the full time student population but only 1.2 per cent of those studying part time. This 1.2 per cent is possibly due to the fact that financial support is not available for part-time students even though part-time studying is more suitable for individuals with ongoing conditions (HEA, 2016). This is an ongoing concern that continues to arise. As well as ongoing policy and implementation concerns, broader conceptual issues continue to resonate in the experiences of students with (dis)abilities accessing higher education.

2.6 - Conceptual Frameworks

2.6.1 - Stigmatisation - even in the wizarding world

"Tonks, will you at least listen to me for a moment?"
"Fine."
"You need to understand, I'm used to people like Mundungus saying horrible things about me. I know how to ignore it and pretend it never happened.... It's almost like second nature to me."
"Well you shouldn't," Tonks mumbled.
"Thank you," he said softly. "But people defending me like you did. Tonks, that's foreign to me. I....I... didn't know what to think. I mean, it just – seemed too good to be true.

Harry Potter and The Order of the Phoenix (Rowling, 2003)

Stigma is conceptualised through convergence of several components. Firstly, people identify and label human difference. Secondly cultural beliefs are linked to labelled persons as negative stereotypes. People are then placed into categories in order to create an 'us' and 'them'. In the next component, labelled persons experience discrimination, which leads to unequal outcomes. Finally, the use of these components places stigmatisation at the forefront for identifying differences. The construction of stereotypes, separating labelled persons into categories consequently provides the execution of exclusion, discrimination and rejection. (Link & Phelan, 2001).

Through my literature research stigma is a reoccurring theme and in some cases prevents people from registering with their HE access office. In 2016 Lynne Kendall's research finds that people do not disclose (dis)abilities all of the time. She describes how one individual only discloses their (dis)ability and registers with the access office mid way through her course as she has fallen ill. The interviewee expresses concerns that her career in teaching might be affected in the future (Kendall, 2016). This is also identified as a barrier in studies carried out by WALK in a report in 2015. This report points out that despite the development of the Social Model of (Dis)ability there are still many old fashioned ideas rooted from the Medical Model and in some cases leads to disempowerment and low expectations (WALK, 2015). The NCSE conducts research and interviewees report conversations with their guidance counsellors. In these conversations interviewees are advised to consider PLC courses instead of HE courses. The researcher also reports that guidance counsellors feel that mock exams are a wake up call and often try to persuade individuals to do the alternative Leaving Cert Applied although interviewees report expressing disinterest in this route to education as it narrows progression options into HE (McGuckin et al. 2013).

2.6.2 - Disclosure & Communication

"Help will always be given at Hogwarts to those who ask for it."
Harry Potter and the Deathly Hallows (Rowling, 2007).

As I read through the HE literature most, if not all of the HEIs ask that students disclose their (dis)ability and register with the access office in order to receive adequate supports however the literature suggests that not all students with disabilities are willing to do so and consequently this may have implications on their progress. An argument put forward by Riddell & Weedon (2010) claims that people do not register with the access office simply because they did not see their (dis)ability as part of their identity. Richardson (2009) also carries out a study and concludes that ultimately disclosure is the only way to receive additional supports and there is currently no evidence to suggest that a large number of people are not making disclosures about their (dis)abilities. Research in HE highlights these problems. Riddell & Weedon (2016) encounter communication issues with HE staff as key for many students with (dis)abilities in their research, especially the individual responsibility on each student to inform staff. Some of their interviewees spoke of how staff has no knowledge of their (dis)ability or condition. Fuller et al. (2004) has similar findings where students express frustration at having to explain to lecturers over and over and some also say that while most lecturers are understanding it can be the case where they feel that lecturers can't see past their (dis)ability and treat them as though they are at a disadvantage. (Fuller et al. 2004). Distinguishing students with disabilities from students without disabilities can have a knock on effect to students' construction of the self (Riddell & Weedon, 2014). However, Riddell & Weedon (2014) argue that managerialist techniques and methods, which are discussed in the next section have been used to promote equality.

2.6.3 - Managerialism – Even the muggles are affected

"But for heaven's sake — you're wizards! You can do magic! Surely you can sort out — well— anything!"

Scrimgeour turned slowly on the spot and exchanged an incredulous look with Fudge, who really did manage a smile this time as he said kindly, "The trouble is, the other side can do magic too, Prime Minister."

Harry Potter and the Half Blood Prince (Rowling, 2005)

The broader context of higher education in Irish society has important implications for how access policies are implemented. Central approaches to recent changes, includes the rise of New Managerialism in Irish education (Lynch et al. 2012). This continues a new set of values and traditions fixed in the complexities of social, political and economical organisational change (Clarke et al. 2000, cited in Lynch et al. 2012). It concentrates on outputs instead of inputs, measuring performance, emphasising the availability of choice and competition and promotes decentralisation of authority to managers and contract employers. (Chandler et al. 2002, Clarke & Newman 1997, Clarke et al. 2000, cited in Lynch et al. 2012). Within Irish context, the increased emigration rates, history of nationalism and much of the poverty is responsible for the weak industrialisation in the country (Chubb, 1982; Lee, 1989, cited in Lynch et al. 2012) and so educating people in science, technology and engineering becomes paramount for the Irish government to improve industrial relations and building a knowledge economy in Ireland.

Several equality and access problems have been identified in the education system for people with (dis)abilities as a consequence of the rise of New Managerialism. The voices of students from non-traditional backgrounds, including those with (dis)abilities can be lost. Education depends on holistic academic, social and emotional investment in people. Positive and negative outcomes for such students often go unmeasured in a managerial performance measurement model, especially care and emotional aspects. However, if educators become confined to recording these aspects, such calculations would dilute the person centred caring that is at the heart of teaching and learning (Lynch et al. 2012).

Foucault's theory on governmentality (Foucault, 1980) helps to explain the success of New Managerialism in education contexts. He explains how individuals govern themselves within managerial organisations. This will be examined later in the chapter but here there is a connection. Foucault believes we take on responsibility for regulating ourselves and strive for self-empowerment and self actualisation however it can be argued that in a HE these goals cannot always be reached as the resources required by people with (dis)abilities are in the hands of the HE and its management. This can result in ongoing concerns and fears for individuals as they make choices about future employment and postgraduate studies.

2.6.4 - Fear of the Future – Harry commits to bravery

"I'm going to keep going until I succeed — or die. Don't think I don't know how this might end. I've known it for years."
Harry Potter and the Deathly Hallows (Rowling, 2007)

Fear is a common emotion that many people experience on a daily basis however it is infrequently studied or analysed in sociological terms, rather philosophy, anthropology or psychology. Furedi (2007) states that fear is not merely an emotion linked to catastrophic events but it is part of our everyday lives and takes into account sociological positions of crime, politics, crisis and the future (Furedi, 2007). People find themselves in situations and these situations impact the fear. It is self determined but also determined by interaction with others. It can also be examined in many contexts as a social structure (Altheide, 2002). It is shaped by the culture that instructs us on how to respond to threats in our security (Furedi, 2007). Fear should be conceptualised as a social phenomenon in the following way. There is no immediate fear when faced with a threat but it is cultural norms that inform people of what is expected, how they should respond and how they should feel when confronted with a threat (Furedi, 2007).

By presenting fear as a concept, as produced here we can examine the fears faced by people with (dis)abilities in HE such as eligibility for funding, application for postgraduate courses or entering the employment sector without educational supports that are provided in college.

In order to find literature, which illuminates fears of the future for students with (dis)abilities I begin with the Google search engine to get a general sense of public discourse about this issue. The headline “Disabled students fear for their future as independence payment cut” (Ryan, 2017) is the first topic to greet me. When I click on it I am met with stories of the impact of the cuts to Personal Independent Payments

(PIP) for higher education students with (dis)abilities in the UK. I have included the link for readers to get a clearer picture of what has taken place but I will also provide you with a summary of their experiences below.
https://www.theguardian.com/education/2017/apr/04/disabled-students-future-independence-payments-cut-benefits

Lauren who is on the autistic spectrum is an undergraduate and has been relying heavily on her PIP to assist her financially through college, however after a needs assessment is completed it is decided she is no longer eligible for this payment and when she asked the department to reconsider she reports being told that 'evidently' she does not need it as she is in attendance in HE. She is now struggling to make ends meet and complete her degree. Lily Boulle describes a similar experience. Lily has Ehlers-Danlos syndrome, a connective tissue disorder that affects joints, skin, internal organs and bones and because she has lost her PIP, she is unable to access other student supports.

During the process of gathering literature I think only of fears for people when they leave HE. I do not anticipate fears like the experiences during HE shown here. According to The Guardian, more than 165,000 people in the UK will be affected by this drastic measure (Ryan, 2017).

AHEAD (2017) investigate employment for graduates and it appears that the loss of (dis)ability entitlements is a significant fear factor in seeking jobs after HE. The system creates a choice for people between full time work without benefits or part time work with benefits. As there is often additional cost in having a (dis)ability people fear for the latter and feel this system offers disincentives to work. Other individuals talk about the fears of disclosing a (dis)ability to their employer as there is a worry that prejudice or rejection may surface. Others express objections to disclosing information that is personal to them and are caught between disclosure and receiving personal supports or not disclosing and risking negative treatment (AHEAD, 2005-2007).

These three key concepts are clearly evident in much of the literature available. They resurface in my findings chapter as described later by my own interviewees. Firstly, it is useful to present the theoretical framework, which guides me through the analysis process.

2.6.5 - Foucault & Governmentality of (Dis)ability

Michel Foucault, the French Postmodernist becomes concerned with understanding how systems of knowledge and human acts of behaviours become specific problems (Tremain, 2005). These problemisations are linked to power and the formation of subject positions to which people become tied to certain identities and so his work is relevant to the understanding of those who are often identified as people with (dis)abilities (Tremain, 2005). Foucault believes the subject (individual) is not a rational thinker acting on it's own terms but rather a product of social structures, epistemes and discourses. He rejects objectivist epistemology and believes our truths and experiences are not fixed and are constructed for us by the same social structures and epistemes that give us our identity (Bevir, 1999). Given that the Social Model of (Dis)ability is believed to be socially constructed by society, and if it is people of power who frame our identities and provide us with labels then it is reasonable to believe that identity is also socially constructed. Considering this, people's actions can normally be explained by the social norms they have been exposed to through socialisation (Thompson et al. 2015).

Foucault's term 'bio-power' refers to the attempt to rationalise problems that a phenomena characteristic in a group of individuals pose to the practice of government. It is the movement to manage or control these problems in the life of individuals and populations (Tremain, 2001). The treatment of individuals with (dis)ability, which has already been discussed, forms new knowledge and discourse as time passes. This treatment contributes to technologies of normalisation and facilitates a system of social anomalies to create a division in society contributing to social control and the exercising of power over a particular social group (Tremain, 2001).

This system can be applied to education. Foucault identifies historical classification in schools and the division of groups based on who can achieve the highest grade, essentially, performance. He identifies this as an exercise of power and this establishes what is 'normal' in the course of education (Foucault, 1979). Performance is measurable and school measures ability. This articulates a domain form of knowledge, which develops and is reinforced by curricula and pedagogical practices. It creates an environment where what is defined as 'normal' also produces 'abnormality'. Hence, 'bio-power' and 'a normalising society' are intrinsically linked (Foucault, 1980) contributing to the success of Managerialism.

2.6.6 - Models of (Dis)ability

Two prominent models of (dis)ability have taken hold in society in the last fifty years, the Social Model and Medical Model of (Dis)ability (LoBianco & Sheppard-Jones, 2008). I describe these in more detail later on in this chapter. The Medical Model works from a biological perspective and conceptualises (dis)ability as a biological construct that results in impairment and requires treatment (Brittain, 2004). It is a problem, which needs to be cured in order for a person to function 'normally' in society (Brandon & Prichard, 2011). The Social Model rejects this discourse and asserts that (dis)ability is caused by the inability of society to take impairment into account making buildings, services, communities and societies inaccessible thus excluding individuals with (dis)ability and causing isolation and exclusion from full participation (Bingham et al. 2013)

Table 4.1 provides a clear understanding of the differences between the two models.

Topic	Medical Model	Social Model
What is disability?	An individual or medical phenomenon that results from impairments in body functions or structures; a deficiency or abnormality	A social construct that is imposed on top of impairments by society; a difference
Access to treatment or services	Referral by diagnosis	Self-referral, experience driven
Targets of intervention	"Fixing" the disability to the greatest extent possible; "normalizing"	Social or political change in an effort to decrease environmental barriers and increase levels of understanding
Outcomes of interventions	Normalized function; functioning member of existing society	Self-advocacy, changes in environment and understanding, social inclusion
The agent of remedy	The professional	Can be the individual, an advocate, or anyone who positively affects the arrangements between the individual and society

Table 2.2

Table 2.2 cont.d

Topic	Medical Model	Social Model
Effects on individuals who are typically functioning	Society remains the same	Society evolves to be more inclusive
Perceptions towards individuals with disabilities	The individual is faulty	The individual is unique
Cognitive Authority	Scientists and doctors	Academics and advocates with (dis)abilities
Perception of disability	Being disabled is negative	Being disabled, in itself, is neither positive nor negative

(Haegele & Hodge, 2016)

2.6.7 - The Relevance of Social Constructivism & Social Constructionism

Social constructivist theory provides us with the possibility to view (dis)ability as situated in socio-cultural contexts develops a more fluid understanding of difference (Trent et al. 1998), which is required due to cultural differences in teaching and learning instead of focusing solely on deficits (Gindis, 1995). We must focus on student strengths and instructional contexts. Taking this into account, is (dis)ability socially constructed?

Exploring (dis)ability as socially constructed involves both those with (dis)abilities and those without. It involves the understanding that it is people without (dis)abilities whom attach meanings to those with (dis)abilities. It involves directing attention towards social change and the physical, cultural and systemic structures in place, which lead to oppression. To think of (dis)ability as social constructed means distinguishing between the biological (dis)ability and the disabling environment in which the person with (dis)ability exists (Asch & Fine, 1988: Trickett, Watts & Birman, 1994).

Imagine a town full of physically impaired people,

Fig 2.4

The link below provides an interesting point of view on models of (dis)ability.

https://www.youtube.com/watch?v=9s3NZaLhcc4

(Social Model Animation, 2011)

2.6.8 - Theocratic Discourses

The first of Foucault's major work examines the history of 'madness' in society and dates back as far as prior to the 1650s. 'Madness' was a term used throughout the ages, which described anyone who behaves outside the realms of what was deemed as 'normal' behaviour. Foucault describes the attitudes of madness among human beings prior to the 1650s. Scientific knowledge replaced religious beliefs and madness was denied as a human condition. In some communities madness appeared as a form of sacred knowledge with the belief that so called mad people descend from spirituality and they were often treated with kindness, freely roaming villages and streets (Foucault, 1967). Some however were forced into performance for locals and became spectacles of entertainment. In the middle ages, the concept of madness was redefined as a human condition within 'the age of reason. Madness became feared and controlled, as it was not the behaviour of reason (Foucault, 1967).

From the 1650s, society began what Foucault refers to as 'The Great Confinement'. Rather quickly, a large number of people were incarcerated in hospitals, workhouses, and institutions, previously called leprosariums for the treatment (or segregation) of leprosy. Initially groups included the 'poor', the unemployed, criminals and the so-called insane. As discussed earlier, this is a practice developed in order to address recession as it provided free labour for the community and the economy at a time that money is scarce (Foucault, 1967).

The middle ages arrived with the concept of madness as a human condition, which stood on its own. This era was also named 'the age of reason' and madness was not the behaviour of reason (Foucault, 1967).

2.6.9 - Medical & Psychological Model

Using a historical lens, the French Revolution marked the arrival of the so-called modern era. The response to insanity consisted of three steps. Firstly, the introduction of asylums for the insane, unwilling or unable to work, secondly, the release from physical restraints, and thirdly, defining insanity as a medical problem. Medical professionals at that time had the power to incarcerate those who were insane for the purpose of medical treatment abrogating the right to live in society. The only way to escape incarceration was to positively respond to treatment. This became the norm of treatment and Foucault argues that the laws governing the treatment of the insane only served to enforce their own definitions of normality and punish those who do not abide by these norms (Foucault, 1967).

By the nineteenth century, in the medical sector, (dis)ability was widely acknowledged and focused heavily on bodily malfunction, disorders and deficiency and how this caused limitations or (dis)ability. The foundations were laid by diagnosis, treatment and recovery focusing on rehabilitation of the individual rather than cure. The individual's 'impairment' resulted in reliance on family members, friends and welfare services and included being segregated into institutions and for much or the twentieth century (dis)ability was depicted as a 'personal tragedy' and a social 'burden' on the rest of society (Barnes & Mercer, 2003).

Sullivan (2011) outlines that this conception towards people with (dis)abilities leads to isolation and low expectations from such individuals. Negative perceptions are constructed and reinforced prevailing to marginalisation of this population. Although Sullivan (2011) acknowledges that the medical approaches have some value, that is, that if a person is in chronic pain or has a reduced chance of living then it is of course acceptable to focus on medical treatment, however medical interventions cannot be the only answer and (dis)ability rights activists reject this model. Banks et al. (2007) further examines this model in relation to education and finds that the historical practice of denying people with (dis)abilities equal access to education accompanies actions of individuals being socially stigmatised and emotionally traumatized. Research in HE by Byrne, et al. (2013) recounts how students with quite sever (dis)abilities do not make contact with the access office for fear it may stigmatise and reinforce ‘otherness’ for individuals despite being admitted through the DARE schemes. Their records show that only 40 per cent of new entrants with (dis)abilities access supports. This type of fear and stigmatisation is a common thread discussed throughout this research.

2.6.10 - The Social Model of (Dis)ability

This social constructionist view develops in the 1970s and 1980s by (dis)ability rights activists, which rejects the Medical Model. Activists believe that modern society is at fault and it is society that fails to recognise or accommodate human diversity associated with impairment. It is society, which disables people and not the impairment itself (Oliver 1983; Zola, 1983). The Union of Physically Impaired Against Segregation (UPIAS) described (dis)ability as

> The disadvantage or restriction of activity caused by a contemporary social organisation, which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities (UPIAS, 1976: 14).

Subsequently the restriction to ‘physical impairment’ has been abandoned to include all impairments (Barnes & Mercer, 2010). As described by Oliver (2004)

> In the broadest sense, the Social Model of (dis)ability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment – whether physical, mental or intellectual (Oliver, 2004: 21).

The solution to (dis)ability within this model is to fix society, make it more accessible and reduce discrimination and negative disposition so individuals can fully participate. This allows for a more critical approach to (dis)ability. This model looks into the equality and diversity aspects that come with physical differences, and portrays (dis)ability in a positive light. For example, Harlan Lane, a psychology professor applies this model to the deaf society. Deafness may be viewed as a culture rather than a deficiency with it’s own language, shared ancestry, common stories and artistic traditions which are passed through generations (Sanger-Katz, 2011).

2.7 - Political critique of Social Model & (Dis)ability Movement

For people with (dis)abilities, The Social Model provides an environment for empowering people to campaign for social change. It provides the understanding that society is the problem not the individual (Shakespeare & Watson, 2002) and challenges marginalisation and discrimination (Owens, 2015). While it is suggested that the Social Model of (Dis)ability is responsible for social change, it is criticised for many reasons. Shakespeare & Watson (2002) suggest "that the very success of the Social Model is now its main weakness" (Shakespeare & Watson, 2002: 5). It has become sacred and difficult to challenge, as it is now so central to the (dis)ability movement. While in public it ignores the impairment, they argue that in private there is still an acknowledgement of aches or pains or difficulties associated with their conditions in their own interactions with each other, surely this inconsistency is wrong and needs to be re-examined (Shakespeare & Watson, 2001). There is no mechanism that rationalises the various ways in which (dis)ability is experienced (Owens, 2015). The Social Model does not account for difference and adjusting the social environment may not always be possible therefore is rendered essentialist (Corker 2002; Terzi 2004). Illness and impairment are portrayed as completely separate entities and by doing so this neglects the social relations of the two. Charmaz (2010) provides the following example 'an individual may have an illness long before they receive a diagnosis that may then constitute impairment, and others may be impaired but receive a diagnosis of illness long afterwards' (Charmaz, 2016: 10).

2.7.1 - Alternative Suggestions to Social Model

Oliver (1996a) recognises limitations to the Social Model of (Dis)ability and believes that a Social Model of impairment must be developed in order to run alongside a Medical Model. Shakespeare & Watson (2002) acknowledge that the ever changing definition of the Social Model still remains problematic and that a more sophisticated approach to (dis)ability is required and revolves around the following points: (Shakespeare &Watson, 2002: 25).

1. Impairment and (dis)ability are placed in different places on a continuum rather than presenting as separate entities.
2. (Dis)ability should not be reduced to a medical condition but the Social Model does not have to be the only other option.
3. It is vital to distinguish between different levels of intervention
4. (Dis)ability should not be generalised
5. This social theory development considers the British population only and not the rest of the world and so 'failure to follow a Social Model line, or join with

> the (dis)ability movement, may be less of a failure of particular individuals, and more a limitation of the model or movement itself.

Arendt (2003) offers a pluralistic view to power, which we can usefully draw on to explain this. As Owens (2014) advises, there are three realms to social life, political, social and private. (Dis)ability is not considered to be a relation of social power that effects everyone. Using her three realms allows us to analyse (dis)ability in relation to intersectionality. The social model focuses mainly on the political, touches on social but neglects the private. Collective process includes the persuasive power of action through logical reasoning. Power belongs to a group, not an individual. Diversity in the community is important and an attack on people with (dis)abilities is an attack on human diversity. Silencing the private realm of (dis)ability conflicts with the preservation of plurality as a condition of their freedom. For Arendt, disabled people are united because they should occupy the same public world as all of us in which we encounter each other politically as equal citizens. Politically we can see the world from different aspects. Using this approach provides a space to fill the gap between impairment and (dis)ability as it enables experiences and voices to be heard emphasising multifacetedness to co-exist in social relations (Arendt, 2003).

2.8 - Conclusion

The literature reviews describes a detailed account surrounding the complex domain of the (dis)ability sector. It comprises of attitudes preceding the enlightenment and the changing societal attitudes as momentum of the (dis)ability movement and the Social Model of (Dis)ability increase. Owens (2015) suggests that by using Arendt’s three realms we can explore the context of experiences rather than automatically assuming oppression. She further suggests that using Arendt’s concept of power produces a more collective action through consensus and solidarity (Owens, 2015).

To summarise the historical and current debates, and understanding proves difficult in such a small-scale research however there are concepts, which emerge again and again which cannot be denied. People with (dis)abilities have long suffered from societal ignorance and fear. The appalling isolation and deprivation experienced until the beginning of the civil rights movement is responsible for stereotyping and misconceptions, which still exist. Improved as it may be, the policy documents suggest that there is still a huge shortfall of resources available in and out of education. The measurement of ability has been a continual feature of education systems from the elite education system of the past to contemporary performance measurement systems. Education is no longer a ‘one size fits all’ system that fits neatly into our society. From the very beginning, stigma and labelling are prominent experiences and the Medical Model of (Dis)ability still holds much weight. It is time that education policy is comprehensively reviewed with more assistance from people with (dis)abilities and (dis)ability is interpreted as diverse individual experiences rather than a singular collective.

Chapter Three - Methodology

3.1 - Introduction

The purpose of this chapter is to illustrate why this research is relevant to my ontological and epistemological viewpoints in the area of (dis)ability and higher education experiences in Ireland. The context of this research chapter informs the reader of my own experience of (dis)ability, which facilitates me in reaching my ontological position. Reflecting upon this position brings me to my epistemological stance, which is influenced by the approach and thinking of Foucault but also the Social Model of (Dis)ability (Oliver, 1996; Ball, 2013). This leads to my qualitative research and how it applies to this study while also outlining my approach, blending social constructivism with elements of participatory research.

Following from this, I discuss some important ethical matters for this research piece. Before beginning the research I have no idea of the personal profile of my participants and so I have to keep in mind that I could be working with vulnerable adults such as those with intellectual (dis)ability. With this in mind, there is much to consider in ensuring everyone has an opportunity to participate if they so wish. I also have an obligation to protect the welfare of vulnerable adults. These matters include consent, boundaries, confidentiality etc and advertising for participants in an inclusive manner. I hope to reach everyone who requires support, as it is important for the research to explore the consequences of this for HE as it could mean that people may not reach academic success without additional supports.

To ensure inclusivity when appealing for participants it becomes apparent that a gatekeeper might be a good idea as a point of contact, particularly to reach as many individuals as possible. Gatekeepers may grant permission on behalf of participants but they may also limit and constraint access and so the role of the gatekeeper is critical. (Gilbert, 2001). A short section examines this later on in this chapter.

The framework I use for data analysis consists of coding processes and is a useful way of analysing qualitative data (Miles & Huberman, 1994). This method along with its advantages and disadvantages are then explained. As with all social research there are limitations but it is significant to restrict your limitations to the research in hand (Brutus, Aguinis & Wassmer, 2013) and so I have included a discussion outlining these limitations. Following on from this, I examine the process of the research through reflexivity, identifying challenges and learning throughout the chosen actions. Finally, the chapter draws to a close by summarising and drawing conclusions from methodology practiced throughout the research.

3.2 - Back to where it all began

Our ontology refers to how we, as individuals view and know the world. It is the starting point of all research (Grix, 2002). Roos (2006) describes it as a systematic account of existence of what makes up reality. This includes objects, concept, beliefs and assumptions. Essentially, our ontology refers to what we know about the world (Creswell, 2003). My own ontological position is aligned with social constructivism, which views (dis)ability in line with the Social Model described in the earlier literature review chapter. As Creswell (2003) outlines, the researcher is heavily influenced by ones own background, cultures and norms.

Growing up my own experience and knowledge of (dis)ability is quite limited. There is a girl in my primary school in the class below me with cerebral palsy and I remember seeing her come into school daily with an assistive walker. Every day she climbs the stairs while another classmate carries up her walker and her school bag. I remember thinking 'why don't they just move her class downstairs, where we are?' Eventually the school moves her class downstairs but that isn't until after at least two years of climbing stairs. This is my very first experience of (dis)ability. Following from this experience I have the pleasure of getting to know a young gentleman in the secondary school I attend. This young gentleman has mobility difficulties also due to cerebral palsy. There is no elevator in our school until this person's leaving certificate year but accessing the classrooms never seems to be a problem for him, or perhaps he just never expresses it. As time goes on, I eventually, like many others leave school to embark on my third level journey. I do not think much about either of these individuals until beginning research.

I go on then to study social care in college and for the first three years we are required to complete three work experience placements, one a placement within the (dis)ability sector. I source one and in second year my placement is a small residential house for adults with intellectual (dis)abilities. I will never forget the fear that instils in me on my first day, not to mention when I go to the day centre to drop residents off. There must be more than twenty people with various (dis)abilities, most of which I have never seen before but as time passes the fear becomes less and less and I begin to see that each individual, just like me have their own personalities, beliefs, likes and dislikes and display a warmth and appreciation for life that I had since long forgotten to appreciate. Many similar experiences follow and these persuade me to begin my career in the (dis)ability sector, working in jobs that assist extraordinary people to lead ordinary lives. Through my work I identify many barriers in society that make this difficult and as someone who is fortunate enough to have the opportunity of a third level education because of the availability of the third level grant and a one parent family payment to support me, I want to further examine why for some people this opportunity is not always possible. Although I did not realise it at the time, this is when my ontological and epistemological stances begin to develop.

There are many barriers affecting the attendance of individuals with (dis)abilities in Colaiste Eolas[2]. Societal interpretation of (dis)ability is among these barriers. The social constructivist approach supports the Social Model of (Dis)ability. As I discuss in the literature review, while the Medical Model has a belief that the individual needs a cure in order to lead a normal life, the Social Model focuses on how society is constructed around able-bodied people without considering differences (Barnes & Mercer, 2003)

3.3 - I love to chat but I also love to listen

Qualitative research is fundamentally interpretive and so the researcher must make an interpretation of the data (Creswell, 2003). After evaluating different methods of research I conclude that the most suitable method for this study is qualitative. A qualitative research method makes meaning of the way in which individuals interpret and make sense of the world (Hughes, 2014). I use qualitative research as it reaches a wide variety of understandings, relationships and experiences (Mason, 2002). Willig & Stainton-Rogers (2008) state that qualitative research explores relationships within real life and phenomena are examined in context. Boxill et al. (1997) discusses some of the advantages of qualitative research and suggests that qualitative research is useful when researching sensitive areas. It provides in-depth assessment of the area, which is being researched and allows for subjective evaluation based on interpersonal interaction between the researcher and participant. Additionally, unstructured interviews are used and combined with a narrative approach.

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[2] Pseudonym of HEI

Before beginning this Masters I have no knowledge of narrative writing, especially for an academic Masters. Half way through the year, along comes Jerry O'Neill. Jerry is a lecturer in Maynooth and he introduces the class to the narrative research (O'Neill, 2017; Claundinin & Connelly, 1990) As I mention, I fall instantly in love with it. I love creative writing and story telling. I used to be good at it in school but as an adult, life gets in the way and we disengage from the talents and fun we once had and so I forget to nurture this talent. This method seems so far removed from the style of writing for my undergrad and I become excited, however, I worry that because I did not set out on the narrative road it might be too late to properly do it justice, I decide to use narratives poems to analyse and present the findings of experience in my interviews.

I feel that this approach resonates with readers and enables people to tell stories of and better illustrate Colaiste Eolas experiences of education. Because statistics are not used, qualitative research uses a more descriptive, narrative style. This type of research might benefit the researcher as a practitioner also as she or he could turn to qualitative information in order to examine forms of knowledge that might otherwise be unavailable, and so gaining new insight (Hughes, 2014).

3.3.1 - Social Constructionism & (Dis)ability

As outlined in the literature review chapter, The Social Model of (Dis)ability separates the concept of impairment from the concept of (dis)ability. It identifies impairment as a perception of function, which is seen by society as abnormal. The concept of (dis)ability is socially constructed and a focus on the way society denies access to facilities and enables people who have impairments to live a normal life style (Barnes, 2010). Society includes citizens, politicians and leaders and so this belief is in line with the social constructionist view. This is the belief that (dis)abilities are defined by arbitrary decisions of those empowered to designate them; and so (dis)abilities are labels, which are determined by public policy and professionals who treat them (Hahn, 1985). Social constructionists also believe that we can only explore the realities of individuals as they experience the world, drawing on the interpretations of others. Interpretivists believe that humans will consider and analyse what they do, which in turns leads them to make judgements about what it is they will say and to whom. Use of naturalistic inquiry - observation, unstructured interviews and transcription are useful to make sense of the participant's experience (Brooksbank, 2013). Dewey (1938) outlines that research is the study of experience. My sense is that research in this area is very personal to the participant. It involves forming relationships and subsequently opening up to the interviewer and speaking about sensitive areas and so narrative research is the most suitable method as it does not offer a strict framework or definitive methodological moves (Andrews et al. 2008/2013). Dewey (1938) suggests that experience is both personal and social, both of which are always present. People need to be understood as individuals but they are always in a social context, which is congruent with the emphasis in the Social Model of (Dis)ability.

3.3.2 - Participatory Research Emerges

I describe earlier that my ontology aligns with the social constructivist point of view with characteristics of the participatory paradigm I will attempt to illustrate where those characteristics emerge for me as outlined by Heron & Reason (1997). Guba & Lincoln (1994) make valuable contributions to the inquiry paradigm and identify four major paradigms, which frame research. These are, positivism, post-positivism, critical theory and constructivism (Heron & Reason, 1997). It is argued by Heron & Reason (1997) that their articulation of constructivism is unclear about relationships and "the original giveness of the cosmos" (Heron & Reason, 1997: 1). They extend Guba & Lincoln's framework to the formation of the participatory paradigm. The belief is that a worldview based on participation and participant realities is more useful (Heron & Reason, 1997). Reflexivity is crucial to the worldview of the participatory paradigm, a skill I have acquired during the course of this project. The participatory worldview allows us to articulate how we are personally acknowledged as part of a whole rather than being placed as a separate creation but live within this creation as *relatives* with all that it implies (Storm, 1972; 1994). It is during the course of the interviewing that I begin to see myself in this way. Narrative, as a method of enquiry tailors to this paradigm. Participatory research is fundamentally experiential which aligns with my research question.

3.4 - Establishing a Cohort

Deciding on a sample brings many challenges as the areas of both education and (dis)ability are so broad. To choose a sample I must be returned to my ontological view. My first experience of higher education has been a very positive experience despite being a young single mother and pregnant in my first year. Because of this I feel I would like to go back to where my own higher education begins. Deciding how to reach a cohort for interviews brings me to my next challenge.

3.4.1 - Gatekeepers in Research

How could I reach my target participants? I want to reach not only people who avail of or have availed of access office resources but those who may not have. I begin by emailing the access officer in Colaiste Eolas (see appendix A) and follow I up with a phone call. It is agreed that the access officer act as my gatekeeper for people who utilise the services but also to help me contact everyone else who attends the college in order to try to reach people who may not make a disclosure to use the additional resources.

De Laine (2000) describes gatekeepers as individuals or institutions who have the power to provide or withhold access to a research population. He also outlines that gatekeepers can impact upon the research so I want to ensure this impact is as minimal as possible while also meeting ethical criteria for the Colaiste Eolas. Glazer (1972) notes the research institution is concerned with the integrity of Colaiste Eolas' work and must consider how research will have a long-term affect on the organisation. Taking this into account I acknowledge a right of reply for the access officer if something negative is revealed about the service or the access office. This is discussed and agreed with the access officer but it is also imperative that participants feel safe and secure in the knowledge that Colaiste Eolas staff cannot identify them even if they read the research or take part in the right of reply interview. I realise here that power becomes an issue. Not only is this person acting as gatekeeper but this person is responsible for the access supports of the participants and so confidentiality is paramount. In addition, I as a researcher could be viewed by participants as having power and responsibility as the mediator between the access officer and the participants.

3.4.2 - Contacting Research Participants

In order to reach those who may not be computer literate I post up some notices in public spaces in Colaiste Eolas providing information on the research along with my contact details looking for interviewees. I design bright, colourful and attractive notices in order to draw people to read more about the research and appeal to the attention of individuals who are visual learners. I use pastel coloured paper, as this is helpful for people with dyslexia because it makes reading easier than if on a white page. This advertisement can be found in appendix B. Permission to do this is sought from the Registrar through the access officer/gatekeeper as per the ethical guidelines of Colaiste Eolas. After a discussion with the access officer, it is suggested that they would contact all the students in Colaiste Eolas via their Colaiste Eolas email address introducing my research and I. This is included in appendix C. I outline the details of the research and the students are directed to contact me in order to take part. Drafting a short email to draw people in includes brief details of the research and hopefully it isn't too much information. Attaching a further information sheet (appendix D) with more defined details of the study provides full information to potential participants so they can make an informed decision on participation. The information sheet and contact conversations stress that all contact is at participants' convenience and I that work around them to for meetings.

3.5 - Ethical Care for Participants

According to Kirby et al. (2006) ethics are paramount when carrying out research. The researcher must ensure that the participants are not harmed in any way, emotionally or physically (Kirby et al. 2006). Oliver (1996) identifies that people without (dis)ability primarily research (dis)ability and so ethics are of the utmost importance in this research. With this in mind he also identifies that the relationship between life and (dis)ability brings about a social movement, which increases the popularity of models constructed by people with (dis)abilities. As a member of society and to be part of this movement through my research I must consider the ethics involved.

3.5.1 - Establishing Informed Consent

Voluntary, informed consent is an essential principle when conducting research and participants need to be free to choose to take part or refuse participation after being given the fullest information concerning the nature and reason for the research and where the research is going. Any risks to individuals also need to be addressed. The participant should also be given the chance to withdraw at any time prior to publication (Gilbert, 2001). To address this, an information sheet is attached to the notices that are posted up around the college and this also includes a phone number I am using for the duration of the thesis and my university email address. Details of my supervisors contact details are also included should participants have any questions that they do not wish to discuss with me. Once people make contact and display interest in participating, a further conversation takes place, which answers any questions that participants ask. I also provide an option to meet prior to the recorded interview. A consent form is drawn up and emailed to participants prior to the interviews or first meeting. I also set aside time when we first meet to go through the consent form and discuss in more detail any concerns participants may have. I am also conscious of the possibility of reading difficulties so I ensure to read the consent form aloud to participants and answer any further queries, particularly concerns around anonymity. I print the consent form out on pastel coloured paper to improve readability for people with dyslexia. (Appendix E).

3.5.2 - Safeguarding Participants

To my interview I bring along an information sheet with contact numbers for the counsellor in Colaiste Eolas and also advice groups and support groups for participants in the hope that they will use these services should sensitive issues arise, which may upset the participants. During the interviews, the conversation can become quite emotional. When I acknowledge interviewees pain and remind them of the gratitude along with commending the interviewee on their honesty and bravery in this research, I find this can put individuals at ease. They are also offered opportunities to pause or stop and continue at another time. Dale (2011) speaks about whether individuals can actually provide informed consent, as they are not fully aware of the dynamic process or the emotional consequences of interviews. When I am drawing up the consent form there is of course, no mention about the feelings which might emerge for participants asking them to consent to this also. When agreeing to take part participants (and researchers) may not factor in the dynamic process involved (Dale, 2011). So is consent for this project really informed? I consider this at the first point of contact with my participants and I discuss this. I disclose to them that I am choosing the narrative method, explaining what it entails, because of the sensitivity of the discussion. I don’t want to be focusing on my own motive for this research by engaging in lists of questions to get through, meanwhile ignoring displays of emotion. This considered, the participants still wish to be involved.

At the interview stage I have no notion of the turn of events surrounding writing poetry so this is not something that participants have originally given consent to. How could I have foreseen this? I don’t think I could have but it certainly something to learn from, as I was fortunate to get a positive response afterwards when I seek permission to produce poems from their transcripts.

3.5.3 - Maintaining Professional Boundaries

Streubert et al. (2007) discuss the relationship between an interviewee and a researcher and while this is important to develop a level of trust, the researcher must take some factors into account. It is possible that the interview may be the only chance the interviewee has to discuss his or her personal feeling about a situation and while participants are consenting to the conversation, they may not be consenting to your reactions or responses required to maintain boundaries by keeping the interview within the related experience. In conjunction with this I must also remain sensitive to the interviewee's personal circumstances. It is important to remember the interview is not grounds for an intervention (Streubert et al. 2007). Taking this into consideration I use temporary contact details. I use my university email at all times for correspondence, which will no longer be usable after graduation and I use a temporary sim card to make and take calls from participants.

I also develop a system of self-care before and after engaging with interviewees. It is common for researchers to become distressed after witnessing the pain and anguish of interviewees. It can cause additional strain to cope with the feelings the researcher experiences (Booth & Booth, 1994). Although I have some sense that the interviews will be difficult, I am underprepared for how the experience resonates with me for the first interview. Research in the social world inevitably involves emotions and social researchers experience many feelings, as I do, such as anger, frustration and emotional distress when conducting research (Johnson, 2009).

Prior to the first interview I prepare a list of resources for my participant, to contact if emotional distress arose, but for myself, I have no such list of resources. After the interview I engage in reflective writing. Perhaps it is journaling to a degree. I prefer the genre of creative writing but I find it useful, after the interviews to write about the emotions I experience while speaking with interviewees. This is useful for reflexivity, which is discussed later in the chapter but it also gives me a safe space to acknowledge my emotions and the role they play in research after the interview rather than during it (Darra, 2008). Participants can react to researchers emotions by changing the subject and can feel it takes from their own experience as researchers stop to deal with their own emotions (Goodrum & Keys, 2007). Transcribing also opens a space for recollection of the emotional experience as this involves listening repeatedly to the emotional nuances of the interview (Bahn & Weatherill, 2013) and so I ensure to take regular breaks during transcribing and have some 'down time' in the evenings and do something I enjoy such as walking, cycling or watching a film. I also engage in mindfulness meditation more regularly than usual in the evenings to stay within the realms of what is happening in my own life and remain present in it.

3.5.4 - Engaging in Proper Use of Language

Participants are not considering informed consent when they are unaware of my biases and attitudes or words I might use. Sim & Wright (2000) discuss sensitivity and the risk of harm to the participants. There is risk of psychological harm if attitudes and beliefs are being examined or if sensitive areas are being discussed. The appropriate use of language when addressing the participants is carefully constructed prior to interviews but also throughout my writing as discussed in chapter one. Asking participants terms or phrases they prefer me to use throughout the interviews gives, I believe a sense of ownership of the interview. It must also be mindful that the researcher remains sensitive at all times during the interview and when analysing data. Language is also very carefully constructed when making contact. The information sheet is drawn up with guidance from my supervisor as per Maynooth University ethical guidelines.

3.5.5 - Confidentiality for Participants

Anonymity and confidentiality must be considered when carrying out research, (Sim & Wright, 2000) so names or identities will not be listed in this research project. Participants are given the opportunity to choose their own pseudonym, which are declined. I later feel that there are discussions in the interview that would most certainly make individuals identifiable to staff at Colaiste Eolas so I give each person a unisex name and avoid the use of his/her throughout the findings. I feel that gender has no influence on the findings of the study. Removing gender terms throughout the text leads to repetitiveness of names in places that might not appear to fit grammatically but the promise to remain unidentifiably outweighs the correct grammar in this scenario. Participants are also shown transcripts of interviews followed by the poetry developed and are provided with the opportunity to remove or change anything that they feel makes them identifiable. I discuss this more later.

3.5.6 - Avoiding Additional Cost to Participants

I recognise that by asking people to commit to the research process is asking a lot of the participants. They are sacrificing time with work, families, studies etc to help me so I want to make sure that the sacrifices they make are minimal and there is no financial cost to the interviewees. Firstly, I can offer communication via email or text. Where there is a number attached in the email I make phone calls so there is no loss of phone credit. For the interviews I give people the choice of where to meet. Robin suggests a coffee shop so we meet in the town of residence so there are minimal petrol costs. I offer to buy coffee as a token of my gratitude but Robin refuses, even when I try to insist. Any communication after the interview takes place through email and when we need to talk I arrange a suitable time for me to ring and also offer another meeting, which Robin declines.

I also speak to Jamie over the phone. After the first email I call Jamie, again to ensure credit does not get used. We meet at the college canteen. I offer tea, coffee or water but it is refused. Once we discuss informed consent and go through ethical queries we complete this interview outside the college as the sun is shining. Jamie is already attending college that day so there is no extra financial cost to attending the interview.

Sam gets in touch through email but then later rings me. Before we continue talking I asked Sam if I could call back but Sam has subscribed to free talk minutes. When we first arrange to meet, we arrange to meet in Colaiste Eolas again reducing extra petrol costs. I offer to buy Sam tea and this offer is accepted much to my relief. I am grateful to be able to give a small token of thanks. We chat for some time and make arrangements to speak again in the future for a recorded interview. After giving Sam some time to think things over I make phone contact and we agree to meet at Sam's house, as there is no access to transport on this day. Again I am grateful, as I want sacrifices to be minimal. Any contact with participants after this takes place through email or at my expense through telephone.

3.5.7 - Recording the Interviews

Interviews are recorded on my phone and participants are made aware of this in the consent form. They are then transferred to my laptop and deleted from my phone. My laptop is password protected and is only accessed by me. As the consent form outlines in the appendix, the information will be stored safely for five years.

3.5.8 - Providing the Ability to Unsay Things

It is explained to each participant that transcripts will be sent to participants via email. However each participant is offered alternative methods such as hard copies of the recording but this is not required. I reassure participants that they have the right to amend it any way or withdraw any piece and this will be respected by me.

3.5.9 - Offering a Right of Reply

I am also aware that including a right to reply from the access officer might influence the interview in some way, as participants know that this person has the power and responsibility to manage the resources that they are entitled to. To address possibilities of being identified in the 'right of reply' interview with the access officer, I outline to participants, in the consent form that this right exists and when explaining this concept to participants I inform them that they will still remain anonymous and questions around my findings for the access officer include open ended questions such as 'can you comment on the need for assessments for individuals?' or 'would you comment on the disclosure policy?'.

After conducting the interviews it is evident that there is a need for a right of reply from the access officer as areas for vast improvement in communication are identified and so after all my interviews are complete I email the access officer inviting a conversation addressing this. This offer is accepted and so prior to the interview, as decided and agreed I forward some topics to be discussed and then follow up with a phone call. I choose this method, as I am concerned that as a novice researcher the ability to keep the participants confidential might be compromised in a formal interview. We arrange a time over email that the access officer is free to talk to me and when I call we have a long conversation, approximately an hour long and converse through the question I have already sent. The questions are included in appendices G. I take notes as we talk rather than recording the call. I purposefully choose not to record the call as I simply feel it is not required in this instance.

3.6 - Developing a Framework for Data Analysis

Data analysis is ongoing and can occur by developing, testing and changing propositions through

> The process of systematically searching and arranging the interview transcripts, field notes and other materials…to increase your understanding of them and to enable you to present what you have discovered to others (Bogdan & Bilken, 1992: 153).

This is without a doubt the experience I encounter in order to present and do justice to what I uncover in my research. After completing my interviews and constructing my first literature review draft I begin the complex process of coding inspired by the Grounded Theory method. Grounded Theory for qualitative data analysis aligns well with the interpretivist approach (Charmaz, 2006). Theory, data and analysis stand in close relationship with one another and the theory is derived from the data collected. It involves a series of steps explained in the Table 3.1 (Strauss & Corbin, 1990) while Figure 3.1 shows you my coding process, which hangs on my study wall.

Types of Coding	Explanation
Open Coding	Breaking down, examining, conceptualising, comparing and categorising data
Axial Coding	Data is put back together in new ways after open coding, by making connections between categories. This is done by linking codes to contexts, to consequences, to patterns of interactions and to causes.
Selective Coding	The procedure of selecting the core strategy, systematically relating it to other categories that need further refinement and development. A core category is the central issue or focus around which all other categories are integrated.

Table 3.1

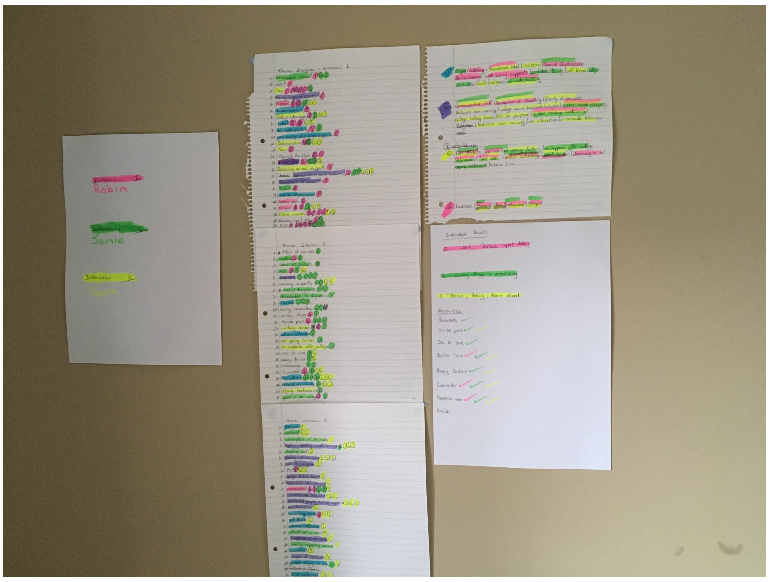

Figure 3.1

I find this method very useful for identifying themes. The narrative interview ensures that my biases of illusions are not exposed. Open coding in the first interview produces vast amounts of data. It's in the second interview that coding becomes more complex, listening out for similar experiences to the first interview but not directing the interview in any way. While there are indeed similarities between the interviews new information also arises in axial coding. This links meanings to categories and sub-categories. Through selective coding core categories emerge and these categories are organised, compared and contrasted until no new information has emerged. This is known as saturation point (Strauss & Corbin, 1998). I reach this point quite quickly and identifying core categories does not prove so difficult. Conceptualising the categories however becomes difficult. Stigma, without a doubt is a key concept in my findings. Fear, also presents as a major element. Issues regarding the organisation of exams, reasonable accommodations, disclosure, funding etc. are difficult to conceptualise so I present these systemic problems as a knock on effect of New Managerialism.

What coding does not do is provide the depth and emotion of experiences for students with disabilities in HE that resonates with me. It is the found poetry, discussed in the next section that I use which captures this.

3.7 - Giving Justice to the Words

During my first interview the participant becomes very emotional and I respond to this emotion with warmth and a touch of the hand. In my second interview, there is anger displayed through the participants tone of voice as well as what is being said. I feel that these emotions have not been captured in the transcripts and may even make me appear to be cold and unsympathetic. Paget (1981/1983) identifies these difficulties in her research and develops a system of notation which preserves hesitations and emotions in everyday language. Pauses and emphasis provide clues and emotion to meaning and these are building blocks for the analysis. I try to adapt this method to my own transcripts but I am still unhappy with how the interviews are presented. The expressions are lost and to read back over these transcripts you would think I have no regard for ethics at all. I recall the lecture from earlier in the year on by Sarah Meaney on Arts Based Research (Meaney, 2016) and I begin to read some more literature relating to this. Butler-Kisber (2002) writes about this in her own research and this resonates with me. As I continue reading her work, I am exposed to the world of what is called ‘found poetry’ (Richardson, 1990) that I don’t even know exists. Found poetry is made up of words that are found in the environment, the transcripts are the environments in this case (Walsh, 2004). It consists of the lived experience of the individual and seeks to evoke emotional responses (Richardson, 1990). I decide to give it a try. I read some more to gain a clearer understanding of this genre.

Although, as I mention, I feel that I have a bit of a flare for poetry, a challenge presents itself that I do not foresee when making the decision to write poems. Because I commit myself to this format, as I feel it is the only way to give volume to the transcripts, I realise I am writing poems using someone else's thoughts, phrases and experiences and not my own. I am also confining myself to the themes I identify when coding but one core element remains, the narrative. This narrative method tells a story and I love stories. The beauty of narrative poetry is the lack of rules to adhere to when writing. This allows me to have a wide variety of narratives unconfined to rhyming or structures.

I interrogate the transcripts by reading and re-reading and making notes as I go, in the same way that Walsh (2004) recommends. I pull out lines and apply them to each of the themes that emerge in coding. At first they appear messy so I formulate verses or stanzas including punctuation and gaps in the page where I can feel the emotions when I read them back. I even show them to a critical friend to see if they can relay the story in their own words. When they can, I know then the story is captured.

Berbary (2011) explores women's negotiations of gendered discourses with the use of Creative Analytical Practice (CAP) and I adapt some of these methods in my own analysis. She established four rounds in her interrogation. The first, coding for the over arching purpose of the research. I am asking an over arching question so I move to part two, that is using coding to specifically answer the research questions. My coding categories are already deconstructed during part one, so this covers step three. Her fourth step however, I find very useful. This involves recoding the original data to categories areas that I might have over looked. This step leads to the deconstruction of shorter, snappier poems where individual issues arise for participants and I feel are also important to my findings in chapter four and relevant to my discussion in chapter five.

When I have the first set of poems written I email them to the interviewees and discuss the flatness of the transcripts initially sent. All participants agree that this is the case and I get a very positive response when I produce the poetry. Robin feels particularly drawn to the poem and states deep happiness with it and feels it delivers the message much more clearly. Jamie is also much happier with poetry instead of transcripts outlining becoming bored while reading the transcript. Sam, initially inquires about lacking rhythm but when I outline the importance of remaining true to the original transcript this settles Sam and so announces satisfaction to use the poems. Because the idea to use found poetry develops so late and so quickly I feel there is not adequate time to meet with participants and write the poems together and this is confirmed when I contact participants with the poems as exam time is approaching for participants and they cannot commit to more meetings.

3.8 - Limitations to study

One of the major limitations to this study comprises also of one of the main themes, that transcribing sensitive issues can produces flat, non-resonant findings. Acknowledging this early on in the process, I am awarded the opportunity of creating my findings in found poetry to address this limitation.

Poetry as a way of producing findings can carry its own limitations. Poindexter (2002) states that traditional methods can be clearly evaluated for quality but poetry cannot. Arts-based researchers contend that aesthetic and qualitative criteria can be used as evaluation and so researchers using poetry should be mindful of poetic traditions as well as qualitative criteria. This method also requires specific attention to detail such as rhyming, lines etc and it can be argued that the aesthetics of poetry can distract the researcher from what is true and real (Furman et al. 2007; Schwalbe 1995). Despite these concern Schwalbe (1995) contends that ‘if writing poetry about the people we study, or writing it as if we were the people we study, means striving to tap into the feelings that make them who they are, then writing poetry will probably help us to understand them more fully’ (Schwalbe, 1995: 404).

Originally, the low response rate concerns me. Are my findings representative of feeling among other students? Creswell (2009) acknowledges that qualitative research is limited because of the lower quantity of participants. Interviews provide a limited conclusion to the population and it does not provide results on frequency of occurrences or prevalence of a particular situation. However the literature I review suggests that the experiences of my participants are depictive of a larger group of students with disabilities attending Irish HEIs.

Hughes (2014) also identifies some problem areas. Researcher's presence and relationship with participants can have a profound effect on the subjects of study and so to address this, I spend time getting to know participants in an informal setting and meet participants prior to recording interviews to build a relationship and minimise the limitation this might cause.

Further identified by Hughes (2014) other potential problem areas include issues of anonymity and confidentiality using this method, which I address in this research with participants when discussing consent. My response to such difficulties is outlined in the Ethical Considerations section.

Narrative interviewing involves building on relationships of trust and confidence (Claundinin & Connelly, 1988) and in such a short space of time it is difficult to develop such relationships even though the process requires much communication. This may lead to a limitation in the depth of the experience. I still feel benefits of this approach outweigh these limitations when I am addressing sensitive issues.

The literature review in a research project also addresses limitations by exploring other empirical research in this area and by offering methodological and conceptual frameworks supporting the research findings.

3.9 - The things we think but don’t share

Practitioner and researcher reflexivity is important to the researcher and the researched, the service user and the employee. Etherington (2004) states the reflexivity involves

> An ability to notice our responses to the world around us, other people and events, and to use that knowledge to inform our actions, communications and understandings. To be reflexive we need to be aware of our personal responses and to be able to make choices about how to use them. We also need to be aware of the personal, social and cultural contexts in which we live and work and to understand how these impacts on the ways we interpret our world (2004: 19).

Applying this concept to me and to my research involves examining my own beliefs and values prior to interviews and leaving these aside to allow the interviewees to express their own experiences. It does not however remove empathy or kindness or feelings of resonation with the individual. I can still acknowledge fears, worries and hopes without acting on them and crossing professional boundaries in the unique conversations I have with my participants. The ability to do this certainly presents itself as a challenge in my interviews. McCormack & Ryan (2011) during a workshop encounter feelings from teachers of the need to 'fix' things. I relate to this in two of my interviews. As I mention before, Robin becomes very emotional during the interview. Perhaps things are tough at the moment, it is exam time after all. Because the narrative experience interview involves less directive interaction by the researcher than traditional interviews this presents as a real challenge for me. As Robin speaks I find my mind wandering to services that could provide support. I feel the urge to even give a hug and say that everything is going to work out. First of all, I don't know that it will work out and I cannot make such a statement, secondly, I have this information to provide after the interview and I must stay within the realms of the task at hand. Thirdly, I realise that giving hugs to participants not only crosses a line but also invades the space of the interviewee, a person I barely know. When I talk to Sam, I have similar feelings. The anger in the interview of the circumstances encountered by Sam set my emotions running high but I must stop myself from giving advice. As a person, I work hard on my own personal development practicing personal reflection and mindfulness but I can only discuss such things after the interview in a very vague manner when the emotional moment has passed.

Goldstein (2016) states that it is argued that the reflexive process can support the emergence of findings because of the interpersonal relationships, which develops. I meet with Sam on more than one occasion and we also talk on the phone. During the first meeting Sam insights me into what is going on and even at that point I can hear the feelings of anger. Because of this I have to ensure to detach myself from Sam's situation when going into the narrative interview. The ability to be subjective in research varies and may depend on the researchers epistemological approach (Bishop & Shepherd, 2011). My own background is in social care and so a while it is plausible to suggest that years of working in a vulnerable sector may influence the research, my awareness of this is crucial for the interview process but will possibly be exposed when analysing my data in the next chapter. Morrow (2005) believes that despite this the value of reflexivity adds more to the quality of the research than it takes away.

As indicated earlier the interpersonal relationships is a key factor in narratives of experience. As researchers we are asking participants to divulge deep and personal information and while I completely understand the importance of this, this takes time, time I worry that I may not have due to my own anxieties about adequate time for this thesis. However, keeping this in mind I must revert back to my ethical consideration of safeguarding the participants. Maintaining an ethical attitude in narrative research involves anticipating such issues and figuring out how best to protect our participants while also maintaining responsible scholarship (Josselson, 2007). And so, taking this into consideration I leave my own anxieties aside and give Sam, Robin and Jamie my full attention.

Reflexivity in the right of reply interview is crucial in this research. Goldstein (2016) in her research describes how she witnesses a cynical attitude toward patients where she works with and hears stories of feeling misunderstood by patients. She refers to this in her interviews and then she is able to converse about these feelings with other clinicians similar to a 'right of reply', I suppose. I reflect on this when I make contact with the access officer in Colaiste Eolas but because I am confined to open questions as promised to my participants, I must remain impartial as I fight the urge to ask why individual participants might feel so disappointed with the services. Again I must return to safeguarding the participant and apply this consideration also and simply see where the conversation leads and interpret this in my analysis.

3.10 - Conclusion

The chapter begins by outlining my ontological and epistemological stance along with my methodology and theoretical approach. I introduce readers to the experience I encounter during transcribing of interviews and the new turn of events, which takes place, forming found poetry. Limitations to qualitative studies are discussed and addressed. In my experience, the narrative style of interview works well as participants seem to open up and a relationship on trust is developed between my participants and I. Despite the limitations of poetry writing identified I feel it is essential upon reflection and really can't imagine having used any other approach.

Chapter Four - Findings

4.1 - Introduction

Following from my methodology, this chapter creatively illustrates the research findings revealed while conducting interviews with students in the higher education institution at the heart of this research project. I begin with a brief contextual overview of the resources and facilities available to students in Colaiste Eolas who avail of the access office. The services applicable to my participants are also reviewed at a general level but I purposefully do not individualise the profiles of two participants, as their identity may be obvious to staff at Colaiste Eolas if I do. Jamie, who has dyslexia, has consented to their learning difficulty being exposed throughout the research. The issues surrounding this difficulty are key to the findings as and Jamie outlines that many individuals present with dyslexia so it is decided there is no reason to conceal this.

I use the grounded theory approach to coding, reviewing transcripts line by line noting descriptive codes. The selective coding re-categorises and condenses first level codes (Glaser, 1978). This is described in chapter three and this is where my key themes emerge. Using Glesne's rules for developing transcripts into found poetry, (Glesne, 1997) I read and re-read the transcripts extracting lines and phrases, which mirror the participants way of speaking but also provide a sense of rhythm. These phrases are then developed into themes that describe different aspects of the lives of the interviewees and I write poetic transcriptions under each theme identified giving each poem a page of their own to further illustrate the importance of each persons individual experience of key areas. This process involves, as she describes it 'searching for the essence conveyed, the hues, the textures and then drawing from all portions of the interviews to juxtapose details into a somewhat abstract re-presentation' (Carr, 2003). This method of coding provides a platform to a section on the common themes that emerge from my findings and it is then the poetic writing illustrates what I uncover during interviews. These are also given phrases or questions as headings to represent the common experiences of all three participants. As outlined in the methodology chapter, I create a series of found narrative poems in consultation with the participants to convey each individual's experience of accessing higher education. I deliberately refrain from giving these poems titles as I feel I have no ownership over them. The words and feelings belong to the participants. I am simply passing on the message reconstructed through this medium of found poetry.

To illustrate the issues and experiences that may not have touched all participants I identify sub areas and write additional poems, which describe these feelings. These have been given headings to create the theme of the poem and are not be mistaken as titles. Finally, I draw conclusions focusing mainly on the benefits of the use of found poetry for my findings analysis.

4.2 - Colaiste Eolas Profile

Colaiste Eolas provides the following resources for people who are accessing (dis)ability access office supports.

- Assistive classes and workshops
- Essay assistance and proof reading
- Academic assistive technology
  - These include Academic/learning support
  - Personal assistance
  - Transport funding

Resources, which are offered to my participants, include

- Voice recorders for exams
- Electronic scribe pen
- One to one tutoring
- Extra time for exams
- Essay assistance
- Computer software to aid reading and writing
- College counsellor
- Separate rooms when completing exams

Colaiste Eolas applies for funding through the ESF fund. The DES sponsors the ESF fund with assistance from the European Social Fund (ESF). It is co-ordinated by The National Office for Equity of Access to Higher and also reviews applications on behalf of the DES. Funding is allocated on the basis of a needs assessment of each individual learner in the learning environment. (esf.ie, 2017). While the DES website outlines a range of conditions that HEIs can apply for ESF funding, there are only some symptoms of such conditions relevant to my own research.

4.3 - Introducing Participants

I am outlining symptoms rather than conditions in order to protect the identity of those who participated in this study. These include:

- Reading difficulties
- Handwriting difficulties
- Short-term memory issues
- Difficulties with fine motor skills including writing
- Difficulties with comprehension
- Chronic pain
- Fatigue and/or chronic fatigue

For this research I interview three people. They are students of this college and registered with the access services. They self-select to participate in the research interview based on posters and emails circulated in the college. Their pseudonyms are Robin, Jamie and Sam. Robin is the first to make contact through email. I respond to Robin with an email as a phone number is not included and after giving thanks for getting in touch we arrange a time to meet at a coffee shop near where Robin lives. This is a long meeting where we begin with an informal conversation getting to know Robin as well as discussing the research in more detail. After the recorded narrative interview we chat a little longer and I provide details of support services, which might help. Jamie is the next person to get in touch via email also and provides a phone number, which I use to make contact. We have a long discussion about the research and the (dis)ability that Jamie requires support for. We arrange then to meet in the college canteen and after much discussion we carry out the interview. Sam is the final person to get in touch with a phone call. Sam has many questions about the interview so we arrange to meet in the college canteen where we have an unrecorded discussion, which Jamie is very grateful for as it puts to rest any concerns about being identified. We arrange then to meet soon after to carry out the recorded interview.

4.4 - Presenting my Findings

Narrative stories are personal and reflect the true experiences of individuals (Claundinin & Connelly, 1998). While conducting the interviews I treat the sensitivity of the dialogue with the utmost respect but I worry that this empathy, this warmth that I display along with the feelings of anger, worry, upset, gratitude and satisfaction is lost in just mere words on paper, like a first draft script for a really bad play. Simply copying and pasting these words do not do justice for getting the message into the public domain for participants so I find myself having to find an alternative method while fulfilling the ethical promises I have made. I am reminded that I have only three participants willing to take part. I need to make sure their messages are loud and clear and their experiences justly exposed, and then I remember…. I remember those times in school where I was praised highly for writing, specifically asked to write poetry and read the poems aloud to the class. I also recollect the lecture on arts based research throughout the year (Meany, 2017), which, at the time I find fascinating but quickly file it under ‘the things I learned but will never use’. Then, after much reflection and feeling a jolt of excitement I allow it to happen, the process of researching narrative approaches and writing found poems to develop my findings. It becomes refreshing for me to open that drawer again as I write my findings (Butler-Kisber, 2002).

4.5 - This is my story

(Power poetry, 2017) provide short guidelines for writing narrative poems, which I adopt. There is no need for a build up to introduce characters. The advice is to begin with an event that draws the reader in. Use descriptive words and while many narrative poems are long, some are short but the use of descriptive imagery and feelings captivate the meaning of the experience just as well as a long poem.

Robin

In school I wouldn’t have been able to sit in class long.
I did all my exams on tape.
The school I was in
Wouldn’t allow me to come back after Junior Cert

I didn’t last there, I couldn’t write.
I just went to full time work.
I don’t even know why I’m upset.

I was afraid I wouldn’t get in,
Because of what happened,
In secondary school
It’s just the experience I had.

I was afraid to talk about my (dis)ability.
The access officer was brilliant.
This is what should have happened ten years ago.
I suppose it shows how times change.

I feel paranoid about it.
They think you're probably getting extra help,
When you're not.
If anything,
I probably work the hardest in the class.

I'm sitting here in so much pain
And they're giving out to us,
And they don't realise,
But they don't because
I'm not telling them.

One part of me thinks,
I ‘m the same as everyone else,
Why do they need to know?
I kind of feel like if I do that,
Then I'm labelled as having a full time (dis)ability.
I don't need that label on me.

Which is why,
I got really upset.
I was like, why is she saying that?
I know why she is saying it.
It's to help me, but then,
I don't want that label on me either.

I wasn't going back to my doctor,
To try and get a referral to a specialist,
Waiting for a year,
And then I'll be finished college,
By the time I get another report.
There's no point.

God knows what next year is going to be like.

And when I’m applying for my masters
Do they think right, she has a (dis)ability,
We already have two people with worse (dis)abilities here.
We're not taking another person on and
And it makes me wonder,
Do I let other colleges know,
When I am applying for my masters or do
I just leave it and apply as a normal person.

I don't want to be unfortunate thinking right,
I'm going to do this.
This is what I want to do.
And I can't do it physically and mentally.

Jamie
I had some form of diagnosis,
In first or second year of school.
Do an apprenticeship I was told.
I was told not to go to school by the school,
Because of the dyslexia,
Which they hadn't picked up on in school.

'Sure why are you going to college?
What good are you going to be with anyone?
You won't be able to do paper work.
Why are you going into that kind of job?
What good are you going to be?'

Like there is still a bad stigma,
'Do you see things upside down, back to front?'
But the olders just see like everything,
Is a competition and,
They think you have an unfair advantage.

"Jaysus I'd love to be dyslexic,
For all the extra time and all that.'
"I wish I had dyslexia.
You get waivers for exams and you get extra time

I hadn't had my official diagnosis
You could get a little bit of extra support
I was going to have to get the full diagnosis done.
To get any extra support I needed
I was going to have to go get the full diagnosis done.
Once I got the full diagnosis…

So I had to go to Dublin to do that then.
Up in the dyslexia association of Ireland offices,
Which was expensive enough.
Now I still owe them some money actually.
It needs to be looked at,
And be lot more accessible at the younger age.
People know that it's there,
But there's a lot of lack of assessment.

I was very nervous going for the test,
Thinking that if I found out………
What if I'm not dyslexic and it's my own fault
For not being able to learn how to read
I was going up hoping that I would be,
Diagnosed as dyslexic,
Because it means I'm not a dumb

I know I won't be going on after this,
Because it's too hard.
They are all going on even though,

I did get better results
Last year than the lot of them.
I know that I am finished now.

And I do have the nerves of when,
I go into work and all that,
What am I going to do that way?
Because of the writing and all that?
We're going to have to go into that environment,
Without the supports
We are used to the supports here now,
And we are going to be going into a world now
Where we mightn't have supports.

I know I manage and all that,
But I'd much rather I didn't have it.

Sam

It was a huge fear of mine.
I informed them of difficulties.
Someone in admissions I would have thought.
Well I would have went to the access office

Very soon after I started as far as I can recall
And I would have informed them.

I would have thought from that point
Something would have been done.
I assumed that help would be forthcoming,
Try and incorporate me into that system.

I assumed there would be further interaction with me.
I assumed that they would react to the information,
That I supplied them with.
Again I assumed. I assumed…
‘
I need to sort of read more’.
So I read more and I kept reading
I felt because of my memory
I had to understand it better than the next person.

So because of my memory difficulties,
I put more of an effort in.
So I put more of an effort in
So I read and read and read.

The exams came and I freaked out
So I went in and I passed some of my exams
I wrote hardly anything but I passed my exams
Well is this a charity thing like? And I said ‘this isn't right’

So they have actually reinforced my label of a person’s (dis)ability.
They've reinforced it and that seems what their effort was to do.
They've reinforced it.
They made me feel.........

So I'm going to have to take a break
If I decide to carry on and go back at all.
But I can't carry on under the way it is at the moment
They've actually put me back now.

They've left me stuck because they did nothing.
And I'm just stuck in a moment so to speak
That I can't see a way out,
A way forward,
A way back.

I’m going to see this out,
Until something happens somewhere,

Well as long more as I can last.
Energy wise.

So basically my life is put on hold,
And it's remained on hold

4.6 - Common themes emerging

In the next section I describe a brief interpretation of the themes that I feel have surfaced in the poems. These are significant findings, which transpire in the next chapter for discussion.

4.6.1 - Nobody said you were different, did they?

"Labelling, stigma, different, unfair advantage". These are all words, concepts and most of all experiences that are present in the lives of those I interview. The need to work harder, to prove to people that they *can* go to college and graduate is common for all of the participants. To have classmates begrudge the extra support that they receive in order to be academically successful surfaces several times during interviews.

Robin describes the fear of telling people about the disclosed condition in case opportunities are taken away, all because of one negative life changing experience of having to change school as a teenager due to newly diagnosed ill health. Friends of Jamie's have expressed their wish to have dyslexia to avail of the 'easy ride' they believe is supplied during exams and Sam who spent many years in physical rehabilitation has overcome so much, feels the door is being closed at every turn because of the (dis)ability status held in Colaiste Eolas.

4.6.2 - So, you want to go to college

Throughout the interviews a theme emerges which all three interviewees associated with systemic problems within our education system both at secondary and third levels. The Equal Status Act, (2000) outlines that reasonable accommodation for people with (dis)abilities applies in school when sitting examinations. Robin avails of a tape recorder for the Junior Certificate but this is not provided in the school of attendance for Leaving certificate prompting Robin to be compelled to change schools, a daunting experience for any teenager. This experience has stayed with Robin throughout life, as conveyed in the poetry.

Jamie describes the advice received from the attended secondary school, which impact the choices Jamie makes before finally finding a gratifying career. Since receiving accommodations for exams at HE a very positive experience has taken place for a journey that might not have taken so long if the dyslexia was diagnosed earlier.

Unfortunately, there is a financial cost for Jamie to receive an assessment in order to qualify for supports and Jamie is still paying that debt.

Sam is still searching for the accommodations to suit the difficulties being experienced while attending Colaiste Eolas and the format of the findings describes how what Sam feels, is a dated system that prevents this.

4.6.3 - What do I do now?

Concerns about their future are a theme that all participants refer to in their interviews. There is fear in many areas. Fear of the future, entering a world with no supports is something Jamie speaks about. There are little or no supports to help with the speed and accuracy required for writing in future positions. Robin fears rejection when applying for a Masters, still carrying the fears of a secondary school experience. Sam feels stuck with no way to move forward or back and is very conflicted about what the future holds. These are real fears that are important to these people, not only as mature students but also as students who are in a limbo where society only in some ways constructs a world where you only fit, just a little bit.

4.7 - The Good, The Bad and The Ugly

Throughout the interviews there are conversations about what I like to call sub themes or sub areas. These areas affect not all of the interviewees but perhaps two interviewees, or else one interviewee speaks with such passion and emotion in their voice I feel, as a researcher it is important these issues are brought to light. These poems contain the different quotes that take place during the conversations with all three. In order to stay true to the dialogue they appear somewhat unstructured but when read aloud the feelings, the struggles and positive encounters are released to the reader. Berbary (2011) takes a similar approach. She develops four rounds of analysis. She too uses coding to identify her categories. Similarly she finds that she needs to conceptualise these categories and their interactions with one another. This has been discussed in the last chapter in more detail but this is where I refer back to categories from the open coding and then I give names to the feelings in the next set of poems.

Unsupported
In school I wouldn't have been able to sit in class long,
I started falling asleep,
I couldn't write for long periods of time,
For junior cert I did all my exams on tape recorder.
For leaving cert, the school I was in
Wouldn't allow me to come back after Junior Cert.
Because of the experience I had in Junior Cert,
I never told them about my (dis)ability.

I left school at sixteen.
Do an apprenticeship I was told.
I was told not to go to school, by the school.
Because of the dyslexia they hadn't picked up on in the school.
Even though we told them.
Even in primary and secondary schools
People know that it's there.
There's a lot of lack of assessment.

Especially from experiences from primary and secondary school
It can cause disruption in families
I'm there not being able to learn how to do my spellings
You have your parent's with the homework
Not understanding and not knowing that I had dyslexia.
Young people can learn how to read with it,
If it's caught at a young enough age.

Under-represented
I think I'd verbalise it a lot better than I'd ever be able to do writing it
The exam process, it's not fit for purpose in my case.
I'm better than what I can do on an exam
Because I can talk and articulate a lot better than I could ever write.

She knew from my in class work and participation that I knew my stuff
But she wasn't able to read my exam paper at all.
My handwriting and spelling, no full stops, no commas, words spelled wrong
She couldn't make head nor tales of it

Exhausted
So I sleep all day.
I'm absolutely exhausted, from a mental point of view
I skipped class because I was…I was too tired to go.

Reading the same thing five times and you are wrecked,
You are exhausted....
And that's before you even start typing.

There was enough course work to be doing
Maybe for someone who hasn't got difficulties it's all right for them,
But for somebody who has difficulties it was too much at the one go.

Supportive
So easy, even from the day I went to the access officer
And that was actually quite useful the first year.

Slides go up so I wasn't going to have to take absolutely everything down
There was also small groups as well, with a proper facilitator.

They're so supportive, you know?
They do have good services in the college for getting stuff proof read

Any software I needed, they would upload the software for me
I still use it and I find it absolutely brilliant,

Now I will say the library staff... They really help as well.
But the access officer really really really really really helps.

I do my exams on tape recorder now, which did bring up my scores
They have the counselling service in the college as well

They have offered classes, which I went to and they explained…
Yes, they have responded from an essay point of view

I'm actually quite happy
Most of the lecturers are quite understanding of it.

Having the access officer there coming up to exams,
Being so supportive as well.

Dissatisfied
I shouldn't have to go and get a note
Because I've missed a day because I'm in too much pain.
It would be an advantage to let lecturers know that people do have a (dis)ability in their class.
I told them that it was okay to inform lecturers of my difficulties
No communication whatsoever regarding the trouble I was having
Get an up to date report. I just couldn't go through that rigmarole.
It's the system is the problem. It's not me.

No. That[3] *was never given to me.*
Unfortunately the services were offered
Did nothing for the difficulties I had.

That's[4] *excellent but that was mentioned to me*
But it wasn't supplied to me in year one
It was offered but again it was never explained to me
Really the advantage of having that,
It could have, could have made a huge difference, huge difference.

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[3] "That" was an unusual request made by a participant, which I cannot disclose for the purpose of remaining anonymous to Colaiste Eolas.
[4] Referring to the live scribe pen.

if you hand someone a list and say well that's the things you can have
That but don't explain to you about the list, well sure that's no good
The whole system has to change. It's just not fit for purpose.
That's all well and good when you haven't got six subjects to study,
A family at home and then on top of the six subjects
Then you are also going to have to take time out to do essays
They made me feel guilty because I'm not able to apply myself,
To their standards so it's my fault.

Determined
Well it’s not true. I am able.
Nearly getting my 1.1, you know?
I had an extremely developed coping mechanism.
I’ll see this through.
Nothing stops me,

Both Robin and Jamie are subjected to uninformed attitude towards their difficulties when attending secondary school, which is expressed in the first poem. Following this, Sam and Jamie encounter the difficulties in the connection between mind and paper. Because of this there is a worry that their full potential for work may be going unrecognised. Exhaustion is also a condition that interviewees outline in our discussions. Student life can be exhausting. All three have family commitments and a condition on top of this creates more barriers to their academic performance.

Despite these difficulties there are positive elements in Colaiste Eolas that the participants speak of. Robin and Jamie especially encounter occasions where their voices are heard, their obstacles are addressed and there is appreciation for the access officer. I witness the determination in all these individuals despite being told they could not do certain things.

As the law of averages suggests, where they is positive, there is negative. Both Robin and Sam have been met with issues, which have hindered progression in some small or big way, as has Jamie. These stanzas are a collective and mixed set of phrases from all of the participants and not just one person and so I give these poems one-word titles to give identity to the feelings rather than names to the poems.

4.8 - Colaiste Eolas' Position

This section gives a brief overview of the conversation, which takes place with the access officer. Although it is a long conversation I select the material in the conversation that gives the most accurate answers to the questions, which are sent to the access office before the conversation. These questions provide the basis for our discussion and I have presented it in a question and answer format but I omit anything that I feel might make the institute identifiable.

Q: *Does a person need to register with the access office to avail of its services?*
A: *Our access office provides supports, which are available to all students. These include essay workshops, and extra tutorials. To avail of ESF funded supports such as one to one learning support or assistive technology you must be registered.*

Q: *When a person avails of the (dis)ability support services is there any planned communication to evaluate resources?*

***A:** Yes, at the time of needs assessment students sign off on a release consent form and we send out service during the year. The consent form provides us with permission to pass that information to DAWN and other lecturers to negotiate their effectiveness. We also encourage an open door policy where students can come to me whenever they wish to discuss their supports. I also have a yearly review with each student registered for evaluation. Students have many opportunities to try different products that they feel might help providing the correct medical reports are up to date. This is an ESF requirement.*

Q: *What is the process involved if a person wishes to make a complaint or needs to apply for a unique resource.*

A: *While we would always encourage students to come to a staff member or to me to make a complaint, our complaints procedure is listed on our website. We have a designated complaints officer in Colaiste Eolas. It is also outlined in the student handbook. The contact details for AHEAD are enclosed in our handbook and also contact details for an external independent advocate if they wish to go outside of the institute for support. If a person requests a unique support for exams we will do what we can once the request is within the 'reasonable accommodation' supports outlined by DAWN. Sometimes students have expectations based on the supports they received in primary school and these are not always possible in third level. We also try to promote independence for individuals. It also sometimes happens that students have witnessed another assistive support which they feel might suit them but when the needs assessment is carried out it may have been found that it does not benefit that person. However, I remain as flexible as I can.*

Q: *What services are offered to students with the following difficulties as part of their condition?*

1. Reading and writing difficulties. eg. Dyslexia or mild learning difficulty

A: *Students need to have an official up to date diagnosis of dyslexia or psychological reports as per requested by ESF to receive assistance. This assistance includes a live scribe pen for recording and note taking and software for writing on their laptop. If they have no laptop one is provided. They may qualify for a reader or scribe or the facility to answer exams on tape, extra time in exams or a room on their own to complete exams. Students may sometimes confuse the term learning support. This is a* *class, which assists people with writing, formulating answers, referencing, essay writing etc and unfortunately not a resource for revision of what was covered in class.*

2. Mobility difficulties?

A: *There is a preservation order on much of the building so we have not got lift access to all rooms but if the condition has been disclosed we can schedule all classes downstairs where necessary for the student in question. If this means separating classes into two groups we can do that. We have ergonomic desks, which can be moved from room to room. Staff transports these desks and we try to be careful to ensure it is in the room before class.*

3. Diagnosed condition affecting memory or concentration?

A: *Students are at liberty to take rest breaks if required. Lecturers are encouraged to upload class notes onto moodle so students will not have to take everything down. The live scribe pen records lectures. We have a resource room for people who need to rest and this is in a private area away from the rest of the building.*

4. Visual and/or hearing impairment?

A: *Assistive technology on laptops is often encouraged to reduce the need for a personal assistant and technology as already described is also available.*

5. Diagnosed condition causing fatigue?

A. *Again we have the resource room where required in a private area. We have a nurse on campus with a bed in her office and in the past, with epilepsy we have a bedroom if so required which we have used. With regard to absenteeism students are not required to submit a doctors certificate each time they are absent, within reason as there is still a curriculum to complete. Is students contact me and let me know they are absent because of their condition I will make allowances.*

Q: *Tell me about the individual and group training sessions for individuals?*

A: *These sessions vary from person to person and group to group. There are classes to show students how to use assistive technology and all individuals can attend these as there is software like read and write gold, which is available to all students. Classes can also include essay support. It really depends on the need of the student.*

Q: *Can you take me through the assessment process for modification of examinations? Modifications are subject to approval from DAWN and I need documentary evidence to support (dis)ability. These can include opportunities to carry out presentations instead of essays, submission of contributions in group work or group tutorials via email, reasonable accommodations in examinations, interpretation of exam papers and again are subject to an up to date medical report.*

Q: *How are students made aware of the disclosure policy?*
A: *We are always encouraging people to make a disclosure about (dis)ability as early as possible however it is their responsibility. Once the disclosure is made I send a list of the names of the individuals to lecturers and head of departments as well as details on their condition. This is updated and re-sent every few months and it is the responsibility of lecturers to read this and familiarise themselves with their students and their requirements. Students are notified that this information is being sent out at the stage of needs assessment. There is also a programme meeting every year and I will identify and remind staff about the list again and I outline any complex needs.*

The Access officer expresses that the eligibility for ESF funding still works very much from the Medical Model approach but is finding that over the last three to four years there is more interest in implementing inclusive pedagogies.

The objective of this conversation offers the right of reply of the access officer, which I feel is an ethical obligation to Colaiste Eolas after individual participants discloses some negative experiences. While presenting this conversation is useful to readers as a step in my research it fails to explicitly provide explanations for the difficulties experienced by individual participants. However to protect anonymity I believe this is the most suitable way of addressing the findings. It also must ensure I do not place myself in the position of being misunderstood by participants to mediate on their behalf.

4.9 - Conclusion

During transcribing, my first and most significant finding emerges, that is that transcription fail to capture the depth, emotion and resonance portrayed during interviews. I come to the idea of writing poems to portray experience due to the concern for the flatness of transcripts. Also, as a novice researcher I rely on the support of previous researchers to help me through this process. Stenhouse (2014) uses poetry to illustrate her findings of a research piece that examines the experiences of adults in a psychiatric hospital. Stenhouse (2014) finds that the poems give people an individual voice and a holistic representation of the experiences of her participants. The narrative style relies on all parts of the text to build a complex picture and I am mindful of this when creating the poems. Upon evaluation of the poetry I feel they are meaningful, representative and accurately display the true experiences of being a student with a (dis)ability HE and particularly in Colaiste Eolas in a way that dialogue of a transcript do not.

With regard to the concepts, which emerge, the narrative style allows for issues to come to light naturally without the biases of the research surfacing. To analyse these findings in more detail, the next chapter discusses these concepts more directly with reference to the literature review also.

Chapter Five - Discussion

5.1 - Introduction

This chapter provides a detailed discussion evaluating the findings in my own interviews as well as assessing them in light of the literature reviewed. The Social and Medical Models of (Dis)ability are the key theoretical frameworks, in particular the social model that provides a basis for much of the policy changes and implementations for (dis)ability services throughout the last number of decades. Moving away from the Medical Model formulates a progressive environment for social change among people with (dis)abilities. Condensing the Social Model of (Dis)ability into such a short summary is by no means an uncomplicated task. The next section re-analyses the Social and Medical Model in light of my research findings and examines approaches to (dis)ability, which might be useful going forward.

While conducting interviews, many emotional factors surface which are often disregarded in social research. The difficulty in justifiably capturing these emotions resonates with me and leads to narrative research and developing found poetry from interview transcripts where the process of resonance as identified earlier by Conle (1996) begins. I discuss the significance of this for inclusive practices in research briefly in this chapter.

When I think back to the beginning of this research I recall the panic I feel when I hear the scale of this research. I wonder how on earth I will find enough words to be able to write about this topic however, as time progresses and the research grows, I feel the opposite. How on earth will I condense this research. The answer is I can’t. What I can do is, stay within the realms of my own interviews staying true to my research participants and discuss recommendations for HE, which can be incorporated into future areas of study. Key themes from my findings are outlined which are discussed further in this chapter.

Specific policy and systemic level issues are discussed in this chapter in terms of their impact on the experiences of these students in higher education. Specifically, implications of policies on reasonable accommodations are discussed followed by the Universal Design of Learning UDL as an alternative pedagogical practice in HE to better meet the needs of diverse learning abilities.

Stigma, which emerges again and again throughout this research, is explored by examining ways in which attitudes towards (dis)ability can change leading to a more inclusive society. The findings in the field research and in the literature suggest that stigma plays a considerable role in society for people with disabilities and so requires significant attention throughout this chapter.

Current policy and legislation have been developed in line with meeting the needs of people with disabilities particularly in education and employment. These include the Equality Act, National Disability Strategy, Disability Act etc but as the research suggests, implementation appears to be slow and this lack of action arises out of interviews as crucial to the experiences of this research cohort. These are outlined in the literature and are conducive to the experiences of my own participants.

5.2 - Social Model v Medical Model – A Re-analysis

The Social Model of (Dis)ability contends that it is society, which disables physically impaired people and creates and excludes people from society unnecessarily (UPIAS, 1975). The Medical Model of (Dis)ability focuses on reducing the complex problems associated with (dis)ability and works to provide prevention, cure or rehabilitation, usually on an individual level (Sullivan, 2011). Both models are not without their merit and their limitations. The Social Model plays a significant role in the development of societal change and improvements in attitudes is driven by campaigning rights for people with (dis)abilities. By adapting to the Social Model society can make changes to barriers for learning such as redesigning curriculum and teaching practices.

Moyne (2012) discusses the Medical Model. When policy makers think about (dis)ability they often concentrate on compensation for what is ‘wrong’ such as providing schemes and benefits and implementing services, which segregate people with (dis)ability. This model also effects how individuals see themselves. These negative feelings are internalised and stem from having something ‘wrong’ with them ensuing the belief that their impairments automatically exclude them from certain things.

Oliver (1996) contends that inclusion rather than integration is the key, the history of the twentieth century portrays vast exclusion and we can only hope that the twenty-first century will see campaigning and the struggle of inclusion go from strength to strength.

Oliver also suggests that a more defined approach to (dis)ability must be developed rather than a binary Social and Medical Model of (Dis)ability instead arguing for a more inclusive societal-based approach (Oliver, 1996).

5.3 - Resonance in Research

The process of resonance emerges throughout the course of this research. It is a complex process and composes of the connection of many aspects of a story and must account for both cognitive and non-cognitive elements Robin's experience provides a good example of this. Cognitive elements refer to Robin's experience of having to change schools for the leaving cert and the non-cognitive aspects of how this impacts on life today eg. fear of disclosure of (dis)ability (Conle, 1996). The following section discusses recommendations, which emerge from such experiences of resonance from participants. It contains lines and phrases from the poetry in chapter four as well as quotes from the transcripts that are not included in the poems.

5.4 - Recommendations for Higher Education

To create an inclusive experience HEIs need to be aware of the architectural, institutional, informational and attitudinal environment that people with disabilities encounter within their college. Examination of its (dis)ability services, policies, practices and activities to ensure that it incorporates inclusive education into the institution culture is important (Mole, 2008).

5.4.1 - Training and Employment

Economic and social independence are important factors of living for people with disabilities and this involves focusing on training and employment. Reliable figures of people with disabilities in the workforce are not available but evidence suggests that unemployment figures are relatively high (NDA, 2012). Links between poverty and (dis)ability are clear and improvements in employment legislation are required to reduce exclusion and reduce the impact of poverty. Education is crucial for employment and is essential in order to compete in the jobs market. Training opportunities and supports for people with disabilities must be provided (NDA, 2012). While reasonable accommodations in state exams have been introduced as a measure to address the needs of people with disabilities in education, the experiences of social stigma, difficult assessment procedures, health implications, etc are not catered for within this.

5.4.2 - Reasonable Accommodations

As suggested by Tonge & Treanor (2017, cited in AHEAD, 2017) reasonable accommodations need to be re-examined to address the apparent diverse learning needs of people with disabilities. Reasonable accommodations are crucial to students in this study in order for them to reach their full potential without compromising the integrity of their courses. Reasonable accommodations include assistive technology, readers and scribes, note-takers in classes, extra time and individual rooms for exams. Each of the participants I interview uses some of these accommodations and feel they are very helpful or even essential to their progress.

Jamie: I do my exams on tape recorder now, which did bring up my scores
Because I can talk and articulate a lot better than I could ever write.

Robin, who I cannot quote for confidentiality purposes in this instance, cannot be without the extra exam time and the individual exam room. The use of reasonable accommodations is argued by Butler (n.d) who believes that they are not in line with UDL policy. The practice of UDL will limit reasonable accommodations and this is required as the growing numbers of students with disabilities in HE, will eventually make reasonable accommodations unsustainable. A great variety of teaching methods and assessment criteria is criteria based on principals of inclusion and diversity is required at a systemic level (Butler, n.d).

Tonge & Treanor (2017, cited in AHEAD, 2017) put forward that individualised reasonable accommodations should be provided where mainstream accommodations are unsuitable. The education system needs to be responsive to these needs on the basis of full inclusion. For example, it should be the responsibility of lecturers to ensure that notes can be electronically accessed as this reduces the need for note-takers in class and promotes independence for students. It makes notes more amendable to multiple modes of presentation and hence more accessible for learners with diverse needs.

5.4.3 - Universal Design for Learning

The UDL model builds on the need for reduced supports and accommodations for students by meeting the diverse learning needs of students through assessment procedures. It fits the call for an educational system, which is based on diversity and inclusion. This model may also serve to address many of the fears outlined through this research.

Sam: The exams came and I freaked out

Jamie:
And I do have the nerves of when,
I go into work and all that,
What am I going to do that way?
Because of the writing and all that?
We're going to have to go into that environment,
Without the supports
We are used to the supports here now,
And we are going to be going into a world now
Where we mightn't have supports

By promoting independence among student while in education fears surrounding entering a workplace with little or no accommodations can be reduced. From an educational perspective, as a new innovation in Ireland it will prove initially costly but the benefits far outweigh the cost of student dropout rates on a social and financial basis (Heelan, 2015). Outputs will be greater as dropout rates reduce and this model can easily fit into the structures still currently in place for example, measurement (a more accurate measurement perhaps) of ability. Introducing UDL assessment practices may also result in a higher number of applicants with (dis)abilities contributing to overall national targets. It also accounts for a greater availability of choice for *all* students and addresses their diverse learning styles. Implementing UDL is consistent with the current management performance measurement model, which will probably remain in place in Ireland for some time yet.

With the UDL becoming slowly widespread across Europe and the Irish economy growing, it appears that the implementing of a UDL for inclusive learning is crucial, not only to provide transparency in assessment but to work towards reducing stigma for people with disabilities. Further research on the benefits of this method for learners provides new scope for assessment practices widening the choice of HE opportunities.

5.4.4 - Alternative Assessment Practices

The assessment practices for students with (dis)abilities remain unclear. There is little understanding of how students with (dis)abilities experience assessment or the effects of assessment on individuals (Bradley, 1995). Assessment practices are created and decided at institutional level and rarely account for diversity of learning. Decisions about techniques are made from a wide range of possibilities and these include essays, examinations, thesis, fieldwork, reports, projects and portfolios to name but a few

(Hanifin et al. 2007). These decisions at systemic or institutional level often focus on a generic level of learner and assume homogeneity rather than the diversity that is essential for students with disabilities, amongst many others. Gardner's model (1983, 1991) highlights a more analytical response to modes and techniques that are relevant for people with (dis)abilities. Assessment dissatisfaction is an issue, which arises in the literature review (Gavira & Morina, 2014) and also in my own research. One of my interviewees Sam, recalls hoping for a system that might exclusively meet Sam's needs however the findings reveal that this did not happen.

Sam: People are different and their needs are different but to have one way of judging someone's ability is just…. it's just unbelievable.

Tonge & Treanor (2017, cited in AHEAD, 2017) contend that assessment and examinations must be person centred, transparent and fair. This requires greater diversity and flexibility on the part of accreditation system, QQI and DAWN, in this case, on what is accepted as proper means and modes to assessment.

UDL aims to address diversity of learning among students and is shown to be successful in one particular HEI in The Netherlands (Van Slooten et al. cited in AHEAD, 2017). The UDL motto is 'firm goals, flexible means', but it may prove difficult to make the assessment flexible without compromising the integrity of accreditation. Dr. Roy Erkins, a lecturer at the Maastricht programme, applies the concept of flexible assessment to his course 'Tropical Technology'. The assessment process is outlined in Figure 5.1

(AHEAD, 2017) Figure 5.1

Applying this method Dr. Erkins allows students to design their own test once they can demonstrate how they achieve the learning outcomes. The formats are very diverse and once he and his students are satisfied with the format and criteria they all sign a contract of transparency and monitor the assessment journey (Van Slooten et al. cited in AHEAD, 2017). The outcomes prove successful and will be implemented again next year. He was encouraged to do so by the accreditation organisation in The Netherlands.

Current assessment practices in Ireland still focus on additional work being placed on individuals and tutors within the boundaries of reasonable accommodation. This is clearly evident in the resentment and self-consciousness that respondents voice in terms of other students' perceptions that they have extra support or have it easy.

Jamie encounters conversations by peers such as:

"Jaysus I'd love to be dyslexic,
For all the extra time and all that.'
"I wish I had dyslexia.
You get waivers for exams and you get extra time

<u>Robin</u>
They think you're probably getting extra help.
When you're not.
If anything,
I probably work the hardest in the class.

5.4.5 - Model of Inclusive Practice

With a large increase of students with (dis)abilities entering HE there is a need for change and so National Plan for Equity of Access to Higher Education 2015-2019 (HEA, 2015) proposes many recommendations including implementing directions from its previous plan (HEA, 2015). Figure 5.2 on the next page is a proposed model of inclusive practice in HE in Ireland, which highlights the changes needed across all levels of the educational system, culture and practices.

(AHEAD, 2017) Figure 5.2

5.4.6 - Eligibility of Funding

Many students with difficulties are not eligible for funding under the current ESF system and greater flexibility is required to meet their needs. Colleges through ESF provide resources. The funding application and needs assessment process appears to slow up immediate eligibility for these resources. As described by the access officer documentary evidence to support eligibility is required. This is causing many problems. Jamie describes the additional financial responsibility involved in obtaining a proper diagnosis of dyslexia. Because of this the student receives no additional access supports until second year.

I was going to have to get the full diagnosis done.
To get any extra support I needed
I was going to have to go get the full diagnosis done.
Once I got the full diagnosis…

So I had to go to Dublin to do that then.
Up in the dyslexia association of Ireland offices,
Which was expensive enough.
Now I still owe them some money actually.
It needs to be looked at,

The need for up to date assessments also presents as an issue. Robin describes failing to benefit from a piece of assistive technology due to having a report dating 2010.

I wasn't going back to my doctor,
To try and get a referral to a specialist,
Waiting for a year,
And then I'll be finished college,
By the time I get another report.
There's no point.
God knows what next year is going to be like.

Robin's condition is a lifetime condition, which will not change so the requirement for an up to date report suggests that the 'one size fits all' motto is being applied here. Recommendations for ESF funding are outlined by Tonge & Treanor (2017, cited in AHEAD, 2017). A review of access is required which takes account of funding changes and also a review of data used to determine such funding. ESF must continue to re-evaluate its provision for students with (dis)abilities ensuring a mainstream approach to educational experiences as suggested by the HEA (2017).

5.4.7 - Communication in HEIs

The findings suggest that there is a concern among students surrounding communication of (dis)abilities to staff and lecturers in this research. This is also echoed in research mentioned in the literature review including Riddell & Weedon, (2016) and (Fuller et al. 2004). Both Robin and Sam in their interviews mention that they feel it would be useful for staff to know when a students presents with a (dis)ability.

Robin: It would be an advantage to let lecturers know that people do have a (dis)ability in their class.

Sam: There was no communication with me whatsoever. There was no communication with any of the lecturers. I told them that it was okay to inform lecturers of my difficulties.

The question of communications to lecturers surrounding students (dis)abilities is discussed with the access officer in Colaiste Eolas who reports providing detailed accounts to lecturers regularly about students who present with difficulties. It is however also specified in the conversation that classes have vast numbers. Perhaps the system and lecturers need to be more proactive in getting to know their students and familiarising themselves with difficulties. This could be improved by inclusion and (dis)ability awareness training. HEI lecturers, although masters in their own field of knowledge can have very limited experience of (dis)ability. By providing (dis)ability awareness training, lecturers are in a more suitable position to meet the contrasting learning needs of students. Similarly creating more inclusive and learner-centred pedagogical contexts, appropriate class sizes and promoting the use of inclusive pedagogical methods would support all students including those with diverse needs.

This research examines the perspective of the access officer but does not provide the perspective of lecturers or other staff or students in HE. Therefore, I suggest for future research, that interviews with lecturers can provide a clearer understanding as to why some participants feel that staff communication is poor. It might also highlight difficulties lecturers have in meeting the needs of a diverse class group. Likewise interviews with other students might give a deeper understanding of their perceptions of their peers. I further recommend that nuanced research methods be carried out to capture the true nature and resonance of student experience, as I have attempted to do in these interviews, so the students voices and messages do not become lost in reports and evaluations.

5.4.8 - Changing Attitudes for the Future

McGuckin et al. (2013) and Barnes & Mercer (2010) talk about the experience of low expectations among people with (dis)abilities. This is identified as arising from discussions between secondary school guidance counsellors and students. It can also be caused by the focus on conditions and impairments rather than possibility, which is an attitude encountered by my participants also. Stigma is a reoccurring theme throughout this thesis also.

Robin
One part of me thinks,
I'm the same as everyone else,
Why do they need to know?
I kind of feel like if I do that,
Then I'm labelled as having a full time (dis)ability.
I don't need that label on me.

Jamie
Like there is still a bad stigma,
'Do you see things upside down, back to front?'

Sam
So they have actually reinforced my label of a person's (dis)ability.
They've reinforced it and that seems what their effort was to do.

A survey carried out for the Department of Work and Pensions by Grewal et al. (2002) reveals the following findings: One in three people questioned believe that disabled people cannot lead a full life due to their health problems; in addition to this, one in five people who take part believe that in general people with (dis)abilities cannot be as effective at work as their non-(dis)abled colleagues; more than one in four people admit they would feel uncomfortable and embarrassed in an encounter with a deaf person using British Sign Language; and sadly, one in four people confess they would go out of their way to avoid an encounter with someone experiencing mental illness. Society needs to replace misunderstandings and misconceptions about (dis)ability with new inclusive constructs. Pettigrew (1998) explores some options for improvement as he believes direct contact and creating a space for the formation between people with (dis)abilities and people without will reduce prejudices. Attitudes evolve due to direct experience and Hewstone (2003) develops five conditions to create a space of direct contact thus improving attitudinal behaviour. These are

1. Under conditions of equal status
2. In situations where stereotypes are likely to be disproved
3. Where inter-group cooperation is required
4. Where participants can get to know each other properly
5. Where wider social norms support equality.

This Hewstone (2003) argues promotes more positive attitudes. Three, four and five are principles, which can be applied to HE, but also much earlier in the lives of children such as school-going age to provide a ‘whole of education’ approach (HEA, 2015).

5.5 - Conclusion

This chapter provides a discussion based on the findings throughout the research process and it is evident that many themes emerge time and again. Negative attitude, although improving is still very much alive in our society. Ignorance, lack of contact between people with (dis)abilities and those without provides a gap in inclusion and acceptance.

The legislation most applicable to students in third level are the Equal Status Acts 2002/04 and the Disability Act 2005. These acts support a student’s legal right to an inclusive experience in third level education in Ireland and inclusion is now recognized as an issue of human rights and equity of access. It must be a central issue in policy and practice and the availability of an inclusive educational experience in third level must be treated as a quality assurance issue’. (Butler, n.d: 4).

Organisations such as AHEAD, WALK and the NDA endeavour to tackle issues in HE by vast amounts of research and publications but this research implies this has not always worked when put into practice. While policy frameworks have been adopted to some degree, comprehensive reform based on full inclusion must be at the forefront of practices within the education sector from an early age and this will contribute to improved social constructs.

HE needs to be willing to redesign the learning and assessment procedures to include all students. All students learn differently and a broader spectrum of teaching and assessment methods can help address diversity in the classroom. It is necessary to realise that non-traditional students are a permanent addition to modern university and it is becoming increasingly unsustainable to rely totally on specialist services to meet their needs. Furthermore, ‘treating (dis)ability or widening participation in isolation will never achieve a holistic cultural approach to inclusive service provision’ (Ball, 2009:3).

Chapter Six - Conclusion

6.1 - Introduction

This is the final chapter, which provides a reminder to the reader of the research question. I also summarise the preceding chapters including the literature review, methodology and findings. This also gives an account of the change encountered as the research progresses. I briefly explore the research experience and after a short conclusion I add some final thoughts.

6.2 - The Research Question

Historically, students with disabilities have been under-represented in Irish higher education because of a lack of support throughout the education system and low educational expectations (NDA, 2013). The term ‘lack of support’ constitutes a very vague description of what this might mean. The research question I pose wants to penetrate deeper into these findings. What is the experience of Higher Education for people with disabilities? Well, this is my original question. What it becomes is something like ‘What is the experience of Higher Education for people with disabilities and how do I ensure that their symptomatic journey is accurately represented by in this research?’.

Methodology and findings are summarised and then I continue by outlining my experience as a researcher which explores in summary my own resonance of conducting and presenting this thesis. This chapter also offers a conclusion and sums up with some final thoughts. However, let me first provide a brief summary of the research.

6.3 - Summary of the Research

The literature review describes a brief history of people with disabilities. From the time of the Enlightenment all the way through to the more recent (dis)ability movements people with disabilities and mental health difficulties are conditioned to accept stigmatisation, ridicule, segregation, imprisonment and even torture. Foucault’s research which dates back to the pre-enlightenment era tells us that the growth in asylums provided isolated spaces for professionals to treat individuals who are so-called mad. These confinements mark the growth of the Medical Model of (Dis)ability, discussed in detail in chapter two. This model constitutes the belief that people with disabilities must be treated or ‘cured’ in order to integrate into mainstream society and as a result a long history of confinement in asylums ensues.

The late nineteenth century marks the rise in activism for social change among people with disabilities. Veteran’s return from war seeking assistance and the deaf movement is on the rise in advocating for universal sign language and deaf schools. This movement leads to the development of the Social Model of (Dis)ability. This concept believes that it is society that causes (dis)ability because of the social and physical barriers and needs to be reformed.

The (dis)ability movement contributes much to the policy and legislation that is currently in place. Governmental initiatives in Ireland are introduced to specifically target and research (dis)ability groups such as NDA, AHEAD and WALK, which are discussed. HEA implement plans to tackle reduced numbers in HEIs of people with disabilities.

The interviews identify key issues, stigmatisation, systematic problems and fears for the future. These systematic problems are examined in context to New Managerialism in the literature review. Taking a Social Constructivist view, I explore Foucault’s theory on Governmentality in relation to HE followed by Models of (Dis)ability, this is examined and critiqued in detail in chapter two.

6.3.1 - Methodology Summarised

Researching from a social constructivist perspective my methodology consists of qualitative interviews using the narrative approach. The narrative approach consists of unstructured interviewing and asks one simple question. ‘What is your experience of Higher Education?’ This leaves the interview wide open for interviewees to construct their story of how the experience is for them.

Focusing on one HEI I have close links with, given the pseudonym Colaiste Eolas, I make contact with the access officer to seek permission to carry out the research but to also ask to act as gatekeeper to reach perspective participants. After considering the ethics process I advertise in the Colaiste Eolas with posters and the access officer sends out an email to all the students in the college suggesting getting in touch with me for this research. I am disappointed at first, to find that just three people are interested in partaking. However, I decide to do what I can and after ensuring to follow the ethical guidelines set out by Maynooth and Colaiste Eolas I begin my journey of researching participants. I soon find that having only three participants proves more positive than negative for the scope of the research and things take an interesting turn of events. As participants' stories begin to unravel emotions run high and I meet with feelings of sadness, anger, contentment, embarrassment among others. I am overwhelmed not only by the emotions of participants but by my own feelings and emotions where boundaries and biases surface and all my reflexivity is tested.

6.3.2 - Brief Synopsis of Findings

After transcribing and coding the interviews three key themes emerge which I outline earlier. However even prior to these three findings, as I begin to present my findings I am saddened by the cold, flat, emotionless transcripts compared to when I remember back to the resonance and intensity of the emotions during the interviews. So I dig deep into my methodology bag of tools to formulate a plan that delivers the messages of my participants in a justifiable manner. This is the point the research becomes participatory. This is when I use 'found poetry' to develop the transcripts into resonant narrative poems (Richardson, 1990). Still remembering the three key themes addressed by all interviews I stay true to the words of interviewers and write poems surrounding these themes. For me, this better supports the experiences of my participants. Using sub-themes, which emerge for less than three of the participants I write a series of short poems to express these findings. These convey some areas of HE that students are unhappy with and this leads to a 'right of reply' conversation with the access officer, carried out over the phone. While I acknowledge the importance of this for ethical reasons, due to the promise of confidentiality it is difficult to analyse whether it rationalises the disadvantages reported by participants.

Emerging the findings of the literature and the qualitative interviews further portrays experiences of students. I must draw together my reflections about the Models of (Dis)ability and examine each in more detail and how they might work together for the future.

Outcomes for students with disabilities are a direct result of the governments and institutions' ability to enforce the policies designed by (dis)ability advocates such as AHEAD and NDA. Key propositions include re-evaluating reasonable accommodations and assessment techniques. Funding, or lack there of is also decisive for entry among people with disabilities and it is clear that funding schemes for part-time students requires re-examination to increase student numbers presenting with disabilities. Changing attitudes, (dis)ability awareness training and direct contact between people with (dis)ability and without (dis)ability reduce stigma and enhance the quality of life for students. However, direct contact is only viable if society creates more accessible and fully inclusive environments for people with disabilities.

6.4 - My Experience as a Researcher

Fortunately, I have the pleasure in this research of experiencing many ‘first times’. I have never written an academic text in the first person. I have certainly never quoted Harry Potter but feel the need after learning all about narrative research and arts based research, which are approaches that are also a first for me. Qualitative interviewing is a new experience and discussing personal events and stories with some of the nicest strangers brings a fresh outlook to my future as an adult educator.

This research set out to explore the experience of people with disabilities in HE but this exploration takes me deeper than I anticipate. As I mention earlier this research takes an unexpected turn. After initially moving past the disappointment of just three participants and spending the hours it takes to transcribe, the flatness of transcription leaves much to be desired so formulating the poetry begins. This presents with some challenges. First of all I am a big fan of rhyming in poetry, as you have probably guessed. Rhyming with my own thoughts and words is easy; rhyming with somebody else’s…not so much. Letting go of this proves challenging for me as I devise un-rhyming story-like messy poems so I have to remember that words in these interviews are not about me. I can write my own poem later. And I do. Instead I write to tell the stories using their words to consecutivise the events. When I pass on these poems to my participants the response is far more enthusiastic than when I produce the first set of transcripts. I learn that conducting the research is the easy part, delivering the answers to the research question is the hard part.

6.5 - How does this research contribute to adult education?

Well, in a number of ways. It is full of information to improve HE for people with disabilities, beginning on a small scale. Front line staff may not be the policy makers but by adopting some of the principles outlined in this research, we can make a difference, such as taking more time to get to know our students, throwing away the curriculum for an hour and focusing on promoting inclusion and (dis)ability awareness in our own classrooms and lecture halls. Communicate with colleagues to exchange teaching ideas or do what Dr. Erkins does and take a chance on an innovative method of assessment. Change starts from the bottom up, not the top down.

6.6 - Conclusion

This chapter is a convenient summary for readers on the overall research project. My favourite part of this research has been meeting the participants. I hope I convey a true and resonant representation of their experiences of HE. Upon reflection, I feel lucky to have been part of this research and if I was to do it all again my methodology would follow the true story of this experience using narrative enquiry all the way through, but instead it becomes part of my research story.

Final Thoughts

Were the walls in this study always brown?
When was the last time I went into town?
Who did the cleaning, the cooking, the clothes?
'Was it me? Was it you?' God only knows….

And what about school and homework and exams?
What about the times I had to break plans?
My how you've grown, were you always that tall?
Sometimes I can't remember what you look like at all.

'I won't be much longer, I'll be there soon.'
I'm sure you are tired of the same old tune.
'I'll finish this chapter, please just wait…'
'Hurry up Mammy, or we will be late'.

The deadline is looming, oh it's so near.
The reason I've done this all becomes clear.
'Why though Mammy, there was so much to do?'
'Not everyone is as lucky as me and as you.'

' I'm almost done now, just finishing up.'
'It's okay my dear, I know you can't stop.'
'Oh look everybody, I'm about to press send.'
'Well done Mammy, this is really the end.'

Or is it the beginning…….?

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Appendices

Appendix A - Email to Access Officer

Dear Access Officer[5]

My name is Patrice Dalton. I am a Masters of Education student in Adult and Community Education of Maynooth University. As part of this, I am conducting a research project based on Access to Higher Education Institutes for students with disabilities. I am looking for a cohort of people who may wish to take part in interviews and share their experience with me. I have chosen Colaiste Eolas[6] as I am a past student of (name of course)[7] in 2005 and again in 2010.

I would like to put a notice in Colaiste Eolas providing people with information about the research and offering them a chance to participate. It is hoped that this research will provide in depth insight into the experiences of students who require additional support to ensure that equal access is available to all. I have attached an information sheet, which describes the research in more detail.

I intend to explore the following:

1. Funding for people with additional needs and the application process involved.
2. Registration for supports with the Access or Resource Officer, process and implications.
3. Effectiveness of the process including retention supports for and rates of people with additional needs in Higher Education.
4. Reasons why people may not choose to access supports.

My supervisor is Bernie Grummell from the Adult and Community Education Department. She can be contacted on (01) 7083761I or bernie.grummell@nuim.ie

I would also like to offer you the opportunity to meet with me to discuss further if you so wish. I look forward to hearing from you.

Kindest regards,
Patrice Dalton

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[5] Name of access officer omitted
[6] Pseudonym for Institute
[7] Name of Course Omitted

Appendix B - Notice for notice boards

LEARNING KNOWS NO BOUNDS,

OR DOES IT?

WOULD YOU LIKE TO TAKE PART IN MY RESEARCH?

Call or text 1234567

Appendix C - Email to all students of Colaiste Eolas

Dear Students,
Please see email below from Patrice Dalton, an MA student in Maynooth University. If you, or anyone you know, would be interested in taking part in this study **please contact Patrice directly.** Her email address and phone number are at the end of her email.

Regards,
XXXXXX

CALL FOR PARTICIPANTS

Dear Student,

I am carrying out research as part of my masters in adult education in Maynooth University. My research will explore access to Higher Education Institutes for students who have different (dis)abilities and require support.

I am doing this research as I have a long history in the (dis)ability sector and I am passionate about inclusive education.

I spent time as a job coach for people with additional needs and I have witnessed both positive and negative experiences of higher education, which I feel needs further exploring. I am looking to speak with different people as to gain insight into the experiences of students with different abilities upon transitioning into higher education including

1. People who have experience of needs assessment with the Academic Resource or (dis)ability Office (as they are still called in some places including Maynooth).
If this was you, did you utilise the services? Whether you did or did not, I would like to talk to you about your experience if you are willing to share this with me. Perhaps you also might pass this on to someone you know that experienced the needs assessment and might be interested in talking to me.
2. I am also interested in people's opinions on information disclosure.
Are you or do you know a person who has chosen not to disclose a learning difficulty or support need to the college? I am also interested in why this might be. Would you share this experience with me? Would a person you know share this experience with me?

Please note that all information is confidential. I have attached an information sheet with further information and if you would like to take part or ask further questions you can reach me at 08X XXXXXXX or email XXXXXXXX

Kindest regards,
Patrice Dalton

Appendix D - Information Sheet attached to email and notices

MA RESEARCH: DO YOU WANT TO PARTICIPATE?

Project title: An exploration of access into HEIs for students with learning difficulties and differences

Who is carrying out the research?
I am conducting this research as part of my masters in adult education in the Department of Adult and Community Education, Maynooth University. This research will contribute to my MA thesis about access into HEIs for students with disabilities

I would like to invite you to participate in this research. Before deciding whether you would like to participate in this study, I'd like to explain why this research is being done and what it will involve. Please take some time to read through this information and discuss it with others if you wish. Please ask if there is anything that is unclear or if you would like more information.

What is the Purposes of this Study?
The aim of this study is to explore how accessible higher level institutes are for people with physical and learning difficulties. I intend to focus on Higher Education Institutes and wish to examine funding available, registration with resource or access officers and the social and academic college experience for these students.

Why have I been asked to participate and what's involved?
I want to understand this topic from the perspective of people with learning or physical difference who require extra support in order to attend higher education. I also would like to speak with you if you have chosen **not** to disclose a difficulty or avail of resource office services. I will be using interviews to gain an insight into this topic. The interview will take as long or often as the participant wishes in order to ensure his or her information is accurately recorded.

If you agree to participate, I will contact you to set up a suitable time to begin the research at a mutually convenient time and place. I will ask you to sign a consent form indicating your approval to participate. We can also discuss any additional resources that may be required.

And if I do not want to participate?
I would appreciate it if you are willing to take part in this research and share your experiences with me. However, you are under no obligation to take part in this research. If you do decide to take part, you are still free to withdraw at any time (and withdraw any information you've provided prior to this) without giving a reason.

What happens to my contribution to this research?
All information that is collected about you during this research will be kept confidential. All information will be kept under lock and key or in password data files, and will be accessed only by the researcher and Maynooth University staff involved in the thesis assessment. It will not be distributed to any other individual without your permission. Interview will be recorded on a mobile phone and transferred to a password protected laptop and folder and deleted from said phone.

The results of the research will be written up as a M. Ed thesis which will be stored in the library in the Department of Adult and Community Education, Maynooth University. In as far as possible, all information used in thesis will be anonymised to remove any details that might identify you or your institution. I will seek your permission to use any data that I feel might identify you or others in your community. You will be provided with transcrips of the information analysis prior to the first draft submission where you have the chance to make any changes until you feel the information is accurately represented.

If you are interested or need more information, please contact me via (details of researcher and supervisor supplied)

Appendix E - Services for Participants post interviews

Counsellor_______________________________

Email**: XXXXXXX**
Phone**: XXXXXXX**

Counselling Services Opening Hours - Omitted for confidentiality purposes

Section providing information on counselling services is included but must be excluded here for confidentiality.

Useful Services

ReachOut.com: Provides mental health information to assist university/college students get through difficult times
www.reachout.com/thirdlevel

Please Talk: Suicide prevention service that offers resources and contact details for college personnel who are always available to listen. Carlow College Please Talk contact is Sr Mary Murphy.
www.pleasetalk.ie

MyMind, Centre for Mental Wellbeing: Accessible mental health provider
http://mymind.org

Grow Mental Health Organisation that provides support to individuals who have suffered, or are suffering, from mental health problems

www.grow.ie

Samaritans Service that encourages individuals going through a difficult time to reach out and talk to someone; 24/7 Helpline
www.samaritans.ie
Helpline: 116 123

Appendix F – Consent Form

Consent Form for Participants

My name is Patrice Dalton. I am conducting this research as part of a Masters of Education in Adult and Community Education. The purpose of this study is to explore the experience of adult in higher education institutes who have varying (dis)abilities and focus on the needs of students throughout their time in college or university.

I chose this study as I have a long history of working in the (dis)ability sector and have witnessed both positive and negative experiences throughout my career that I feel requires more exploration.

During the interview, I will ask you to discuss your experience in relation to enrolment in higher education, engaging (or not) with the academic resource office, resources available and any areas you feel are important for me, as a researcher to know. It will be an informal and relaxed conversation where you can tell me your experience with stories and events at a pace, time and place that suits you. It may take more than one meeting and this can be decided together. I have included my supervisor details below should you require any further details.

What does giving your consent mean?

I ____ give permission to Patrice Dalton to use information I provide through her interviews for her research. I understand our conversations will be recorded on her mobile phone but will then be removed to a password-protected computer and deleted from said phone. This information will be stored safely with Patrice for five years. Patrice has explained to me that when she has transcribed the interview she will send me a copy in whatever form I request before submitting the first draft of her thesis and I can make any changes I wish. I understand that I can withdraw at any point. I understand my real name, or the name of the institution will not be provided in the thesis. Patrice has also explained that she may discuss some of her general findings with the Academic Resource Office. However I will not be identified in any discussion or publication of findings.

The results of the research will be written up as a M. Ed thesis which will be stored in the library in the Department of Adult and Community Education, Maynooth University.

Participant Signature: ______________________________

Researcher signature: ______________________________

Date: ________________________________

Contact person: Bernie Grummell, Department of Adult Education, Maynooth University, Co. Kildare. Bernie.Grummell@nuim.ie 01 7087361

Appendix G - Questions to discuss with Academic Resource Officer

Does a person need to register with the Access Office to avail of its services?

Can you tell me about the process involved in registering with the Academic Resource Office?

When a person avails of the services are there any planned communication to evaluate the resources?

What is the process involved if a person wishes to make a complaint or needs to apply for a unique resource?

What services are offered to individuals with the following difficulties as part of illness or disability?

a. Reading and writing e.g. dyslexia and/or intellectual disability.
b. Mobility difficulties e.g. walking, climbing stairs
c. Diagnosed condition affecting memory or concentration.
d. Visual and/or hearing impairment.
e. Diagnosed condition affecting motor skills such as writing
f. Diagnosed condition causing fatigue.
g. Absenteeism due to illness or fatigue

Tell me about the individual and group training sessions offered. How can someone avail of these?

Can you take me through the assessment process for modifications of examinations? Can you provide examples of the modifications?

How are students made aware of the disclosure policy?

Have you anything you would like to add that is important to note?