

Disability, Impairment, Stigma,
Oppression, Discrimination &
Ridicule..... Sounds Like LLLLLLLLLLife
WWWWWWWWWith A SSS SSS SSS
SSS SSSSSSSSSSSSSStammer

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ABSTRACT

Living with a disability and/or impairment can be a constant battle. Oppression, discrimination, ridicule, stigma and the patronising attitudes that have to be endured, all contribute to the battle. The motivation that drove this Dissertation was to explore and highlight the social construction of disability and to raise awareness of the disabling attitudes of a society that falls short of recognising the needs of disabled people, furthermore people who stammer/stutter.

Stammering has been portrayed in the media as a weakness that is connected with psychopathic, unintelligent and irresponsible tendencies – figures of vulnerability to be ridiculed and bullied. However, has its portrayal been one of reality. What would you do if each time you opened your mouth to speak you punched your leg, stamped your feet, stuck out your tongue or sharply jerked your head in the colossal effort to move from syllable to syllable. Furthermore, how do you think others would perceive you? With suicidal thoughts lurking in the background could we begin to challenge accepted knowledge and make a difference for the future generations of children and young people who stammer. Given the opportunity would you contribute to the alleviation of oppression, discrimination, stigma and ridicule. If your answer is yes please read on.

INTRODUCTION

Nine out of ten people have never invited a disabled person into their home, only two out of ten disabled people have non-disabled friends and eight out of ten children with learning disabilities are bullied at school (Quarmby 2011).

The main objective of this dissertation is to highlight the social construction of disability and impairment, and to take the reader on a brief journey of life as a stammerer/stutterer. Could a paradigm shift in social awareness help towards the liberation of disabled and impaired people? And could you contribute to this possible paradigm shift?

Disability is without doubt a delicate subject matter with no one wanting to offend anyone therefore requires a great deal of sensitivity when the subject is being probed. However, the importance of understanding the issues that lie with and within such individuals and groups could lead to new ways of looking at the phenomenon. This could certainly lead to more empathy and less sympathy, which would arguably contribute, to the lessening of the misconception of societies patronising attitudes. In some ways I feel that accepted knowledge and beliefs without challenging them, which is the study of epistemology (see methodology) is responsible for the beliefs that disabled people are helpless victims who should be pitied. This dissertation is of great importance and value to the field of disability because it cuts through much of the politically correct drab and cuts right to the heart of the truth of what it is like to live with a disability and impairment and more specifically, what it is like to live with a stammer.

This dissertation is an attempt to challenge the sociological construction and thought of disability and impairment in the hope it will alleviate some of the oppression, discrimination and stigmatisation that is thrust upon such individuals and groups.

This dissertation is of great significance to humanity and anti-oppressive and anti-discriminatory practice. People who are perceived as different, threatening or incompetent because they may communicate in a different way that is perceived to be normal or have a physical mental or learning disability are still human beings and surely have the right to be listened to and treated with respect. This dissertation is special in its approach, delivery and objectives.

Approach-Honest and sincere, written and researched with integrity and put together without an ounce of self-pity.

Delivery-Straight talking whilst respecting the reader and subject group, backed up with sound references.

Objectives-More empathy and less sympathy, more understanding and less ignorance leading to the liberation of oppressed groups.

Methodology

I will be placing myself in the research as a stammerer, disabled and impaired person. I will also be using extensive secondary research and my method will be qualitative research, I will discuss the pros and cons of the two popular research methods (qualitative and quantitative) and explain why I have chosen qualitative. The methodology chapter will also look at epistemology, which is the study of learned knowledge and why we accept some things to be

true without finding out for ourselves or challenging them. In addition, it will look at the autobiographical method of research in sociological terms.

Lit Review

The literature review sets the foundation of which the main body will stand upon. It will explore the general social construction of disability and impairment looking at issues of oppression, discrimination, and stigma and labelling. The dominant model of disability is the medical model, which views the disabled person at fault and they need to change. This model also suggests the disabled person should be pitied and is a helpless victim. In addition, it will discuss the social model of disability which is a relatively new paradigm shift in sociological thought and supports a view from which disabled people can challenge their social exclusion, oppression and prejudice which arguably has stemmed from the medical model.

Main Body

Conversation, language and talk is fundamental to social life, however, what if every time you wanted to speak the words became stuck in your chest, neck or mouth. In addition to the words being trapped in your body, you also do many movements with your whole body as your brain tries to find a way of getting the words out. The main body will take the reader on a brief journey of life with a stammer. From the first conscious moment, a person stammers their lives are never the same again. Frustration, depression, embarrassment and the guilt of not being a normal son, daughter, brother, sister or person leads to thoughts of suicide. In addition, there is the stigma, bullying, labelling, ignorance and patronising attitudes of society to, continually come to terms with. The wonderful

gift of speech is truly a treasure. How do you think you would have done or where do you think you would be right now if you had had a severe stammer throughout your life. The main body may help you with that thought.

Conclusion/Recommendations

The conclusion will review and highlight the main points that are illustrated in this dissertation. Additionally the conclusion chapter will offer recommendations to the reader offering new ways of alleviating the oppression and discrimination of stigmatised individuals and groups.

Please keep an open mind whilst reading this dissertation.

METHODOLOGY

Throughout my life I have stammered – from as far back as I can remember (38 years), there is not a time that I can recall when this perceived ‘curse’ did not hinder my life-chances. I have been stigmatised, labelled, judged, bullied, belittled, ignored, discriminated against, oppressed and affected by these negative experiences. To combat this obvious disadvantage I have been on every course available and read many books – I have tried old and new techniques (Slurred speech, singing my words, stammering on a purpose, breathing techniques, projecting my voice and pausing between words) of which none are transferable into every situation and speaking experience due to further anxiety or ridicule.

Therefore, I feel that it is not a matter of me speaking in a more controlled way; rather, it is society that falls short of understanding, and recognising the needs of people who stammer. My views coincide with those of the sociologist Shakespeare (2006), who uses such illustrations as: the person who is in the wheelchair is not the one at fault – it is society who builds steps rather than a ramp. Alternatively, the person who is ‘labelled’ with bad eyesight has to struggle to read books that are written in font ten when they could be universally written in font fourteen.

Due to my emotional, passionate and caring involvement with people who stammer, I am mindful that my personal pre-disposition may cause a bias towards this research subject. This could be a potential pitfall and would lead to the dissertation being one sided and ethically compromised.

Quantative and qualitative research methods are popular in the field of sociology. Quantative research methods attempt to measure social phenomena by using statistics and mathematics to interpret their findings. On the other hand, qualitative research – which is the method I will be using in this dissertation – attempts to collect rich and detailed information, giving way to a deeper understanding of individuals within the framework of social life (Giddens 2009). Qualitative research is in line with humanistic theory, which was pioneered by Maslow (1943) and Rogers (1959). The humanistic approach argues that ‘Objective reality is less important than a person’s subjective perception and understanding of the world’ (Mcleod 2007). It is hoped that my status as a lifelong stammerer will bring a certain respect to this research.

I have specifically chosen to use secondary research for two reasons:

1) The time constraints I have to produce this dissertation because, as Descombe (2010) suggests, a disadvantage of primary qualitative research is the time it takes to analyse the results. Furthermore, other personal commitments inhibit me from doing primary research.

2) I have a wealth of personal knowledge on stammering and the ‘suggested’ effects that a disability/ impairment can have on an individual.

I represent the research subject; therefore, the main body of this dissertation will have an autobiographical feel to it. Autobiographical research, along with oral histories, narratives, biographies and life

histories (Bryman 2008) belong purely to sociology and other social sciences; all of which have no place in natural science.

Autobiographical research has become hugely popular and widely utilised in all fields of sociology. Autobiographical research is being used to explore, examine and investigate how individuals experience social life and how they interpret their relationships with others. This style of research paves the way for new voices to enter into the world of sociological research. Not without its critics, some sociologists feel that autobiographical research can be unreliable and 'poses considerable problems in terms of assuring methodological rigour' (Oliver, 2010, p.10), whereas others believe that it offers invaluable new insights for exploration that few other research methods can offer. Some researchers have reflected on and analysed their own lives in an attempt to enhance their own life experiences, giving voice to their 'theoretical assumptions' (Giddens, 2009, p.58).

The autobiographical research will be reinforced by the secondary research. Giddens (2009) suggests that making comparisons is helpful because it allows researchers to generalise what is going on in a specific field. This is known as comparative research, which is of central importance to sociology.

The social is different from the natural. We all inherit a culture that is partly made up of accepted knowledge about the world and how it works; this is the study of epistemology (Audi, 2011; Fumerton, 2006). We may learn from others that smoking will stunt your growth; that grey hair comes from worrying, or if you are different in some way then you are not perceived to be a so-called 'normal' human being. We put some of this knowledge to the test; however,

we simply accept that generally most things we hear are true. By accepting such traditions, we refrain from submerging ourselves in undertaking the search for alternative understandings and regularities. Tradition can severely hinder human enquiry. The power of tradition is certainly evident, however, new knowledge and understanding appears every day. New discoveries can be extremely beneficial, but they often depend on the status of the discoverer. You will be more inclined to believe that failing to wear bed socks in winter would give you the common cold if you are informed by a doctor rather than an electrician (Babbie, 2007).

This study is being done in the hope that it will raise awareness of the negative effects of disability, impairments and, more specifically, stammering. Furthermore, to reinforce the social model of disability – which argues that non-disabled people view disabled people as victims who should be pitied due to their ‘perceived’ disability – which has been helpful in raising awareness of the unhelpful attitudes towards disabled people. The social model of disability argues that if such attitudes were removed there would be less oppression and discrimination, which is my goal and inspiration for The BLAZE Foundation (A not-for-profit organisation that I have founded) (Saraga, 1998; Oliver, 1990; Quarmby, 2011; Barnes and Mercer, 2011; Thompson, 2011; Giddens, 2009).

This study is also being done because its writer suggests that most people who stammer are overlooked, and are looked upon as ‘easy targets’ (to be taken advantage of) in social terms; hence, they are not given the opportunities to fulfil their potential.

LITERATURE REVIEW

Introduction

This literature review sets the concrete foundation that the main body of the dissertation will stand upon. It will review many social aspects (the social construction, impairments/difference and the sociological thought of disability). Enormously important to this subject are issues of stigma, oppression, discrimination, social identity and labelling which have profoundly negative impacts on individuals dealing with the issue of being different - or to be more accurate should I say the social attitudes and ideologies towards people with disabilities and impairments stigmatise, oppress, discriminate and label individuals. Although not without being challenged (Johnson 1996), The World Health Organisation (WHO) has distinguished an invaluable concept between a disability and impairment. Impairment is the impartial physiology or psychological difficulty, whereas, disability is the effects impairment has on an individual or group in terms of their social and occupational roles. (Gross & McIlveen 1998)

This literature review will also delve into the world of disability, impairment and difference, giving the reader at least a basic understanding of the issues connected to this topic. Old and new ideologies and social constructions will be reviewed as will old and new terminology. Furthermore It shall address the social model of disability, this will be critiqued by the medical model of disability which to date is the more dominant model.

A further consideration is great sensitivity is required with this subject since it comes under great criticism from both disabled and non-disabled writers. Therefore, I would ask the reader to keep an

open mind whilst reading the content of this literature review. The purpose of this literature review is for the reader to look beyond a person's disabilities, impairments and differences and to look at the person beneath.

Main Body

When a stranger comes into our presence, our first impressions of their appearance are likely to enable us to anticipate characteristics related to their 'social identity'. While the stranger is present before us, it can become evident they possess an attribute that would make them different from others (for example, people with communication difficulties, people with learning difficulties, people in wheelchairs and people with Downs-Syndrome). In addition to this, the attribute could be seen to make the stranger a less desirable kind or in extreme cases, as Goffman (1963) suggests, the attribute of a stranger could lead us to believe they are dangerous, weak or perceived to be lower than ourselves in terms of social identity. This person is downgraded in our minds from a whole and normal person to a blemished and overlooked person. Goffman (1963) Swain, French and Cameron (2010) and Barnes and Mercer (2011) imply such an attribute could be labelled as a 'stigma', especially when its discrediting effect is extensive. In some instances it could also be seen as a failing or a handicap, although Giddens (2009 p. 415-416) proposes that the word 'handicap' has largely fallen out of use because it originates from 'cap in hand', which implies begging or charity (Barnes and Mercer, 2011; Swain, French and Cameron, 2010; Saraga, 1998). A more appropriate and politically correct term used to describe such an attribute in today's world is 'impairment'. Other terms that are less common in today's society that would now

be perceived as insults would be 'spastic' 'bastard' 'moron' or 'cripple.' Giddens (2009) goes on to say that 'some metaphors are still in everyday use, like 'turning a blind eye' or 'a deaf ear' however such sayings have been criticised because they imply a sense of exclusion.'

According to Goffman, a 'stigma' (1963 p. 14) is a blemish of individual character that is perceived as a weak will. Furthermore, it can be seen as a common social notion of some sort of mental disorder where the person is received as 'easy' (vulnerable or to take advantage of) in day to day social intercourse. Goffman further implies 'a stigma is a characteristic that can obtrude itself upon attention and turn away the people they come into contact with'. Quarmby (2011) Goffman (1963) and Barnes and Mercer (2011) suggest the term 'stigma' derives from Greek times, and referred to bodily signs which exposed something unusual and different about an individual. The individual would then be slashed, burned or branded to advertise that the bearer was a slave, a criminal or a traitor-'a marked person 'ritually polluted', and to be avoided at all costs, especially in public places. Quarmby (2011) goes on to say that some disabled people are still victims of this sort of behaviour today. By definition, many people in today's society still believe that a person with a stigma attached is not quite human. We then develop a stigma theory; an ideology to explain the inferiority and take into account the dangers the person represents. Jenkins (2008 p.95-96) suggests that the book '*Stigma*' is arguably the poorest of Goffman's books; however, Jenkins does note that the book offers much that is useful, in terms of the emphasis of the demands that other people make of us, solely on the basis of our public image. As a by-product of these demands, trajectories that are anything but

those we would choose can be thrust upon us (labelling). Other people do not just perceive our identity; they actively construct the framework for it –not only in terms of naming or categorising, but in terms of how others respond or treat us. In the dialect of individual identification the external moment can be hugely consequential. Identity of any kind is consequential, otherwise it would not be identity, and internally what people think about us is no less significant than what we think about ourselves (Jenkins 2008). Research suggests that the consequences of labelling people with disabilities or impairments can be hugely detrimental (Swain, French and Cameron, 2010; Morris, 1991; Kent, 2000; Crow, 2000; Linton, 1998; Shakespeare, 1996) as the following quotes imply. ‘I’m done with names. Names are nothing but collars men tie around your neck to drag you where they like.’ (Gray, 2001, p. 72) ‘Our ideas about disability and about ourselves are generally formed by those who are not disabled’. (Morris 1991, p. 37)

Furthermore Giddens (2009 p.400) argues that ‘stigma is a relationship of devaluation in which one individual is disqualified from full social acceptance.’ Giddens goes on to say that, stigmas are seldom based on valid understandings; rather, they arise from perceptions or stereotypes, which most of the time are false or only partially correct. Unfortunately, this is true for many people with impairments or disabilities and can also have an impact on the person’s family and friends. Many writers suggest that close friends and family more often than not share some of the discredit and acquire a ‘courtesy stigma’, reinforcing the notion that the lack of social approval connected to people with a disability is also potentially contagious (Barnes and Mercer, 2011; Birenbaum, 1970; MacRae, 1999).

Whether or not an impairment or a disability is a significant matter for you personally, it can be a regular topic of conversations, jokes, portrayed negatively in the media and also in some cases may be deemed as a 'taboo' subject as Saraga (1998, p.45 & 190) explains; disability has historically been a 'taboo' subject. Anthropologists are in agreement that a taboo is a thing, act or person that is subject to social prohibition, therefore rendered unmentionable. It would seem that taboos are a subtle mechanism of social control. The existence of taboos quite possibly make the world a more classified and orderly place by establishing an apparent boundary which separates 'normal' and 'abnormal' , 'safe' and 'dangerous', 'natural' and 'unnatural', or 'pure' and 'impure.' Douglas (1996) and Saraga (1998, p. 52 & 82) note that writers like Oliver (1990) verify that the 'difference' experienced by people with impairments is constituted by the processes of oppression and marginalisation in society. Therefore, disabled people are open to experience a particular type of compounded oppression; where they are marginalised and discriminated against by social institutions and the able-bodied (this model of disability is reviewed in a later chapter). Marginalisation is the term used by social scientists to characterise the intricate process of the social rejection of deviant parties, such as disabled people from the dominant culture.

'The dominant social structure of disability (which is reviewed later) has arguably established a deviant and relatively powerless status for the disabled as the 'other' which is distinct and apart from the supposedly 'normal' and 'natural' majority.' (Saraga, 1998 p.51)

People are disabled by discrimination and prejudice, and not necessarily by their impairments (Robinson and Stalker, 1998; Giddens, 2009; Chappell, 1992; Wolfensberger, 1983; Oliver, 1996;

Morris, 1991). Furthermore, these writers suggest that the challenges that disabled people face are not the consequences of their individual differences; they are more likely to be the consequences of a society that falls short of addressing their needs. These challenges are twofold – in the delivery of services and its social organisation. This is known as ‘the social model of disability’, which argues that:

‘Rather than investing time and effort in medical or psychological efforts to correct the impairments, it is more appropriate to remove the barriers in society which cause problems for people with impairments; these may be discriminatory employment, negative stereotypes or prejudiced attitudes.’ (Robinson & Stalker, 1998 p. 14)

The social model of disability (Saraga, 1998; Oliver, 1990; Quarmby, 2011; Barnes and Mercer, 2011; Thompson, 2011; Giddens, 2009) is a relatively new ‘paradigm’ or conceptual framework for coming to terms with disability. In this model it is not the physical, cognitive, mental or sensory impairment that disables an individual; rather, it is the result of the structurally limiting effect of society that is geared towards able-bodied people as the neutral norm. In addition, Swain, French and Cameron (2010) suggest that the key point of the social model of disability is that it supports a view from which disabled people can challenge their social exclusion and oppression, which they have endured for far too long. Instead of being ‘fair game’, disabled people would like to be given a ‘fair chance’ and have the same opportunities in life as people without a disability. For instance, to be able to make decisions about issues that could potentially have an impact on their lives, to have relationships, to gain an education and to live in affordable accessible housing. The

social model of disability is important as far as it provides a different angle from which to view disabled people.

Disabled people have been utilizing the social model as a basis for explanation by drawing attention to the 'real' challenges of disability. As mentioned above, the limited options that are available to them by means of low expectations of society (which can include their own family members), as well as the barriers that they face and the patronising attitudes which have to be endured.

'The social model of disability has enabled a vision of ourselves free from the constraints of disability (oppression) and provided a direction for our commitment to social change. It has played a central role in promoting disabled people's individual self-worth, collective identity and political organisation. I don't think it is an exaggeration to say that the social model has saved lives.' (Crow, 1996, p. 207)

However, as Crow (1996) and Shakespeare (1996) explain, the social model is not without its critics. Although the social model of disability has proved to be a priceless instrument in the lives of disabled people, it has been suggested that the disabled peoples' movement has overemphasised the discrimination ingrained in disabling relationships at the cost of acknowledging the significance of impairment within people's lives.

For example: 'For some, the social model focuses too heavily or exclusively, on socio-structural barriers (determining access to life's material necessities) and downplays or ignores the cultural and experiential dimensions of disablism.' (Thomas 1999, p.24)

Disablism is the term that describes the ideological processes (one of them being medical knowledge) that legitimise the existing

powerful framework which the social construction of disability and its foundations are based upon prejudice, discrimination and oppression of disabled people (Saraga, 1998).

To critique the social model of disability the more dominant, traditional or accepted model of disability is the medical model which is sometimes known as the individual model. The dominant view of this model suggests there is something wrong with the individual rather than the attitudes of a disabling society. The individual model sees a disabled person as someone who cannot see, cannot hear, cannot walk, cannot talk, has Down syndrome, or has a mental illness and so on. The wording here is crucial; 'cannot' and 'has.' The individual is at fault, therefore the individual needs to change, rather than society (Swain et al., 2010; Thompson, 2011; Robinson & Stalker, 1998; Quarmby, 2011; Barnes & Mercer, 2011). Little or no account is taken of the broader issues of disability that relate to attitudes, cultural expectations and the socio-political context. The medical or individual model of disability has been subject to criticisms by many writers (Finkelstein, 1980; Lonsdale, 1990; Oliver, 1990 & 1996; Oliver & Sapey, 2006). Thompson (2011, pp.113-114) suggests there are five main criticisms of the Individual Model of Disability, which have been simplified below. After each one, I will give the social model alternative.

- 1) Limited focus on the individual fails to understand the importance of disability as the social response to a physical, sensory or mental impairment. In addition to this first point, any barriers brought about by the disability itself or unhelpful, demeaning and patronising responses bring further restrictions. The social model views disability as a form of social oppression which involves the social imposition of limitations in regards to activities for people with

impairments and the social provocation and undermining of their psycho-emotional well-being. (Thomas 1999).

2) The individual approach views the individual as a tragic victim to be pitied or, in some cases, a brave hero who is to be respected.

The social model would be geared towards the alleviation of oppression instead of the compensation of an individual.

Furthermore, it would focus on the prejudice and discrimination of society rather than the individual victims of circumstance. 'To put it simply it is not the ability to walk which disables someone, but the steps into the building' (Morris, 1991 p.10)

3) Disabled people are seen as the 'deserving poor' who are in need of care and attention. This view can be seen as a patronising approach that exaggerates the amount of personal care required and under-plays the importance of rights and empowerment. The social model would argue that disabled people have the right to an education, employment, affordable and accessible housing, to have relationships and to be able to make their own decisions on issues that could potentially have an effect on their lives (Swain, French and Cameron, 2010).

4) People with a disability encounter discrimination and social exclusion. Central to the social model of disability is the foundation for disabled people to argue that social exclusion has been endured for far too long. Disabled people have the right to the same chances and opportunities that non-disabled people have (Swain, French and Cameron, 2010).

5) Individualistic approaches to disability do not address the ways that disability blends in with other social factors such as race, gender, age and sexual identity. Together, these factors produce a

complex framework of multiple oppressions, whereas Crow (1996) proclaims a 'new norm' that carries an anticipation that within a population there will be a diversity of differences and attributes- which given time will lead to an acceptance of valuing differences. This will further lead to a lessening of the social demand to place labels on individuals with a disability or impairment who experience other oppressions such as race, gender, age and sexual identity.

Conclusion

This literature review has affirmed what I already thought; however, I have never had it confirmed to me that people with disabilities and impairments are treated differently. Social exclusion, patronising attitudes, stigma, labelling and oppression are most certainly the biggest barriers that such individuals face. The social model of disability is definitely more helpful than the medical model; however, I cannot foresee the social model becoming the more dominant one overnight. Nevertheless, it is evident that there is a new day dawning – or, to put it another way, there is a light at the end of the tunnel. I would ask you to consider the possibility of contributing towards the liberation of people living in oppression by adjusting your attitude from the medical model to the social model of disability. Of course, that is if you haven't already.

MAIN BODY

Introduction

Before reading the main body of this dissertation, I would like to set you a challenge. Go to the nearest mirror you can find and make sure you are alone. When you get to the mirror, look into your eyes. Then, whilst you're there, start jerking your head from side to side whilst blinking rapidly and sticking out your tongue to its furthest extent – almost snapping the skin that connects the bottom of your mouth to your tongue. After you have completed this challenge, please come back and read on.

Ok, now you have done that, go to the nearest shop and ask the shopkeeper for something that is behind the counter doing all the same things that you did in the above challenge. My guess is that you skipped the first challenge because you felt too conscious of doing the mirror challenge even though you would have been alone. Moreover, as for going into the nearest shop and asking for something whilst doing all the additional tasks, I bet that was too much for you as well. However, if you did, I have the utmost respect, appreciation and admiration for you because I know how much courage it takes.

Main Body

Imagine with me – you are standing at the train station waiting to go to university; you are 38 years old, and have a girlfriend and a son. You can see the train coming; your intuition tells you to make a run for it, or to not get on it and wait until the next intercity 125 comes and jump in front of it. Imagine you did get on the train and you

made it to Leeds. You are walking to university from the train station and you have not had breakfast. You go into Greggs sweating from anxiety and with tears of sadness and frustration rolling down your face because of a traumatic experience you had on the train. You know in your mind you are about to have another traumatic experience ordering a bacon and sausage sandwich and a cup of coffee; however, you go ahead and do it anyway. You walk out of Greggs totally deflated and make your way to your first lecture whilst anxiety, sadness and frustration push you to the verge of insanity; tears are now streaming down your face, you can taste a hint of salt as the tears start to settle on your lips. There are people all around you, but you cannot make them out; they are like silhouettes, and with each step you know you are getting closer to the pedestrian crossing where you have contemplated throwing yourself in front of one of the speeding cars that go by at least a hundred times. You think of your son – how much you love him and how much he loves you – you begin to breathe deeply in through your nose, and you blow out the air through rounded lips. You wait until the cars stop and then make your way over the road whilst strangers are looking at you; mostly with a weird stare, although the odd one will either give you a sorrowful smile and a little nod, or raise their eyebrows at you. The thought of reading your son a bedtime story provides a glimmer of hope, and gives you a comforting tingle up your back as if the hairs were doing the opposite of when a line of dominos are falling down. You wipe your tears away, tell yourself you can do this, and for today, you do not think about throwing yourself from the bridge that is just before you walk into Broadcasting Place for your first lecture of the day.

'The pen is mightier than the sword but the art of speech is beyond all doubt the greatest of human power' (Beasley, 1902, p.28)

There are social rules of interaction and although we use body language and non-verbal cues in our behaviour, as well as when rationalising the behaviour of others, most of our interaction is done through speaking to people – unplanned and random verbal exchange, which is traded through simple conversation with others (Giddens, 2009). Language is what differentiates humans from non-humans (Brown, 1965; Gross & McIlveen, 1998; Hinchcliffe & Woodward, 2004) Gross & McIlveen (1998) go on to say that other species can communicate with each other; however, they communicate in limited ways. Language – and talking in particular – is fundamental and essential to social life; in addition, it is central to identification (Jenkins, 2008). It is also the most important way that our lives are maintained in a rational and stable manner. We are most at ease when the 'normality' of 'small talk' is abided by: if this is infringed, we can easily feel disorientated, insecure or threatened (Giddens, 2009).

'The process of language acquisition the powerful human learning predisposition leaves the individual open to forceful and consequential definitions by others' (Jenkins, 2008, p.84)

Stammering is the UK term and stuttering is the American term for the same condition, although some people in the UK also use the term stuttering (Turnbull & Stewart, 1996; Lewis, 1997; Byrne & Wright, 2008; Byrne, 1994). For this paper I will use the term stammering, which is a stand-alone condition not to be confused

with other conditions such as aphasia (Carlisle, 1985), selective mutism or performance anxiety (Horwitz, 2002). Stammering is a condition which produces speech that is hesitant, stumbling and tense or jerky, all of which interrupts the rhythm and smooth flow of speech (Bloodstein & Ratner, 2008; Byrne & Wright, 2008; Stewart & Turnbull, 1997). Additional symptoms are commonly linked through having a stammer. These include stamping your feet, punching your leg, sticking out your tongue, closing or rapidly blinking your eyes, and jerking your head and body in the colossal effort to move from syllable to syllable (Carlisle, 1985; Riper, 1982; Williams, 2006).

I was 8 years old and stood at the front of the stage at Common Road Middle School. I was in a school play and I was about to say my lines; I had practiced them at least a hundred times and learnt them off by heart. All the mums and dads, teachers and peers were watching me. I went to say my lines and nothing came out of my mouth. I kept on trying, however, after what seemed like an eternity I ran off stage embarrassed, frustrated and confused. In addition, at that moment, on that stage, in that school you could say with confidence that was the end of my acting career. It has been suggested that the stammerer should try to maintain a sense of humour (Murray, 1991; Byrne & Wright, 2008; Carlisle, 1985). Something happened to me that day when I was a little boy - that moment on the stage would change my life forever. I was to embark on a journey where many had gone before me and many will after me; however, has anything changed? Has there been any improvement or breakthroughs since I was at school some 25 plus years ago?

Sending a stuttering child to school is like making a lame boy run in the one hundred metres (Murray, 1991), or like throwing a kitten into the dog pound; however, the kitten must take its chances in the dog pound and develop sufficient agility and sharp enough claws to survive (Carlisle, 1985, p.34). Children who stammer are frequently teased and bullied at school (Beasley, 1902; Rustin et al., 2001; Turnbull & Stewart, 1996; Rustin et al., 1998; Lewis, 1997; Riper, 1982). In my case, bullying started after my traumatic experience in the school play when I was eight years old. I was kicked, punched, spat on and mimicked. One boy who was a year older than me would get me in a headlock and thrust the clenched middle part of his middle finger into the top of my head whilst shouting 'stutter boy' at the top of his voice for all the other children to hear so they would all laugh. Fredrick Murray (Murray, 1991), also a stammerer, was teased and bullied in the playground from 5 years old. The children would call him 'stutter cat'. Frederick escaped some of the bullying when he played a silent Indian in a school play; this came much to his relief; had he been given a speaking part, ridicule would have been sure to follow. Byrne and Wright (2008) write an account of a boy, aged nine, who was being bullied at school: 'He would say words over and over and over in a silly voice and call me 'stutter boy'. Once he was doing it in the dinner line and I couldn't get away. I got so mad I hit him hard and the teacher saw me and I got into trouble. I was so angry I couldn't talk to her, and just went off by myself into a corner of the playground' (p. 23). The same thing was happening over a century ago, as Beasley (1902, p.27) suggested schoolchildren who stammer are 'heavily handicapped' and their young lives are made 'unbearable' through the thoughtless and ignorant behaviour of other children. Beasley goes on to say that there are children in every school who 'take delight' in mimicking,

laughing and ridiculing children who stammer. Some passionate children will give in to such heartless behaviour and lash out, whilst others of a different nature become heartbroken and socially isolate themselves. This research suggests that nothing has changed socially in the last 110 years.

Carlisle (1985, pp.32 & 33) tells us that Western society is fiercely competitive, and has never been kind to its children. As soon as the umbilical cord has been severed, intense pressures are placed on children. Some parents even expose the developing foetus to extremely high levels of oxygen in the hope it will give their child a greater chance of becoming a genius. Pressures on children begin at home; however, the pressures spiral out of control when the child is introduced to education, where communication and *achieving* with a capital A is paramount. A study conducted by UNICEF in 2007 reinforces Carlisle's point. The study focused on child well-being in developed countries and looked at different types of pressures that included education, family and peer pressure. The UK landed at the bottom of many of the categories, which placed the UK bottom overall, with the USA just above (Vanderbloemen, 2011). Several primitive societies have provided clues of the link between social pressures and stammering. In groups of people from New Guinea, the Australian Outback and Eskimos, investigations revealed that there was not even a name for such a condition (Carlisle, 1985; Bullen, 1945; Bloodstein & Ratner, 2008). Carlisle (1985, pp.34-35) goes on to say that the speech studies of North American Indians provided invaluable information into the effects of social pressures on children. Snidecor (1947) studied these tribes from 1937-1939 and after thorough investigation he found they did not have a word for stammering. These tribes lived on isolated reservations and were

called the Bannock and Shoshone Indians. They experienced a minimal impact of Western social customs; there was no pressure to speak and perform. These children experienced a great deal of freedom until adolescence, and they were not forced to conform to rigid cultural standards— children were highly unlikely to be placed under pressure for the way they spoke. In stark contrast, a study by Lemert (1953) of Northwest coast Indian tribes – the Kwakiutl, the Nootka and the Salish tribes – suggested the exact opposite. During his study, Lemert was exposed to large numbers of people who stammered; these tribes also had words in their own language to describe stammering and had rituals to treat the condition. Much like the Western world, these tribes lived in fiercely competitive communities that placed severe pressures on their young. Poor communication skills were simply not acceptable. Perceived weaknesses and differences were disapproved of, whilst individual prowess reflected favourably on the tribe.

Because of society's disapproval of stammering, children begin to avoid speaking and avoid situations where they would have to speak (Turnbull & Stewart, 1996; Riper, 1982; Lewis, 1997; Byrne & Wright, 2008; Holte, 2011). Bloodstein and Ratner (2008, p.34) report cases of children as young as 2 years old that stopped talking for a couple of days after their first 'experience' of stammering. However, avoidance becomes fairly consistent from the age of 5. The most commonly avoided speaking situation was classroom recitation; usually in the form of children not putting their hand up to answer a question, or appearing to be confused or unprepared even if they knew the answer to the question. I can vividly remember being highly skilled at not putting my hand up to answer questions; even if the teacher directly asked me a question and I knew the

answer (which most of the time I did), I would shrug my shoulders and act spaced out or appear to be dumbfounded. This would spare me from being laughed at, however, this type of avoidance only serves to fuel the part of the child's stammer that no one sees – the underlying iceberg that the stammerer keeps all to himself, arguably because of societal expectation and pressure. Originally the work of Joseph Sheehan, Turnbull and Stewart (1996, p.48) describes the stammering iceberg – the distinctive feature of an iceberg is the part that protrudes through the water, the part that is visible. However, below the water is the huge expanse of ice that no one can see, but is of greater concern (it's this part of the iceberg that sunk the Titanic). The young stammerer adds to the huge expanse daily each time he stammers aloud, avoids a word or avoids a situation. The underlying iceberg is where the feelings and emotions are stored. Self-hate, frustration, guilt, depression, mental torment and suicidal thoughts are common among people who stammer. (Rustin et al 1998, Manning 2001, Stewart & Turnbull 1997 and Williams 2006). Unfortunately, for some people the underlying iceberg is so great and the burden of stammering is too great that they may take their own lives, as Dominic Barker did, whose parents set up a trust fund in his memory – known as Dom's Fund, The Dominic Barker Trust (1997) – which was set up to fund research into stammering. The trust is in memory of a witty, intelligent and much loved young man for whom the burden of stammering was so great that he took his own life. Most of us take the ability to use the telephone for granted; to ask for what we need when shopping, or to answer questions in a job interview. However, people who stammer frequently struggle to make themselves understood by those who do not recognise the difficulties and frustrations of stammering.

Media is closely connected to society's ideologies, thus it has an impact into the ideas, beliefs and actions of people that has major implications on sociology (Giddens, 2009). It is a fact that stammering is often portrayed as a joke in films and books in a way that few other disabilities are (Rustin et al., 2001). This notion is reinforced by Lewis (1997), who suggests that many people look upon stammering as something of a joke, reinforced by the fact that those who stammer are usually portrayed on television and in film as figures of fun. Carlisle (1985, pp.188-189) tells us that television and film play a major part in influencing society in today's world. For decades, authors and actors have been cashing in on the notion that the paying public find disability funny or disturbing. This view has been further reinforced by their tasteless and stigmatising performances. You would think we would be more 'enlightened' today; however, two years ago I watched a drama on the television about a circus. One of the main attractions of the circus was a young man who had a stammer, and he earned his keep by entertaining the public by simply talking. Many movies have portrayed stammerers as 'weak and sinister' to illustrate psychopathic tendencies. Alternatively, an actor who plays a sadistic killer could be portrayed to have a mental illness, which would imply they had an unhappy childhood and as a result developed a stammer. Nearly all characters in films and television who stammer play the part of being pathetic, dumb and irresponsible – as soft, faint hearted or dangerous; to be avoided. Such films are *A Fish Called Wanda* (1998), *One Flew over the Cuckoo's Nest* (1975), *It* (1990), and *Primal Fear* (1996)(Kuster, 2011). *The King's Speech* (2010) with its sprinkle of Hollywood glitz and glamour, gave people who stammer something to look forward to in the hope that it would represent stammering in a true light, and raise some awareness of

the real anguish of what a stammerer is like to live with. It is also a true story about King George VI, who had a stammer. The king was helped by the 'maverick' speech therapist, Lionel Logue. Mr Logue helped the king to bounce through his speeches before, during and after the Second World War; however, the king continued to stammer throughout his whole life (Holte, 2011). I believe this film had a positive effect and raised some much-needed awareness; what a shame that the comedian Lenny Henry overshadowed that with his sketch that opened the 2011 Comic Relief television programme. Norbert Lieckfeldt, the Chief Executive of the British Stammering Association (BSA), felt the opening sketch of Comic Relief was inappropriate in its context. Comic relief, an entertainment television programme that raises money and awareness for disabilities, is not the type of show you would expect to see people mocking disabilities on. Mr Henry's reply to Colin Firth's character – 'Oi, get on with it, I haven't got all day' – was boorish and bullying. Many parents of stammering children contacted the BSA for support following the sketch, since many adults and children who stammer sat down with their families to watch Comic Relief. One child raised £37:50 for the programme and the first thing he heard was his stammer being mocked. An upset mum said, 'it is the exact same language the bullies in his school use every day'. Following the sketch, the BSA were inundated with stories about young people cancelling their participation in the school play for the fear of being laughed at or bullied. A teenager who desperately tried to hide his stammer, because of the cruelty he is subjected to, had agreed for his speech therapist to speak to his teacher, only to later pull out. A speech therapist reported months of speech therapy had been done in vain when trying to 'coax' a man who stammers out of 'mutism', as he had stopped speaking because

his line manager tapped his watch every time he spoke. Finally, Mr Lieckfeldt suggested that the child who stammers that gets up every morning to face school with courage – since they know what awaits them, which is the habitual embarrassment of the register, reading aloud in class and the daily battles of the playground bullies - deserve much better than this (Lieckfeldt, 2011). This begs the question, would there have been a ‘boorish’ or ‘bullying’ scene done about someone in a wheelchair, someone who was blind or someone with downs syndrome? In all the disability books I have read there is never anything on stammering, whilst the blind, deaf, mentally and physically disabled are regularly referenced. To attain any information on stammering, you have to read a specific ‘stammering’ book.

My high school mornings were ones of fear, depression and anxiety. My mother or father would shout up the stairs to wake me up for school. Before I would open my eyes on a morning, my first thought would be: how are you going to pay for your bus fare today? How would I force the words out and what tricks could I use? Would I stamp my feet, punch myself on the leg (bruising myself), jerk my head in different directions whilst sticking out my tongue so far that on several occasions the skin connecting my tongue to the bottom of my mouth would snap? Or would it be a mixture or all of them? Whichever way it came out, the pupils on the bus and more often than not the bus driver would be in hysterics. Byrne & Wright (2008, p.34) write about a young person who had to buy a train ticket – ‘Craig had to buy a train ticket to Waterloo Station every few weeks. He was convinced that he could not say ‘waterloo’ because ‘w’ was a difficult sound for him. He acquired an avoidance trick. This entailed him going up to the ticket counter, and then pretending to

have a coughing fit, he would pull a used ticket out of his pocket and point to the word 'Waterloo' – and thus obtain his ticket'. After my traumatic experiences paying my bus fares, I would have to somehow stay balanced and sane whilst experiencing the intensity of multiple insufferable panic attacks and focus on how I would say 'here sir' at register, where the horror, terror and frenzy would begin again.

The word count of this dissertation permits me to carry on, and I have merely started my argument. I have made it to high school and told you about my first two speaking experiences (paying my bus fare and answering at register). I have not mentioned girls, exams, speech therapy, drugs, alcohol, jail, employment, suffering from deep depression, having suicidal tendencies, becoming a dad, getting married, or becoming a motivational speaker who speaks to audiences of up to 3000 people. With the words I have left, I would like to say that if you ever have the privilege to speak to someone who stammers please do not pity them, patronise them or pull their strings (take advantage of them). Give them a 'fair chance' and do not treat them like 'fair game'. Maybe you are thinking to yourself that you are tough and you would have been able to beat a stammer or maybe that you feel empathy for people who stammer. Please do the exercise that is in the introduction to see how courageous you are or to feel even more empathy towards people who live their lives courageously with a stammer.

Conclusion

Being able to speak and hold a conversation is of paramount importance, and truly is fundamental to one's social life. It is the

golden rule of social interaction and if breached, it can leave an individual open to many consequential behaviours such as being laughed at, teased, bullied and even getting punched, kicked and spat on.

The journey of the stammerer seems not to have changed much over the last 110 years, not just the last 25 since I was at school myself. A stammerer's life is one of hardship, pain, vulnerability, shame, stigma, exclusion, discrimination, oppression – I will stop there because I do not want you to pity me or to think that I am a helpless victim in need of sympathy. My hope is that this part of my dissertation has made you at least think twice and given you an insight into the world of stammering. Do you stammer? Does your son or daughter stammer? Do any of your family or friends stammer? Maybe you have never even encountered anyone who stammers. Either way, I hope you do something positive, unlike the comedian Mr Lenny Henry.

Maybe my life has been changed by writing this dissertation too.

'A true friend knows your weaknesses but shows you your strengths; feels your fears but fortifies your faith; sees your anxieties but frees your spirit; recognizes your disabilities but emphasizes your possibilities'. (Ward, 2009)

Would you be my true friend, just for today?

CONCLUSION / RECOMMENDATIONS

What do you see when you come across a disabled person?

Do you see a victim of circumstance? Someone who should be pitied? Someone who has to endure patronising attitudes every day of their lives? Or do you see disability as a social response to a physical, sensory or mental impairment?

What do you feel when you come across a disabled person?

Do you feel sorry for them? Do you feel angry or frustrated because you view them as a drain on society? Maybe you feel genuine empathy and want to help in the alleviation of their oppression, discrimination and disablism that is thrust upon disabled people.

What do you think when you come across a disabled person?

Do you think about what an easy life they must have? Do you think rather you than me? Do you think wow, and you are overcome with respect and admiration for them? Or maybe you think here comes an easy target that you can manipulate, bully or ridicule.

What do you do when you come across a disabled person?

Do you go out of your way to avoid having to make conversation or contact with them? Do you patronise them, even if you do not intend to but you do not know what else to do in that situation? Do you attempt to make them look or feel small in the hope it will make you look or feel bigger than what you actually are? On the other hand, maybe you would be warm and genuine towards them.

When was the last time you had a conversation with a disabled or an impaired person? And furthermore, when was the last time you

had a meaningful heart to heart with one? Have you invited a disabled person to your home for dinner or a party, and when was the last time you went to see a movie, shopping or for a couple of drinks with one? If you are a parent, does your child or children have any disabled friends? Has your child ever invited a disabled child or young person to one of their birthday parties? Would you like to be seen with a person who stammers in a shopping centre whilst they were struggling to speak, jerking their head, and sticking out their tongue? Furthermore, what would you do if you were there and the shopkeeper who the person with the stammer was speaking to said 'come on I haven't got all day', or blatantly started to laugh at them? How would that make you feel if it was your mum, dad, son, daughter, sister, brother, family member or friend; how would that make you feel if it was you?

I do not think the iceberg analogy is exclusively for people who stammer. I would argue that everyone has an iceberg of some description, whether it is through bereavement, family break up, illness, insecurities or a secret of some kind. As a man who stammers, I have shared my iceberg with you. My hope in sharing my iceberg with you is to raise awareness of the life that a stammerer has to endure, as well as encouraging you to share your iceberg with someone too.

'There are wounds that never show on the body that are deeper and more hurtful than anything that bleeds.' (Hamilton 2006, p.121)

Whether you are disabled, impaired or not you are different; different to anyone else. No one has the same face, body, brain, fingerprints or thoughts as you do. You are uniquely different. Imagine a society – or even world, if you dare – that embraced difference. Now there is a thought. We could so easily be fooled into thinking that unless we

scrap all that we know, remove all the stigmatising media and got rid of all of the patronising attitudes, some demographics will always be oppressed and discriminated against. Whilst this is a possibility, my view is that if we begin to change our thinking on this issue and offer new ways of thinking that would challenge accepted knowledge about the world and how it works, offering new ways of engaging with this particular issue, together we could begin to turn things around.

My suggested model of disability, that I believe would change our thinking and challenge accepted knowledge leans toward the social model of disability. This model would offer new and helpful ways of engaging with disabled and impaired people and is called 'The Liberation Model of Disability' – this paradigm shift is threefold and simple.

- 1) Take the time to get to know a disabled or impaired person in the same way that you would anyone else. Be patient. If you already know a person that is great, get to know more. Invite them to tea or for a coffee in the same way that you would with anyone else. You may even find out that they are not that different after all, and you might very well become lifelong friends.
- 2) Look beyond the external visibilities and focus on what is inside. Give them a fair chance. My prediction is that you will be pleasantly surprised.
- 3) Be genuine – there is nothing worse than a patronising attitude. Try not to mind read, and if you have any questions you would like to ask then please ask them in a genuine

manner. It's the only way we are ever going to get to know and understand each other.

Remember, it is the tiny rudder that steers the one hundred and fifty thousand ton cruise liner.

How important is conversation, language and speech in your life? Is it a basic ingredient of your social life? Furthermore, if the normality of small talk was infringed upon would you become flustered, disorientated, and insecure, threatened and feel vulnerable? If you had the courage to do the mirror or shop challenge in the main body's introduction my assumption would be you experienced all of the above. What will you be thinking the next time you are waiting for a train, walking into Greggs, approaching a busy road or walking over a bridge? You cannot do anything for the ones that have gone before me, however, you can do something for this and the next generation of children and young people for whom the playground bullying, school plays, bus fares, reading in class and the register beckon. All of which are closely followed by not speaking, frustration, depression, embarrassment, mental torment, physical abuse and sometimes suicide all because the normality of small talk is infringed upon.

'In every phenomenon the beginning remains always the most notable moment' (Carlyle, n.d.)

Please read the three above points again, and then take a look around so you can remember where you were when you started the new phenomenon that will come to be known as the 'liberation model of disability'.

Wordcount 9,754

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