# The Social Representations of Disability: Fears, Fantasies and Facts

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The Social Representations of Disability

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### Abstract

This thesis uses the Theory of Social Representations to examine how non-disabled and disabled people perceive disability. This thesis only deals with representations of physical, learning or sensory impairments. The study has set out to be an initial mapping exercise of the Social Representations currently in circulation within society. It does not aim to test any firm hypotheses but is designed to offer some indicative data which may be useful to formulate some more detailed research. This research focuses on the psychological processes involved in the development of Social Representations about disabled people. in terms of thinking and feeling about impairment. This study will also discuss the role of the print media in the development of Social Representations of disability, and the views of disabled people themselves.

The primary method used was the storyboard technique. Participants were presented with a set of photographs and asked to write a fictional story about the central character, who may have a born disability, an acquired disability, or be non-disabled. There were 211 participants in this part of the study. All the stories were analysed to develop a typology of the Social Representations of disability. The second method was a print media survey: One hundred and fifty-two articles with disability as their central focus were identified from eleven national newspapers over a sixweek period. The study identified the Social Representations of disability presented in these articles. The final method was nine focus groups comprising of ninety-seven disabled people with different impairments, who were asked how they felt non-disabled people perceive disability and how disabled people perceive themselves.

The storyboard technique elicited ten distinct Social Representations of disability, including Brave/Determined, Tragedy and Sad/Lonely. In

addition, the study presented images of non-disabled people with no mention of disability as a control procedure. However, even these images generated stories about disability in terms of mental health. This was an unexpected Social Representation of disability in the context of the study. The study found that non-disabled people do have different Social Representations of born disabled people compared to acquired disabled people. Furthermore, there are indications that there are occupational differences in the Social Representations used. For instance, medical professionals tend to write Sad/Lonely stories, while charity workers write more Brave/Determined stories. The print media survey found that newspapers use different Social Representations from those found in the subjects' stories. Newspapers use Social Representations such as Legal/Ethical, and Life and Death. The focus groups confirmed our findings from the storyboards and the print media survey.

This thesis confirms that Social Representation Theory is a useful way to understand how non-disabled and disabled people think about disability and how people use common knowledge and popular myth in order to understand reified knowledge. This study is a basis on which much more detailed research can be developed using Social Representation Theory as a means of understanding the development of representations in terms of the origins of impairment (born/acquired), gender, age and contact with disabled people. This study has developed a typology of Social Representations of disability which can be used by other researchers in many fields.

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### Declaration

This is dedicated to the memory of David Barnett, whose hope, wisdom and laughter inspired many.

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Most people think that writing a doctoral thesis is a lonely process. It can be lonely in the middle of the night when you wake up in a cold sweat and you can't remember where you put that reference. However, in real terms it is an immensely social experience, whereby many people make an important contribution to the final piece of work. In that context there are many people to thank for this research.

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### Spasticus Autisticus, by Ian Dury

I'm spasticus, I'm spasticus I'm spasticus autisticus I'm spasticus, I'm spasticus I'm spasticus autisticus I'm spasticus, I'm spasticus I'm spasticus autisticus

I wibble when I piddle Cos my middle is a riddle

I'm spasticus, I'm spasticus I'm spasticus autisticus I'm spasticus, I'm spasticus I'm spasticus autisticus I'm spasticus, I'm spasticus I'm spasticus autisticus

I dribble when I nibble And I quibble when I scribble

Hello to you out there in Normal Land You may not comprehend my tale or understand As I crawl past your window give me lucky looks You can be my body but you'll never read my books

I'm spasticus, I'm spasticus I'm spasticus autisticus I'm spasticus, I'm spasticus I'm spasticus autisticus I'm spasticus, I'm spasticus I'm spasticus autisticus

I'm knobbled on the cobbles Cos I hobble when I wobble Swim!

So place your hard-earned peanuts in my tin And thank the Creator you're not in the state I'm in So long have I been languished on the shelf I must give all proceedings to myself

I'm spasticus, I'm spasticus I'm spasticus autisticus I'm spasticus, I'm spasticus I'm spasticus autisticus I'm spasticus, I'm spasticus I'm spasticus autisticus 54 appliances in leather and elastic 100 000 thank yous from 27 spastics

Spasticus, spasticus Spasticus autisticus Spasticus, spasticus Spasticus, spasticus Spasticus, spasticus Spasticus autisticus

Widdling, griddling, skittling, diddling, fiddling, diddling, widdling, diddling spasticus

I'm spasticus, spasticus Spasticus autisticus Spasticus, spasticus Spasticus autisticus Spasticus, spasticus

Spasticus, spasticus Spasticus autisticus I'm spasticus! Spasticus!

### Chapter One: Introduction: Setting the scene...

### **Overall Introduction**

As a child I was fascinated and puzzled why non-disabled adults treated me differently from non-disabled children. As you may realise I have a disability myself. I was born with cerebral palsy with a speech impairment. My childhood experience of being labelled different made me very conscious of how people interact with people who are not like themselves. This experience and observation may have been the unconscious foundation of this thesis.

Many psychologists have attempted to document and study nondisabled people's attitudes and beliefs about disabled people. However, much of this work has been focused on the nature of the difference and otherness rather than the psychological origins of how these different beliefs or attitudes may arise and how they affect people's actions and thoughts. This is where the theory of Social Representations offers a new way into this complex issue, because of its dialectical approach to communication, knowledge, interpersonal behaviour and inter-group dynamics.

In this thesis the researcher will use Social Representation Theory alongside some useful complementary theories such as Media Theory, Social Disability Theory, the theory of Widespread Beliefs and Focus Group Theory in order to examine and demonstrate how non-disabled adults have a stable set of Social Representations based on their everyday knowledge. The researcher will compare and contrast these findings with the Social Representations of disabled people found in print media and the actual lived Social Representations experienced by disabled people themselves.

This chapter will deal with the following topics. Firstly, the researcher will briefly set out the basic political and sociological status of disabled people in modern day Europe and in historical terms. Secondly, the researcher will explain the justification for this piece of work, both in academic and social terms. Thirdly, the researcher will detail the research hypotheses and some of their potential implications. In addition, the researcher will deal with some of the ethical matters relating to the methodology and the subject sample. Finally, the researcher will give an overview of some of the theoretical frameworks that this thesis will draw upon. It must be said from the outset that this research is essentially based on Moscovici's theory of Social Representations and all other theoretical frameworks are being used within this context. It is the opinion of this researcher that Social Representation Theory spans over many complementary theoretical works and gives a unifying approach to understanding the nature of representations of disabled people. It is important to note that when this research discusses the Social Representations of disabled people it is referring to non-disabled people's representations of disabled people, unless otherwise stated.

# A Brief History of Representations of Disability in Europe

#### Introduction

It is important to put the theory of Social Representations of disability into a historical framework. There is much evidence of a consistent negative representation of impairment and disability, prior to the emergence of

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modern capitalism in the West. These earlier representations run in three main themes: Cultural Understanding, Religious Belief and Pagan Myth. In addition, art and drama used negative images and representations of disability to make social, cultural and political points. Many examples can be found in ancient Greek culture, Judeo-Christian religions, as well as European art and drama well before the Renaissance (Barnes, 1991, 1992; Shearer, 1981 and Thomas 1982). It is widely accepted that ancient Greece laid the basis of what we consider modern Western civilisation. Their achievements in philosophy, science and architecture made a profound impact on the development of Western society. However, one must always remember that the Greek economy and its success were completely founded on slavery and an openly hierarchical and often violent society. The Greeks were famous for asserting the rights and dignity of the individual. However, these citizenship rights were not extended to women, or non-Greeks. At this time ancient Greece was made up of warring city states. This was partly due to the need to maintain a constant number of slaves. The other preoccupation of the Greeks was the fate of the soul after death. This led to the emphasis of the enjoyment of physical pleasure in this world (Cahn, 1990; Russell, 1981). In this context Greek society became obsessed if not paranoid about physical and intellectual fitness. There was little room for any flaw or imperfection. It was common practice for babies with impairments to be killed. For instance, in Sparta, one of the two most important Greek city states, all newborn children were inspected by the city elders and if they were deemed to be 'weakly' or impaired they were taken and left exposed to the elements to die (Tooley, 1983). All Greek men were expected to compete individually and collectively in pursuit of physical, mental and aesthetic perfection. It is clear from this beginning that the Social Representations of disability were negative and of primary importance to the nature of society. This obsession with total beauty was reflected in the

arts and philosophy of Greek culture. All Greek gods and goddesses were seen to be the model on which everyone should base their achievements. It is very important to note that there is only one impaired god. Hephaestes, who was the son of Zeus and Hera. Zeus banished him from heaven. However, Aphrodite the goddess of love takes pity on him and marries him, though she takes a non-disabled lover named Ares because her husband was a 'cripple'. This firmly embedded the representation that impairment means exclusion and impotency.

Another important link that the Greeks made is that impairment is a punishment for sin. For instance, in Sophocles' famous story of Oedipus Rex, who commits incest with his mother and blinds himself as a means of retribution.

Finally Greek architecture, which had enormous influence on building design throughout Europe and America (Riseboro, 1979). This meant many great public buildings were inaccessible with mobility related impairments (Romans conquered Greece they took up many of the cultural aspects of Greek society. The Roman Empire was also based on slavery and was very militaristic. The underpinning values of Roman society were of materialism Davenport, 1995).

When the Romans conquered Greece they took up many great public buildings that were inaccessible with mobility related impairments (Davenport, 1995).

When the and hedonism. The Romans were equally enthusiastic about infanticide of sickly and weak children; for instance, it was 'popular' to drown impaired babies in the river Tiber in Rome. For people with hidden impairments, life was harsh. It is also recorded that people of small stature or 'dwarves' were used to fight women in the coliseum for the amusement of the crowd. The most famous impaired Roman was Claudius, who before he became emperor was physically and verbally abused because of his multiple impairments. However, once he was chosen to be emperor by the imperial guard he became respected for his intellect and wisdom. Claudius was at heart a republican and laid the foundations for the later republic of Rome (Graves, 1934).

Ironically both the Greeks and the Romans made strenuous efforts to develop treatments for acquired impairments that were scientifically based. For instance, Aristotle attempted to study deafness. Galen and Hypocrites tried to cure epilepsy, which they felt was a physical problem and not a metaphysical problem (Thomas, 1982). The Romans introduced many hydro-therapeutic and fitness treatments for acquired impairments, such as arthritis. These treatments were normally only available to the rich and powerful (Albrecht, 1992). From this we are able to see the beginnings of the Medical model of disability. The Social Representations are that disabilities are something to be cured or treated and not accepted within civilised society. This is very much reflected in the art and literature of the time. As this research will show, many of the key concepts and ideas relating to disability and impairment still remain the same. It is also interesting that children with born impairments were systematically removed from society. This reflects some present-day law about termination of impaired foetuses. This is not to undermine a woman's right to choose, which is essential. However, it is worthy of note that impairment is singled out as a special case. It is often the case that potential parents of disabled children are given the most negative prognosis and life scenario. This makes the decision-making process rather biased. From the Focus Group data, it was clear that many parents were told that their child would not be able to achieve an independent lifestyle or have a good quality of life.

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#### **Religious Traditions**

Many of the above issues are manifest in Judeo-Christian beliefs. These religions make up the basis of much of modern Western morals and values. The Jewish culture of the ancient world perceived impairment and disability as being a result of wrong doing or evil and therefore ungodly. This is why any impaired person was excluded from religious rituals (Helveticas, 21:16-20). However, the Jewish faith did not accept infanticide. This became the beginning of charity, whereby it was customary to take care of the 'sick' and 'less fortunate'. This help was offered either by allowing begging or, in more developed societies, through hospitals (Davis, 1989). The reasons behind this new approach to disability were that the Jewish people lived in a mainly pastoral economy and had experience of oppression themselves. Disabled people often made some contribution to that economy and the well-being of the community.

After the fall of Rome, Western Europe entered the Dark Ages, which was a very violent period of history. Not much is known about social responses to impairment during this time, but it is reasonable to assume they were harsh.

By the 13<sup>th</sup> century, there was a considerable level of social and political stability in Europe. In England a market economy was being developed with a mobile labour force. This was the basis of private ownership and profit making. In this context the attitude to dependence and, by implication, impairment, was illustrated by the fact that elderly people were often evicted from their property (Macfarlane, 1979: 141). It must be noted that in 1388 the British crown established the distinguished difference between the deserving and undeserving poor. This was a precursor to the poor law of 1601, which was the first formal state intervention into disabled people's lives. This law placed responsibility on

the church for the deserving poor, many of whom were people with impairments.

In the 17<sup>th</sup> century, people with severe impairments were often admitted to small medieval hospitals. These were usually run by monks or nuns and the approach was ecclesiastical rather than medical (Scull, 1984). Earlier, there had been a theological and philosophical debate about the nature of impairments in terms of the relation to evil and Satan. For instance, in 1487 a book named Malleus Maleficarum stated that children with impairments were born by mothers who were witches. Martin Luther (1485-1546) said that he saw the devil in every disabled child. He recommended killing them (Shearer, 1981). This was very much part of the new protestant ethos. Martin Luther was one of the key writers of the time and distributed his books and ideas throughout Europe. These representations and attitudes were reflected in medieval art and literature. For instance, Shakespeare's Richard III had a deformed body and mind. With the emergence of Social Darwinism and the Eugenics movement, 'science' was used to justify that any physical or mental impairment was a threat to society (Jones, 1986 and Kevles, 1985).

However, these ideas were balanced by the development of Victorian philanthropy, which was rooted in the Christian belief of 'love thy neighbour'. This meant a mushrooming of charities and institutions to take care of the 'sick' and 'infirm' (Barnes, 1991). This Victorian approach underpins the social policy approach to disability up to the end of the First World War. It is clear that the Medical model and the Charity model, which will be discussed in detail later in the text, have long histories and have produced many representations of disability which are still present in modern-day thinking. This research will demonstrate how these remain in modern day forms.

The two world wars necessitated a radical review of social policy toward disabled people because of the many service people who became impaired during these conflicts. Laws relating to employment and care were implemented throughout the mid 20<sup>th</sup> century in relation to the needs of disabled people. Disability became a state matter. Disabled people were subject to regulation and institutionalisation. Disabled people were perceived to be passive recipients of help and of institutional patronage. Most disabled people were not seen to be active members of their community. The development of special education meant that children with disabilities were in effect removed from everyday society. In addition there was a major programme of building huge hospitals in which to put disabled people. For instance, the Putney Hospital for the Incurable, which housed over one thousand disabled people. Most of these disabled people did not need any medical care. It was not until after the Vietnam War that disabled people, led by disabled Vietnam veterans, started to become organised as a political and social group and began to question the political and social policies, which were meant to help them. During the 1970s and 1980s the disability movement grew and became a political force in its own right. By its efforts, in 1995, the Disability Discrimination Act was made law and gave disabled people equal civil rights to non-disabled people in terms of physical access to all buildings, education, employment and all other services. A summary of this law is in Appendix 4.

Disabled people are now in the process of reclaiming their identity and attempting to produce and portray positive images and representations of disabled people. However, in today's society, where bodily perfection is endemic in our culture, the oppression of disabled people is still very apparent. There are new issues to be discussed and explored, such as genetic engineering, selective abortion and the withdrawing of treatments from disabled people. This manifests itself in very explicit terms in the use of 'do not resuscitate' notices on disabled patients (Barnes, 1991; Morris, 1991 and Rogers, 1995). It will become clear from this research that many historical representations of disabled people have been adapted for a more politically correct society. However, it is clear that underlying discomfort and fears held by non-disabled people of disabilities remain. This research will demonstrate that there is a difference between representations held by the general public and those that are portrayed in the print media. These findings will be discussed in detail throughout the following chapters.

### Justification for Research

The marginalisation of people with disabilities has often been addressed in terms of sociological processes or legislative needs, but very rarely in psychological terms within society. The research will investigate the psychological processes by which Social Representations construct a societal supra-structure of assumed knowledge about disability. Despite the introduction of the Disability Discrimination Act in 1995, there are still many strong discriminatory barriers facing disabled people in society. Disabled people continue to be more likely to live in poverty and lie outside the usual economic framework of everyday employment. The fundamental assumption that disabled people need to live on benefit and are in need of care distorts their real value. The research will attempt to discover how the Social Representations of disability act as conduits of knowledge, group roles, identities, and stereotypes.

In terms of social psychology research, there are three key reasons why we should study the Social Representations of disability. First of all, the actual Social Representations of disability have not been explored in psychological terms. Since its conception by Serge Moscovici in the late 1960s, the theory of Social Representations has been used to tackle many important issues such as the Social Representations of mental health, of race, of gender, of parents' perceptions of their children, and of communities. It has even been used to study the Social Representation of food. However, the issue of disability outside of the mental health context has never been approached. This study is a first attempt at dealing with some of the basic issues surrounding the Social Representations of physical disability, both in congenital and acquired conditions. There is no doubt that many different Social Representations of physical, sensory or learning disability exist within society. But to date the research on attitudes towards disability has always been of a functional nature, such as the attitudes of non-disabled people towards people in wheelchairs in an employment interview situation. There has not been any research that has determined why non-disabled people have particular attitudes regarding disability, or what knowledge base and psychological associations are involved in the formation of these attitudes.

### **Research Questions**

The central aim of this doctoral study is to identify whether or not there is a set of core Social Representations relating to disability within society. The researcher will use examples of physical, sensory and learning disabilities. This will enable me to explore a range of disabilities in relation to their Social Representations. The researcher is not concerned whether these Social Representations reflect the life experience of disabled people but only that they actually exist and how they may arise. It is the contention of the researcher that these Social Representations are directly related to different knowledge bases such as the occupation of the subject, direct or indirect experience of impairment and exposure to media coverage of disability. In terms of occupational knowledge, the current view that people's understanding of disability can be categorised as being within the Medical, Charity or Social models of disability is too simplistic. No one has looked at the psychological aspects of how nondisabled and disabled people perceive and represent disability in everyday life. This study aims to identify distinct Social Representations of disability which reflect different people's perceptions of the experience of disability. It is not clear whether these Social Representations are separate in themselves or are part of a multifaceted overall representation of disability. This study aims to map out a typology of Social Representation relating to physical, sensory and learning disability. This study aims to be the first step in highlighting how disability is represented in society within the general population and within the print media. This study is designed not to be a systematic analysis of the Social Representations circulating within society today, but more of an indicative, exploratory and discursive study into some of the key Social Representations of disability and psychological themes which are related to disabled people. The researcher will use the study findings to suggest more detailed hypotheses which will need systematic and mass research techniques. This study will, however, attempt to indicate some trends in terms of different occupational groups, gender, disability type, age and whether or not there is a difference in the Social Representation of born disabled people compared to people who acquire disability.

This work will examine issues relating to 'Otherness', 'ugliness' and 'comfort zones'. It will consider whether the ability to use language by disabled people in a socially acceptable manner and the physical appearance of disabled people, influence the construction of particular Social Representations of disability. It will also address the importance of fear of disability.

For the purpose of this study, 'born disabled' or 'born disability' means that the physical impairment was present from birth or from early childhood. 'Acquired disabled' or 'acquired disability' means that the impairment was a result of an accident, illness or condition that happened later in life but not as a young child. This is because children who acquire disabilities early in life experience the particular negative circumstances, such as distinctive physical characteristics and segregated education, which relate to congenital disabilities and may generate distinct Social Representations.

The primary hypothesis that the Social Representations of born and acquired disabled people will differ, stems from the actual experience of disabled people. It has been documented by The Royal Association on Disability and Rehabilitation (1989) and the King's Fund Centre (1992) that born disabled people are seven times more likely to be admitted to residential care than people with acquired disabilities. Therefore one must ask the question why society treats two similar groups in terms of their functional impairments so differently.

It is important here to consider whether born disabled people can be said to have the same sorts of functional impairments, life experience and lifestyle expectations as people with acquired disabilities. Both born and acquired disabled people experience problems with transport, access to buildings, manual dexterity, personal care and so forth. Their functional impairments are not dissimilar. However, among born disabled people there is a higher incidence of learning disability than for people with acquired disabilities. This makes it much more likely for institutional Social Representations to be applied to all born disabled people in terms of care, education and employment. In contrast, people with acquired disabilities were 'normal' at some point in their lives, and therefore society could be expected to think that they warrant a lifestyle as ordinary as possible. Becoming disabled is seen in terms of trauma, accident or fate, whereas being born disabled is often seen in terms of abnormality. This is quite a different platform from which to be seen and treated by society. Therefore, their own experience and the attitudes of society towards them mould the life expectations of each group. Non-disabled people can perhaps more easily identify with acquired disabled people, as they were 'normal' previously. In contrast, born disability is almost an alien experience. In this context I introduce some statistics relating to disability in the UK.

There are an estimated 8.4 million disabled people in the United Kingdom, which represents 16% of the population (Disability Rights) Commission, 2001). Only about 15% of born-disabled children attend mainstream education, compared to 97% of children who acquire their disabilities after entering school. It is clear that there is a societal distinction between the way born-disabled people and people with The difference in these Social acquired disabilities are seen. Representations may in part be based on a particular lack of interactive experience with born-disabled people. People who go to school with or work with people who become disabled have a different understanding of that person. Therefore if they encounter other people with acquired disabilities, they have a common frame of reference through which to draw their knowledge and form Social Representations. As born-disabled people are generally segregated from the mainstream throughout their lives, the ability of individuals to form accurate perceptions, opinions and Social Representations of them becomes restricted. This in turn leads to an institutionalised and false construction, i.e. that born-disabled people are somehow intrinsically different from acquired disabled people, and that disabled people per se are intrinsically different from the norm. It is the aim of this study to isolate some of the key attributions that are used to make this false distinction.

The second hypothesis of this study, that medical professionals and charity workers will have distinct Social Representations of disability, is given a methodological precedent in the empirical research undertaken by D'Alessio (1990). She identified different Social Representations of the same child held by the mother, a health professional, and a teacher. This study will attempt to use this same methodology in the context of disability. In the researcher's MPhil thesis, the researcher was able to indicate that different occupational groups may have different Social Representations of disability. In this study, the researcher wants to confirm those initial findings and define more clearly the different Social Representations. The common experience of disabled people, expressed through many personal and academic writings, pinpoint noticeable differences in the approach taken to disabled people from charity workers and medical professionals, as opposed to from the general public. It is the researcher's aim to identify what attributions may be active in these professionals' construction of Social Representations of disability. For instance, the use of rehabilitation for born disabled people is generally a means of teaching them everyday life skills, whereas the rehabilitation of acquired disabled people is aimed at returning them back into the Simon community as useful employees. Brisenden (1986), by interviewing different types of disabled people, discovered that medical and charity professionals treat born disabled people differently from those with acquired disabilities. This difference was based on the assumption that people who became disabled were essentially still 'normal' and therefore merited treatment that the professionals themselves would expect. Born disabled people were more likely to be the object of experimental techniques, which often did not help them or made their impairment more serious. There was an implication that doctors felt that if a patient was always impaired anyway, the risk of impairing them further was acceptable in case the new technique worked. Brisenden found that

medical professionals were totally focused on problem-solving in terms of functional or sensory impairments, rather than considering the impairments in a social context and thinking of non-invasive treatments or solutions. Medical professionals appeared to be trained to see bodily dysfunction as being undesirable, and therefore invasive measures such as operations were warranted. In the view of many disabled people, changing their body image does not change the social discrimination that they face. Finkelstein (1993) describes this phenomenon as 'body fascism'. I hope that this study will throw some light on what specific factors of disablement charity workers and medical professionals focus on in the construction of their Social Representations of disability.

### **Ethical Considerations**

This study was approved by the University of Cambridge Ethical Committee and followed the British Psychological Society guidelines on ethical use of human subjects. Due to the nature of the research it was necessary to develop a rigorous debriefing protocol, which is in Chapter 2. This allowed all subjects to withdraw their material and participation once they had been debriefed. However, no participants withdrew.

### **Overview of Theoretical Frameworks**

### **Social Representation Theory and Disability**

As has been discussed there are three major explanations within psychosociological study to understand how non-disabled people respond to and perceive disabled people, i.e. the Medical model, the Charity model and the Social model. In this section, I will detail the reasons why Social Representations theory enables this research to create an innovative way of understanding the perceptions of disabilities and their consequences. All the previous models of disability have been based on either the functional impact of any one impairment and the relationship between the person with the impairment and society, or at the other extreme only the social impact of any one impairment and its consequent relationship between the disabled person and society.

One must note that when the research refers to society, it means both non-disabled people and disabled people. This is an important point to make, because there are differing perceptions of different impairments within the disabled community. In this case the research will exclude people with mental health problems because they have a particular standing within society. The theory of Social Representations presents the opportunity to take a more dialectical and materialist approach to the underlying psychological reasons for people's perceptions of disabled people. The theory of Social Representations provides three important principles, in relation to disability research. First of all, Social Representations are based on the concept of knowledge, both in terms of facts and of hearsay. These are not the same. One is a material fact based on evidence; the other is based on assumption and myth. Social Representation theory is important in analysing knowledge, because by using suitable methodology and analysis in this research, the two types of knowledge can be distinguished. It is important also to mention the role of personal experience in terms of the knowledge of disability. This is not common knowledge; it is experiential knowledge. Therefore it is in some way a form of reifying. Disability has always been explained and understood in a psychological context in terms of difference and prejudice. Social Representation theory does not make a judgement on people's perceptions, but examines the underlying emotions and

psychological constructs that non-disabled people have about disabled people.

This leads me to the second reason for using Social Representation Theory, which is the emphasis on the role of communication in the development of Social Representations. This is particularly important when it comes to disability, because much of the information relating to disability is of a negative nature. This was well illustrated by Markova and Farr (1994), when they undertook work on professional and lay representations of health, illness and handicap. It is clear from the print media survey carried out as part of this thesis that newspapers generate and use different Social Representations from those elicited from the storyboards. This supports much work that suggests (Shakespeare, 1997, and Livingstone, 1990) that print media do not influence public opinion as much as people thought. It appears that print media may shape and debate issues, but it cannot directly change people's opinions. This was particularly important during this study, because of the ethics relating to disabled people having a right to die. It is the opinion of this researcher that until the debate relating to disabled people's right to live is completely resolved, the debate on the right to die is redundant. Communication of knowledge takes many forms, such as conversation, reading, films, television and experience. In terms of disability, there seems a disproportionate negative portrayal of impairment in all media (Shakespeare 1997, Darke 1997). If this were true it would directly influence the types of Social Representations of disability that some people may hold. However, it is clear that this is probably a minor influence. It is the opinion of the researcher that there are fundamental psychological fears relating to impairments. This may be linked to the cultural needs to be independent and able to live without help. The material fact is that no one is independent of help. Communication and culture are intimately linked and through history have projected differing

perspectives of disability, such as disability being linked to evil or, under the Nazis, the need to exterminate disabilities in order to achieve 'the pure race'. This is brutally highlighted in Hitler's *Mein Kampf* (1942) where throughout it implies, 'The lame and insane are a scourge on humanity'.

Moscovici (1976) offers a brilliant and simple analysis of the media in terms of propaganda, propagation and diffusion. This will be discussed in detail later. The interaction between the individual and their society is key in the context of development of Social Representations in any sphere. In disability terms, fears and fantasies play an important part as will be discussed later. For instance, in literature many of the most famous 'bad, mad and sad' characters are people with impairments, such as Captain Hook in Peter Pan or Quasimodo in The Hunch Back of Notre Dame. Therefore from a cultural point of view negative images are constantly reaffirmed. This is particularly important when they are represented in the context of significant cultural items such as classical books. In this study the print media survey has thrown up Social Representations of disability that do not appear to have importance to individuals in the storyboard study. However, they do form a backdrop to the cultural understanding of disability and its consequences. In this way the cultural landscape relating to disability is mapped out for the individual to take his or her own path.

The final component of Social Representation Theory that is unique in helping to understand disability is its underlying and constant acceptance of change. Social Representations in any context are not static. They are dynamic, dialectical and developing concepts, ideas and images. This is very important in disability terms because as society changes, its Social Representations of disability change with it. Social Representations are in effect part of human social evolution. This is important when studying people's perceptions of disability because it allows an examination of how new knowledge and new means of communication affect the Social Representations of disability at any moment in time. This can be illustrated by a comparison to the Victorian era, when disabled people were put into workhouses because they were seen to be in need of care; whereas today, in Britain, we have laws to protect disabled people's civil rights. The consequent Social Representations still have a common theme, but are set in a different cultural and political context.

The basic notion of society and culture discussed in the writings of Durkheim and Wundt needs to be updated in the light of modern communication technology. Print media and literacy have become an essential means of distributing new representations. Moscovici (1984) discussed the seminal distinction between the social and the collective and suggested that these were the same phenomena, but seen from different perspectives. This is very important in terms of disability research because it identifies not only the individual as an active participant in generating and communicating representations, but also recognises that inter-group communication is central to the development of Social Representations. In disability terms, this idea of the social/collective may refer to scientific discussion between medical professionals institutional discussion or between social care professionals.

The role of language is central to both communication and representation. It is worth noting that the work of Billig (1987) takes the route of a more rhetorical approach to the concept of Social Representations. It must be pointed out that in this era, television has an important part in expressing representations. Livingstone (1990) in her book, *Making Sense of Television*, makes a crucial point that the viewer is an active interpreter of what they are watching. Livingstone says that the audience develops a proto-relationship with the characters. For this research, this has immense implications. Firstly, there are very few representations of disabled people on television that are not related

directly to their impairment. In other words, there are no incidental characters. Therefore television depicts а narrow range of representations of disability. Secondly, Livingstone's work highlights that people interpret images by means of identification and empathy, or in terms of anger and disgust. This is important in the analysis of the storyboard stories, because the participants are being forced to interpret the scenario in which there are disabled and non-disabled characters. They are in effect having a proto-relationship with the characters. The influence of print media on the Social Representations of disabled people is somewhat uncertain. However, the work of Farr (1994) on representations of disabled people in advertisements by charities, gives an insight into how important such images and words are in transmitting messages about disability. Farr makes some very good points, such as most often disabled people are referred to in the third person plural, or are portrayed as someone who is at present dependent, doesn't need to be, but needs money to enable them. However, Farr's work is flawed by its own language and presentation. Farr talks about 'the handicapped' and his use of emotive language, such as 'deeply perplexing' indicates an incomplete understanding of how disabled people perceive themselves. However, Farr's work offers a good foundation for the analysis of print media in this research. Farr concluded that in charity advertisements, disabled people were portrayed as disadvantaged, alienated and separate from society. The aim of the advertisements he studied was to change the Social Representations of disabled people, but in fact they often reinforce the negative Social Representations in order to maximise the impact and to raise more money. From the work of the Focus Groups, it has been found that disabled people feel that this is still the case, not only in advertisements, but also in print media.

In the light of Livingstone's work (1990) it becomes clear that Moscovici's theory of Social Representations is an essential tool to uncovering non-disabled people's unconscious representation of disability. Markova and Farr (1994) consider that the mass media attempts to generate collective representation of disabilities, but not social ones. However, no one has dealt with the issue of whether this is a thinking process or a feeling process. It is an assertion of this research that Social Representations of disabled people occur both within individuals and within groups. This is primarily a feeling process, rather than a thinking process. This is because there are many irrational fears and myths relating to disability that are not based on fact, evidence or experience. This links very neatly to the Freudian analysis of irrational fears, which Moscovici (1976, 1981, 1982) and Jodelet (1983) refer to in their work on mental health patients and minority groups. Work by Eavers, Ellis, Jones and Miller (1990) on disability related advertising has shown that these images and words have a measurable effect. However, in this work it was not clear if it was a conscious thinking process to formulate an opinion or an unconscious reaction to a feeling which may have been part of the participants' present Social Representations, or part of their cultural understanding of disability. It is the aim of this research to begin to examine the psychological reasons behind non-disabled people's approach to disability and to demonstrate that Social Representations of disability are different within occupational groups.

#### Theory of Social Representations

The purpose of this section is to discuss the conceptual frameworks and theoretical ideas from Social Representation Theory (Moscovici, 1976, 1984, 1993, 1994 and 2002) as applied to perceptions and representations of people with physical, sensory or learning impairments. In addition this section will touch on the relevance of Social Identity Theory (Tajfel, 1972, 1978, 1981, 1982, 1984; Forgas, 1981; Turner,

1984; Turner, 1987), the theory of Widespread Beliefs (Fraser and Gaskill, 1990), as well as other works on stigma and stereotypes. This section will also address itself to the interdisciplinary works by Gilman (Gilman, 1985, 1988) on the concept of otherness. Finally this section will briefly examine the contribution of aesthetics (Adorno, 1970; Croce, 1913) to Social Representations of disabled people.

Moscovici developed the concept of Social Representations based on Durkheim's notion of collective representation. Moscovici (1981: 181) states that:

By Social Representations, we mean a set of concepts, statements and explanations originating in daily life in the course of interindividual communications. They are the equivalent, in our society, of the myths and belief systems in traditional societies; they might even be said to be the contemporary version of common sense.

The primary role of Social Representations is to enable individuals within different communities and differing groups within society to make familiar the unfamiliar (Moscovici 1981). The process by which this is possible is driven by the communication of knowledge. Moscovici and others (Moscovici 1988, Duveen and Lloyd 1990) have highlighted the important role that communication has in the development of any Social Representation. The processes of communication can be divided up into three types of transformation. First, sociogenesis; the means whereby Social Representations are produced by social groups about particular objects. Moscovici (1976) illustrated this point in his work on the dissemination of scientific knowledge by using the example of how psychoanalysis was understood and represented by different social groups. It is important to remember that sociogenesis is not static. It is dialectical in nature, because at any one time one Social Representation will be influenced and reconstructed in the context of past and present knowledge, and of other relevant Social Representations. The second type of transformation is ontogenesis, the acquisition and acceptance by individuals of Social Representations held by their social groups. This process occurs throughout an individual's life. It assumes that we are all born into what Moscovici calls a 'thinking environment' (cited in Duveen and Lloyd 1990:7) Duveen and Lloyd (1986) suggest that ontogenesis is the process through which individuals reinterpret their learnt Social Representations in order to create their own social identities. We will see later in this paper that ontogenesis has been a powerful tool for the disability movement in terms of reconstructing the images and language relating to disabled people. The third type of transformation, microgenesis, is the component of Social Representation which involves the social interaction between members of social groups, during which they will discuss any issues such as potential conflicts, controversies and everyday talk. It can be said that social identities are mediated by these social interactions, and the resulting social identities are functions of the Social Representations of that time.

The development of Social Representations depends upon two interrelated functions of social groups. First, anchoring is whereby social groups and individuals assimilate the unfamiliar or unknown into their familiar and known realm of experience. This is done by classifying and labelling objects or ideas. This is beautifully illustrated by the work of Jodelet (1983), in which she studies a village in France in which there are patients from a local mental asylum housed within the local community. The villagers assimilated these patients as being members of a category such as half-wits, tramps and mental defectives, despite the actual characteristics of the patients themselves. The mere fact that the object or idea is classified within the bounds of their acceptable knowledge makes it possible for that object or idea to be discussed and thoughts communicated about it. By this very communication, the Social Representation can be reconstructed and reinterpreted. Moscovici (1981) states that this anchoring process cannot be a neutral process. It is inherently a judgmental process. Second, objectification is when an individual or social group transforms an abstract notion into a concrete one. Language and memory are the essential tools by which individuals objectify abstract thoughts. As Moscovici (1981) points out, by comparing God to a father, people automatically transpose the abstract invisible

concept into something that we all have an image of, with all the corresponding feelings. Anchoring and objectification provides meaning where meaning was absent. Moscovici (1988) elaborated three types of Social Representations. Hegemonic representations are those which are held common in a well-organised community such as a city, country or political party. These representations are generally not produced by the groups members themselves. These representations are consistent and unite the group. Emancipated representations are outflows of knowledge and ideas belonging to sub-groups that are, in some degree, in contact. These new representations are versions of existing representations. For instance, representations about mental illness (Jodelet 1983, Herzlich 1973) are within this category. The experience and knowledge of doctors, psychiatric professionals and lay people are brought together with the populus at large. Finally, there are polemical representations which are generated as a result of controversy and conflict, and may be seen as a minority viewpoint within society.

In historical terms Social Representation Theory stemmed from the work of Durkheim on 'collective representations'. Durkheim was interested in the consensual process of individuals whereby they understood group and intergroup relations. This 'social' approach to society and its underlying psychological processes was overtaken by the North American individualist psychology of attitudes, belief systems and opinions. This work was epitomized by Allport (1935, 1937, 1954). This work gave birth to the behaviourist school of psychology, by BF Skinner (1972, 1974). Some American psychologists, such as McGuire (1986)

and Gergen (1971), argued for a more social type of psychology. Moscovici, along with Tajfel began to develop a more social conception of social psychology. The birth of Social Representation Theory can be seen in Moscovici's book entitled *La Psychanalyse, son image, son public* (1976) and was further developed in his later works. I will now detail some of the key concepts of his theory and how they are applied to this study.

First of all it is important to define Social Representations. Moscovici states that Social Representations are:

system(s) of values, ideas and practices with a twofold function; first, to establish an order which will enable individuals to orient themselves in their material and social world and to master it; and secondly to enable communication to take place among the members of a community by providing them with a code for social exchange and a code for naming and classifying unambiguously the various aspects of their world and their individual and group history. (Moscovici, 1973: 13)

In simple terms, Social Representations are about the psychological processes involved in making the unfamiliar familiar. These processes are based on knowledge, communication and action. This study will examine how non-disabled and disabled people's knowledge, communication and behaviour relate to their Social Representations of disabled people. Moscovici also uses the term Social Representations to mean the mechanisms by which Social Representations are formed and changed. As Duveen and Lloyd state, the mechanisms could be termed as 'social representing'. They define this as follows:

If the English language were more flexible one could refer to this process as social representing, but to avoid such solecisms we shall use the singular form without an article to refer to social representation as process, and the singular with an article or the plural to refer to a social representation or Social Representations as structures. (Duveen and Lloyd, 1990: 2)

The two primary pillars of Social Representation Theory are anchoring and objectification. Anchoring is the process whereby people understand and accept unfamiliar or strange experiences or information into their familiar categories, which are part of their everyday life and cognition. Objectification is the means whereby abstract concepts and ideas are transformed into concrete knowledge and perceptions. These two functions of Social Representations are independent. However it would be impossible for a representation to be objectified unless it was first anchored, though it is possible to analyze both separately. It is important to note that Moscovici makes a distinction between common sense knowledge and reified knowledge.

Moscovici's distinction between common knowledge and scientific knowledge is very important within the context of this study. Throughout history disability and disabled people have been categorised as specialised knowledge or scientific knowledge. Therefore disability is reified. A prime example of this would be the life of John Merrick (The Elephant Man) and his doctor at the Royal London Hospital during the late 19<sup>th</sup> century. A more recent example would be the conjoined twins from Iran who were separated by a team of surgeons in Singapore in July 2003. The central point being made by this distinction is that scientific knowledge is seen to be different from everyday common understanding. Therefore if something is seen to be scientific, such as disability, this knowledge takes on a reified form and is therefore in the realm of experts. As Moscovici (1981: 187) explains, science

attempts to construct a map of the forces, objects and events unaffected by our desires and consciousness. [Social stimulates Representation] collective and shapes our consciousness, explaining things and events so as to be accessible to each of us and relevant to our immediate concerns.

This enables society to operate common sense knowledge in tandem with scientific knowledge. This allows social psychology to determine the underlying psychological processes of how Social Representations are developed and communicated. It must be noted that all Social Representations must be of something, of someone or of a collection. Social Representations are the means by which individuals or groups construct an understanding of objects or concepts that are in their social life (Duveen and Lloyd 1990; Moscovici, 1976). In terms of disabilities, Social Representation Theory allows us to study the development and transfer of knowledge between individuals and groups. If one accepts that disabled people are an identifiable group in society it is possible to analyse their social relationships with other groups in terms of Social Representations. The process by which Social Representations are generalised is known as sociogenesis (Moscovici, 1976). Sociogenesis takes place over time. Therefore it is a dynamic concept and must be seen in a historical context. Sociogenesis is always a dialectical and material process. Ontogensis is the process whereby children, adults and groups access Social Representations that are held by their peer groups or other relevant social groups. Microgenesis is the process where individuals discuss, meet, talk and resolve conflicts. This communication develops social identities of individuals and of groups. However these social identities may change within different social interactions and allow different Social Representations to be constructed within and between groups. Communication is a central plank to the development of any Social Representation. Moscovici says in the introduction to Herzlich's (1973) study of health and illness that a representation

enable(s) communication to take place between the members of a community by providing them with a code for social exchange and a code for naming and classifying unambiguously the various aspects of their world and their individual and group history (Moscovici, 1973)

and

The points of views of individuals and groups are then seen as much from the point of view of communication as from that of expression... In reality an individual or community communicate their ways of seeing things to their interrogator.

Moscovici (1993) reaffirmed the importance of communication and explicitly aligned himself with Wittgenstein. He argues that Social Representations must go beyond the semantic level and take into consideration their pragmatic, representational and social contexts. This is particularly important in terms of disability, where the language used relating to disability is highly contextualised. For instance, an article discussing 'a new cure' for a particular disability will be highly medicalised. Moscovici's concept of communication may be compared to some sociolinguistic work such as that by Bell (1976). The underlying emphasis of Moscovici's works on communication is that there is a 'collective' memory of images and words embedded in language that relate to individual or group beliefs, ideas and emotions. Moscovici asserts that 'Tradition exerts a force against which our mind and conscience is powerless' (Moscovici 1984: 950). This makes it clear that when people do communicate they are not free from their individual and collective histories. Representations offer a 'world of meaning' by which actions and thoughts become understandable.

Social Representations can be categorised into three types; hegemonic, emancipated and polemic. Hegemonic Social Representations are those Social Representations that are consensually held by any one group or groups. These Social Representations are the most prevalent with any one group or groups. Hegemonic Social Representations often have a role in the development of group and intergroup social identities. For instance, most non-disabled people do not identify themselves with becoming disabled because they have a hegemonic belief that disabled people have a lower status within society. This leads to other Social Representations about disability that support this primary representation. Emancipated Social Representations can be thought of as being 'specialised expert' Social Representations of objects and people within the context of any group or groups. They supplement

the hegemonic Social Representations by offering a more detailed analysis of the subject. For instance, in terms of disability, social workers who have been trained to work with disabled people may present differing arguments about the status of disabled people and the consequences of becoming disabled. Emancipated Social Representations do not directly challenge the hegemonic views of the group or individual, but attempt to adapt the hegemonic view by knowledge and communication. Polemic Social Representations usually arise from outside the group or groups involved and are a direct challenge to the hegemonic and emancipated views held. The groups being represented in the hegemonic and the emancipated Social Representations very often promote polemic Social Representations. For instance, the disabled people's movement has challenged many of the stereotypes, ideas and myths relating to disability. They put forward a social model of understanding disability that is a polemic Social Representation, stating that disabled people's status within society is a function of how society operates rather than a function of their individual impairments. From this research it has become clear that the hegemonic Social Representation can be seen to be the Charity or tragedy model of disability and that the Medical model is the emancipated Social Representations of disability. In order to understand this more fully different models will be discussed in detail in the next section.

In terms of this study the unfamiliar is seen to be physical, sensory or learning impairment, i.e. disability. Anchoring and objectification allows the strange and disturbing nature and perceptions of impairment to become benign and explained. The process of categorisation is an important mechanism to enable a group or groups to accept things which are associated with evil, abnormality and 'the other'. Moscovici conceptualised the process of anchoring in terms of 'canonic themes' at the level of symbolic and metaphysical life. There is an issue relating to the levels of unfamiliarity within a group or groups which may make this process uneven. The level of experience of group members in terms of meeting and living with disabled people will affect the overall Social Representations of disability held by individuals and group members. Unfortunately in this study it was not possible to ask subjects about their experience of disability without undermining other aspects of the research. Moscovici writes, 'The mentally handicapped, or people belonging to other cultures, because they are like us and not like us; so we say they are "uncultured", "barbarian", "irrational" and so on.' (1984: 25).

One question that needs to be asked in all of this work is whether or not labelling the unfamiliar makes it familiar or does it only maintain its 'otherness'? These options are not mutually exclusive. It may be that by labelling, the unfamiliar is made understandable, but remains in a category which is feared, but safe in that it remains 'the other'. This position is partly supported by Tajfel's analysis of racism (1981, 1984; Turner, 1984) and the work of Brown (1996) on prejudice. Markova and Wilkie (1987) studied the Social Representation of people with AIDS and they found that they were linked to Social Representations of plague, leprosy and war. Moscovici (1984) postulated that ambiguity may be an important process in the anchoring of Social Representations. However, he later amended his view in terms of its significance. Ambiguity may be seen as a disruptive state of affairs in the development of Social Representations. The role of ambiguity is an interesting one. If we see a person staggering down the road do we think that this man has cerebral palsy and mobility problems or is he drunk? Is he ill? Is he an eccentric? This mixture of ambiguity and fear of the unknown makes representation difficult. It is likely that fear is an important component in terms of categorisation.

Another important aspect of Social Representations is the recent work on the core and periphery of representations. Abric (1984) argues that Social Representations consist in a homogenous, stable, rigid, consensual 'core' and a flexible, individual 'periphery'. This view is not universally held. It can instead be argued that people form Social Representations in many different ways and many will not have a stable core nor a periphery. However, Wagner (1995) has found evidence for a stable core by using empirical techniques of multi-dimensional scaling. In this study it will become clear that there are core Social Representations of disability and also periphery representations. This finding develops the work of De Rosa (1987) on madness where she found core representations of madness within her subjects. De Rosa used a drawing exercise, which is not dissimilar to the method this study employs, that of using storyboards to generate images and representations. However, when she administered a semantic deferential scale the representations became less distinctive. De Rosa writes:

Images, even at the level of pure perception, are an essential vehicle for the study of Social Representations, especially when utilised to project externally latent symbolic structures (often refractory to verbal expression) in a more articulated system of representations. (1987: 56)

This is an important point in terms of this study as this research uses both narrative and images to elicit Social Representations. De Rosa has always put forward the importance of a multi-method approach to Social Representations in order to capture a complete picture of any one Social Representation. This is why this study has used three different methodologies: storyboards, an analysis of the newspaper print media and the Focus Groups of disabled people, which will be discussed in detail in the Methodology section. De Rosa asked subjects to draw images of a 'mad-man'. Firstly she asked subjects to draw a picture; second, a picture of a madman; and third, the subject him- or herself as a mad-man. This study in contrast uses readymade images in order to elicit narrative about the Social Representations of disability, but De Rosa's work helped to frame the methodology, particularly in the storyboard techniques.

The way Social Representations are communicated between and within groups is an important aspect of this work. One of the key means of communicating information and knowledge in modern society has been the use of newspapers and other media. It is important to understand the nature of communication as a supra-individual process in terms of print media. It is a misplaced conception that print media is able to be analyzed in terms of an isolated individual. It is also misleading to analyze print media in terms of conversation or dialogue, as was suggested by Potter and Wetherell (1987). This assumes that there is an ongoing dialogue between the writer and the reader. Billig's (1987) concept of dilemmatic thinking has equally many problems when it comes to print media. Conversation is not a suitable model to explain the relationship between the reader and the writer. It is the very nature of print media to tell a story interspersed with facts or alleged facts. This offers the reader a false sense of security and common knowledge. This is particularly important when it comes to topics such as disability which may not be in the everyday experience of the readers. It is very interesting that even Discourse analysis has not completely addressed the concept of objectification. Social Representation Theory allows us to analyze the underlying ideas which may be presented in an article. It is important to note that this study has used two forms of storytelling; the storyboards are by non-professional writers and are fictional and the newspaper articles are by professionals and are meant to be factual. However, what we will find throughout this study is a commonality and stability of representations and themes relating to disability.

Moscovici, in his book La Psychanalyse, son image et son public (1976), puts forward three fundamental types of media reportage; diffusion, propaganda and propagation. It is important at this point to examine these concepts. Diffusion in this context needs to be distinguished from the normal use of the term. In this context diffusion means a form of communication that does not or may not relate to a very well defined group, but may be related to what we often term 'the masses'. This is important for this study because this research aims to identify what Social Representations of disabled people are held by 'the masses'. In this study 'the masses' are represented by ordinary people using the storyboard technique. However it would be possible to argue that all the subjects in this study are part of the masses. The main aspects of diffusion are that its style is concrete, rapid and attractive. Many of the articles within this type have a short title which may be amusing or thought-provoking, but the article is short, correct and engaging. Moscovici explains the importance of the unseen relationship between the transmitter and the receiver, i.e. the writer and the reader. These types of articles allow the reader some discretion in the application and interpretation of the facts and opinions within the article. This allows the reader to adapt the information received in the context of their existing knowledge. These articles do not have well defined intentions and do not direct themselves towards one conclusion. This allows the reader to have a margin of decision in what they absorb from the piece. In many ways the writer aims or tends to become an expression of the reader. Therefore this is a dialectical process which is dependent on the knowledge basis of both parties. It is clear that the newspaper is acting as a mediator between common knowledge and new knowledge. Diffusion is not a direct means of communication, but rather a means of percolating ideas and facts through the masses. The writer (or transmitter), i.e. the newspaper, is not actively taking a point of view, but presenting a range of perspectives for the reader to act upon. As we will see later, this is very apparent in some of the sample articles. One important thing to notice is that most of the articles within this type are from broadsheets. This is not what one might expect given the format, which might be more associated with tabloids. It may be thought that the broadsheets have a more subtle approach to complex social issues such as the rights and wrongs of allowing disabled people to have the right to die with dignity. These articles tend to be longer than one might expect in this type, although this may be a function of the complex moral and ethical issues which are being discussed. However these articles do conform to the main principle of diffusion.

The role of propaganda is two-fold; First, to regulate the ideas, knowledge and understanding within any one group or between groups; second, to underpin and reaffirm all core belief systems within and between groups. The key function of propaganda is to eliminate conflict relating to activities or ideas within the group and sometimes between groups. The organizing role of propaganda is often undertaken by the media as the means of communication, in order to resolve contradictions within the group. For instance, in the case of the conjoined twins from Iran (Bijanani twins) the newspapers promoted the benefits of separate lives as opposed to the extremely high risk of death to both women. This allowed non disabled people to feel more at ease with the proposed action of the doctors. What the newspapers did not report until after both the twins died was that the doctors were not happy about the procedure. Simply, when propaganda is used it can be seen in 'black' or 'white' terms. This is because the 'other' is 'black' or 'white', depending on your standpoint. Propaganda is an important form of communication because it is a uniting force in a group's social field and is responsible for the consequent actions which are taken based on information provided. Propaganda aims to unite a group around a Social Representation which

reaffirms and highlights the group's social identity. In many ways this representation takes on a real concrete character whereby this representation becomes an integral part of the group identity. In this study we will understand propaganda as a manipulation of the group and its consequent expression. The primary role of propaganda is to manoeuvre ideas and thoughts of any group in order to produce a particular set of actions or representations.

Propagation is a form of communication that aims to generate norms within groups. These norms are based on already well recognised doctrines or group beliefs. The focus of propagation is not to generate new ways of thinking or reinforce existing thinking. It is about enabling individuals within the group to have additional rationales so they can adhere to already held beliefs. This form of communication is essentially highlighting the significance and importance of the group's Social Representations of objects or other groups. Moscovici spoke about propagation in the context of the Catholic press and psychoanalysis. In this study propagation can be seen in terms of particular groups such as those people who are of the opinion that disabled people should have a right to have assisted suicides. These points are communicated via interviews within certain newspapers. Unlike Moscovici's work this study did not obtain data from a recognised section of the press. However, it is clear from this print media analysis that important pressure groups and minority groups use mainstream media to get their message across. This might be termed secondary or indirect propagation. Propagation uses very structured and explicit messages to transmit ideas about Social Representations within a well-defined reference framework. The sender is completely familiar with the receiver's social field. The main features of propagation can be summarised as follows: its scope of action is relatively limited; its aim is to integrate a social object such as disability into an existing framework; finally, it aims to make the most prominent

Social Representation acceptable to all of the group. One important aspect of this form of communication is that it is not designed to generate schisms within groups. Contradictions are managed by propagation. Propagation is founded on the group's respect for authority. Individuals within a group retain a level of autonomy. However, the communication process is one that is framed or conceptualised in terms of the group's authority. This is quite an interesting point in the context of this study, whereby disabilities are sometimes seen and represented in very particular ways. For instance, in some religious cults, disability is represented as being a result of the sins of the parents or in Buddhism, a blessing from the Buddha.

The concept of 'the other' is central to both the theory of Social Representations and to Disability Social Theory. Gilman (1985) stated:

Everyone creates stereotypes. We cannot function in the world without them. They buffer us against our most urgent fears by extending them, making it possible to act as though their source were beyond our control.

Gilman was not a social psychologist. He was an art historian with a leaning towards a psychoanalytic perspective on art. Otherness has been used in many contexts, for instance in Simone de Beauvoir's 1953 *The Second Sex* or Edward Said's work *Orientalism* (1978). It is clear that the context of 'the other' can be applied to a range of groups or discourses that occupy a position outside the accepted norm. Gilman considers that the nature of stereotypes is always bi-polar. In simple terms, good or bad. De Rosa (1987) supports this argument. Stereotypes are seen to be inner perceptions of the world particularly when 'the self' is under attack or may be undermined. 'Bad objects' will trigger a response within the individual in accordance with group beliefs. This response is about a need to retain control and understanding of the world in which s/he lives. The group uses the concept of 'the other' to protect and maintain its own social identity and Social Representations act as real time buffers whenever the

group encounters an object or an event that is unfamiliar. Disabled people may be seen in this context to be a 'bad object'.

Stereotypes are used to help order perceptions of the world; this order is used to maintain group values. One of the main components of any stereotype is the fear of difference; therefore in most cases stereotypes are representations that induce anxiety, apprehensions and avoidance of the unfamiliar object. This was demonstrated by the work of Jodelet (1983) whereby she examined the Social Representations of madness among a small community in France where former psychiatric patients were lodged in people's homes. This work demonstrated that people use stereotypes in order to understand other people's behaviour and actions, who were labelled different. In Jodelet's work people often attributed characterisations to their lodgers on the basis of their mental health, rather than an individual characteristic or a common everyday action, for instance a lodger who was meticulous at washing up plates and saucers was seen to be obsessional rather than very hygienic. 'The other' is one embodiment of the 'out-group'. The fear of the other may be seen as a fear of the breakdown of the representational process, because it highlights the divide between self and other. This may be seen in terms of a lack of language held by the self adequate to represent the other.

A most extreme form of stereotyping is stigmatisation. This concept was developed by Goffman (1963) in his book *Stigma*, where he argues that some categories of individuals are seen to have 'spoiled identities'. This means that individual and group members do not only perceive and assess a negative feature of another individual, but it becomes a deviant characteristic. Scheff (1966) called these deviant features the 'master status'. He describes how the master status overwhelms and adds meaning to every action and characteristic of the category of person. Scheff (1966) also developed Labelling Theory. This work can be criticised for its deterministic properties. It must be noted that most of this work has been done in the context of mental health. However, there are strong comparisons to be made with the experience of physical, sensory and learning disabled people. Despite what the disability movement thinks, there is a hierarchy of oppression and stigmatisation of disabled people. Campbell and Oliver (1996) in their book *Disability Politics* argue that all disabled people are equally oppressed and equally stigmatised. From this study's work with the Focus Groups this certainly is not the lived experience of disabled people. It is nearly impossible to rank oppression or stigmatisation; however it will become clear later that, for example, white men in wheelchairs appear to have fewer problems than black learning disabled people. This is a qualitative and experiential assessment of what Social Representations disabled people might experience within their lives.

It is important to highlight that even if Goffman's theory is 'sociological', it remains at the inter-individual level and therefore is highly psychological. Jones et al. (1986) use ideas from Attribution Theory and the social psychological work on stereotypes in order to provide an analysis of stigmatised or 'marked' relationships. Once more this was in the context of psychiatric patients. In their book Social Stigma it is clear that they are emphasising the importance of cognitive social psychology and their commitment to Attribution Theory means that they concentrate on inter-personal relations and not Social Representations. All of the above have been very clear to highlight the effective dimension of stigma. However, none have ever undertaken an analysis of print media. It has been argued that some stereotypes are completely inflexible because they perform an individual and group psychological and social function (Finkelstein, 1993). This is very much based on Allport's (1954) concept of In-group and Out-group Theory. It is not difficult to think that people with disabilities are an out-group. This leads onto a brief discussion of Social Identity Theory (Tajfel; 1978, 1981, 1984, Turner, 1984)

Tajfel's Social Identity Theory states that groups will differentiate between themselves on certain critical attributes. Tajfel explains this as a cognitive process. These critical attributes are normally ones which have evaluative significance. In the context of disability, non-disabled people tend not to socialise with disabled people for the fear of secondary stigmatisation. One of the important psychological functions of this process of differentialisation is to enable the group to develop a positive image of itself; i.e. positive group distinctiveness. This is done by making negative representations of any out-groups. De Rosa (1987) sums up this process very well when she writes:

The process of classification of social elements in relation to Social Representations plays a role in the development of social identity and the consolidation of in-group and out-group relations. (1987: 92)

This may be seen as an attempt to connect Social Identity Theory with Social Representation Theory. It may be postulated that the use of negative attributions made by in-groups about out-groups are better expressed as Moscovici's (1993) 'branches of knowledge' or 'canonic themes'. It is worth asking whether the concept of 'normality' is so elusive that it is possible to have a group of 'normal' people and a group of 'disabled' people. In this research it will become clear that there are such groups.

#### Attitudes and Widespread Beliefs as Social Representations

The theory of Widespread Beliefs as developed by Fraser and Gaskell (1990) is somewhat different from the traditional, primarily North American approach to attitude research. Fraser and Gaskell put forward an important hypothesis that the study of similarity in attitude or near consensus of opinions is as important to examine as individual or group differences. In the past, studies of beliefs, opinions or attitudes have been concentrated on differences between people. For instance, how attitudes

and beliefs relate to personality types (e.g., Adorno et al. 1950; Rokeach 1960) or how differences in people's behaviour can be predicted in terms of their attitudes or understanding of what is normal (e.g., Ajzen and Fishbein 1975). Fraser and Gaskell argued that it is not only the dramatic or controversial aspects of popular thought or common knowledge which are important to study. They highlight the importance of examining what might be called taken for granted knowledge about issues as being equally important to social psychology. It is clear that society has a certain range of views surrounding disabled people which have become either common knowledge or cultural truisms. This is why the application of Fraser and Gaskell's theory of Widespread Beliefs is so apt in terms of disability.

In this context, it is useful to look at how attitudes have been defined by social psychology. Three important questions relating to attitudes have been asked. First of all, why do people have similar or shared views? (Thomas and Znaniecki 1918-1920). This question was very in evidence in terms of racism during the 1930s and still persists. The second question is what is the relationship between people's private views and their public actions? This question has been explored from LaPiere (1934) up to the present day. Finally, it is important to consider how individuals' views are organised in terms of their internal thought structure. The question remains: Is attitude formation a social learning process, a function of education or even parental attachments? These thoughts and concepts relating to attitudes follow a historical path. In recent years researchers concentrated on the relationship between private thought and public action. A range of empirical work from Wicker (1969) to Bentler and Speckhart (1981) and finally to Breckler (1984) have attempted to construct qualitative and quantitative models of attitudes. Other theorists have taken different paths, such as Lalliee et al. (1984) who have taken a psycholinguistic approach to attitudes. In

contrast, Abelson (1986) thought of attitudes in a metaphorical sense as being possessions. It was not until Tajfel (1972) and his theory of Social Categories and Social Identities that a wider perspective was taken. This allowed Moscovici (1981, 1984, 1993) to develop his theory of Social Representations.

In this context, the theory of Widespread Beliefs can see attitudes as being Social Representations, as explained previously. The central issue is that Social Representations must have content, and this content must be meaningful in a common setting within society. The groups in question in this study are non-disabled people and disabled people. It is the content of non-disabled people's Social Representations that we want to elucidate in this study.

As Social Representations are based on society's interchange of knowledge, and new ways of communicating, I will aim to analyse what knowledge bases people are using to construct their Social Representations of disability. This is in the light of disabled people being more 'visible' as a result of policies such as community care.

#### Models of Disability as Social Representations

Three distinct models of disability have been identified within British society (Finkelstein 1980, Oliver 1983, Devenney 1987, Campbell & Oliver 1996, Shakespeare & Watson 1997). These most prevalent explanations, or models, of disability, which are the Medical model, the Charity or tragedy model and the Social model, are the three Social Representations of disability currently present in society.

The Medical model views disability as an individual medical issue that needs to be solved. This is currently the most commonly held belief about disability throughout society, and therefore can be said to be hegemonic. The Charity model sees disability as a problem that needs to be tackled by professionals with specialised knowledge. This model arises out of the hegemonic Medical model and considers itself to be a liberal and progressive approach to disability. Therefore it can be said to be an emancipated representation because it is an outgrowth of knowledge from the hegemonic representation.

The Social model has been developed by disabled people themselves and challenges the other two models, and therefore is polemical in nature. Let us examine each model in turn, and explore how they generate Social Representations and social identities of disabled people. The Medical model makes several assumptions about disabled people. For example, disabled people are passive and cannot decide for themselves; doctors and other paramedical professionals always know more about the 'illness' or 'condition' of the disabled person; disabled people are 'not normal'; disabled people need to be categorised by their physical, sensory, learning or emotional impairments. Essentially. disability is seen to be an individual problem that needs to be 'cured'. The basic assumption is that disabled people cannot like being the way that they are. This assumes that the quality of life of disabled people is somehow qualitatively different to their non-impaired peers. This is eloquently summed up, if not disturbingly so, by Kriegel in the book Images of the Disabled, Disabling Images (1987):

The world of the crippled and disabled is strange and dark, and it is held up to judgement by those who live in fear of it. The cripple is the creature who has been deprived of his ability to create a self.

...He is the other, if for no other reason than that only by being the other will he be allowed to presume upon the society of the "normals". He must accept definition from outside the boundaries of his own existence.

It is clear that by perpetuating this understanding of impairment and disability, the Medical model presents a Social Representation which is

very powerful. It is important to note that because of the power relations between the medical profession and society, this view of impairment and disability has become known as the Medical model and has been underpinned by a layer of medical respectability. This model neatly illustrates Deschamps' idea of power within social identity (1977, 1983). The social identities of disabled people which stem from internalising the medical Social Representation put forward in this model, mean that many disabled people see themselves as abnormal; as a burden; in need of special care; not attractive; asexual and many other negative self concepts. Nasa Begum (Campbell & Oliver 1996: 110), who is now an important disabled activist and policy analyst, admitted how she first saw herself as a disabled person. She says:

because everything around me made me feel that you're just being an ungrateful git, I began to think, Well, maybe I am and that life would be a lot easier if I just swallowed it all and said - fine, I'll be carried up steps. I don't mind if I can't get to the library and I do like to spend my adolescence at local shopping centres, shaking cans for money

The Medical Social Representation of impairment and disability directly impinges upon disabled people's view of themselves and may be important in the process of identity formation.

The Charity model is primarily promoted by large charities concerned with disability. The images and ideas that charities portray of disabled people include pitiful, needy, helpless victims, eternal children, asexual, incurable, courageous, special, exceptional and in need of care. But most of all, they need your money. Despite strenuous efforts by some progressive charities, this Social Representation of disability remains the norm within charity work. Three themes underpin this representation: disability is something to fear; disability makes you helpless; and finally, disabled people are always special, brave or exceptional - never boring, normal or ordinary. The reason that charities do this is to raise funds. These categories which charities put disabled people into relate very closely to how Tajfel (1972) would understand social categorisation. The consequent social identities of disabled people which arise out of this type of representation include that they should be helpless, institutionalised, segregated within education and excluded from employment and everyday life. Once more we can see that the power of the Social Representation smothers any possibility of a social identity outside the constraints of that Social Representation.

The third model of disability is somewhat structurally and conceptually different from the other two. The Social model asserts the idea that disabled people have their own identity as people with within impairments society. lt challenges the existing Social Representations made about them. In this model, the problems of impairment or disability are turned on their head and become the collective problems of society, not of the individual disabled person. Three determining factors are identified by this model which do not relate to the individual's actual impairment, but to the structure and nature of society. The first being society's attitudes towards disabled people which are driven by the previous two models. These attitudes (or as we perceive them, Social Representations) are disempowering, excluding and deny the real identity of disabled people. The second disabling factor is the built environment, which denies disabled people access to buildings and public space. This is well illustrated by the lack of accessible housing, transport and schools within our community. Finally, the policies and practices of institutions such as banking, insurance, the church and the police, the list is goes on, are disabling. For instance, disabled people still pay higher insurance premiums, even when there is no actuarial reason for this premium rating. By developing this understanding of impairment and disability, disabled people have been agentic in their ownership of their own identities, and are in the process of generating Social

Representations which are consistent with this model and their lived reality. For example, the Social model has led multinational companies such as Nike, Coca Cola and McDonald's, to include disabled people as characters in their television advertising campaigns. Disabled people are now seen by many companies as 'ordinary consumers'. Without disabled people promoting their own identity, i.e. one of being a valid person with a functional impairment within a society, these new Social Representations would not have been created. At present, the Social model is not without its critics, even amongst disabled people because some still feel that part of our identity is determined by the nature of our bodies. However, as Tom Shakespeare (1992: 40) puts it:

The achievement of the disability movement has been to break the link between our bodies and our social situation, and to focus on the real cause of disability, i.e., discrimination and prejudice. To mention biology, to admit pain, to confront our impairments, has been to risk the oppressors seizing on evidence that disability is "really" about physical limitation after all.

The models of disability, as described above, have never been empirically tested as being the Social Representations of disability held by society. This study attempts to discover what Social Representations are held by individuals, and whether these match the theorized models of disability.

Over recent years, disability has become politicised by the international disabled peoples' movement (Davis 1993; Driedger 1989; Oliver 1990). Many academics, some of whom are disabled people themselves, have reconceptualised disability as a complex and sophisticated form of social oppression (Oliver 1996) or institutional discrimination on par with sexism, racism and heterosexism (Barnes 1991).

Explanations of disability fall into three broad categories; Sociopolitical, Functionalist and Materialist. Socio-political explanations of disability come in two main forms, one American and one British. The American view is founded on the 'Social Construction' of the problem of disability as an inevitable outcome of the social evolution of contemporary society. Whereas, the British perspective has been developed by Sociologists who are very much influenced by Marx and Engels and suggest that disability and dependence are 'social creations' of western industrial capitalism. This latter theoretical framework led to the construction of the Social model of disability.

This Social model approach stems from the direct experience of disabled people within society. It is based on the premise that the real disabling factors in disabled people's lives are not their impairments but are non-disabled people's attitudes towards disability; an inaccessible environment and institutional policies and practices which bar or hinder the progress of disabled people. This research will examine how well this model of disability is understood and expressed within present-day Britain. It is the aim of the researcher to emphasise the intrinsic link between the Social Representations of disability in society and the everyday attitudes held by individuals, which determine their behaviour towards disabled people. The research will be based on the premise that the current Social Representations of disability relate to the Medical, Charity, and Social models of disability. This will allow present day political and sociological thinking to be meshed with a new psychological perspective of disability.

During the 1960's American sociologists concentrated on Functionalist accounts of disability with their emphasis on meaning, identity and the process of labelling. They were also concerned with the relationship between impairment and disability. Goffman (1963) and Scott (1969) both looked at the importance of stigmatisation and the social construction of dependence generated and maintained by health professionals. In doing so, they challenged the assumption that the problems related to disability were a direct result of an individual's impairment or medical condition. De Jong (1979) took these ideas into the fledging American disability movement and developed what Oliver (1983) termed the Social model of disability. Stone (1984) took these arguments further. She maintains that all societies operate via a complex network of commodity distribution, the principle conduit being work. But since not everyone is able, or willing, to work, a secondary system develops based on the perception of need. Through an historical account of nineteenth century social policy in the USA, Germany and Britain, Stone demonstrates that access to this needs based system is regulated by both medical and political considerations. Hence, the 'social construction of disability' is explained with reference to the accumunulation of power of the medical professions and the state's need to ration access to state sponsored welfare (1984).

Wolfenberger (1989) argues that the growth of the 'human service industries' has enabled 'post primary production economies' such as the USA or Britain to create and sustain a large population of dependent and devalued people in order to secure employment for others. Albrecht (1976) has developed this notion further and says that 'disability' has given rise to the 'disability business'. In essence, servicing disability has become a commercial enterprise and requires the Medical and Charity approaches towards disability to remain in place in order for this 'disability' business' to survive. These arguments, however challenging, do not examine the structural factors involved in the analysis of disability such as effects of poverty, race, gender, individualism, profit and the consumerism. At no point do these theories even attempt to address the underlying psychological reasons why many people view disability as a negative and dependent set of circumstances, which eventually result in institutional discrimination.

The Materialist theories were led by Hunt (1966) in which he saw disabled people as being thought of as, 'unfortunate, useless, different, oppressed and sick'. 'Unfortunate' in that disabled people were perceived not to 'enjoy' the benefits of modern life; 'useless' is terms of their employability; 'different' because their bodies were abnormal'; 'oppressed' as they were a minority group and 'sick' because disabled people were thought to suffer. In short, disabled people represented what most nondisabled people most feared – the 'tragedy, loss, dark, and the unknown'. This was the first modern attempt to locate disability in the collective psyche of society. A decade later the Union of the Physically Impaired Against Segregation (UPIAS) of which Hunt was a founder member made the crucial distinction between impairment and disability. Impairment was defined as the individual's actual bio-physical condition. Disability was defined as 'the disadvantage or restriction of activity caused by a contemporary social organisation of society which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.' (UPIAS, 1976:14). This was updated by the British Council of Organisations of Disabled People in 1990 to include all impairments such as sensory or learning impairments.

Finkelstein (1980), a disabled psychologist with the Open University put forward the idea that disabled people's oppression was a staged progress. Starting with feudalism which needed all labour, exclusion within the industrial society and liberation with the onset of the technological world. This view has been heavily criticised for its simplicity but I cannot help see its charm and optimism!

Other perspectives have become increasingly dominant in Disability Theory. Feminist writers such as Morris (1991), Crow (1992) and Begum (1994) have strongly emphasised the role of gender and race when considering the experience of and reaction to disability. Shakespeare (1994) has highlighted the importance of culture in relation to disability. Shakespeare has also drawn on the work of Simone de Beauvoir in terms of analysing the effects of body image and the concept of 'other'. Shakespeare has promoted the work of cultural anthropologist Mary Douglas in the context of disability. Douglas (1985) suggests 'primitive' societies react to anomalies such as impairments by reducing ambiguity, physically controlling it, avoiding it or adopting it as ritual. Shakespeare (1994) draws the comparison with the historical experiences of disabled people such as being the court jester, the freak show, the asylums and the Nazi death camps as falling into one or more of Douglas' categories. Furthermore, Shakespeare picks up the work of Susan Griffin (1984) on women's oppression in terms of their relationship with their bodies, instincts and sexuality. Shakespeare argues that non-disabled people do not fear disability itself but the notion of being imperfect and mortal.

The approach developed by Shakespeare is definitely important in terms of setting out cultural and psychological reasons for different Social Representations of disability. However, it does depend largely on Douglas' essentially phenomenological work, which implies that all cultures respond negatively to disability. There is ample anthropological evidence to support that not all cultures are negative about disability (Safilios-Rothschild 1970).

#### Media and Communication Theories

The pervasiveness of television and newspapers in our society cannot be dismissed. It has been argued that they are the primary cultural tools by which mass communication now takes place. This is not to ignore the extraordinary impact of the Internet. If we accept the Moscovician notion that Social Representations are borne through knowledge and disseminated by communication then the role of the media in the construction, development, reflection and presentation of Social Representations becomes clear. Ideas about disability are constantly being presented, debated and represented in all the media. In this study the researcher will be examining the narrative structure, content, meaning and language of both print media and television. Although they have very different traditions and formats, it is the view of the researcher that they can be analysed using the same techniques. Here I will briefly outline the relevant literature and research which connect Media Studies with Social Representations and thus puts this research into this context.

Durkheim (1898) and Wundt (1911) laid the foundations for the concepts of collective representations and cultural communications. Wundt in his work *Volkerpsychologie* highlighted the importance of language in cultural development and in communicating new ideas from one group to another. This is one of the major themes that Moscovici developed in his Social Representations Theory and we are able to see an historical and intellectual progression.

If we take Halloran's argument that 'the media's function is the provision of social realities where they did not exist before, or the giving of new directions to tendencies already present' (1970b: 31), we can see how this resembles Moscovici's view of the function of Social Representations. However, Livingstone (1990) raises the question whether media representations are the same as Social Representations. She points out that media representations are mediated through constraints such as technology, artistic merit, legality and viewer/reader expectations whereas Social Representations exist regardless. Related to this issue is the role of meaning within media representations (Hall 1980) and how audience interpretation and knowledge affects the dynamic between the media representations and the Social Representations on any one topic. For instance, Booth (1994) discusses how television was used in the 1950's to help promote stable family life after a severe

increase in marital breakdown in the immediate post-war years. He cites a four-part BBC drama-documentary The Pattern of Marriage, made in 1953, as having this goal.

Following on from this, one must note the considerable importance placed on the negotiation of meaning by literary criticism and Cultural Studies. The relationships between reader and text and viewer and programme are complex and multifaceted. Texts can be seen as mechanisms by which the reader/viewer infers, elaborates and interprets using experience, convention and imagination. Researchers have in the past concentrated on the texts rather than how the reader responds to the text. In this research, as the participants will be generating text, the researcher hopes to compare these storyboard texts with those of newspapers and television in terms of how they interpret and negotiate the meanings of disability. This will allow some insight to what experience, knowledge, assumptions and pre-conceived Social Representations the subjects may be using.

Other general media research which needs to be taken into account when analysing in terms of representations and audience/reader interpretations is semiotic approaches to text (Eagleton, 1983, Fiske 1982, Hawkes, 1977, Weedon 1987) ; Narrativity (Sarbin 1986, Livingstone 1990, 1994).

In terms of disability related media research, Ann Karpf's chapter, *crippling images*, in her book *Doctoring the Media* (1988), lays the foundation of our understanding of how disability was presented and represented in the media. What she found was an abundance of stories that related to cures, charity appeals and suffering. Research by Cumberbatch and Negrine (1992) which examined six weeks of British television using content analysis, found that most story lines are linked to either cures or medical treatment or programmes about their special achievements. Only 0.5% of fictional characters were disabled people

and nearly all of these were wheelchair users. Most of these characters were stereotyped as being criminal, helpless or pathetic and were used to evoke feelings of fear, menace or pity. In terms of newspaper analysis, SCOPE has just published a report entitled *Stop Press – How The Press Portrays Disabled People.* (SCOPE 2000). This looks at newspaper coverage in both National and Local Press for four weeks under 18 subject areas such as, education, benefits and sport. Their findings were that disability is still portrayed as a problem issue and the language used is still regarded as being negative in the eyes of disabled people. The worst offenders were local newspapers and tabloids.

The main problem with all the media research on disability is that it focuses on the actual textual content, language and portrayal, rather than the constructions of disabled people, which may not reflect the actual lived experience of people with disabilities. However, non-disabled people's Social Representations do construct a society into which very disabled people's lives are constrained by the Social Representations that non-disabled people have about their lives. This is a dialectical process. The role and status of disabled people is inextricably linked to the Social Representations that society holds of them. The consequence is that the status and role of disabled people within society becomes determined by the Social Representations rather than by their actual value as individual people.

The second reason for this research is that there have been many other fields of psychological research which have dealt with issues of discrimination and prejudice. There is much research on issues around prejudice against black people, and this has formed a coherent body of knowledge and understanding related to racial discrimination. Attribution Theory has dealt with issues surrounding ugliness and beauty. The theory of Social Representations has investigated people's knowledge bases relating to psychoanalysis and gender. All this research has developed a methodology, which has helped to elucidate hidden psychological processes in society. It is logical, therefore, to take these studies of difference and perception into the field of disability. Disability in psychological terms remains a taboo subject. It is loaded with fear and misconception. Given the fact that disability can happen to any person throughout their life, it is important to know how society understands it and responds to it in psychological terms.

Finally, this research seems timely in the context of the arrival of the Disability Discrimination Act in Britain and the Americans with Disabilities Act in the United States. British society at least has reached a point in its social evolution where it is actively considering the issue of discrimination against disabled people. This research will fit into this context of social thought, hopefully helping us to understand how Social Representations of disability lead society into discriminatory policies and practices, which undermine the potential of disabled people. This study may help governments and other organisations to develop training and educational programmes that tackle some of the roots of the prejudices and misconceptions relating to disability. This research aims to suggest a new way forward in understanding perceptions and knowledge of disability, and providing some useful tools for change.

### **Aesthetic Theory**

In this section, the study will briefly examine the key components of Aesthetic Theory with reference to the work of Hegel (1920), Adorno (1970) and Croce (1913), who were three of the main proponents of modern Aesthetic Theory. It is not the central theme of this research to discuss the philosophical aspects of impairment and disability, but it is however useful to offer an intellectual backdrop to some of the more abstract issues relating to beauty and its perception within society. The key issues to be addressed here are the concepts of ugliness and beauty in the context of Social Representations and disability. In terms of disability, the argument is whether beauty lies in nature or in human perception of nature. It is also related to the historical representation of 'what is beauty?' (Adorno, 1970).

For Hegel artistic beauty is always privileged over natural beauty. This is because of the presence of contingency and imperfection in the naturally beautiful. Hegel situates artistic beauty above the natural, because of the abstraction and synthetics of art, compared to the flawed and contingent natural world.

Croce refers to this privileged artistic act as one of expression. There is no art without expression, but these cannot be reduced to each other because there can be expression without art, or expression in bad and ugly art. Croce's view implies that disabled people are part of 'flawed natural beauty' and therefore cannot be in themselves objects of art. Adorno does not agree with this view. For him, natural beauty is not flawed, it is different.

It is clear that the argument between natural beauty and Art is a constant dilemma for philosophical argument. Disability is a human experience which cuts across both realms. How disabled people are portrayed in society and in the media presents complex representations of their lives and human form. Aesthetic Theory has never addressed the issue around 'body fascism' until recent times (Shakespeare, 1997). In this study the role of aesthetics is marginal. However, it will become clear later, within the print media analysis in this study, that the representation of 'deformity' and difference is often couched in terms of a wider notion of beauty. It appears that newspapers assume that there is a collective or social understanding within society of 'what is beauty', and impairments are outside of this understanding.

# Chapter Two: Storyboard Technique: Telling tales...

# **Overall Introduction to Storyboard Technique**

This chapter deals with the storyboard technique that is the primary tool of this research. This chapter will report the methodology used, the research, the analysis and offer a detailed discussion of the outcomes of this work. This will make up a substantive part of this thesis. This chapter will also deal with coding issues and most important of all, will attempt to identify the different types of Social Representations of non-disabled people, towards disability.

# Methodology

# Introduction

This was the primary data source to elicit Social Representations from non-disabled subjects. The storyboard technique has been used in many psychological and sociological studies in different contexts. The researcher originally found the technique effective in his Master's thesis. In this section the storyboard technique, the subject profile, the administration of the list and the material used are explained.

## **Materials**

Subjects were presented with one of twelve sets of images. Each set of images was made up of four black and white photographs which were

each 5"x 7" in dimension. There were four characters, two obviously disabled and two not apparently disabled. There were two male characters and two female characters and one of each was disabled. The characters names were Max, Tom, Eve, and Caroline. Max and Caroline were genuinely not disabled. Tom and Eve were born disabled. Tom was born with cerebral palsy, which meant that he could not use his limbs or voice and was a permanent wheelchair user. This was clear from the photographs. Eve was born with Down's Syndrome, which has affected her ability to learn in an everyday manner. However, her Down's Syndrome has not affected her mobility. Once more, this is clear from the photographs. Each storyboard had a preamble, which told the subject something about the character in the photographs. The storyboard preambles were as follows:

#### Type 1 Storyboard preamble

This is Max. Please use the following photographs to write a story about Max. (See Figure 1)

#### **Type 2 Storyboard preamble**

This is Max. He was born profoundly deaf. Please use the following photographs to write a story about Max. (See Figure 1)

#### Type 3 Storyboard preamble

This is Max. He lost his right leg in a car accident fifteen years ago. Please use the following photographs to write a story about Max. (See Figure 1)

#### Type 4 Storyboard preamble

This is Caroline. Please use the following photographs to write a story about Caroline. (See Figure 2)

# Type 5 Storyboard preamble

This is Caroline. She was born profoundly deaf. Please use the following photographs to write a story about Caroline. (See Figure 2)

# Type 6 Storyboard preamble

This is Caroline. She lost her right leg in a car accident fifteen years ago. Please use the following photographs to write a story about Caroline. (See Figure 2)

## Type 7 Storyboard preamble

This is Tom. Please use the following photographs to write a story about Tom. (See Figure 3)

# Type 8 Storyboard preamble

This is Tom. He was born with brain damage which effects the use of all his limbs. Please use the following photographs to write a story about Tom. (See Figure 3)

## Type 9 Storyboard preamble

This is Tom. He had a brain tumour in his late teens. This affects the use of all his limbs. Please use the following photographs to write a story about Tom. (See Figure 3)

## Type 10 Storyboard preamble

This is Eve. Please use the following photographs to write a story about Eve. (See Figure 4)

## Type 11 Storyboard preamble

This is Eve. She was born with brain damage which affects the way she learns. Please use the following photographs to write a story about Eve. (See Figure 4)

### Type 12 Storyboard preamble

This is Eve. She had a brain tumour in her late teens. This affects the way she learns. Please use the following photographs to write a story about Eve. (See Figure 4)

Therefore the types can be summarised in the following categories:

Type 1: Max; no mention of disability.

Type 2: Max; born deaf.

Type 3: Max; acquired amputee.

Type 4: Caroline; no mention of disability.

Type 5: Caroline; born deaf.

Type 6: Caroline; acquired amputee.

Type 7: Tom; no mention of disability

Type 8: Tom; born brain damage.

Type 9: Tom; acquired brain tumour.

Type 10: Eve; no mention of disability.

Type 11: Eve; born brain damage.

Type 12: Eve; acquired brain tumour.

Each storyboard pack, whatever its type, contained the following:

Title page – i.e. type of story 1-12.

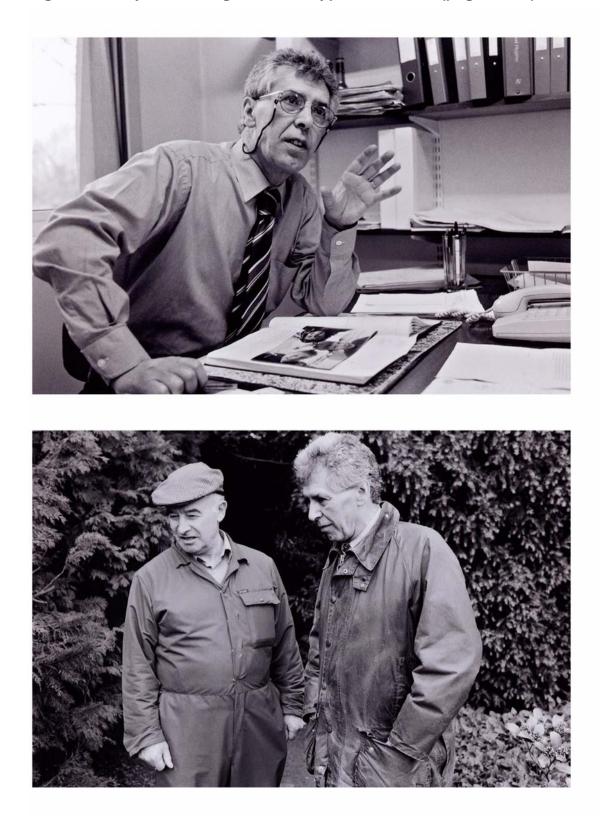
Project explanation.

Hints and tips on how to use the storyboard.

Consent form.

Two pages of storyboard.

A sample pack is in Appendix 1. Each set of storyboard images are shown below.







## Storyboard images: Max – Types 1, 2 and 3 (page 2 of 2)



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Figure 2: Storyboard images: Caroline – Types 4, 5 and 6 (page 1 of 2)





The Social Representations of Disability



Storyboard images: Caroline – Types 4, 5 and 6 (page 2 of 2)



The Social Representations of Disability

## Figure 3: Storyboard images: Tom – Types 7, 8 and 9 (page 1 of 2)



## Storyboard images: Tom – Types 7, 8 and 9 (page 2 of 2)





Figure 4: Storyboard images: Eve – Types 10, 11 and 12 (page 1 of 2)

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The characters in the storyboard photographs were friends or work colleagues whose true identities are named in the Acknowledgments. Max is the Director of Catering at a Cambridge University College and has no known disabilities. In the photograph Max is fifty-five years old. Caroline is a senior administrator at a Cambridge College with no known disabilities. In the photograph Caroline is thirty-four years old. Tom was a friend who was born with Cerebral Palsy and lived in a residential home in Perth, Scotland. He was not employed. In the course of this doctorate, he unfortunately died of a respiratory problem. However, his family wanted the photographs to be used. Tom was forty-three at the time of the photographs. Eve was a Further Education college student with Down's syndrome. Eve lives at home with her parents. Eve was nineteen years old at the time of the photographs.

All the photographs used in this thesis were taken by a professional photographer, Rupert Mardon, between April 2000 and October 2000. The photographs of Max, Caroline and Eve were all set in Cambridge. The photographs of Tom were taken in Edinburgh and Perth in 1998.

#### Administration of the storyboard task.

There were four sets of photographs with four images per set. These were of Max, Caroline, Tom and Eve. Each set of photographs was then given one of three preambles: no mention of disability; mention of born disability; mention of acquired disability. Therefore there were in total twelve possible storyboard combinations. However, it must be made clear that only one of these combinations was allocated to any one participant. The allocation of storyboards was random for any one subject.

Each subject was given one set of storyboards from which they were asked to generate a fictional story or prose within a 30 minute timescale. Each subject was instructed to look at the pictures as a whole before attempting to write his or her story. The subjects were not told by the task administrators about the true nature of the research until the task was completed. Subjects were told that the research was about language and imagination in relation to the images, and not about the Social Representations of disability. This approach was designed to ensure that the study elicited more natural responses to the images relating to disability rather than a politically correct response. The storyboard task was not administered by the researcher because of his very apparent disability. It was felt that this would stop any research or experimental bias creeping into the stories written by the subjects. The storyboard task was administered by non-disabled colleagues, two of whom were psychologists, three of whom were professional trainers, and two who were graduates of the University of Cambridge and were working as the researcher's personal assistants at the time. The task administrators were fully briefed about the nature of the research and the details of the task. Each administrator was given a protocol checklist in order to ensure continuity of administration with different occupational groups and different workplace contexts. Some subjects completed the task en masse while others completed it at their work stations at the same time. No subjects were allowed to communicate with each other until the tasks were completed. Every subject was then debriefed according to the debriefing protocol. Every subject was given the opportunity to speak with the researcher directly about the research and given the opportunity to withdraw their material. No subject took this option. All subjects were interested in the nature of the research and did not mind being slightly misled.

#### **Debriefing Protocol for Storyboard Technique**

All debriefing was undertaken by either the author or one of two trained administrators. There was no formal script which the researchers followed, as the subjects were from a range of different work places and different work cultures. For instance the debriefing of the civil servants in this study was much more formal whereas the debriefing of charity workers was often conducted over a cup of tea or coffee. However, the same key points were covered in all cases. These are detailed as follows:

- All subjects were informed of the true nature of the study, i.e. it was not about language and imagination but about Social Representations.
- Subjects were then asked in the light of this new information whether or not they wanted to continue to submit their stories based on their storyboards.
- Subjects were asked if they felt if the storyboards were a useful exercise.
- 4) Subjects were asked if they had any questions relating to the research
- 5) All subjects were told that they would receive a summary of the research findings.
- 6) All subjects were thanked for their participation in the study.

#### Subject profile

All the subjects were obtained through previous employment contacts. Therefore the sample was a convenience sample and not random. Any inferences from this sample must be made with utmost caution. However, it is hoped that this sample will indicate any strong trends within the population. The subjects came from several major or national and local organisations. The key organisations involved in the research project were as follows:

The British Home Civil Service South Essex Health Trust The Scottish Executive Scope Capability Scotland The Papworth Trust Royal National Institute of the Deaf Royal National Institute of the Blind Disability Rights Commission Barclays Bank The South Bank Centre Addenbrookes Hospital Birmingham University Medical School Cambridge University

All these organisations were canvassed for volunteer subjects between October 2000 and October 2001. 1073 subjects were identified who said they were willing to take part. Out of this potential sample, the task administrators managed to obtain 211 usable stories. The target return rate was one in five and this was achieved over the period of data collection. It became clear that volunteers, when confronted with the real task, were much more reluctant to take time to complete it. This is why the researcher made sure a high number of potential subjects were available. The optimum number of stories (from a methodological point of view) in terms of equal cell size was 240 stories (five stories per cell). This was not achieved. However, these 211 stories are well distributed across story types and occupation types. Therefore there is no serious undermining of the methodology from a statistical point of view.

#### Coding of the stories

All the stories were initially numbered and coded for storyboard types and for the gender of the subject who wrote them. The stories were then collated with their consent forms in order to prove their validity. All the stories were inputted into Atlas.ti so that analysis could begin. Using Atlas.ti, the researcher made a detailed and qualitative analysis of each story and developed microcodes for each relevant point within the story. A relevant point was defined as any comment, opinion, statement or character reflection which impacted on a character's life. This was most significant when a character was identified as disabled.

#### **Code Definitions**

In order to be completely consistent in the reliability and validity process, the microcodes have been defined using four parameters.

- 1) Context
- 2) Language
- 3) Meaning
- 4) Code overlap

This enables the study to be consistent throughout analysis of the stories, newspaper articles and the notes from the Focus Groups. It also enables the research to compare the use of similar terms across the stories. Not all microcodes will explicitly be defined by all these parameters, and some microcodes are very clear and straightforward. Below are the definitions used to apply the microcodes to the storyboard text.

Abandoned	
Context	This is used where the central character in the story has been
	left by their spouse, partner, parents, family or friends.
Language	left by, divorced by and separation
Meaning	The central character is no longer worthy of love or is too
	different to love, or is now a burden.

#### Abilities not disabilities

Context	This is used when a direct reference or comparison is made
	between the apparent disabilities of the central character with
	their underlying less recognised abilities.
Language	unrevealed potential or hidden talents
Meaning	When this code is used, it is usually to promote a more positive
	image of disability.

Accident	
Context	This is usually used directly to describe an event which
	resulted in impairment, such as a road traffic accident.
Language	This is always straightforward, relating to the actual accident
	itself.
Meaning	There is no underlying meaning but a direct description of what
	happened to the central character.

Admiration	
Context	This appears when the central character is praised by the
	writer or other characters in the story.
Language	admired, adored
Meaning	The writer is attempting to present a positive view of the
	central character.

Adversity/struggle	
Context	This code is used when the writer refers to the central
	character overcoming a very difficult situation in his or her life.
Language	overcome, battle with, faced with
Meaning	The central character confronts a major obstacle in his or her
	life.

Allusion to	Allusion to impairment	
Context	This is when the writer does not directly mention the	
	impairment of the central character but indicates that the	
	central character has a problem.	
Language	has difficulty with, is dependent upon	
Meaning	The writer is reluctant to address disability directly and may be	
	embarrassed.	

Alone	
Context	This is where the central character is explicitly or implicitly by
	him or herself.
Language	lonely, lives alone
Meaning	The central character has no close relationships or has lost
	them.

Ashamed of impairment	
Context	This is where the central character expresses a negative
	attitude to his or her own impairment.
Language	feels guilty, tries to cope
Meaning	The central character does not like being a disabled person or
	thinks that other people find him or her unacceptable.

Aspiration	
Context	This is when the central character expresses a wish or
	intention to achieve a goal in his or her life.
Language	wishes to, dreams of
Meaning	That the central character wants to improve the quality of his or
	her life or attempts to do something greater than he or she has
	so far.

Being ridiculed	
Context	This is when the central character is perceived or referred to in
	a mocking or derogatory way by other people in the story.
Language	often stared at, giggling behind his back
Meaning	The central character is seen to be an object of pity, disgust or
	derision.

Body image	
Context	This refers to references to the character's physical
	appearance.
Language	deformity, unattractive, fat
Meaning	Disability is not beautiful.

Cause of disability/impairment	
Context	Any reference to how the disability or impairment has been
	acquired.
Language	brain tumour, result of, amputated because
Meaning	Usually used purely as a description of how the central
	character became disabled. On occasion, this code is linked to
	tragedy and fate.

Charity	
Context	Any reference to charities or related organisations.
Language	Charity
Meaning	Usually implies central character is dependent on money or
	help from charitable bodies.

### Communication

Context	This is used primarily when the central character is seen to
	have problems in making him or herself understood or being
	understood.
Language	communication, being understood, communication aid
Meaning	Usually implies that other people have difficulty communicating
	effectively with the central character.

Consequence of disability/impairment	
Context	This identifies all the outcomes experienced by the central
	character of having a disability or impairment.
Language	difficult access, barriers, people's attitudes
Meaning	Having a disability is a difficult experience which involves many
	social and environmental barriers.

Contentment	
Context	This is used where the central character in the story appears to
	be satisfied with his or her life or a particular event that occurs
	within the story.
Language	content, contentment
Meaning	This is when the central character is calm and at ease.

Coping	
Context	This is where the central character is managing to deal with his
	or her disability or impairment.
Language	copes, dealing with, comes to terms with
Meaning	This indicates that the central character has developed
	different ways of dealing with the problems of their disability or
	impairment.

Courage/bravery	
Context	This is used when the central character explicitly or implicitly
	demonstrates courage or bravery.
Language	courage, brave, fighter
Meaning	This implies that the central character confronts frightening or
	difficult problems in his or her life.

Criminality	
Context	This is when the central character undertakes an illegal act.
Language	criminal gang, illicit, wanted, amphetamine, toke
Meaning	The central character is an unexpected criminal because
	disabled people are meant to be nice and good.

Death	
Context	Any reference to people dying or the central character being in
	a life or death scenario.
Language	death, dying, life or death situation, lost her husband
Meaning	For non-disabled characters this is part of everyday life. For
	disabled characters this is usually related to their impairment.

Denial	
Context	This is where the writer appears to make a conscious decision
	to deny the disability or impairment of the central character.
Language	No language is distinctive.
Meaning	Very difficult to identify meanings. However, this only happens
	with storyboards that are clearly of disabled people, and where
	mention of impairment would be appropriate to the storyline.

## Determination

Context	The central character is portrayed emphasising his or her
	determined nature.
Language	determined, fighter
Meaning	Central character is overcoming adversity or is in the process
	of a personal struggle.

Disability equipment	
Context	Any mention of any equipment, accessories or adaptation
	relating to the central character's impairment.
Language	whizzy wheelchair, artificial leg, adapted
Meaning	Disability is associated with the need for 'special' equipment.

Disability language	
Context	This is where the writer is using language that has become
	associated with impairment or disability, usually in a negative
	context, in terms of the Social model.
Language	suffering from, amputee, Down's, struck down by, victim
Meaning	Having a disability or impairment is usually a negative
	experience.

Disabled people's perceptions	
Context	Any reference to a disabled character's opinion or thought of
	disability.
Language	No specific language.
Meaning	The writer is aware that disabled people might have different
	opinions of their impairment from non-disabled people.

Discrimination/law	
Context	Any reference to the unjust treatment of disabled people, or

	laws relating to disability.
Language	Disability Discrimination Act (DDA)
Meaning	The writer is aware that disabled people face prejudice.

Education	
Context	Any reference to education, such as schools, colleges or
	university.
Language	school, university, higher education, training
Meaning	No particular meaning for non-disabled characters but when
	the character is disabled the writer is sometimes aware that
	disabled people might have a different educational experience.

Employment issues	
Context	Any reference to when the central character is employed or unemployed.
Language	work, job, catering, administrator
Meaning	For non-disabled characters, employment or unemployment is
	a matter of everyday life, whereas for disabled characters,
	employment often takes on other dimensions, such as
	overcoming barriers.

Exceptional ability	
Context	This is when the writer emphasises the outstanding qualities of
	the central character, usually when he or she is disabled.
Language	exceptional, special, outstanding, brilliant
Meaning	For non-disabled characters this is usually related to their
	success at work, and with disabled characters it is normally
	associated with overcoming the barriers associated with their
	impairment.

Family life	
Context	This is when the writer refers to the central character's family,
	such as wives, husbands, children, partners, parents, sisters
	and brothers.
Language	mother, father, wife, sister, daughter, son
Meaning	For non-disabled central characters there is no specific
	meaning, but for disabled characters it is very often associated
	with dependency or being left alone.

Fate	
Context	Any reference within the storyline to luck, chance or destiny.
Language	lucky, unfortunate, destined
Meaning	In terms of non-disabled characters this is used in the usual
	everyday way of describing unexpected events, whereas with
	disabled characters it is more often used in a more mystical
	way. For instance, 'he was fated to become disabled and
	became a better person for it'.

Finances	
Context	Any reference to money or personal finances.
Language	money problems, rich, poor
Meaning	No particular meaning.

First line	
Context	First line of every story, excluding any title. For reference
	purposes only.
Language	No particular language.
Meaning	Often indicates tone of the whole story.

Food	
Context	Any reference to the central character eating or drinking or
	consumption of food.
Language	roast dinner, likes her food, canteen, tasty
Meaning	For non-disabled characters, this is used in an everyday
	manner, but for the Down's syndrome characters, it seems that
	the writers place particular emphasis on their enjoyment of
	food.

Friendships/relationships	
Context	Any reference to the central character's friendships or
	relationships that appear personal and important. This
	excludes parental relationships, but includes sexual
	relationships.
Language	friend, mate, husband, wife, boyfriend, girlfriend
Meaning	No particular for most central characters but sometimes
	important for disabled characters as they are often depicted as
	alone.

Frustrated	Frustrated/angry	
Context	Any reference to the central character being frustrated or angry	
	with his or her life or with events in his or her life.	
Language	frustrated, angry, annoyed, fed-up	
Meaning	No particular meaning for non-disabled characters except	
	everyday annoyances. However, for disabled characters it is	
	usually related to some aspect of their impairment.	

# Grateful/thankful

Context	This is where the storyline makes a reference to the central
	character being grateful or thankful for events in his or her life
	or people's responses towards him or her.
Language	grateful, thankful, appreciative, glad
Meaning	In terms of non-disabled central characters, this is a normal
	polite response. However, with disabled characters, it is
	usually associated with not expecting help.

Нарру	
Context	Any reference to the central character being happy and
	enjoying life despite any problems.
Language	happy, cheerful, smiling, laughing
Meaning	The central characters are more than content with their lives or
	events and people around them.

Health/illness	
Context	Any reference to the health or an illness or medical condition of
	the central character without direct reference to their
	impairment.
Language	Medication
Meaning	In non-disabled central characters, this is about everyday
	health problems, but in disabled characters it is often implicitly
	related to their impairments.

Helpful	
Context	Any reference to the central character being helped or being
	helpful.
Language	helpful, dependent, assistance
Meaning	Disabled people are in constant need of help.

Hiding disability	
Context	This is where the central character hides his or her impairment
	or pretends not to have an impairment.
Language	disguises her prosthetic leg, learned to lipread
Meaning	Disabled people are often forced to pretend they have no
	impairment in order to lead a more normal life.

Humour	
Context	The writer attempts to make a humorous scenario or
	statement.
Language	No specific language.
Meaning	Meant to make the reader laugh (or at least smile).

Idealisatio	dealisation	
Context	This is where the central character is built up to be pretty much	
	perfect and a bit of a superhero or hero.	
Language	extraordinary, exceptional, remarkable	
Meaning	The writer portrays the central character as having a perfect	
	life and being a perfect person despite his or her	
	circumstances.	

Incidental/	Incidental/no mention	
Context	This is where the writer may or may not mention disability but it	
	is not a feature of the storyline, it is an integral part of the	
	central character's life without making it a particular issue. This	
	is only used when the character is either visibly disabled or	
	described as disabled in the preamble to the storyboard.	
Language	No specific language.	

Meaning	The writer does not use the impairment or disability as a main
	feature of the story.

Independe	Independence	
Context	The central character is depicted as being independent and/or	
	self-reliant, or wants to be.	
Language	likes her independence	
Meaning	No particular meaning for non-disabled characters, but for	
	disabled characters there is a real sense of a need to have	
	autonomy.	

Institution	Institutionalised	
Context	This is where the central character lives in or is associated with public or private social care provision, such as day centres and residential care units.	
Language	No particular language.	
Meaning	No non-disabled people live in residential care units. This is only used when the central character is disabled.	

Interview format	
Context	This is where the story has been written in the format of a
	newspaper, TV or radio interview.
Language	No specific language.
Meaning	No specific meaning.

Labelling	
Context	Any reference to the central character being labelled in some
	way, primarily in relation to his or her impairment.
Language	name-calling

Meaning	This is mainly used where the disabled character has been
	picked out by other non-disabled people on the basis of his or
	her impairment.

Lack of confidence	
Context	This is where the storyline indicated that the central character
	has, or has had in the past, a lack of personal confidence.
Language	lacks confidence, shy, became more confident
Meaning	In terms of non-disabled characters this is used in an everyday
	sense, but with disabled characters it is much more related to
	their impairment.

Last line	
Context	Last line of every story. For reference purposes only.
Language	No particular language.
Meaning	This often sums up the tone of the overall story.

Learning disability	
Context	Any mention of difficulties in learning, either implicitly or
	explicitly related to impairment.
Language	finds it difficult to understand, cannot read
Meaning	This generally applies only to disabled characters where an
	obvious impairment is seen or mentioned.

Leisure interests	
Context	Any reference to hobbies or leisure activities.
Language	in his spare time, shopping, gardening
Meaning	No specific meaning but disabled characters seem to have
	more spare time.

Literature/poetry	
Context	This is where the writer of the story has used a poetic format or
	made substantial reference to other literary sources. Quotes or
	references to literature.
Language	No particular language.
Meaning	No particular meaning.

Lives at home/with parents	
Context	Any reference to the central character living with his or her
	parents.
Language	lives with, stays at
Meaning	In most cases it is the disabled characters who live at home
	with their parents, therefore implying that they are more
	dependent than their non-disabled peers.

Mental health	
Context	Any reference to the central character's state of mind.
Language	depressed, anxious
Meaning	The writer is attempting to give the reader an insight into the
	underlying feelings of the central character.

Normality	
Context	Any reference or inference to wanting to be normal. This
	usually means not having an impairment.
Language	normal, ordinary life, like every other person
Meaning	Very often this is used as a discursive topic within the storyline.

## Other people's perceptions

Context	Any reference to how people perceive or think of the central
	character within the story.
Language	No specific language. However, when discussing disabled
	characters, it is more often expressing extreme perceptions,
	such as very brave or sad and lonely.
Meaning	Quite often this is another discursive theme in the storyline.

Overprotection	
Context	This only refers to disabled characters who have led sheltered
	lives, whether they wanted to or not.
Language	his parents took great care of him at home
Meaning	This usually means that the parents of the disabled character
	did not allow them to meet his or her potential or give him or
	her independence.

Pain	
Context	Any reference to pain or physical discomfort.
Language	Pain, sore, aching, phantom itching
Meaning	No particular meaning except that the central character was in discomfort.

Patronising language	
Context	This is language that is implicitly or explicitly patronising about
	the central character. The central character is usually disabled.
Language	brave, lovely, sweet, always smiling despite
Meaning	This is a matter of personal interpretation. However,
	essentially, the overall linguistic effect is to imply that disabled
	people need to cared for, pitied or admired.

Physical access	
Context	This is any reference about the physical barriers in the
	environment for disabled people.
Language	inaccessible, too many steps, not adapted
Meaning	Disabled people face many physical barriers in the
	environment and this is the central issue to their life.

Prove oneself	
Context	This is where the central character is shown as needing or
	wanting to be worthy of respect.
Language	wanted to prove himself, needs to prove people wrong
Meaning	This is basically when the central character has overcome
	some barriers in his or her life.

Quality of life	
Context	This is generally used in relation to disabled central characters
	about how good or bad their lives are.
Language	No specific language but <i>quality of life</i> does come up as a
	term.
Meaning	The main meaning is usually that disabled people have a
	poorer standard of life because of their impairments.

Rehabilitation	
Context	Any reference to a disabled character needing physical or
	sensory rehabilitation in a hospital or residential setting.
Language	No specific language, but quite obvious when used, such as
	rehabilitation.
Meaning	Generally this means the disabled character has been in an
	accident and is in the process of recovery.

Religion	
Context	Any reference to religion, faith or spirituality.
Language	religion, faith, belief
Meaning	No specific meaning but sometimes connected to an event or
	relationship in the central character's life which is attributed to
	fate.

Resignation	
Context	This is references to disabled people being resolved to their
	'unfortunate' state of impairment.
Language	come to terms with, happy with his lot
Meaning	Disabled people often need to accept their impairments when
	they really do not want to.

Sad	
Context	Any reference to being sad, down or in low spirits.
Language	sad, fed-up
Meaning	No particular meaning, but more often used in relation to disabled characters.

Self-reflection	
Context	This is when the central character is ruminating about him or
	herself.
Language	No specific language.
Meaning	The writer is attempting to give you insight into how the central
	character thinks.

## Sentimentality

Context	This is where the writer describes or depicts the central
	character in a romanticised or soppy manner.
Language	sweet, precious, delightful, wonderful
Meaning	Very often used in the context of disabled characters being
	'special'.

Sex/sexuality	
Context	This is any reference to the central character's sexuality or
	sexual relations, implicitly or explicitly.
Language	he likes pretty shop girls
Meaning	That the central character has an identifiable sexuality and has
	a sexual life.

Social model	
Context	This is any storyline that depicts a disabled character in terms
	of the social barriers he or she faces, rather than the
	consequence of his or her impairment. See definition of Social
	model in Chapter 1.
Language	No particular language.
Meaning	The impairment has social consequences and the resulting
	disability is a societal problem not an individual problem.

Sorrow	
Context	This any reference to the central character expressing feelings
	of regret, longing or unfulfilled desire.
Language	Sad language, which is not more long-term in the central
	character's life.
Meaning	That the central character has regrets or feelings that are
	unresolved.

Support/dependence	
Context	Any reference to the central character, mainly disabled
	characters needing help or assistance.
Language	care, carer, support worker, helper, dependence
Meaning	This almost always relates to disabled characters needing help
	and support in their everyday lives.

Success/achievement	
Context	Any reference to the central character's personal or work
	success.
Language	successful, has come far
Meaning	No particular meaning, but generally the writer highlights
	disabled characters' achievements more in terms of
	overcoming adversity.

Surreal	
Context	Any weird or quirky storylines or parts of storylines that are
	unrealistic in their basis but 'arty' in their literary style.
Language	No specific language.
Meaning	No specific meaning.

Survival	
Context	This is any reference to surviving a life or death event, such as
	an accident or hospital treatment.
Language	No particular language.
Meaning	The central character is usually depicted as courageous or
	determined.

Tolerance	
Context	Any reference to the central character being tolerant of other
	people or other people being tolerant of him or her.
Language	tolerated, put up with
Meaning	No particular meaning, except that the central character is
	essentially a reasonable and patient person.

Tragedy	
Context	This is any reference within the storyline that implicitly or
	explicitly indicates that the events in the central character's life
	are unfortunate and have negative consequences.
Language	tragic, unfortunate
Meaning	Primarily this means that having an impairment is a tragic
	experience with no positive outcomes.

Transport/access	
Context	Any reference to the central character's means of getting
	around, such as cars, buses or adapted vehicles. Also it
	includes references to physical access to buildings or the wider
	environment.
Language	adapted van, dropped kerb
Meaning	No particular meaning, but primarily used when relating to the
	physical impairment of the central character.

Treatment/medication	
Context	Any reference to the use of drugs, surgery or therapy to help
	with an impairment or medical condition.
Language	No specific language, but terms such a physio, medication and
	therapy are common.

Meaning	This mainly relates to the disabled characters and implies that
	they need more medical input.

Unrealistic		
Context	This is any scenario whereby the central character is meant to	
	be able to do things that are physically or sensorily impossible	
	with their capabilities.	
Language	No specific language.	
Meaning	The central character is superhuman, despite his or her	
	impairment.	

Upset	
Context	Any reference to the central character being distressed but not
	sad, i.e. it was a definite event that made them distressed.
Language	she was upset by
Meaning	No particular meaning.

Works hard		
Context	Any reference to the central character being a hard worker,	
	particularly in an employment context.	
Language	works hard, long hours	
Meaning	No particular meaning but indicates the central character is a	
	busy and committed person.	

## **Results and Analysis of Storyboard Stories**

All the stories were categorised using the microcodes into macrocategories. The macrocategories were identified by using a

combination of the microcodes and the macrocategory criteria. The macrocategory criteria were made up of: the types of language used in the stories; outcomes and consequences of the stories on the character; the state of mind of the character; the tone of the story; and finally the overall meaning promoted by the writer about the character's life. Macrocategory criteria for each macrocategory as detailed below. This methodology of a multi-tiered approach to the data allowed the researcher to analyse the raw material at both a micro and a macro level. It enables the consequent data to be examined in both a qualitative and quantitative manner.

#### Macrocategory Definitions

The macrocategories are detailed below.

#### (1) Brave / Determined

(a) <u>Language</u>: The language in these stories is always of heroic qualities. Words such as 'brave', 'courageous', and 'determined' are common.

(b) <u>Outcomes / consequences</u>: The outcomes and consequences in these stories are very varied. A sense of unjustified optimism is expressed by the character in these stories and latent patronisation on behalf of the writer is the general feeling.

(c) <u>State of mind</u>: The central characters in these stories are eternally happy and positive despite what the real world throws at them. These characters may be described as being 'chirpy'.

(d) <u>Tone of story</u>: Very much related to the outcomes in the story. A general sense that central characters have become 'better people' because of their impairments.

### (2) Denial

(a) <u>Language</u>: These stories tend to avoid using disability-related language when it would be very appropriate to mention a character's impairment.

(b) <u>Outcomes / consequences</u>: The outcomes in these stories tend to be slightly unrealistic, given the obvious impairment of the central character. This is different from Happy/Idealisation (5) where the central character's impairment or condition is mentioned within the story.

(c) <u>State of mind</u>: The central characters in these stories are most often positive, successful and active.

(d) <u>Tone of story</u>: These stories are usually optimistic and upbeat in an unrealistic way.

### (3) Exceptional / Special

(a) <u>Language</u>: The language used in these stories is one of extreme or special ability. Words such as 'intelligent', 'creative', and 'imaginative' are used.

(b) <u>Outcomes / consequences</u>: The central characters in these stories are very successful either in employment or in a personal way. This is attributed to their organisational ability and special equipment.

(c) <u>State of mind</u>: These central characters are very motivated, intelligent, determined, and happy people. Their impairments are almost seen as an inconsequential distraction to their ability, but at the same time the reason for their ability.

(d) <u>Tone of story</u>: The tone is upbeat, humorous, and fun to read with some interesting twists as well.

## (4) Fate

(a) <u>Language</u>: These stories are couched in language that refers to fate, faith, or natural mystery. Words such as 'blessing', 'nature', and 'faith' are used.

(b) <u>Outcomes / consequences</u>: The outcomes of these stories are spiritual resolutions of the character's predicament, such as 'the accident meant they met someone special to them'.

(c) <u>State of mind</u>: Usually the characters are very reflective and are working through their dilemmas.

(d) <u>Tone of story</u>: These stories are very much about 'it was meant to be' or 'why me?' They deal with issues that are teleological and attribute the cause of disability to an external cause such as God or a mystical natural force.

## (5) Happy / Idealisation

(a) <u>Language</u>: In these stories words such as 'happy', 'smiling' and 'content' are commonplace, despite the central character's impairment or condition.

(b) <u>Outcomes / consequences</u>: In these stories the central character is living an almost idyllic life despite his or her obvious impairment.

(c) <u>State of mind</u>: The central characters are always overly positive and happy.

(d) <u>Tone of story</u>: These stories tend to be either about triumphing over adversity or remaining cheerful in the face of adversity. Alternatively, they are about there not being any adversity despite our common knowledge that with an impairment there must be some adversity.

## (6) Incidental (Disabled)

NB: These stories can only be storyboard types 2, 3, 5, 6, 7, 8, 9, 10, 11 and 12.

(a) <u>Language</u>: In these stories, when disability is mentioned it is very matter of fact and functional and in many cases disability is not mentioned at all. No emotive terms such as 'suffer' or 'victim' are used.

(b) <u>Outcomes / consequences</u>: Very varied. The characters are leading a 'normal life' with incidental reference to their impairments or needs.

(c) <u>State of mind</u>: Characters are generally positive and happy with their lives. If there are problems, they are not related to their impairments.

(d) <u>Tone of story</u>: Stories are generally positive and full of everyday themes. For instance, the implications of stress at work, or the difficulties of relationships.

## (7) Medical

(a) <u>Language</u>: These stories make reference to operations, treatment, and medication. Reference to medical conditions and their effects are common. Usually the illness or condition is seen as a problem to be managed or overcome.

(b) <u>Outcomes / consequences</u>: Characters in these stories are constantly battling against their impairments, particularly in terms of pain, discomfort, or inconvenience.

(c) <u>State of mind</u>: Characters in these stories are portrayed as being resolute and being determined to make the best of a bad job.

(d) <u>Tone of story</u>: These stories vary in tone. The medicalisation of the problem is a notable feature.

## (8) Sad / Lonely

(a) <u>Language</u>: The language used in these stories directly or indirectly implies an unhappy and/or dissatisfied person. Words such as 'depressed', 'sad', 'lonely', and 'unhappy' are used. Other situational language such as 'being left' or 'being alone' are also common.

(b) <u>Outcomes / consequences</u>: In these stories the central character has always been either abandoned or is lonely in some way. This means that the character lives alone and has few friends. This is often explicitly related to the acquirement of an impairment. The employment status of the central character is always poor.

(c) <u>State of mind</u>: Central characters are always depressed, resentful, or sad about what might have been.

(d) <u>Tone of story</u>: These stories are bleak in their analysis of the past and the future. Being disabled is very hard work and does not provide a good quality of life.

## (9) Support / Dependence

(a) <u>Language</u>: These stories most often use words such as 'dependent', 'help', 'support', 'assistance' and 'care'. The language directly implies that the central character is in need of constant help.

(b) <u>Outcomes / consequences</u>: The outcomes of these stories are very varied, however, one of the main themes is the central character's need to be given help by a non-disabled person.

(c) <u>State of mind</u>: No particular state of mind, but the disabled central character is often frustrated or annoyed that he or she is dependent on help.

(d) <u>Tone of story</u>: No particular tone in these stories but the relationship between the disabled central character and his or her non-disabled helper is quite important.

## (10) Tragedy

(a) <u>Language</u>: These stories always use terms such as 'tragic', 'unfortunate' or 'if it wasn't for...' The language is always related to a tragic consequence of becoming or being born disabled.

(b) <u>Outcomes / consequences</u>: There are a wide range of outcomes in these stories, but most of them are related to the negative consequences of the impairment or condition.

(c) <u>State of mind</u>: The disabled central characters in these stories express a wide variety of mental states, however, they tend to be on the negative side of life.

(d) <u>Tone of story</u>: These stories are often melodramatic and heavy to read.

### **Control (non-disabled)**

NB: These stories can only be storyboard types 1 and 4.

(a) <u>Language</u>: The language in this category does not refer directly or indirectly to disability and generally expresses non-disabled lifestyles.

(b) <u>Outcomes / consequences</u>: In these stories, the central characters have a variety of life outcomes, which are not disability related.

(c) <u>State of mind</u>: These central characters have a wide variety of mindsets, which are definitely not disability related.

(d) <u>Tone of story</u>: No particular tone, as these stories are the control stories.

## **Disability (non-disabled)**

NB: These stories can only be storyboard types 1 and 4.

(a) <u>Language</u>: The language in these stories is very wide, but the central theme of the language is the mental health of the central nondisabled character.

(b) <u>Outcomes / consequences</u>: The outcomes in these stories are very varied, however, they are related to the mental health of the non-disabled character.

(c) <u>State of mind</u>: The central character has a recognisable mental health problem.

(d) <u>Tone of story</u>: These stories tend to be quite sad and stressful.

## **Macrocategory Frequencies**

The frequencies of each macrocategory are demonstrated in the below table.

### **Table A: Macrocategory Frequencies**

		Frequency	Percent	
Valid	Brave/Determined	25	11.8	
	Control (non-disabled)	19	9.0	
	Denial	12	5.7	
	Disability (non-disabled)	5	2.4	
	Exceptional/Special	20	9.5	
	Fate	11	5.2	
	Incidental (disabled)	33	15.6	
	Medical	5	2.4	
	Sad/Lonely	27	12.8	
	Support/Dependence	20	9.5	
	Tragedy	10	4.7	
	Happy/Idealisation	24	11.4	
	Total	211	100.0	

Macrocategory

## Introduction to Storyboard Data Analysis

It is clear from the context and length of the stories by the majority of subjects that these disability storyboards offer an opportunity for subjects to use their imagination and apply their narrative skills. One hundred and seventy-nine out of 211 subjects reported either verbally or in writing that they had enjoyed completing the task (the remainder made no comments on the matter). None of the subjects withdrew their material when they were debriefed about the true nature of the study. On the debriefing no subjects expressed any annoyance or dismay by the fact that the true nature of the study was disability related. Seventeen of the subjects admitted to suspecting that the study was disability related, but the rest did not admit to guessing the true nature of the study.

It is essential in order to fully understand the development and application of the microcodes and macrocategories that the study takes an in-depth look at some 'typical' stories within each macrocategory and examine how the coding was applied and what underlying attractions, attitudes and assumptions are present in each. I will use quotation maps and microcode association diagrams from each macrocategory to compare and contrast other stories in the same macrocategory. I will deal with each macrocategory in turn, using two different stories with a third story in the Appendix (Appendix 5). These sample stories will highlight the key points to be made about each macrocategory, but they are not completely exhaustive in terms of the issues they raise relating to disability. However they will demonstrate the key component of each type of Social Representation of disability that non-disabled people actively present and represent.

### Sample story analysis

I will first of all undertake a detailed analysis of two stories per macrocategory and I will incorporate quotations from other relevant

stories within that macrocategory to illustrate the points that I want to highlight. Finally, I will present an overall characterisation of the key themes within each macrocategory with an analysis of the possible meaning, motivation and origin of this Social Representation.

#### Quotation map analysis

In order to offer a wide appreciation of each macrocategory, the study has developed quotation maps, whereby particularly relevant quotations from a wide range of stories within the macrocategory are displayed and open to scrutiny. A quotation map is generated by Atlas Ti when the programme is asked to collate quotations with the same microcode or macrocategory. Out of these the most relevant of each macrocategory has been discussed. These will not be discussed in detail, however particularly good examples have been highlighted. These quotation maps allow us to examine and explore a wider range of stories within the macrocategory, without needing to include the full text. This allows a deeper understanding of the range of narrative styles used by the subjects.

#### Microcode analysis

For each macrocategory the microcodes and their frequency will be discussed in terms of their ranking, context and potential meaning. This study applied a semiotic approach to the development of these microcodes. There are three types of microcode, which in this study will be treated as having equal value in terms of meaning, motivation and representation. First, there are microcodes that are organic in their origin from the actual narrative within the stories, such as 'Determination', 'Happy' and 'Courage/bravery'. These microcodes are based on the same words that are repeated in different stories. Second, there are interpretative microcodes where the researcher has deduced or inferred a particular meaning, motivation or emotion from the narrative within the story. Examples of these microcodes are 'Patronising language', 'Disability language' and 'Self reflection'. Finally, there are thematic microcodes, such as 'Employment Issues', 'Leisure Interests' and 'Transport Access'. This analysis will concentrate on the microcodes which are mentioned 5 or more times within each macrocategory. However, this does not rule out examination of other microcodes which may be of interest. This allows the study to include what is not mentioned as well.

### Word count analysis

The word count of each macrocategory will be analysed in a semiotic framework. Each word count will be analysed in terms of context, meaning and language. The analytical process used to identify the key words within each macrocategory was as follows.

- All words were counted in each story within each macrocategory, using Atlas.ti. This gave a massive range, consisting of almost 60,000 words, most of which were everyday words.
- Each story was then analysed in terms of disability related words, disability related context and disability related outcomes. This gave a much narrower range of words.

Although this was a purely qualitative technique and open to subjectivity, the selection was affirmed by two independent inter-raters. It is likely that the selection criteria were somewhat more conservative than may have been necessary. However, this was to minimise any research bias.

## **Detailed Macrocategory Analysis**

## (1) Brave/Determined

### **Overall analysis**

This is the third most prevalent macrocategory with 25 stories designated to it. This represents 11.8% of all stories. Eighteen women and 6 men wrote these stories with 1 missing gender in the data. The expected count is marginally less for female participants and marginally higher for male ones. There is no statistical significance; however it may indicate a minor trend. Eleven out of 25 stories were written by medical professionals. This is marginally higher than one would expect from this sample size. There was no difference in the numbers produced by charity workers and ordinary people. This macrocategory is characterised by the use of flamboyant and emotive language. The characters are depicted as being almost larger than life in that their struggle with their disability or impairment is the central part of their life.

### Sample story 1 discussion

The first sample story (see page 106) illustrates many of these points well. The story is set out below in full. This story was written by a white male charity worker in the age range 46-60. It is written about a Type 3 storyboard, which is Max with an acquired disability (amputee). The opening two sentences are representative of how the story continues: 'Max is a tough cookie. You have to fight back after such a terrible accident.' This sets the reader up for an emotional rollercoaster ride. A theme of triumph over adversity is repeated: First, he grew up within a poor family; Second, after the accident when he overcame his impairment with his father's spirit. There are constant references to determination, bravery and exceptional ability. Like many of the best stories there is a good helping of humour. The foot joke is particularly good. It indicates a

sense of irony in the writer showing that disability can be a source of humour. The language is explicit in different ways: 'from terrible accident' to 'Max had soaked up these attributes like a sponge.' In comparison to the control stories, the language used in the disability stories is much more dynamic and emotive. In the Brave/Determined stories the central characters, particularly if they are male, are real fighters with exceptional abilities and a sense of their own worth. Achievement is a central theme of this macrocategory. It is almost as if being or becoming disabled provide the central character with a new inner-strength and ability. This is a very interesting psychological analysis of what non-disabled people perceive disability to be in some instances. It is indicative that there is an underlying myth that having a disability makes you somehow special whether or not there is any actual evidence of this assumption. This is particularly true for male characters within the Brave/Determined macrocategory.

#### Sample story 2 discussion

The second sample story (see page 109) was written by a white female medical professional aged 18-25. This was a Type 10 story, which is Eve with no mention. The story is set out in full below. This is a good example of the Brave/Determined macrocategory for a female character. For instance, the opening sentence is 'Eve is a bright and lively thirty-year-old who loves life as well as Steps and Westlife!' The final sentence ends, 'the sense of achievement is so much better when she succeeds.' Throughout the story, her disability is only alluded to rather than explicitly mentioned. Her independence is emphasised, and everyday activities such as going to college and the supermarket take on a special meaning. The story is aspirational and gives the reader a real sense that Eve is a strong character coping with many difficulties. The writer appears to feel that Eve's apparent disability is a central part of her life in terms of how

she relates to the rest of the world. The writer does not explicitly say this, but the tone of the story implies it such as 'at college she gets help learning how to cope on her own.' Some of the language is quite patronising - not many thirty-year-old women are going to be fans of Steps or Westlife. It is as if Eve is an eternal adolescent. It also may say something about the taste of the writer!

# Figure 5: Brave/Determined Sample Story 1 (page 1 of 3)

# Brave/Determined Sample Story 1 (page 2 of 3)

# Brave/Determined Sample Story 1 (page 3 of 3)

# Figure 6: Brave/Determined Sample Story 2 (page 1 of 1)

#### **Quotation Maps**

In the Brave/Determined macrocategory, there are three pages of quotation maps with 20 selected quotes. From the quotation map for Brave/Determined it is clear that Tom is the main recipient of this type of quote, followed by Max. For instance, Quote 51:4: 'Tom is an extremely courageous man' is a classic example of a Tom story, whereas Quote 186:2: 'Max is an extremely tough cookie' is also a good example of Brave/Determined. The quotation map reaffirms that most of the Brave/Determined quotes are about male characters. This is a very interesting finding. There are of course quotations relating to female characters, such as Quote 61:4: 'All her life she had learnt to cope', which refers to the life of Caroline. However, these quotes are much less common. It becomes clear that non-disabled people appear to think that disabled men are braver and more determined than disabled women. Examining the data within this macrocategory, there is an underlying feeling that women cope with disability in a quieter manner. This is an interesting Social Representation of gender difference in the context of disability.

# Figure 7: Illustrative Quotation Map: Brave/Determined

# Figure 8: Additional Key Quotations

#### Microcode Frequencies within Macrocategory

In terms of the Brave/Determined macrocategory there are 23 microcodes with 5 or more hits (see Figure 9). These are: 'Other people's perceptions'; 'Employment issues'; 'Family life'; 'Friendships/relationships'; 'Adversity/struggle'; 'Happy'; 'Disability equipment'; 'Support/dependence'; 'Alluding to impairment'; 'Selfreflection': 'Transport/access'; 'Aspiration'; 'Disability language'; 'Independence'; 'Determination'; 'Frustrated/angry'; 'Leisure Interests'; 'Cause of disability/impairment'; 'Communication'; 'Mental health'; 'Sex/sexuality'. From the microcode map it is notable that there are 7 microcodes with more than 10 mentions. The most common microcode in this macrocategory is 'Other people's perceptions'. This is always related to how non-disabled people perceive the disabled character in the story. In this context the perceptions are always associated with determination, bravery and courage. This is supported by the presence of the fifth most common microcode, 'Adversity/struggle'. It is very interesting that the microcode 'Courage/bravery' only has three mentions. This is because in the stories within this macrocategory, much of the meaning and sentiment is indirectly implied in the narrative. This may be because the writers did not want to appear patronising, but their underlying Social Representation of disabled people was that they were brave and determined. This point is supported by the microcode 'Alluding to impairment', which has 8 mentions; i.e. the writer did not directly address the existence of an apparent impairment. It is also interesting that 'Employment issues', 'Family life' and 'Friendships/relationships' come very high on the list. Many of these stories portray a positive, if sometimes patronising and unrealistic, lifestyle of disabled people. There is an underlying implication that because these disabled people are brave and determined that they are successful, have relationships and are, overall, happy. In addition,

mention of disability equipment and independence underpin this theme. Finally, this is one of the few macrocategories where sex and sexuality are mentioned. This is a further indicator that the writers want to normalise the disabled characters in a way that they understand.

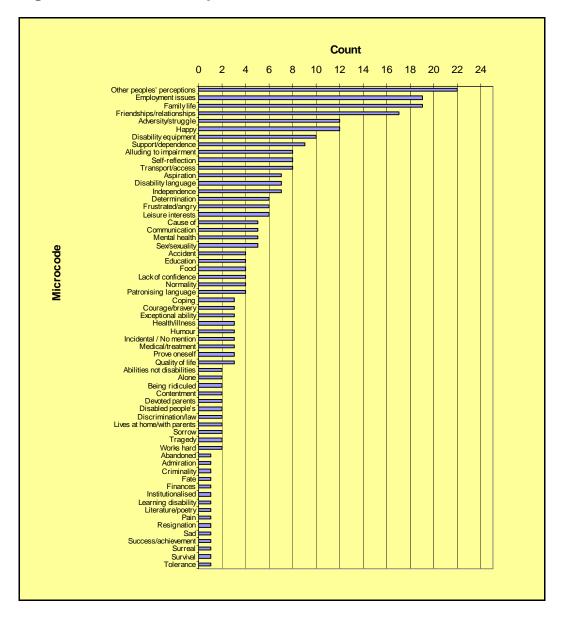


Figure 9: Microcode Graph: Brave/Determined

### Word Count Analysis

In the Brave/Determined macrocategory, there were 37 disability-related words either in language terms or context terms. Eighteen of these words have 2 counts or more. The highest counts were for 'Downs' and 'help'. This is a real indicator of how people use specific words when depicting disabled characters. It will become clear in every macrocategory that the word 'help' is very often one of the most used words. Other important words were related to equipment or accidents and mental health. The word counts are in Figure 10 below. It is interesting to note that people recognise Downs syndrome and use the term appropriately in most stories. This may be because Downs syndrome is a well recognised impairment and is visually quite striking. Also, Downs syndrome people, because of the development of community care, are more often seen out in everyday society. Finally, it is noticeable that most words used in this macrocategory have an undertone of overcoming adversity.

Figure 10:	<b>Brave/Determined</b>	Word Counts
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Down	16	Blind	1
Help	14	Deafness	1
Home	9	Determined	1
Disability	8	Difficulties	1
Wheelchair	7	Dignity	1
Accident	6	Disabilities	1
Able	5	Discriminated	1
Deaf	3	Disease	1
Disabled	3	Enlightened	1
Helped	3	Illness	1
Lucky	3	Limbs	1
Needed	3	Normality	1
Cope	2	Overcome	1
Depression	2	Prosthesis	1
Difficulty	2	Rehab	1
Helps	2	Therapy	1
Independence	2	Treated	1
Normal	2	Tumour	1
Ability	1		

## (2) Denial

### **Overall analysis**

In this macrocategory there are 12 stories, which represent 5.7% of all stories. All of the 12 stories were written by female subjects. This is 2.5% above the expected count. More stories in the Denial macrocategory were written by younger people than older people. 8 of the 12 stories were written by people under 35. This may be an experimental artefact, however it may also indicate the 'political correctness' in younger people when confronted with images of disabled people. In terms of the gender difference this may well be related. It is very interesting that there were no stories about the character Tom, who is severely disabled in a wheelchair, in this category. However, when the character is less noticeably disabled, denial-type stories can be designated to this macrocategory. Max and Eve both have a higher than expected count in this macrocategory with 4 and 5 stories respectively, compared with an expected count of 2.8. This study cannot make any firm conclusions from this small sample. However, it is clear that when the disability is completely apparent, denial does not take place. In terms of the preamble, there is no significant difference from the expected count. In terms of this image, when this is a non-disabled image there is a higher than expected count. This needs to be cross-referenced with the preamble. 7 of the 8 preambles have disabled images, therefore it is clear that the image is having an effect. It is possible that people do not want to be seen to be disrespectful of the images of disabled people and so do not write about them when it would have been appropriate. There is a more noticeable difference between characters with born disabilities than with acquired disabilities in this macrocategory.

#### Sample story 1 discussion

The first sample story (see page 119) is written by a white female medical professional aged 26-35. This writer wrote about a type 3 storyboard, which is Max with an acquired disability (Leg amputee). In this story Max is depicted as having a 'rags-to-riches' life. Throughout this story his hard work and success are emphasised. The writer highlights Max's exceptional abilities. At no point in the story is his impairment or the outcome of the car accident mentioned. Either the writer did not read the preamble, which is unlikely given the experimental format, or the writer made a conscious decision to ignore this aspect of Max's life. The latter seems more likely because of the way Max is portrayed as being exceptional. This may be a case of 'political correctness' out of context.

### Sample story 2 discussion

The second sample story (see page 120) is written by a female charity worker aged 18-25. She wrote about a type 10 storyboard, which is Eve (no mention of disability). At no point in this story is Eve's Down's syndrome mentioned, which is very apparent from the images. However, in this story there are common misconceptions relating to Down's syndrome, such as Eve is 'happy', 'friendly' and 'likes her food'. It is clear that the writer is avoiding mentioning her impairment. This may be related to the writer not knowing much about Down's syndrome people or being too embarrassed to make it part of her story. This macrocategory of Denial is different from the macrocategory of Incidental (disabled), because in Denial the disability is quite apparent either in the image or preamble and is noticeably absent from the storyline. Whereas in the Incidental (disabled) macrocategory the disability is used in the storyline, but only in terms of a natural part of the character's life. The disability is not the central theme of the story, but is incidental to it.

# Figure 11: Denial Sample Story 1 (page 1 of 1)

# Figure 12: Denial Sample Story 2 (page 1 of 1)

#### **Quotation Maps**

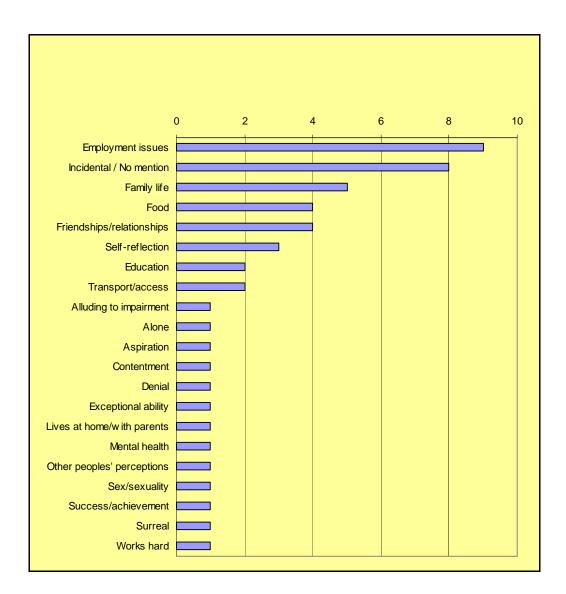
There are not many quotes within the macrocategory of Denial. One of the difficulties about this macrocategory is that because the writer is in denial when the impairment is apparent or explicitly mentioned it is hard to identify individual quotes without presenting the whole text. The underlying problem in highlighting this macrocategory is that the nature of quotation is to identify a particular meaning or motivation, however in this instance it is the absence of meaning and motivation where it would be appropriate in relation to disability. All the quotes included however, are quite striking in their complete denial of the character's impairment. For instance, Quote 58:9: 'Her mum told her it was because she was special.' This is about Eve, whose Downs syndrome is very apparent, but no mention of this is made in the story.

# Figure 13: Illustrative Quotation Map: Denial (1 of 1)

#### Microcode Frequencies within Macrocategory

This is an interesting set of microcodes because there are only 3 with 5 or more mentions. These are 'Employment issues', 'Incidental/no mention' and 'Family life'. It is noticeable that the nearest mention of impairment is 'Alluding to impairments', which is the tenth most common in this macrocategory. These subjects were presented with apparently disabled people and, unlike the Incidental/No mention macrocategory, have avoided the issue of disability in their stories, even when it would have been appropriate. This narrative strategy has definitely narrowed the field of topics discussed within the stories. All the stories only mention 'Employment issues' or 'Family and friends' save 'Incidental/no mention'. To examine these stories from a semiotic perspective, it is clear that they are written by subjects who are resistant to tackling issues around disability when they would make good narratives. This is why this study has designated them as in denial. It is not clear why this should happen, but it could be a combination of embarrassment, political correctness or a lack of knowledge or experience of disability.





### Word Count Analysis

In this macrocategory word count there are 10 disability related words; the highest, with 2, being 'able'. Denial is an interesting macrocategory because the writer is actively denying the disabled theme on the storyboard. In this macrocategory word count there are positive words, such as 'ability', 'achieve' and 'expertise'. This is a real indicator that the writer is making a conscious effort to avoid negative images of disability.

### **Figure 15: Denial Word Counts**

2
1
1
1
1
1
1
1
1
1

### (3) Exceptional/Special

### **Overall analysis**

This macrocategory was designated 20 stories, which represents 9.5% of all stories. 9 of the stories were written by charity workers, which is one third more than the expected count. Ordinary people and medical professionals wrote 5 and 6 stories respectively. This was marginally below the expected count. Fourteen women subjects wrote exceptional/special stories compared to 6 men. However this is not significant since there are twice as many women than men in this sample. The stories were reasonably distributed throughout the age range. It is very interesting that charity workers tended to write more of these types of stories than the other groups. This may be because, having contact with disabled people, they have met disabled people who have been

inspirational to them or made an impression upon them. It could also be the case that charity workers feel that they are exceptional/special people for working with disabled people and therefore like to believe that the people they work for and with are exceptional or special in their own way. All these stories make the central character outstanding in their achievements, and their disability has been overcome by the character's exceptional ability.

#### Sample story 1 discussion

The first sample story in this macrocategory is by a female charity worker aged 36-45. She wrote about a type 2 story, which is Max with a born disability (deafness). In this story Max is exceptional because he is one of the few deaf forensic scientists in the world. The story continues in much detail about how he overcame his impairment by using new technology. In the story Max's wife has died. Therefore there is an underlying sense of him needing to overcome another barrier, which is his loneliness. The whole story vividly depicts him as an exceptional and special man who is admired by his friends and work colleagues. In addition, Max is portrayed as having a deep faith in God and is very self-reflexive about society. This story is interesting in the way that it depicts Max overcoming his impairment with the use of new technology. As a charity worker, the writer is apparently aware of what is possible. However, the story is still very dark in its tone despite Max's achievements. This is actually a very interesting mixture of representations, because many non-disabled lives are successful and sad at the same time. Therefore this writer may have decided to tap into that blend of exceptional with a tinge of sadness.

#### Sample story 2 discussion

The second sample story comes from a white male charity worker aged 26-35 who is writing a type 5 storyboard, which is Caroline born deaf. Once more we see in this story an extremely dynamic and exceptional

person, despite her mentioned impairment. In the story Caroline is very successful, confident and creative. However she still seems to be alone, although this is not the main theme of the story. The writer may have an insight into the lives of deaf people where this is quite well documented, primarily concerning deaf people in their leisure time. This is possible because the writer works in the Royal National Institute for the Deaf. This is a direct example of how first hand knowledge imprints on the content of the story. Throughout this macrocategory there was a real emphasis on born disabled people being exceptional. Twelve out of the 20 stories were of born disabled people storyboards. This was almost double the expected count for this sample. In the no mention storyboards exceptional/special came out at under half the expected count. This gives a clear indication that non-disabled people perceive born-disabled people to be more exceptional than acquired disabled people. This may be because they have a concept that born disabled people must confront many more barriers throughout their life and overcome them. This is demonstrated in other stories within this macrocategory. It also implicitly indicates that perhaps becoming disabled in late life does not automatically make the character exceptional or special since they had led 'a normal life' before. This may mean that we need to examine the reification of born disability. This is connected to people's common sense knowledge relating to born impairments. This is aligned with Moscovici's theory that reified knowledge is separate from common knowledge. It is more likely that non-disabled people experience an acquired disability rather than a born disability. The reason for this is that only 17% of all disabled people are born disabled. Therefore the likelihood of direct contact with a born disabled person is much less likely compared to that with an acquired disabled person.

# Figure 16: Exceptional/Special Sample Story 1 (page 1 of 2)

# Exceptional/Special Sample Story 1 (page 2 of 2)

# Figure 17: Exceptional/Special Sample Story 2 (page 1 of 2)

# Exceptional/Special Sample Story 2 (page 2 of 2)

#### **Quotation Maps**

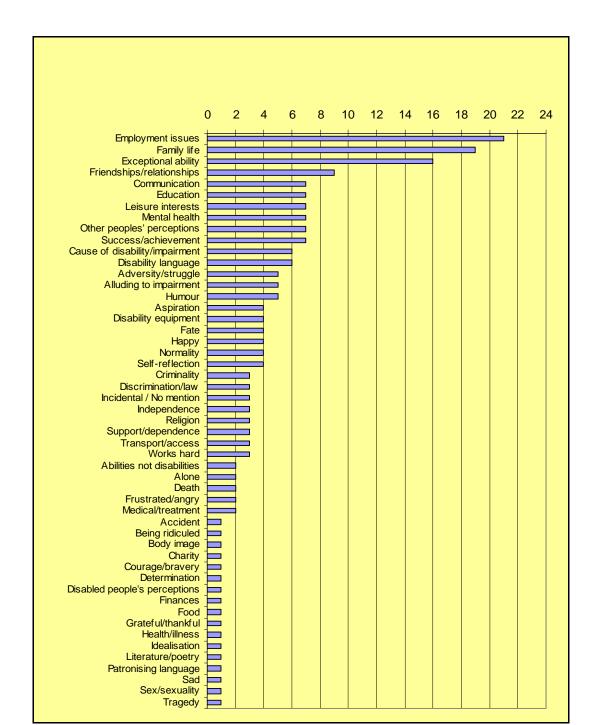
In this macrocategory there were a huge number of possible quotations. I have summarised some of them in the three quotation maps. The overwhelming majority of quotations are related to Tom. It is reasonable to infer that there is a relationship between Tom's apparent severe disability and him having exceptional or special qualities. For instance, Quote 153:2: 'Having won the Turner last year' or Quote 125:4: 'Being an academic child, Tom sailed'. Both of these quotes imply that the writer considers Tom to be unusually gifted, despite his impairment. This may be seen to be a 'Professor Stephen Hawkins syndrome'. It is interesting that Tom has not appeared in the sample stories because despite having many quotes relating to Exceptional/Special, most of Tom's stories do not fall into the Exceptional/Special macrocategory. Max and Caroline are often attributed Exceptional/Special qualities, whereas Eve is rarely seen to be exceptional or special, except in a patronising context. For instance, Caroline in Quote 49:10: 'Despite being a "superwoman" in her spare time' or Max in Quote 118:7 'Max will go far!', where as Eve's representation of the exceptional is unrealistic, see Quote 67:9: 'Then she wouldn't have to be head of a crime ring'.

# Figure 18: Illustrative Quotation Map: Exceptional/Special

# Figure 19: Additional Key Quotations

### Microcode Frequencies within Macrocategory

In this macrocategory there are 15 microcodes that have 5 or more mentions. These are 'Employment issues', 'Family life', 'Exceptional ability', 'Friendships/relationships', 'Communication', 'Education', 'Leisure interests'. 'Mental health'. 'Other people's perceptions', 'Success/achievement', 'Cause of disability/impairment', 'Disability language', 'Adversity/struggle', 'Alluding to impairment' and 'Humour'. It is noticeable that the third most common microcode is 'Exceptional ability' with 16 mentions. This is very much emphasising how these stories concentrate and highlight exceptional ability among disabled people. In addition, it is worth noting that 'Education', 'Success', 'Achievement' and 'Adversity/struggle' all have quite high scores. This is very much about the writer painting a picture whereby disabled people are extremely able despite their impairments. Also, this is the only macrocategory where humour is noticeable. This may be because non-disabled people are able to see humour in successful disabled people, but not in unsuccessful impaired people. This is possibly because the writers do not want to be politically incorrect. All these stories are positive and involve imaginative, charismatic disabled characters.



### Figure 20: Microcode Graph: Exceptional/Special

### Word Count Analysis

In this macrocategory word count there are 41 different words which are disability related, with 24 having more than 2 counts. The highest counts are for 'deaf' and 'help'. It is very interesting that many of the words relate to deafness or communication. This is because the Exceptional macrocategory stories are related to Max, when he is deaf or Caroline, when she is deaf. Tom is often Exceptional as well. It is possible than non-disabled people find the concept of living with deafness an extraordinary feat and therefore write about its consequences in terms of communication, discrimination and being special. Therefore the words are all related to different kinds of support and communication.

Deaf	22	Normal	2
Help	10	Skills	2
Profoundly	7	Weakness	2
Able	6	Autonomy	1
Special	6	Braving	1
Difficult	5	Diagnosed	1
Accident	4	Difference	1
Different	4	Dyslexia	1
Hospital	4	Epilepsy	1
Support	4	Human	1
Communication	4	Illiterate	1
Disability	4	Independence	1
Discrimination	3	Kindness	1
Needed	3	Mobility	1
Victim	3	Ordinary	1
Wheelchair	3	Signing	1
Ability	2	Specialises	1
Deafness	2	Specializes	1
Determined	2	Tragedy	1
Independent	2	Tumours	1
Interpreter	2		

### Figure 21: Exceptional/Special Word Counts

### **Overall analysis**

The fate macrocategory has 11 stories designated to it, which is 5.2% of the total story numbers. The distribution between male and female is roughly equal with 5 male and 6 female, which are very close to the expected counts. However, men did write slightly more stories than expected and women wrote slightly less. Therefore there is no direct significant gender difference within the macrocategory. In terms of age it is noteworthy that 5 out of 11 stories were written by people aged 46-60. Although this may not be statistically significant, it may be an indicator that older people have a stronger belief in fate in terms of their religious faith or their spiritual approach to life. Tom and Max were designated 5 and 4 stories respectively. Both of these are almost double their expected count. Not too much can be made of this small sample, however it is very interesting that male characters were seen to be written in more fatalistic and spiritual scenarios. There is no major occupational difference within this macrocategory, however charity workers did write slightly more stories than the expected count.

A major feature of this macrocategory is that acquired disabled storyboards produced twice as many stories as born disabled storyboards. Therefore it is clear that subjects are of the opinion that becoming disabled is more a mater of fate than being born with a disability. This would also have a knock-on effect of making that 'fatal accident' a more serious matter than simply being born with an impairment. This is a theme that comes up in other macrocategories, that the 'loss of normality' is the real problem rather than the impairment itself. In terms of the images used there were no differences between the number of stories produced when the image was apparently disabled or non-disabled. However, there was a small difference when there was a mention of disability in the preamble.

### Sample story 1 discussion

The first sample story (see page 141) within this macrocategory was written by a white female charity worker aged 46-60. This subject wrote a type 3 story, which is Max with an acquired disability. This is a very interesting piece of work because it is in the form of a poem. It is very much focussed on the central character's religious faith and that their accident was part of their spiritual journey. This story is an excellent example about how people rationalise unfortunate events in their life through their faith in God. This is particularly important when people become disabled, because they need to understand why it has happened to them and not to someone else. From a scientifically rational point of view, accidents can happen to anyone, this is what makes them accidents. However, where there is some kind of overarching belief system accidents are often interpreted as meaningful signs. In the last verse of the poem it is clear that Max is determined to start a new life despite his new disability. There is an implicit sense that he has been reborn.

### Sample story 2 discussion

The second sample story (see page 142) is written by a white female medical professional; age unknown. She wrote about a type 8 storyboard, which is Tom who lives in an institution and has a chance meeting with a medical consultant. This consultant finds funding for a new wheelchair and communication equipment. The story is somewhat patronising because Tom is always passive and dependent. It is clear that the writer thinks that disabled people have a poor quality of life and need medical intervention. The language used is quite emotive, such as 'he may still be chairbound with no quality of life.' This is an example of a story where the

writer is saying that disabled people are dependent on other people to rescue them. This is a medicalised approach to disability. However, the central point is that the consultant just happens to take an interest in Tom. This is very much based on fate according to the writer. As a medical professional, the writer may have experienced that doctors sometimes stumble over patients who have been ignored before. There is an intellectual rationale to the story.

# Figure 22: Fate Sample Story 1 (page 1 of 1)

# Figure 23: Fate Sample Story 2 (page 1 of 1)

### **Quotation Maps**

When the quotations for this macrocategory and examined in a wider context one finds three key themes: Firstly; God, Secondly; luck and thirdly; faith. It is clear from the quotation map that many people connect impairment with a religious intervention. This can be highlighted by Quote 28:3: 'He always thanks God for what he has achieved', which refers to Tom with a born disability. Another example is Quote 202:12: 'Where is a sovereign God when evil comes?'. This refers to Caroline having her leg amputated after a car accident. There are many other religious references in all the macrocategories, which are not related to fate. However, what they have in common is an implied causality that the outcome was somehow preordained. This may be seen to be a need for non-disabled people to distance themselves from the actual experience and consequences of impairment, i.e. it was out of their control and was meant to happen. This may be a form of self rationalisation of their feelings towards disabled people.

Many quotations in this macrocategory refer to luck, such as Quote 152:20 'He was lucky, and glad, to be alive.' This is about Max with an acquired disability. Luck is very often connected to an acquired impairment. However, many examples are not as explicit. For instance, Quote 40:10: 'But the strange hand of fate was about to intervene'. This is about Caroline with no impairment, which indicates that luck is a concept which is used in everyday story telling and not only related to disability. Luck is a convenient narrative vehicle which enables the writer to develop the storyline. However it becomes a much more useful tool when the writer may be expected to explain and understand an unfamiliar scenario such as living with a disability. This is an example of non-disabled people trying to rationalise their experience of disability. The third theme is faith, which is distinct from God because it is not explicitly religious. For instance, Quote 175:8: 'Some people don't share my faith'. This is a Type 3 storyboard, which is Max who lost his leg in a car accident. Once more faith is very much attached to becoming disabled rather than being born disabled. It is also related to an inner stoicism which is not religious but spiritual. For example, Quote 40:2: 'Once again she reflects on how strange life is'. This is about Caroline who has become disabled in a car accident. In the story Caroline develops an inner strength from her experience which was there before. It is clear that non disabled people need to highlight that disability must be there for a reason, rather than just part of humanity.

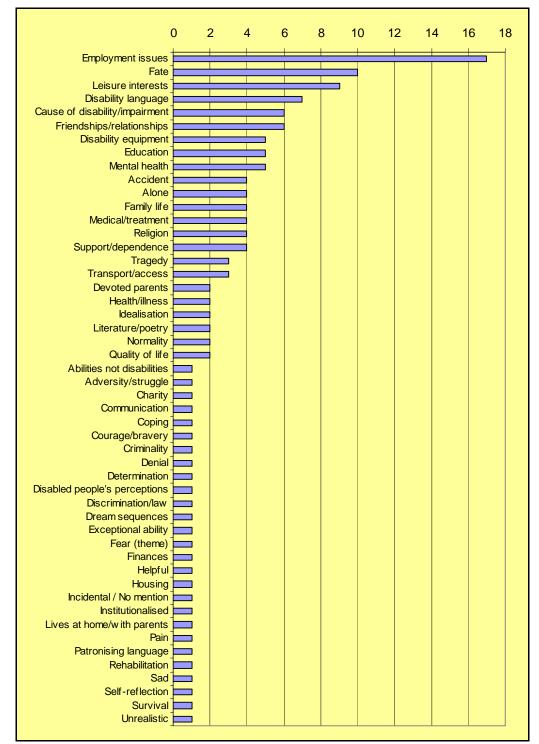
# Figure 24: Illustrative Quotation Map: Fate

# Figure 25: Additional Key Quotations

### Microcode Frequencies within Macrocategory

This macrocategory has 9 microcodes with 5 or more mentions. They are 'Employment issues', 'Fate', 'Leisure interests', 'Disability language'. 'Cause of disability/impairment', 'Disability equipment', 'Education' and 'Mental Health'; once more 'Employment issues' is at the top of the list. This is almost certainly because subjects were undertaking this task in the workplace; therefore employment was in the forefront of their minds and is not directly related to the storyline. The microcode 'Fate' was the second most mentioned. The stories within this macrocategory cover a wide range of issues. However, all the stories focus on the nature and cause of the central character's impairment. This macrocategory has one of the widest ranges of microcodes with 52 different microcodes mentioned. All the stories highlighted a moment in time when the character's life changed forever. These stories focus on a personal outcome of impairment. The microcodes are so varied that it is not possible to identify one theme, except that something or someone external to the central character had power or a mysterious reason for the central character to become disabled. This is a natural way of rationalising unexpected circumstances and making the unfamiliar familiar.

Figure 26: Microcode Graph: Fate



### Word Count Analysis

In this macrocategory word count there are 47 identified disability related words. The highest counts were for 'help' and 'lost', with 7 each. Most of the words are of a negative tone, such as 'burdens', 'crippling' and 'suffering'. There are 16 words with more than 2 counts. Within this group there are significant words, such as 'chance', 'accident' and 'diagnosed'. It is clear that the writers imply that becoming disabled is a chance event, which may be by accident or be diagnosed with a progressive impairment. It is clear from the stories that the writers consider that becoming disabled is a negative life event. Only in the Incidental macrocategory is an acquired disability seen to be part of the human experience. It is worth noting that there are no religious words listed within this macrocategory. However, there are religious words used in relation to Tragedy and Sad/Lonely. The word list for Fate is very much impairment centred and overwhelmingly negative.

### Figure 27: Fate Word Counts

Help	7	Diagnosis	1
Lost	7	Disability	1
Wheelchair	5	Disabled	1
Accident	4	Hear-attack	1
			1
Limbs	3	Helped	1
Chance	2	Helpful	1
Content	2	Humour	1
Dedication	2	Impaired	1
Delivered	2	Inaccessible	1
Diagnosed	2	Life-long	1
Difference	2	Normal	1
III	2	Palsy	1
Institution	2	Physiotherapist	1
Mobility	2	Positive	1
Ramp	2	Recovery	1
Schedule	2	Scope	1
Accepted	1	Sex	1
Burdens	1	Spastics	1
Capable	1	Suffered	1
Cerebral	1	Suffering	1
Chairbound	1	Trauma	1
Crippling	1	Tumour	1
Deskbound	1	Virus	1
Determination	1		

### (5) Happy/Idealisation

### **Overall analysis**

This macrocategory was the fourth most identified story type with 24 stories designated to it. This represents 11.4% of the stories. 13.9% of female subjects wrote Happy/Idealisation stories, compared to 6.3% of men who wrote Happy/Idealisation stories. The expected counts were 7.3 for men and 16.7 for women. This is a very interesting difference. It may be that the female subjects have a more positive experience of disability or a more optimistic view of disabled people's lives. On the other side it may mean that male subjects have a more realistic view of the problems faced by disabled people. 13 of the 24 Happy/Idealisation stories are about the central character Eve, compared to an expected count of 5.6

stories. This may be because Eve is obviously learning disabled, having Downs syndrome, and that there is a general popular myth that Downs syndrome people are happy and cuddly. This is an example of a piece of common knowledge forming a reified condition, which has been accepted into popular myth. The other characters, Max and Caroline, were designated 3 and 6 stories respectively, compared to a 5.6 and 5.3 story count respectively. These figures do not seem to be significant in any way. However, Tom only received 2 stories in this macrocategory when the expected count was 7.5 stories. This is intriguing because it may indicate that the apparent severity of Tom's impairment influences the writer to make Tom a less happy character. In all the storyboards, all characters show some indication of happiness. There was no apparent age difference from the expected count. There was no difference from the expected counts in terms of disabled or non-disabled images. However in terms of the preambles, this was slightly higher than the expected count when the disability was mentioned. This is not significant, although it may indicate that there is an interactive factor between a disabled preamble and image. 12 of the 24 Happy/Idealisation stories were written by medical professionals. The expected count for medical professionals was 9.3; 7 by charity workers and 5 by 'ordinary people'. One may speculate that either medical professionals know that many disabled people lead happy and fulfilled lives or that they are denying the problems faced by disabled people because they feel partly responsible for them. This will be explored in more detail in the Focus Groups section.

### Sample story 1 discussion

The first sample story (see page 154) is from the Happy component of this macrocategory, by a white female charity worker aged 26-35. She wrote a Type 11 story, which is Eve with a born disability (brain damaged). From the outset, the writer presents Eve as a very happy and

contented person, despite many non-disabled people staring at her. The opening line is 'Eve smiled' going on to say 'she was happy'. Throughout this story her disability is not explicitly mentioned, only alluded to. Such as, 'sometimes she could get a bit confused' or 'people stared'. The writer depicts Eve loving simple things such as flowers and only having very few friends such as Andy. Eve lives in a community home, which is obviously for disabled people, but this is not made explicit. There seems to be a contradiction in that Eve is often frustrated and angry, but she is still depicted as being happy. For instance, 'she was happy to be different. Except maybe when she got angry'. Also her parents seem very supportive and devoted. However some of their relationships appear quite patronising, for instance, 'my bundle of joy'. This is not a normal thing for a parent to say to an adult without that person feeling patronised or humiliated. There are implicit assumptions that Eve is still very childlike, despite her age. Eve's friendship with Andy is very much one of Andy being in control because he is a university graduate and is depicted as being more intelligent and able than Eve. Eve is depicted as guite passive and dependent. On the other hand, the writer is perhaps aware from her work about some of the stereotypical assumptions about people with Downs syndrome. There are recurring themes in the story, such as having over-protective parents, being childlike and having few peers as friends.

### Sample story 2 discussion

The second sample story (see page 157) is also by a female charity worker, but this time she is aged 46-60. This is a Type 5 story, which is Caroline with a born disability (born deaf). This story is an example of Idealisation rather than happiness. In this story, Caroline, who is deaf and went to special school is depicted as having 'a normal' family life. She never 'felt disadvantaged' and was involved in all activities that hearing people did. Caroline used sign language and learnt how to lip-read. This component of the story is more plausible. However, working as a receptionist seems unlikely, even with the new concept of reason adjustment. No mention of special equipment or help is made except for Flora, her hearing dog. Caroline's life seems close to perfect, particularly when she marries her long-term boyfriend. In reality as will be shown in the Focus Groups, deaf people still face enormous problems in education and employment and are rarely taught sign language from an early age. Very few deaf people have the luxury of being able to access a hearing dog. It is clear that the writer is attempting to depict the ideal lifestyle of a deaf person. From this one can infer that either the writer thinks that deaf people do not have problems relating to their impairment or that she is attempting to highlight some of the key basics that deaf people face, although these are surmountable with the right attitudes and equipment. However, overall the story is idealised and stylised, and it offers and presents a very positive picture of deafness, which is not present in other macrocategories.

# Figure 28: Happy/Idealisation Sample Story 1 (page 1 of 3)

# Happy/Idealisation Sample Story 1 (page 2 of 3)

# Happy/Idealisation Sample Story 1 (page 3 of 3)

# Figure 29: Happy/Idealisation Sample Story 2 (page 1 of 2)

# Happy/Idealisation Sample Story 2 (page 2 of 2)

#### **Quotation Maps**

In this macrocategory there are a huge number of quotations which are relevant and which are pertinent. This study will deal with Happy and Idealisation separately in terms of quotations. Most of the quotations are related to Eve or Tom, particularly in the born disabled scenario, although many are in the acquired disability as well. Some typical Eve quotes for happy are Quote 76:1: 'Eve is a happy young woman who', Quote 85:1: 'Eve is an essentially happy girl' or Quote 91:1: 'Eve was a happy go lucky woman'. It is interesting to note that all these quotes are the first line of stories. It may be suggested that the character's happiness is the defining feature that is important to the writer and the reader. None of these quotes were from storyboards with born disability mentioned. The images of Eve were no more 'happy' than any other on the storyboards. However, because Eve has an apparent learning disability the writers appear to be making the assumption that she is 'essentially' happy, despite her impairment. There is a common myth that learning disabled people, particularly those with Downs syndrome are very happy and content people. There is an underlying meaning that being learning disabled means you do not understand the problems you face, as the Focus Groups will show. This is not the lived experience or understanding of learning disabled people. The overriding happiness theme is also emphasised by Quote 163:2: 'Eve smiled. She could feel her face stretching'. This highlights that the writer seems to imbue Eve with happiness in a completely physical way and therefore Eve's character becomes stylised as happy, almost personified by a smile. Many of the happy quotes relate to Tom too. For instance, Quote 32:9: 'Tom really enjoyed flowers', Quote 32:4 'Tom was really excited and couldn't wait' and Quote 32: 8: 'It was a really nice day '. It is interesting that in contrast to Eve, Tom is depicted in a more active way, where he enjoys hobbies

and going out. It may be that even as a disabled man he is seen to be more active in the world than a disabled woman.

In terms of Idealisation it is very often what is not written rather than what is written which is important. Idealisation is a complex component of this macrocategory because it relates to the writer's overcompensation for the storyboard character's impairment. For instance, Quote 169:4 'When growing up Caroline never felt disadvantaged', which is about Caroline who is born deaf, attempts to say that being born deaf is not a problem in interacting with the hearing society. As will be shown by the Focus Groups this is not a realistic standpoint. This particular quote is indicative of one of the key themes within this macrocategory, which is that the impairment does not make any difference to the type of lifestyle of the character. This is very much idealisation on behalf of the writer. This is not denial because the impairment is mentioned. However, the character's life is always near perfect, despite their impairment. Another example is Quote 128:5 'Materially successful, emotionally bereft'. This refers to Max who is born deaf and is portrayed as immensely successful, while deafness has not impaired him. It is interesting to note that most of the Idealisation quotes relate to born disabled people. This may be because non-disabled subjects are not able to imagine what it's like to live with an impairment all their lives, therefore one psychological rationale is to imagine a perfect life with an impairment. It is also possible that non-disabled subjects can not imagine how they would cope with having an impairment and enjoying a good guality of life, therefore they perform a form of wish fulfilment by depicting disabled characters as having very good lives as they would wish for themselves with an impairment.

# Figure 30: Illustrative Quotation Map: Happy/Idealisation

# Figure 31: Additional Key Quotations (page 1 of 2)

# Figure 32: Additional Key Quotations (page 2 of 2)

### Microcode Frequencies within Macrocategory

The microcodes for Happy/Idealisation with 5 or more mentions were as follows: 'Happy', 'Food', 'Friendships/relationships', 'Family life', 'Alluding impairment', 'Transport/access', 'Employment issues', 'Leisure to interests', 'Other people's perceptions', 'Alone', 'Cause of disability/impairment', 'Education', 'Incidental/no mention', 'Normality' and 'Patronising language'. This last macrocategory was mainly related to the images of Eve, because of her Downs syndrome. Most of the happy microcodes were attributed to Eve, along with her love of food. This representation of happiness is a 'classic' myth related to people with Downs syndrome. Non-disabled people's association with the love of food and Downs syndrome people is partly because most Downs syndrome people are slightly overweight and they do tend to enjoy eating. However, many other people enjoy eating and it is not associated with any particular personal characteristic, unless they are overweight or obese. This may be an example of indirect Social Representations, particularly related to Downs syndrome. There is an underlying implication that people with Downs syndrome can only enjoy 'simple' activities, such as eating; i.e. they are in some way behaving like a primitive being.

None of the other primary microcodes were directly related to happiness or Idealisation. They were much more issue based, such as regarding employment, leisure and education. This is partly because the stories did not deal directly with the central character's impairment and its consequences when it may have been appropriate.

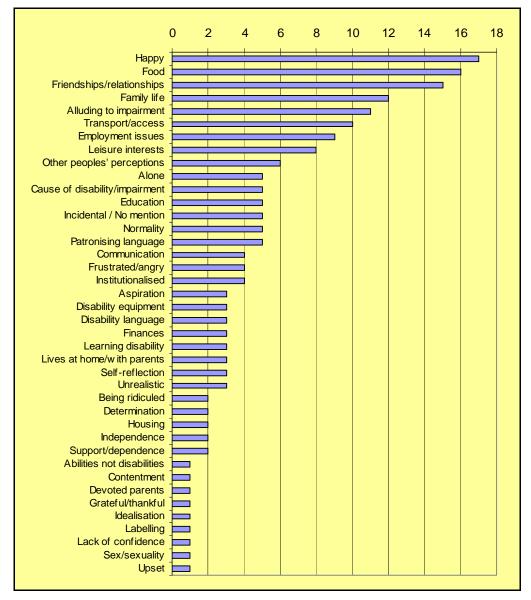


Figure 33: Microcode Graph: Happy/Idealisation

### Word Count Analysis

There are 55 disability related words in this macrocategory word count. The highest count is for 'happy' and the second highest is for 'different'. Most of the stories within this macrocategory are related to Eve, particularly when she has Downs syndrome. There are many 'nice' words, such as 'cheerful', 'smile', 'excited' and 'laugh'. The word count reaffirms this study's findings that non-disabled people have a strong representation that people with Downs syndrome are constantly happy and smiley. However, from the work with the Focus Groups, this is not how they perceive themselves. This may be a function of the 'positive' campaigning of charities such as MENCAP, who portray people with learning disabilities as being positive, happy people; whereas the reality is they are as different from one another as any other set of people. Tom's stories are also prominent in this macrocategory. It is interesting that the main bulk of stories within this macrocategory are about born disabled people. It is almost as if people who are born with an impairment are resolved to their predicament. Once more from the Focus Group study, participants thought this was a way of non-disabled people not acknowledging the problems that disabled people face in everyday life. It is also a symptom of thinking that disabled people are eternal children. In other research, many older people have experienced the same mind set (Ogg; 2002).

Happy Different Favourite Able Birthday Normal Enjoys Cheerful Disability Friends Hearing Independence Accepted Deaf Determination Independent Need Smile Lovely Enjoy Enjoying Excited	23 13 12 10 8 7 6 4 4 4 4 4 4 4 4 3 3 3 3 3 3 3 3 3 2 2 2 2	Assistance Beautiful Birthdays Brilliant Care Cared Colourful Contented Deafness Development Difficulty Disabled Enabled Friendly Giggled Gratitude Helped Helpful Illness Institutionalised Isolated Laugh Out-going	1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1
•	2 2		
Enjoying	2	Isolated	1

### Figure 34: Happy/Idealisation Word Counts

### (6) Incidental

### **Overall analysis**

This was the most frequent macrocategory in the study, with 33 stories being designated to this macrocategory. This represents 15.6% of all stories. There was no difference in the expected count between men and women from the observed count. Younger people in the age bracket 18-25 wrote almost double the number of stories than the expected count. Seventeen out of the 33 stories were written by people in this age range. This may be because younger people had been to school, college or University with disabled peers. This experiential knowledge may have

helped them to write stories where disability was not the main focus, but viewed the disability in context. Also, younger people may have a more positive view towards life and do not dwell on practical problems. In all other age groups the observed count was slightly under the expected count. This means that older people may not see disability as incidental to the storyboard character. It is therefore reasonable to propose that older people are more likely to see the problems relating to the character's disability, rather than seeing the disability as an incidental, but important part of the character. This macrocategory was the most used by the sample population and is very much related to the Social model of disability. This indicates that a reasonably high percentage of nondisabled people perceive disability in its appropriate context as part and parcel of the character's life. In their storylines the disability or impairment is mentioned in a way in which it is not seen to be a personal problem, but in terms of disabled people meeting barriers within society.

In this macrocategory there was no noticeable difference between the observed count and the expected count in relation to the disabled and non-disabled image. In terms of the preamble there were marginally more of these types of stories where there was no mention of these types of disability and slightly less when there was a mention of disability. It is reasonable to propose that the image and preamble in this macrocategory balanced their effects out. In terms of the characters, Caroline and Tom were designated 25 % more stories than the expected count. Eve received almost exactly the expected count and Max was designated under half as many stories as the expected count. There does not seem to be an obvious explanation for this distribution. In terms of occupational type there is a noticeable difference from the expected count. Medical professionals wrote 14 out of the 33 stories in this macrocategory and were expected to write 12.8. This may be the result of many medical professionals being young and having had disability

awareness training. Charity workers produced just over half of the expected count. 'Ordinary' people produced nearly as many as the expected count.

#### Sample story 1 discussion

The first sample story (see page 171) is written by a white male 'ordinary' person. This subject was about a type 12 story, which is Eve, with an acquired disability (Brain tumour). In this story the writer depicts Eve as being independent and a fun person. However, the story mentions her 'reading problems' and other people's patronising attitudes towards her. It is obvious to the reader that Eve has some disability or impairment, but it is never taken out of context. The consequences of her disability are well explained, but the emphasis is on Eve's abilities and other people's misconceptions of them. This is very much in line with how the Social model explains how society deals with disability. It is interesting that in this story Eve is confronted by other people's negative attitudes; environmental barriers in terms of the shop not having accessible notices to identify what types of birthday cards the shop has. These components of other people's attitudes and environmental barriers are key components of the Social model.

#### Sample story 2 discussion

The second sample story (see page 172) is written by a female charity worker age 46-60 with no ethnicity mentioned. This writer wrote about a type 6 storyboard, which is Caroline with an acquired disability (Leg amputee). This is a very amusing and unusual story, where the character Caroline becomes 'Peg-leg-Poll, the scourge of the Birmingham jewellery quarter'. 'Polly' is a jewellery thief. She uses her prosthetic leg to stash her loot! In the story Polly uses her leg to steal some gold Kruger Rands, which prove to be too heavy for her to move with; so she is caught in the end. However, the intervening narrative is very funny and is very much in the style of slapstick, with a tongue-in-cheek moral context. Throughout the story her disability is used as a vehicle for humour, but never in a patronising or pejorative way. It is clear that the disability is an important part of the character and is used as an enabling aspect of her life, rather than a disabling aspect of her life. This neatly fits into the Social model of disability, where someone's disability is an integral part of them, and can be used in a positive way.

## Figure 35: Incidental Sample Story 1 (page 1 of 1)

## Figure 36: Incidental Sample Story 2 (page 1 of 3)

## Incidental Sample Story 2 (page 2 of 3)

## Incidental Sample Story 2 (page 2 of 3)

#### **Quotation Maps**

This is the most common macrocategory where subjects refer to the character's disability in an appropriate manner, without making it the central theme of the storyline. There are hundreds of possible quotes within this macrocategory, some examples are as follows: Quote 8:2 'It was easy to get to, not too many steps', which is about Tom (no mention of disability) but his apparent disability is not the central theme of the story; Quote 36:3: 'His deafness doesn't affect his work', which is about Max born deaf. In this story the deafness is completely contextualised as it is mentioned in an appropriate manner; and Quote 93:9 'Caroline got into her friends (sic.) car', which is Caroline who had her leg amputated, only mentioned in passing when it is relevant the story. Most of the quotes within this macrocategory do not actually mention the impairment.

## Figure 37: Illustrative Quotation Map: Incidental

# Figure 38: Additional Key Quotations

#### Microcode Frequencies within Macrocategory

In this macrocategory there are 20 microcodes with 5 or more mentions. These are as follows: 'Friendships/relationships', 'Family life', 'Humour', 'Transport/access', 'Disability equipment', 'Incidental/no mention', 'Other perceptions', 'Employment issues', 'Alluding to impairment', 'Leisure interests'. 'Support/dependence', 'Cause of disability/impairment', 'Sex/sexuality'. 'Education', 'Independence', 'Communication', 'Criminality', 'Disability language', 'Food' and 'Happy'. The microcodes for these stories are very varied with over 40 mentioned. All the most common microcodes are related to people, family life, friendships and humour. These stories do not deny the disability, but they weave the disability throughout the storyline without making it the central theme. This is why most of the microcodes within this macrocategory are about lifestyle issues and personal choices. It is apparent from the microcodes within this macrocategory that the writers were comfortable in talking about disability in a positive and natural way.

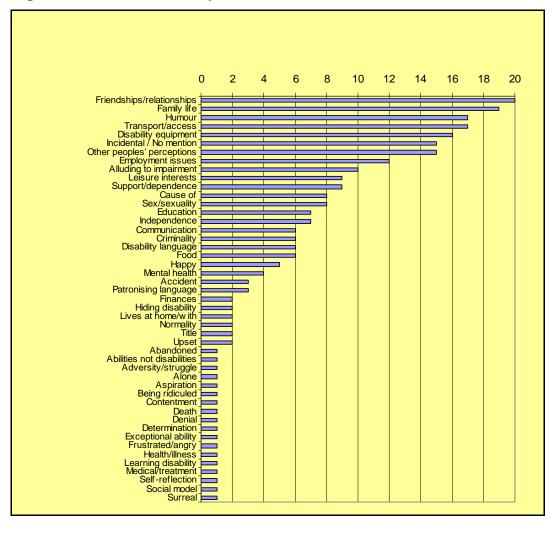


Figure 39: Microcode Graph: Incidental

### Word Count Analysis

There are 31 disability related words in this macrocategory word count. The 2 highest counts are 'wheelchair' and 'help'. Unlike other macrocategories, the disability related words are used in the appropriate context and solely in a descriptive manner, without any negative connotations. It is interesting to note that the word 'retard' is used in the context of another person's opinion. All the other words are very much disability centred. Many of them are technical terms, such as 'prosthetic' and 'dynarox'. It is interesting to note, even in the Incidental stories, that 'wheelchair' is the most common term. Only one of the study's characters used a wheelchair. It is clear that disability has become linked to the use of wheelchairs. In actual fact only 7% of disabled people use wheelchairs. This may be a function of how disability is universally depicted using a wheelchair symbol.

### Figure 40: Incidental Word Counts

Wheelchair	14	Artificial	1
Help	12	Assistance	1
Different	8	Diagnosed	1
Able	5	Disgusting	1
Accident	5	Dynarox	1
Tumour	5	Fate	1
Disabled	4	Impairment	1
Independent	4	Independence	1
Carer	3	Paraplegically	1
Deaf	3	Progression	1
Disability	3	Progressing	1
Helped	3	Prosthetic	1
III	3	Retard	1
Deafness	2	Therapy	1
Difficult	2	Unhappy	1
Acquired	1		

### (7) Medical

### **Overall analysis**

The Medical macrocategory is the least commonly used macrocategory with only 5 stories designated. This represents 2.7% of all stories. There was no occupational difference within this macrocategory as the sample was very small. There was a small difference in the number of stories within this macrocategory that related to acquired disability. This may be because the writers were able to imagine becoming disabled much more than being born disabled. All the stories in the medical macrocategory were from preambles that mentioned impairment. In terms of character, Max had 2, Eve 2 and Tom 1. In terms of image, there were 3 apparently disabled and 2 seemingly non-disabled people. It is interesting that only 1 medical professional wrote a medical macrocategory story. This may be that the sample was made up of new and young medical professionals who may have a less medicalised approach to disability. Alternatively, they might have realised that the study was about disability and therefore made a conscious effort not to medicalise the stories. The research administrators who worked with the medical professionals do not feel this was the case. It is important to note that medical professionals tended to write Sad/Lonely stories in significant numbers. This may have been a psychological spin on disability. There was no significant difference in age range in the type of stories written. This is because of the small number.

### Sample story 1 discussion

The first sample story (see page 184) is by a male 'ordinary' person, who wrote about a Type 8 storyboard, which is Tom, born disabled. This story is set in the future where the use of marijuana for disabled people is legalised. There is a lot of 'tongue in cheek' humour about this scenario, such as the fictional 'Weed Transport Division'. It interesting to note that Tom is meant to be in pain and the use of marijuana is a means of relief.

The writer relates disability to pain and only in the future is it possible to put this right. However, at the same time, the writer may be making a social-political point that marijuana is known to help disabled people as a pain reliever. Also because it set in the future, it enables the writer to distance themselves from the present reality of disabled people's lives. This story offers a more positive representation of disability, but only in the future.

#### Sample story 2 discussion

The second sample story (see page 185) is written by a medical professional from an Afro-Caribbean background, aged 46-60. This story is a Type 11 storyboard, which is Eve with a brain tumour. This story is very much medicalised and concentrates on Eve in terms of her condition and the treatment that she is undertaking. It is very much about health and illness. This story is littered with medical terms, such as 'prognosis'. Also, one of the key themes is about how Eve's illness has made her understand not only her own needs, but other people's needs. This is a common theme within many stories in different macrocategories, whereby the character's own experience of impairment makes them more positive in understanding other people's problems. This is an expression of people's need for reason and redemption. This is only related to acquired disability. In both of the sample stories, the writer takes a detached perspective of the disabled person's experience and, in many ways, objectifies them as disabled people. This is an interesting psychological mechanism which allows non disabled writers to write about disability in a rationalised manner. This means that the writer does not need to identify with the disabled character, but is merely a narrator or observer. This is particularly notable in the medical macrocategory as medicine objectifies all people, particularly disabled or ill people. Some of these qualities are in other macrocategories as well, such as Sad/Lonely and Tragedy. This

is because they concentrate on negative perceptions of disabled characters.

## Figure 41: Medical Sample Story 1 (page 1 of 1)

## Figure 42: Medical Sample Story 2 (page 1 of 2)

## Medical Sample Story 2 (page 2 of 2)

#### **Quotation Maps**

By examining the quotation map in the Medical macrocategory, it can be seen that there are definite themes which support the sample stories. First of all quotation 38.1 mentions Max is profoundly deaf. This is a direct reference to a particular impairment and medicalises deafness. This is further emphasised by quotation 38.2 which relates to diagnosis. In addition quotation 38.8 mentions tests. This is very much in the Medical model. Quote 107.6 speaks about Eve's going to see a consultant who says she only has six months to live. Therefore death is connected to the medical profession. In quotes 194.1, 194.10 and 202.3, hospitals and medical equipment are emphasised. It is clear that in these stories disability is connected to and equated with medical interventions, hospitals, treatment, tests, diagnoses and death. This implies that disability is solely a medical matter. From the Focus Groups the research will show that this is often how disabled people experience the world.

## Figure 43: Illustrative Quotation Map: Medical

#### Microcode Frequencies within Macrocategory

In the Medical macrocategory there is one microcode with 5 or more mentions, which is 'Medical treatment'. There are 29 other microcodes mentioned. However, each has less than 3 mentions and most only have 1. This macrocategory is very much impairment centred, speaking about the reasons for the impairment, the need for support and disability equipment. It is clear that the writers are concentrating on the consequences of the central character's impairment. There are no positive microcodes mentioned. These microcodes all relate to the negative aspects of impairment, such as death, coping and mental health.

Figure 44: Microcode Graph: Medical

	) ,	1 2	2 3	3 4	4 5	5 6	6
	• 		-	• 	· · · ·		1
Medical/treatment							
Education							
Employment issues							
Cause of disability/impairment							
Death							
Family life							
Grateful/thankful							
Religion							
Support/dependence							
Abilities not disabilities							
Communication							
Contentment							
Coping							
Denial							
Determination							
Devoted parents							
Disability equipment							
Disability language							
Exceptional ability							
Fate							
Friendships/relationships							
Health/illness							
Idealisation							
Learning disability							
Mental health							
Other peoples' perceptions							
Prove oneself							
Sad							
Social model							
Tragedy							
Transport/access							

### Word Count Analysis

In the Medical macrocategory word count there are 30 disability related words. Most of which are technical or semi-technical terms, such as 'diagnosed', 'pain' and 'prognosis'. The highest count was for 'hospital' with 7. In the light of this macrocategory being small, it is quite interesting that 'hospital' is the main focus of many stories. Most of the stories in this macrocategory were related to acquired disability. Many of the words in the word count are directly related to particular impairments such as deafness or tumours, while the others are related to treatments. This is a very medicalised approach to disability.

### Figure 45: Medical Word Counts

7	Ability	1
5	Career	1
5	Centres	1
4	Disabled	1
3	Doctors	1
3	Handicap	1
3	Healed	1
2	Helped	1
2	Medicinal	1
2	Motability	1
2	Pain	1
2	Prognosis	1
2	Prosthetic	1
2	Surgeons	1
2	Treatment	1
	5 4 3 3 2 2 2 2 2 2 2 2 2 2 2 2	5Career5Centres4Disabled3Doctors3Handicap3Healed2Helped2Medicinal2Pain2Prognosis2Prosthetic2Surgeons

### (8) Sad/Lonely

### **Overall analysis**

27 stories were allocated to this macrocategory. This represents 12.8% of the stories. This was the second most popular Social Representation to be identified. There were definite occupational preferences for writing these types of stories. 15 of the 27 stories in this macrocategory were

written by medical professionals. 7 were written by 'ordinary' subjects and 5 by charity workers. 21 of the 27 stories were written when subjects used the storyboards which presented an apparent disability i.e. the characters were Tom or Eve. No Sad/Lonely stories were written about the character Max. However, 6 were written about the storyboard of Caroline. This may indicate a general bias towards non-disabled female characters in terms of their mental health and how they are represented. There were no noticeable gender or age differences in this macrocategory.

#### Sample story 1 discussion

The first sample story written within this macrocategory set out in full below (page 194), was written by a female medical professional within the age range of 18-25. The storyboard that she wrote about was type 9, which is Tom with an acquired disability (brain tumour). This story paints a pretty bleak picture of acquired disability. Not only does it say that the central character Tom no longer has a 'normal' life because he cannot play football anymore, but he also no longer has a girlfriend since becoming disabled. The story continues with this rather sad and lonely theme by saying how his life has 'changed' and how his other life seems 'miles away'. His social life is dictated by his mobility problems and therefore he no longer goes to the pub much. The story strongly implies that prior to his acquired disability, Tom's life was very happy and positive. The story implies that he was an 'average' sort of chap before. He did reasonably well at school, played football and had a girlfriend. Although on a positive note, Tom did apply to university in the story. It is clear that Tom has 'suffered' and he is depicted as being strong in the face of adversity. Tom is now living with his sister, but from the story it seems that his parents do not think that Tom is as independent as he feels. This is an interesting component in the story because it indicates that there is an understanding by the writer that once one becomes

disabled one becomes more dependant. Also there is an underlying element that disabled people need to be protected and are 'childlike' and that parents want them back in their home. The associated microcodes for this story are quite wide ranging, however 'aloneness', 'sorrow', 'friendships' and 'relationships' are particularly important. This story illustrates that the writer feels that becoming disabled will inevitably change more of someone's lifestyle than their adapting their usual lifestyle around the acquired disability.

### Sample story 2 discussion

The second sample story for this macrocategory was written by a white male charity worker aged 18-25. The story is type 10 which is Eve with no mention. Once more no disability or condition is explicitly mentioned by the writer. However it is clear that the narrative alludes to disability or difference. The researcher finds this story quite sad. It is a piece of reminiscence narrative where Eve, the central character, remembers her partner/friend Adam. Despite her protestations it is quite apparent from the narrative that Eve is lonely and sad. There is a real sense that Eve will never meet another friend like Adam and that her apparent disability is the underlying reason for this. This is not an unusual theme for non-disabled people either. However, Eve seems resolved not to meet anyone else. This may imply that the writer thinks that it takes a special person to love someone like Eve.

## Figure 46: Sad/Lonely Sample Story 1 (page 1 of 1)

## Figure 47: Sad/Lonely Sample Story 2 (page 1 of 2)

## Sad/Lonely Sample Story 2 (page 2 of 2)

#### **Quotation Maps**

There are many quotations in this macrocategory. Tom and Eve are the two most common recipients of this type of quote. For instance, Quote 78:5: 'At times, however, Eve feels isolated', which is about Eve with an acquired disability. Eve is often depicted as being isolated and set apart from society by her impairment. This is possibly what non-disabled people think happens to learning disabled people. In this instance, this is an accurate perception. Another example is Quote 87:1 'Jose (AKA Eve) was a simple sole'. Once more she's portrayed as being alone and unhappy. This story is very bleak and its central theme is Eve's loneliness. The same pattern is repeated for Tom. For example, Quote 102:6 'In many situations, as in the last frame' or Quote 31:11 'Tom does not have a girlfriend'. In most of the quotes relating to Tom within this macrocategory he is living alone and is dependent on help, but has very few friends. All these quotes demonstrate that non-disabled people have quite definite negative perceptions of disabled people's lives. If these quotes are compared with the control macrocategory, disabled people appear to have a much lower quality of life and are friendless, unhappy and resigned to their situation. None of these themes appear in any notable way in the control macrocategory.

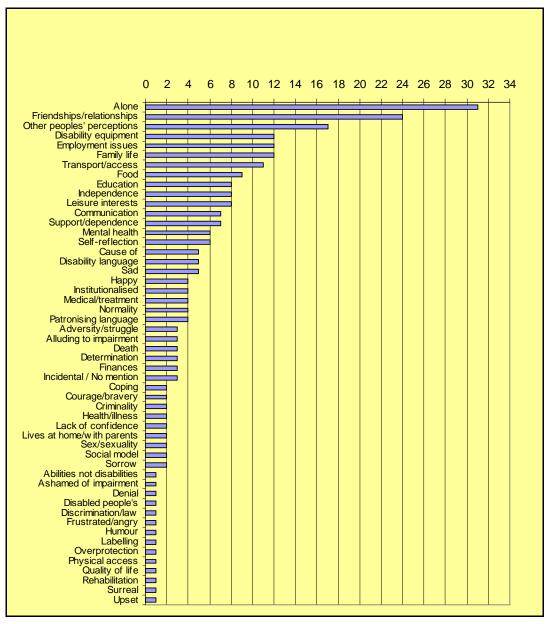
## Figure 48: Illustrative Quotation Map: Sad/Lonely

# Figure 49: Additional Key Quotations

#### Microcode Frequencies within Macrocategory

There are 18 microcodes within this macrocategory with 5 or more mentions. These are as follows: 'Alone', 'Friendships/relationships', 'Other people's perceptions', 'Disability equipment', 'Employment issues', 'Family life', 'Transport/access', 'Food', 'Education', 'Independence', 'Leisure interests', 'Communication', 'Support/dependence', 'Mental health', 'Self reflection', 'Cause of disability/impairment', 'Disability language' and 'Sad'. It is important to note that the microcode 'Alone' has the highest number of counts with 31 mentions. This is illustrative of how strongly people associate disability with loneliness. It is interesting to note that 'Sad' has only 5 counts; therefore there seems to be a contradiction within the macrocategory in that disabled people can be represented as alone, but not sad. Although 'alone' is a neutral description of a state of being, in the stories it is nearly always used in the context of loneliness in this macrocategory. Most of the other microcodes within this macrocategory are of the thematic type, such as 'Employment issues', 'Other people's perceptions' and 'Leisure interests'. Within this macrocategory there are many microcodes relating to mental health and personal feelings, such as 'Mental health' and 'Self reflection'. It appears that the writers who write Sad/Lonely stories consider that disabled people often have negative self images. There is an additional underlying theme of worrying about how people perceive them as disabled people. The writers emphasize the links between negative self image and their mental health.





#### Word Count Analysis

In the Sad/Lonely macrocategory word count there are 41 disability related words, 22 have more than 2 counts. The 3 highest counts are 'birthday', 'wheelchair' and 'friends'. This is an interesting set of words. 'Birthday' is only used in the context of Eve getting a birthday card for her best friend. It is never for a boyfriend or another anniversary. This is another small indicator that people with Downs syndrome are happy and caring. 'Wheelchair' is always used in relation to Tom. Tom's wheelchair is often seen as a liberator, but sometimes a nuisance. 'Friends' is almost always used in the context of not having any. Therefore disabled people are lonely in the eyes of non-disabled people. From the work with the Focus Groups, this outlook is definitely rebutted. However, the Focus Groups did highlight that disabled people have a much tighter network of friends and therefore may appear not to have a lot of friends. All the other words in this macrocategory are very negative, such as 'depressed', 'sadness' and 'suicide'. It is clear that non-disabled people are more likely to use negative terminology when discussing disability.

Figure 51	: Sad/Lonely	Word Counts
-----------	--------------	-------------

Birthday	16	Wheeled	2
Wheelchair	13	Acquiring	1
Friends	12	Bound	1
Centre	9	Depressing	1
Disabled	8	Depression	1
Able	7	Diagnosed	1
Нарру	7	Difficulties	1
Needs	7	Difficulty	1
Normal	7	Disabilities	1
Special	7	Gay	1
Independent	7	Loneliness	1
Needed	6	Mobility	1
Difficult	4	Physically	1
Disability	4	Problem	1
Tumour	4	Sadness	1
Hospital	4	Suffers	1
Concerned	2	Surgery	1
Depressed	2	Therapist	1
Leukaemia	2	Treated	1
Suicide	2	Upsetting	1
Upset	2		

### (9) Support/Dependence

#### **Overall anlaysis**

This macrocategory was equally as frequent as Exceptional/Special. There were 20 stories designated to it. The gender balance for this macrocategory was equal, which indicated that women wrote less support/dependence stories than expected and men wrote more. In terms of occupational type, medical professionals wrote less support/dependence stories than were expected, whilst ordinary people and charity workers wrote marginally more than expected with 8 stories each. Nine of the 20 stories in this macrocategory are about born disabled characters. This is almost half. The no mention and acquired storyboards are nearly evenly split with 5 and 6 stories respectively. These are aligned with the expected counts. However the born storyboards are 25% above the expected count. There is no significant statistical difference, but it indicates a trend. In this macrocategory there is a clear division between characters. Max and Caroline, who do not appear disabled in the images, but only in the storyboard preamble, do not have any stories which make them in need of support or dependence. Tom and Eve are the only characters who are seen to be in need of support and are dependent. Tom, who is the most visually disabled character, has 16 stories within this macrocategory, whilst Eve has 4. It is clear that there is a strong effect of Tom and Eve's images on the writer's perception of their lifestyle. Tom's 16 stories are almost three times the expected count in this sample, where as Eve's 4 stories are about what would be expected if not slightly under. The zero story count for Max and Caroline is below the expected count for this sample. One must infer that the severity of the physical impairment in Tom's images led people to believe that he needs more support and care. This may be function of the fact that very few people are in daily contact with severely disabled people. This is very much related to the reification of knowledge in that contact with severely disabled people is uncommon and therefore everyday common received knowledge based on assumptions about disability is used to generate Social Representations.

#### Sample story 1 discussion

The first sample story (see page 207) comes from a white female medical professional in the age range 18-25. The storyboard used was a type 9, which is Tom with an acquired disability (brain tumour). In this story it is clear that the writer considers Tom to have a rather terrible life. The first sentence is 'Tom has been unfortunate in life'. This sets up the story as it continues in this bleak manner. There is much made of the central character's need for help and assistance without him having much control over it. The story says that Tom is 'fairly' independent because of his wheelchair, but that his appearance makes people stare at him and this

makes him frustrated and angry. The language used is emotive and sometimes quite patronising. The story emphasises that Tom has needed to adapt to cope with his impairment rather than accept and develop new ways of working. The writer says that Tom wanted to be an architect, but now this is impossible. This indicates that the writer does not believe that a severely disabled person can achieve high employment status. I wonder if anyone has told Professor Steven Hawking this assumption! It is interesting that in this storyboard more of the images actually promote the idea of the central character being dependent. If anything the storyboard makes the central character appear a very confident and happy person. This indicated that a visual image of a severely disabled person is a very powerful one and is often interpreted in a very negative way. This story makes a point of saying that making new relationships is difficult, implying that this was less difficult prior to the impairment. Also the story emphasises that other people's perceptions are negative because of Tom's impairment. This indicates that the writer assumes that most non-disabled people would have negative attitudes and feelings towards severely disabled people.

#### Sample story 2 discussion

The second sample story in this macrocategory (see page 208) is by a white female medical professional aged 18-25. She wrote about a type 8 storyboard, which is Tom with a born disability (brain damage). In this story Tom, who is quite a mature man, is apparently still living at home with his mother. It is implicit from the story that Tom is dependent on his mother and on his friend Martin, who helps him. There is a lot of discussion around access and disability equipment, such as 'a brilliant car', which is adapted for a wheelchair. At no point in the story is Tom actually independent of non-disabled people, despite his motorised wheelchair. The language used is very patronising in many ways, such as

'Tom was wrapped up in a blanket' or 'Tom had a splendid day.' In the context of the story this indicates that the writer sees Tom as rather a passive character. Tom is portrayed as being happy, but we do not learn anything about Tom's opinions or character. It is primarily about the people who help him. We know that Tom loves flowers and car journeys, but we don't learn anything else about his personality. In many ways in this story, Tom is treated like an object that needs help. This is very interesting because in the Focus Groups, as this study shows later, many wheelchair users feel that they are treated like objects that need help.

# Figure 52: Support/Dependence Sample Story 1 (page 1 of 1)

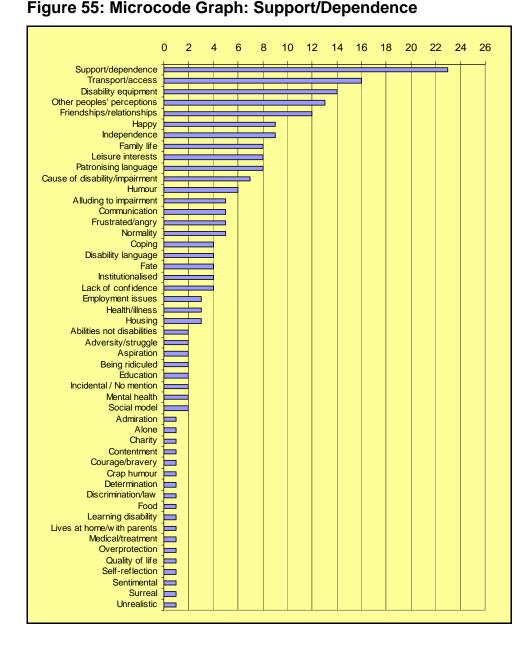
# Figure 53: Support/Dependence Sample Story 2 (page 1 of 1)

### **Quotation Maps**

# Figure 54: Illustrative Quotation Map: Support/Dependence

#### Microcode Frequencies within Macrocategory

In this macrocategory there are 16 microcodes with 5 or more counts. These are as follows: 'Support/dependence', 'Transport/access', 'Disability equipment', 'Other people's perceptions', 'Friendships/relationships', 'Happy', 'Independence', 'Family life', 'Leisure interests', 'Patronising language', 'Cause of disability/impairment', 'Communication', 'Frustrated/angry' and 'Normality'. Once more it is noticeable that the microcode directly related to the macrocategory, that is 'Support/dependence', is the most common. There is an emphasis on access and disability equipment in this macrocategory. Many writers discuss the disabled character's relationship in terms of their support needs rather than their emotional needs. This indicates an underlying theme that disabled people are passive recipients of care. It is evident from the Focus Groups this is not how disabled people perceive themselves.



#### Word Count Analysis

In this macrocategory word count there are 33 disability related terms, including 19 with more than 2 counts. The highest counts are for 'able', 'wheelchair' and 'Downs'. In terms of 'able', it is most often used in the context of not being able to do something. 'Wheelchair' is always used in the context of Tom, as he needs to use a wheelchair to get around. Both of these terms are always connected to a non-disabled person helping a disabled character. This presents the disabled person as being a passive recipient of care and therefore many words relate to this, such as 'support', 'carer', 'independence', 'problems' and 'capability'. There is an underlying theme in this macrocategory that disabled people are dependent on the help of non-disabled people in order to live a better quality of life. From the evidence gained from work with Focus Groups, this is partly born of the truth. However, disabled people have a different approach to this. Rather than thinking about it in terms of dependence, they think about it in terms of independence. This is because they see employing non-disabled people as a means of gaining their independence as of right and facilitating them to carry out their lives.

Able	14	Problems	3
Wheelchair	11	Ramps	2
Down	10	Alone	1
Disabled	9	Bodied	1
Нарру	7	Breathing	1
Independent	7	Capability	1
Need	7	Caring	1
Support	7	Helpless	1
Carer	5	Independently	1
Limbs	5	Operation	1
Normal	5	Paraplegic	1
Tumour	5	Quadriplegic	1
Independence	4	Suffering	1
Birthday	3	Supported	1
Communicate	3	Supportive	1
Difficult	3	Tumour	1
Disability	3		

### Figure 56: Support/Dependence Word Counts

### (10) Tragedy

### **Overall analysis**

In this macrocategory there were 10 stories designated to it, which represents 4.7% of the stories. 7 stories were written by female subjects and 3 by male subjects. The expected counts were exactly the same as the observed counts. This means that there is no direct gender effect within this macrocategory. However there may be an indirect gender effect when looking at the character story distribution. Therefore in terms of the sample size, there is no real difference. Across character types, Max was depicted in this macrocategory 4 times compared with an expected count of 2.3. All the other characters were more or less within their expected counts. This Max count is not quantitatively significant, but is worth noting. If you remove all the controls, which are the type 1 and type 4 storyboards, i.e. Max no mention/not apparent and Caroline no mention/not apparent, you are left with 9 stories out of 10; 7 of which are about acquired disability compared to 2, which are born disabled. This

may be partly due to the concept of the loss of normality on becoming 'the other'. Charity workers wrote 6 out of 10 stories within this macrocategory, compared to an expected count of 3. Taking into account the small sample size, this is still noticeable, but not statistically significant. However, this does show that charity workers do tend to see disability as a tragedy compared with the other occupational groups. Medical professionals only wrote 1 story within this macrocategory, compared to the expected 4. This may be a function of their training as seeing acquired disability as somewhat connected to fate. This is discussed in more detail later under the Fate macrocategory. There does not seem to be a difference in this macrocategory in the way that subjects respond to the images. However there is a noticeable difference in terms of the preamble when a disability is mentioned.

#### Sample story 1 discussion

The first sample story in this macrocategory (see page 217) is by a white female charity worker aged 36-45. This writer wrote a type 6 storyboard, which is Caroline with an acquired disability (leg amputee). In this story, Caroline is seen to be initially alone after the car accident and has practical problems about coping with her new impairment, such as 'wet pavements only added to her stress'. In the story Caroline meets a male colleague, Richard. However, 'she also feared his reaction when he finds out about her disability'. This is a real indicator of a tragic pathos within the whole story. At no time do we see Caroline coming to terms with her accident. At the end of this story there is some positive indication that Caroline might have a relationship with Richard, but the story has already set up the possibility of Richard having a negative reaction to her impairment. Within the story it is clear that Caroline has not mentioned her impairment to her new lover or friend. One imagines that there is no sexual intimacy; one cannot disguise a prosthetic leg when you are

making love. The story says that she lost her sister in a car accident and this is always a tragic event within a family. We are not told if Caroline's decision to tell Richard about her 'secret' was actually successful. The writer assumes that it was, however, Caroline's experience was of 'mixed reactions'. Even if it was successful, the overall tone of the story is tragic.

#### Sample story 2 discussion

The second story in this macrocategory (see page 219) was written by a white female charity worker aged 26-35. She wrote about a type 9 storyboard, which is Tom with an acquired disability (brain damage). This story is completely tragic. Tom was in the process of recovering from a brain tumour and having done so set up a very successful business, but in the end he dies in a road traffic accident. If this is not tragedy taken to the extreme, I do not know what is. This is a real example of how some people perceive disability. Disabled people's lives are taken to be full of tragedy and death with moments of pleasurable relief. This is reflected in the media survey, which is discussed later. In this story Tom is always going to be dependent and 'will suffer constant degeneration'. This is a stark prospect for anyone. Despite his momentary success, it was all wiped out by the road accident. The writer doesn't express any feelings of sorrow about this untimely end for Tom. It is also possible that the writer thought this was a relief to Tom's misery, despite his business success. We will see this theme recurring in the print media survey. This theme is connected to releasing people from a life of disability.

# Figure 57: Tragedy Sample Story 1 (page 1 of 2)

# Tragedy Sample Story 1 (page 2 of 2)

# Figure 58: Tragedy Sample Story 2 (page 1 of 2)

# Tragedy Sample Story 2 (page 2 of 2)

#### **Quotation Maps**

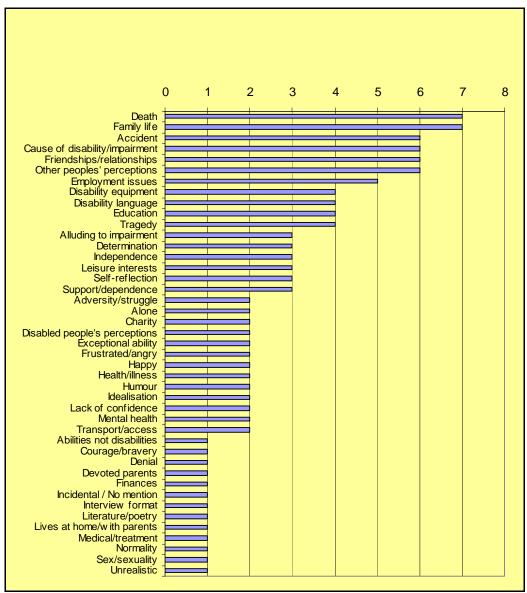
In the quotation maps for tragedy there are a number of excellent examples of this macrocategory. For instance, Quote 188:13: 'Last week there was a...' This is a story about Tom with a born disability where in the story he has a very successful life, but this all ended in tragedy. This is a common theme within this category where disabled people's lives are marred by tragic events. It is as if the writers are not able to allow disabled people to have a 'happy ending' and if they do it is unrealistic. Another example is Quote 208:6: 'Caroline had only 13-year...' This is about Caroline, who lost her leg in a road traffic accident. This story's main theme is how it was for Caroline to come to terms with her impairment because she was a very sporty young girl prior to the accident. This is an example of tragedy in terms of bereavement of ability. This is a common theme within this macrocategory and many other macrocategories have similar references. Tragedy and disability are constant links in not only the storyboard stories, but also in newspaper articles. This is one of the few overlaps between the two sets of data. There appears to be two forms of tragedy expressed. First, when there is a born disability it is not directly a tragedy for that disabled person, but more a tragedy for their parents and families. This theme is echoed in many of the storyboard stories. It may be thought that this about 'affliction', which is associated with a cruel departure from the 'natural' course of life. This could also be linked to negative images of the 'abnormal'. Second, there is a 'bereavement' theme, which is seen to be connected with acquired disability. This is very common among the storyboard stories and is mirrored very well in the newspaper articles. In these stories and articles the loss or affliction is visited upon the individual, rather than family and friends. These two types of tragedy make up an important Social Representation of disability. Disability in this context rests upon loss of ability, loss of dignity, sadness and an irreparable loss of value to society. However, as we saw in other macrocategories, such as Brave and Determined, there is a counterpoint to this representation.

# Figure 59: Illustrative Quotation Map: Tragedy

#### Microcode Frequencies within Macrocategory

In this macrocategory there are 7 microcodes with 5 or more counts. However, there are another 40 microcodes with mentions; therefore, there is a diverse range of microcodes. One should note that the two highest counts are 'Death' and 'Family life'. This is an interesting combination because it is very much socialising tragedy as a collective experience. The next highest microcodes counted are as follows: 'Accident', 'Cause of disability', 'Friendships/relationships', 'Other people's perceptions' and 'Employment issues'. It should be noted that the microcode 'Tragedy' only gets 3 counts. However, within this macrocategory it is very much a summation of microcodes that makes any one story tragic. There is a strong link between 'Accident' and 'Cause of impairment'. In all these stories tragedy is not directly mentioned, but it is implied. The Tragedy macrocategory is very identifiable in its themes of untimely death and the negative effects on family and friends. It appears that the writers of these stories are not able to perceive impairment in any positive way.





#### Word Count Analysis

In this macrocategory word count there are 51 different words which are disability related, including 19 with more than 2 counts. The highest count is for 'accident', with 9. The next two highest are 'different' and 'disability', with 7 counts each. It has become clear in the research that both 'different' and 'difference' are both euphemisms for disability. Most of the stories in this macrocategory are about acquired disability, which is why 'accident' is so prominent. Also, the word 'normal' is high. All the other words in this word count are either negative, such as 'unfortunately', 'mourning' and 'suicidal', or related to negative mental states. There are some medical terms, such as 'arthritic', 'spastics' and 'syndrome'. Overall this word count paints a bleak picture of disability, particularly noting that the words 'gravedigger' and 'graveyard' both have 2 counts each. It is the researcher's assertion that these words would not normally be used so often in a sample of this size. The word count reaffirms that becoming disabled is a tragedy and is written in that manner. This is an indicator that non-disabled people fear becoming disabled.

### Figure 61: Tragedy Word Counts

Accident	9	Depressed	1
Different	7	Derision	1
Disability	7	Determined	1
Normal	5	Disabilities	1
Assistant	4	Disillusion	1
Independence	4	Dysfunctional	1
Wheelchair	4	Fail	1
Able	3	Frailties	1
Treat	3	Handicapped	1
Carer	2	Hospital	1
Coffin	2	Hospitals	1
Crash	2	Medical	1
Flood	2	Mourning	1
Gravedigger	2	Remorseful	1
Graveyard	2	Self-confidence	1
Mentally	2	Self-esteem	1
Problems	2	Spastics	1
Unfortunately	2	Special	1
Wheelchairs	2	Stigma	1
Arthritic	1	Suffer	1
Bruised	1	Suffered	1
Capabilities	1	Suicidal	1
Care	1	Syndrome	1
Collapse	1	Tragic	1
Concern	1	Vomit	1
Debris	1		

### **Control (non-disabled)**

### **Overall analysis**

All the stories within this macrocategory were either Max (no mention) or Caroline (no mention). (Types 1 and 4 storyboard.) These stories were the control stories. They were meant to show the nature of stories when disability was not visibly apparent or not mentioned. This gave the researcher a baseline for comparison with the other storyboard types. There were 19 stories within this macrocategory, which was 9% of all stories. Ten of the stories were about Max and nine about Caroline. They were evenly spread across the age ranges, gender and occupational type; although the medical professionals were on the low side of the

expected count. This is because the study targeted the other storyboards involving disabilities at the medical and charity professionals. This was to highlight any difference in their Social Representations of disability, rather than to skew the outcomes. We compensated for this in the analysis, by taking account of their numbers and relative percentages.

#### Sample story 1 discussion

The first sample story (see page 230) within this macrocategory is written by a white British female charity worker aged 36-45. She wrote about Max from a type 1 storyboard, which has no mention of disability and no apparent disability. In this story Max is a very successful manager. Throughout the story Max is upbeat and positive. There is no reference to any negative aspects of his life. This is in marked contrast to all the other Max stories where disability is mentioned. It is clear that when disability is not seen or mentioned subjects tend not to write about physical, sensory or leaning disabilities. However, as we have seen from the disability (nondisabled) macrocategory, they do write about mental health problems. This was a very interesting finding because it illustrates that non-disabled people are more able to consider mental health problems than other disabilities. This is almost certainly because of life experience. Most people have stress or sadness in their lives and therefore can relate to that, rather than having their leg amputated. In knowledge terms it may be reasonable to say the experience of mental health is more familiar to nondisabled people than that of any physical, sensory or learning disability.

#### Sample story 2 discussion

The second sample story (see page 232) is written by a female charity worker with her age and ethnicity missing. This was a type 4 storyboard, which was Caroline, non-disabled. Once more in this story, Caroline has a very positive experience both in her work life and family life. Despite the story starting in an anxious mood, everything ends up 'happy ever after'. It is clear that the writer may think that female characters may have a harder time, but they will always win through. This is in stark contrast to other stories about Caroline when disability is mentioned. Therefore it is apparent that the control group of stories present a consistently positive interpretation of the everyday life of non-disabled people. In almost every story designated to this macrocategory the characters are happy, successful in employment terms and well balanced. In addition most are married or with partners in a happy, family life. This is in contrast to the same characters when they're disabled, who are often sad and lonely.

# Figure 62: Control Sample Story 1 (page 1 of 2)

# Control Sample Story 1 (page 2 of 2)

# Figure 63: Control Sample Story 2 (page 1 of 2)

# Control Sample Story 2 (page 2 of 2)

#### **Quotation Maps**

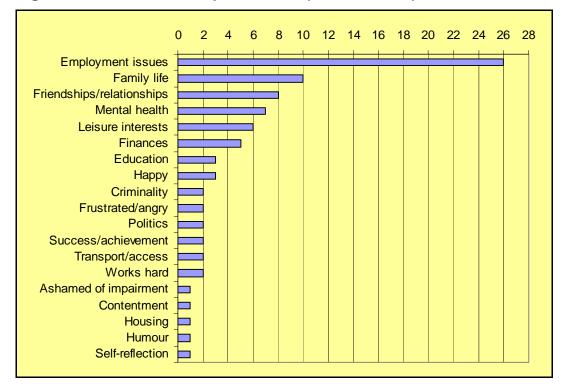
In all of this macrocategory's quotation maps there is no mention of disability. This is what we should expect as all the characters in the storyboard are non-disabled. All these quotations are of everyday non-disabled life. The subjects have attempted to make their stories interesting by many different scenarios. However, none of them within this macrocategory have used disability as a storyline. This is interesting because when disability is not apparent or not mentioned, disability is not a scenario which is used for storytelling.

# Figure 64: Illustrative Quotation Map: Control

#### Microcode Frequencies within Macrocategory

These microcodes are related to the macrocategory Control. This is where subjects did not have an image of an apparently disabled person, nor a preamble that mentioned disability. Therefore there were no reasons why disability would be mentioned in these stories, unless nondisabled people wrote such themed stories as part of their normal narrative repertoire. By examining the microcode frequency it becomes clear there are much fewer microcodes with five or more mentions in this macrocategory. In this instance there are only six which are 'Employment issues', 'Family life', 'Friendships/relationships', 'Mental health', 'Leisure interests' and 'Finances'. It is interesting that 'Mental health' has 7 mentions. This mirrors the study's findings in the macrocategory disability (non-disabled), where once more non-disabled people discussed mental health issues, where no apparent disability was in the image or preamble. This is a further indicator that non-disabled people are aware of mental health issues as being part of 'normal' life, whereas physical, sensory or learning impairments are not. It is noticeable that all key microcodes within this macrocategory are related to employment, finance and relationships. These are very much everyday concerns of non-disabled people. The control microcode underpins that in general non-disabled people do not write about disability as a matter of course, therefore the control macrocategory allows this study to examine other macrocategories as being what non-disabled people write when supplied with an apparent physical, sensory or learning disability.

Figure 65: Microcode Graph: Control (non-disabled)



#### Word Count Analysis

In the Control macrocategory word count there are only 11 disability related words and the most common is 'able' with 3 counts. All of the words in the control macrocategory are used in a non-disability context. Therefore it is apparent that subjects may use disability related words in a non-disability context. Therefore it is reasonable to conclude that nondisabled people do not normally use disability related words out of context, unless they have multiple meanings, such as 'operations'.

### **Figure 66: Control Word Counts**

Able	3
Help	2
Depended	1
Difficulty	1
Inspiring	1
Medical	1
Operations	1
Physically	1
Speech	1
Support	1
Weird	1

### **Disability (non-disabled)**

#### **Overall analysis**

This is an intriguing macrocategory and one that the researcher did not anticipate. This is where the subjects were asked to write about a Type 1 or Type 4 storyboard, which are non-apparent disability images with no mention of disability. These were the control storyboards. 5 people wrote stories with a mental health theme. There was no noticeable age or occupational difference in this macrocategory. 3 of the 5 stories were written by medical professionals. One of the key themes of this macrocategory was depression in relation to their family life. It is interesting that non-disabled people spontaneously write about mental health problems whereas they never write about other disabilities or impairments without a prompt. This may be because non-disabled people have experience in their own life in what they take to be issues around their own mental health.

#### Sample story 1 discussion

The first sample story (see page 241) is written by a female medical professional aged 18-25. She wrote about a Type 4 story, which is Caroline (non-disabled). In this story the key theme is around Caroline's difficult family life and her history of depression. Caroline in this story is constantly worried about family finances and she is very tense most of the time. For instance, 'so once she has done the family shopping and taken it all back home, she feels she can relax'. It appears that the writer considers that Caroline is only able to work part-time, because of 'long periods of depression,' but her colleagues are very 'supportive'. It is very interesting that all the stories within this category deal with mental illness, particularly depression. It is possible, being a medical professional, that this writer is aware that mental health problems are very common amongst working women, especially those with financial problems. It is likely that this scenario was taken from the writer's own life experience or learned experience.

#### Sample story 2 discussion

The second sample story (see page 242) is written by a male 'ordinary' person aged 36-45. He wrote a Type 1 storyboard story, which is Max (non disabled). This story is beautifully written from a literary point of view. The story deals with the work/life dilemma of the central character Max. The key issue in the story is Max's mental health being affected by the pressure of work. Obviously the writer has a deep understanding of the issues and may have experienced them himself or knows of someone who has. It is very interesting that this very current topic is used. It is clear that the writer understands that work/life balance is not only topical, but

has serious implications. The story deals with not only mental health, but also physical health. However, once more there is no mention of physical, sensory or leaning disabilities. One may suggest that non-disabled writers are able to imagine problems relating to mental health without prompting from either image or preamble.

# Figure 67: Disability (non-disabled) Sample Story 1 (page 1 of 1)

# Figure 68: Disability (non-disabled) Sample Story 2 (page 1 of 4)

# Disability (non-disabled) Sample Story 2 (page 2 of 4)

# Disability (non-disabled) Sample Story 2 (page 3 of 4)

# Disability (non-disabled) Sample Story 2 (page 4 of 4)

#### **Quotation Maps**

In terms of the quotations map for this macrocategory, all the relevant quotations deal with stress related problems. It is interesting that most of the quotes are relating to Max, who has a very expressive face and therefore may engender more interpretation by the writers.

# Figure 69: Illustrative Quotation Map: Disability (non-Disabled)

#### Microcode Frequencies within Macrocategory

In this macrocategory there is only one microcode with 5 or more mentions, which is 'Mental health'. These subjects were presented with storyboards that had no mention of disability in the preamble and no apparent disability in the images. Once more it appears that non-disabled people are able to contemplate issues around mental illness, but not any other impairments. What is more, all the references were related to depression. This underpins the findings from the control group. There were no other noticeable microcodes in this macrocategory. This macrocategory highlights that non-disabled people have some working knowledge about mental health and its related issues. They understand that mental illness is expressed through body language and facial expressions, which may have been inferred from the storyboards. Also, they may be using personal experience of mental illness or that of a family member or friend. This raises the point that non-disabled people can contemplate a complex psychological problem where one might appear non-disabled, but find it difficult to imagine having a more visible impairment. This is definitely related to body image and its consequent psychology.

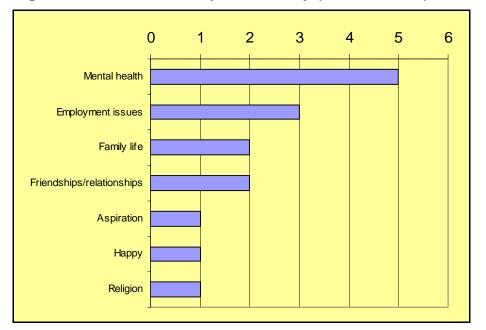


Figure 70: Microcode Graph: Disability (non-disabled)

### Word Count Analysis

There are 18 disability related words used in this macrocategory word count. Most of which are mental health related, such as 'despair', 'worrying' and 'trouble'. As has been said already, all these stories are mental health related, where there no disability mentioned in the storyboard. It is clear that non-disabled people perceive mental health mainly in terms of depression and despair, rather than different types of mental health, such as mania.

Нарру	3	Normal	1
Body	2	Strange	1
Down	2	Suffered	1
Bodies	1	Supportive	1
Compassion	1	Trouble	1
Dead	1	Weakening	1
Despair	1	Wheeling	1
Difficult	1	Worries	1
Idiot	1	Worrying	1

# **Reliability and Validity Method**

In order to ensure that all the macrocategories were reliable and valid, three inter-raters were used to re-examine the storyboard material. Each inter-rater analysed thirty-six stories which comprised of three stories from each macrocategory. The researcher was not aware of which stories were used. The inter-raters received a thirty minute briefing on the methodology and the thinking behind the study, along with the macrocategory definitions and a copy of the microcode definitions. The inter-raters were instructed to allocate each one of the thirty-six stories to one of the defined macrocategories using the definitions and microcodes as they saw appropriate. In effect, they were re-coding the material at a macro level. The inter-raters did not know how the microcodes had been

used on any individual story, but they were informed of the general application of the microcode system. They were given two weeks to complete the process. The inter-raters were one disabled professional, one psychologist (non-disabled) and one medic (non-disabled).

The researcher undertook a Cohen's Kappa analysis on their allocation of stories to each identified macrocategory. The mean Kappa value was 0.76. According to Robson (1993) this indicates an 'excellent' result. However, it is worth noting that one of the inter-raters' Kappa's was below the mean by 0.3. When the data were analysed it appeared this was an issue relating to the macrocategories of Denial and Incidental.

#### Statistical Analysis and Discussion of Storyboard Data

In this section the data will be examined from a purely statistical perspective. It must be made clear that essentially this study is a qualitative piece of research as all of the data are of a narrative nature. Therefore any statistical significance must be treated with caution. However in the analysis there are several significant findings which merit recognition (which were found by using Chi square tests). These are detailed as follows

#### Comparison of stories with or without a disability theme

When the study compared story themes (see Table B) it became clear that it was highly significant ( $p \le 0.000$ ; df=1; n=211). In this test stories with a disability theme were compared with those without a disability theme. This result indicates that when presented with a disability type story, most people cannot resist writing about disability as the main theme.

# Table B: Theme / Character Crosstab

			Story ch	naracter	
			disabled	non disabled	Total
story theme	Disability theme	Count	154	5	159
		% within Story character	82.4%	20.8%	75.4%
	No disability theme	Count	33	19	52
		% within Story character	17.6%	79.2%	24.6%
Total		Count	187	24	211
		% within Story character	100.0%	100.0%	100.0%

story theme \* Story character Crosstabulation

## Comparison of medical professionals versus others

Comparing medical professionals with the rest of the sample group the analysis found that medical professionals produced significantly more Sad/Lonely stories ( $p\leq0.046$ ; df=1; n=211). This indicates that medical professionals have particular Social Representations of disabled people (see Table C)

## Table C: Medical / Sad/Lonely Crosstab

#### medics versus others \* Sad/Lonely Crosstabulation

			Sad/Lonely		
			.00	1.00	Total
medics versus	ordinary/charity	Count	117	12	129
others		Expected Count	112.5	16.5	129.0
		% within medics versus others	90.7%	9.3%	100.0%
	medics	Count	67	15	82
		Expected Count	71.5	10.5	82.0
		% within medics versus others	81.7%	18.3%	100.0%
Total		Count	184	27	211
		Expected Count	184.0	27.0	211.0
		% within medics versus others	87.2%	12.8%	100.0%

If one compares Happy/Idealisation stories across storyboard characters there is a very significant result ( $p \le 0.001$ ; df=3; n=211). Although it is not completely conclusive where this significance is coming from, it is a reasonable assertion in the context of the qualitative analysis that this is directly related to Eve who is a person with Down's syndrome. This result underpins the popular myth that Down's syndrome people are always happy (see Table D).

#### Table D: Character / Happy/Ideal Crosstab

			Happy/Ide	ealisation	
			.00	1.00	Total
Character	Max	Count	46	3	49
Recoded		Expected Count	43.4	5.6	49.0
		% within Character Recoded	93.9%	6.1%	100.0%
	Caroline	Count	41	6	47
		Expected Count	41.7	5.3	47.0
		% within Character Recoded	87.2%	12.8%	100.0%
	Tom	Count	64	2	66
		Expected Count	58.5	7.5	66.0
		% within Character Recoded	97.0%	3.0%	100.0%
	Eve	Count	36	13	49
		Expected Count	43.4	5.6	49.0
		% within Character Recoded	73.5%	26.5%	100.0%
Total		Count	187	24	211
		Expected Count	187.0	24.0	211.0
		% within Character Recoded	88.6%	11.4%	100.0%

#### Character Recoded \* Happy/Idealisation Crosstabulation

The above result is further confirmed if one compares the Happy/Idealisation stories of Eve versus all other characters ( $p \le 0.0000$ ; df=1; n=211). (See Table E)

# Table E: Eve / Happy/Ideal Crosstab

				Happy/ Idealisation	
			.00	1.00	Total
Eve versus	Eve	Count	36	13	49
other disabled		Expected Count	43.4	5.6	49.0
characters		% within Eve versus other disabled characters	73.5%	26.5%	100%
	other	Count	151	11	162
	disabled	Expected Count	143.6	18.4	162.0
C	characters	% within Eve versus other disabled characters	93.2%	6.8%	100%
Total		Count	187	24	211
		Expected Count	187.0	24.0	211.0
		% within Eve versus other disabled characters	88.6%	11.4%	100%

#### Eve versus other disabled characters \* Happy/Idealisation Crosstabulation

#### Comparison of characters in Exceptional/Special macrocategory

Comparing Exceptional/Special stories across characters gives a significant result ( $p \le 0.040$ ; df=3; n=211). Closer analysis indicates that this stems from the characters Max and Tom. This implies that men are Exceptional/Special and not women (see Table F).

			Exception	al/Special	
			.00	1.00	Total
Character	Max	Count	40	9	49
Recoded		Expected Count	44.4	4.6	49.0
		% within Character Recoded	81.6%	18.4%	100.0%
	Caroline	Count	44	3	47
		Expected Count	42.5	4.5	47.0
		% within Character Recoded	93.6%	6.4%	100.0%
	Tom	Count	59	7	66
		Expected Count	59.7	6.3	66.0
		% within Character Recoded	89.4%	10.6%	100.0%
	Eve	Count	48	1	49
		Expected Count	44.4	4.6	49.0
		% within Character Recoded	98.0%	2.0%	100.0%
Total		Count	191	20	211
		Expected Count	191.0	20.0	211.0
		% within Character Recoded	90.5%	9.5%	100.0%

# Table F: Character / Exceptional/Special Crosstab

The above result was confirmed by comparing Max with all other characters in the Exceptional/Special stories ( $p\leq0.24$ ; df=1; n=211). (See Table G)

#### Crosstab

# Table G: Max / Exceptional/Special Crosstab

			Exception	al/Special	
			.00	1.00	Total
Max vs other	Max	Count	40	9	49
characters		Expected Count	44.4	4.6	49.0
		% within Max vs other characters	81.6%	18.4%	100.0%
	other disabled characters	Count	151	11	162
		Expected Count	146.6	15.4	162.0
		% within Max vs other characters	93.2%	6.8%	100.0%
Total		Count	191	20	211
		Expected Count	191.0	20.0	211.0
		% within Max vs other characters	90.5%	9.5%	100.0%

Max vs other characters \* Exceptional/Special Crosstabulation

#### Comparison of character gender across macrocategories

Comparing male and female characters across all macrocategories which have only disability storyboards was found to be significant ( $p \le 0.000$ ; df=9; n=187). However this result must be taken with caution because 15% of the cells did not meet the test criteria (see Table H). However this result indicates that women are seen to be Sad/Lonely. When the Sad/Lonely macrocategory is analysed across character gender there is a significant result ( $p \le 0.063$ ; df=5; n=211). (See Table I.)

#### Table H: Character gender / disabled storyboard macrocategories

			Count		Expected Count		% within story character gender			
		-	haracter nder		story c	haracter nder		-	haracter nder	
		male	female	Total	male	female	Total	male	female	Total
macro- categories only	Brave/ Deter- mined	16	9	25	13.6	11.4	25.0	15.7%	10.6%	13%
disabled	Denial	4	8	12	6.5	5.5	12.0	3.9%	9.4%	6.4%
	Special/ Except- ional	16	4	20	10.9	9.1	20.0	15.7%	4.7%	11%
	Fate	9	2	11	6.0	5.0	11.0	8.8%	2.4%	5.9%
	Incident al	16	17	33	18.0	15.0	33.0	15.7%	20.0%	18%
	Medical	3	2	5	2.7	2.3	5.0	2.9%	2.4%	2.7%
	Sad/ Lonely	10	17	27	14.7	12.3	27.0	9.8%	20.0%	14%
	Support/ Depen- dence	16	4	20	10.9	9.1	20.0	15.7%	4.7%	11%
	Tragedy	7	3	10	5.5	4.5	10.0	6.9%	3.5%	5.3%
	Happy/ Ideali- sation	5	19	24	13.1	10.9	24.0	4.9%	22.4%	13%
Total		102	85	187	102.0	85.0	187.0	****	100.0%	****

story character	gender *	macrocategies	only disabled	Crosstabulation
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# Table I: Character gender / Sad/Lonely

#### Crosstab

			Sad/Lonely		
			.00	1.00	Total
story character	male	Count	105	10	115
gender		Expected Count	100.3	14.7	115.0
		% within story character gender	91.3%	8.7%	100.0%
	female	Count	79	17	96
		Expected Count	83.7	12.3	96.0
		% within story character gender	82.3%	17.7%	100.0%
Total		Count	184	27	211
		Expected Count	184.0	27.0	211.0
		% within story character gender	87.2%	12.8%	100.0%

# Comparison of character gender in Exceptional/Special

#### macrocategory

When the Exceptional/Special macrocategory is analysed across character genders there is a significant outcome ( $p \le 0.018$ ; df=1; n=211). This contradicts the previous result as it implies on closer analysis that female characters are seen to be more Exceptional/Special than men. However, this test includes all female characters whereas before the test was only applied to disabled female characters. (See Table I.)

### Table J: Character gender / Exceptional/Special

			Exceptional/Special		
			.00	1.00	Total
story character	male	Count	99	16	115
gender		Expected Count	104.1	10.9	115.0
		% within story character gender	86.1%	13.9%	100.0%
	female	Count	92	4	96
		Expected Count	86.9	9.1	96.0
		% within story character gender	95.8%	4.2%	100.0%
Total		Count	191	20	211
		Expected Count	191.0	20.0	211.0
		% within story character gender	90.5%	9.5%	100.0%

Crosstab

# **Summary Discussion of Storyboard Results**

It is the opinion of the researcher that the storyboard technique has been successful in eliciting some of the current Social Representations of disability in society. The researcher is extremely aware that this is not a systematic or exhaustive study. However, it is the belief of the author that this study provides very good indicators of the Social Representations in circulation at present and helps to frame future research hypotheses. This study's methodology was based on a sample of convenience; therefore no firm conclusions can be made. But the consistency of the findings appears to indicate that there are a set or sets of distinctive Social Representations of disability. This amounts to a first attempt to develop an understandable and definitive typology of the Social Representations relating to disability.

It is clear that when subjects are presented with images or information which explicitly illustrates disabled people, subjects appear to have an overwhelming need or desire to make the disability the central theme of their story. This is consistent across all macrocategories and storyboard characters. It is particularly noticeable when the image of the storyboard character shows a disability. However the born and acquired preambles have a similar effect, but to a lesser degree. This is an interesting point because in this study the researcher has used visually apparent disabled characters in two out of the four storyboards (Tom and Eve), though in the other two storyboards the characters were apparently non-disabled (Max and Caroline). However, when non-apparently disabled characters were defined as being disabled, the resulting stories were still very often centred on their impairment, but in a more appropriate manner, such as Max coping with a new style of life.

This raises an important question about the way that people assimilate information and communicate their representations. It is often

thought that disability is a very visual phenomenon, indicated by wheelchairs, walking sticks, noticeable limps and prosthetics. But in actual fact, 68% of all impairments are hidden (Campbell and Oliver, 1996). However there is a strong undercurrent that impairments are aesthetically displeasing and are noticeable. In very few stories the disabled characters depicted have been sexually active or were seen to be attractive. This links to the idea that disabled people are sad and lonely.

The macrocategories fall into three major groups or sets of Social Representations, which relate to the types of impairments presented by the characters: born disabled people are much more often seen to be Exceptional/Special, Brave/Determined and Support/Dependence. It appears that subjects attribute strong personal characteristics in relation to born-disability. This was particularly noticeable in Tom's stories where he is often depicted as being very intelligent or successful in some way. This may be seen as a Christy Nolan of *My Left Foot* scenario. In contrast, people with acquired disabilities are often seen to be sad, lonely, tragic and victims of fate. This is noticeable when subjects discuss the personal relationships of the characters. In many cases a newly disabled character is left by their partner. Finally, there is a particular sub-category for Down's syndrome people, who are depicted as being happy all the time and almost as eternal children.

In the opinion of the researcher, the storyboard technique has been able partly to expose the inner fears of people, relating to disability. Certain themes have emerged from the storyboards which are in the main negative representations of disability. There is a consistent theme of loss and sadness, either in terms of personal relationships or of functional ability. There is an indication that disabled people are perceived to have different lifestyles and are on the margins of society. They are not seen normally as active ordinary people, but more as 'the other'. Social Representation Theory allows us to map out a spectrum of understanding and consequences of disability in that it enables us to construct a narrative picture of the way non-disabled people think about disability. The findings from the storyboard technique offer an insight into wider questions of how non-disabled people develop and use their knowledge relating to disability. The researcher feels that the storyboard technique offers a more accurate perspective on how disability is represented as the technique was indirect and attempted to seek out a more unconscious component of people's Social Representations. It is clear that much more detailed research is needed to underpin these initial findings.

# Chapter Three: Print Media Analysis: What the papers say...

# **Overall Introduction to Print Media Survey**

This chapter will deal with the print media survey. It will examine the survey methodology, results, analysis and identify the different types of Social Representations of disabilities portrayed in British newspapers. There will be a discussion relating to each type of Social Representation identified.

In this part of the study the researcher examined a wide variety of newspapers, both broadsheets and tabloids, i.e. the 'more serious' newspapers and the 'more populist'. The survey methodology is described in detail below. This section of the study examines how different newspapers represent disability issues. In this part of the work it must be clear that the narratives that the study is dealing with are related to real people and real life events, that is it is not fictional material which supplied the explorations of the storyboard stories, but based on actual events that should be reported as accurately as possible. The articles within this part of the study were written by professional journalists and headlines produced by professional sub-editors. The quality and nature of the stories produced are fundamentally different from the fictional stories produced by the storyboards. This is an important distinction to make at this point as the subsequent Social Representations produced in some cases are quite different from the storyboard technique. It is also important to note that the target audience of these stories was the general public and not the researcher in particular. In addition, it must be noted that the agenda of some of these articles often had a direct influence on

how the story was presented. For instance, some stories were related to injustice or needs for funding. Therefore the criteria of a journalist writing this article would be related to a social outcome. This was not the case in the storyboard stories as it was an invented scenario.

At this point it would be useful to return to Moscovici's analysis of media use of reified information. Moscovici (1976) examined the French press for articles relating to Psychoanalytical Theory and came to the conclusion that there were three key types of reportage of reified knowledge, which were propaganda, propagation and diffusion. As knowledge relating to disability is deemed as reified, i.e. outside the normal experience or external to common knowledge, Moscovici offers a useful framework to understand how the print media discusses and represents disability related issues. I will deal with each reportage type in turn.

# Methodology

## Introduction

It was decided to undertake a print media survey in order to identify the Social Representations of disability in leading newspapers in the UK. The selection of the newspapers was based on their national readerships as identified by market research in the period January to February 2000 (Press Association data). Outlined below is the administration, coding and article criteria used in this part of the methodology.

# **Administration of Print Media**

It was thought to be more realistic to buy copies of the national newspapers to be analysed than depending on Internet copies. This decision was taken for three reasons: (a) most people still read newspapers as hard copy in the UK; (b) the internet articles are very often different from the hard copy articles; (c) the format and layout of hard copies can be influential in the tone of the article. There is also an important related point that hard copy newspapers may be read by more readers and discussed within a shorter time frame. Internet readerships are more likely to be solitary, therefore the impact on the Social Representations of disability may be less social. The following newspapers were included in the study:

Broadsheets	Tabloids	Sundays
The Guardian	The Sun	The Observer
The Independent	The Daily Star	News of the World
The Times	The Mirror	
The Daily Telegraph	The Daily Express	

Very first article: 04/03/00 Observer-'Mark is unable to speak'

Very last article: 27/06/02 Independent-'Diversity is essential for success'

Newspapers were bought in two-week blocks over 27 months from 03/2000 to 06/2002. This gave a total of eight week's worth of newspapers out of which 153 articles were identified that met the criteria. The criteria for selected articles were as follows:

- Articles needed to contain reference to the cause of impairment or consequence of impairment of the central character in the article or theme of the article.
- 2) Articles about illness were not included unless they resulted in a defined impairment, e.g. John Diamond who lost his speech.

- 3) The impairment was an integral part of the article or theme of the article.
- 4) Any articles which referred to disability as a discrimination issue, tragedy, medical or lifestyle issue were included.

The articles were cut out, documented, and coded using Atlas.ti. The coding system for the articles was a thematic one. These themes were the macro themes. Each story was made up of micro themes, which were defined in the same way as the macro themes. A macro theme is an overall impression given by a story made up of micro themes. These articles and macro themes were then analysed using SPSS in order to identify any statistical significance in the patterns within the themes. The main themes identified were as follows:

#### (1) Brave/Determined

This is any story where the central character is depicted as being courageous or committed to overcoming their impairment despite facing adversity.

#### (2) Charity/Dependent

These articles focused on how disabled characters were dependent on help from others. These stories imply that disabled people need to depend on other people and have little or no control over their own lives.

#### (3) Children and Babies

These articles were the most popular amongst the printed press. They focused mainly on the negative aspects of growing up with a physical, sensory or learning impairment. These articles were normally quite sensational in their language.

# (4) Devoted Parents

These articles highlighted the non-disabled parents of children, babies and adults who were disabled. The central focus of these articles was that the parents were dedicated, unselfish, and committed to the care and welfare of their family member with a disability. Many articles implied that the burden placed upon them by a disabled family member was unreasonable and that they were very special people for taking such responsibility.

# (5) Exceptional/Special

These articles always depict a disabled character as being extraordinary and special in one way or another. Most of these articles imply that disabled people's achievements are about overcoming their impairments and that they are not just ordinary people with abilities.

# (6) Fate/Miracle

These articles imply that the incidence of becoming disabled has some metaphysical component such as luck or it was meant to be for some special reason.

## (7) Idealisation

In these articles the central character is depicted as being, not only extraordinary, but their lifestyle is near perfect, despite their disability.

## (8) Incidental

These articles deal with the disabled person's impairment or condition in a very matter of fact way. They discuss the disability or impairment in an appropriate context without sentimentality or apparent bias. They treat the disability as part and parcel of everyday life for that character.

## (9) Legal/Ethical

These articles concentrated on the legal, ethical and moral issues relating to stories about disabled people. These articles focussed mainly on the psychological and philosophical debates rather than detailing the social and medical complications of the disabled person's predicament. These articles were usually very formal and pragmatic.

# (10) Life and Death

These articles fall into two types. First, articles discussing the rights of disabled people, whether born or acquired, to terminate their life at the time of their choosing. This debate was at its peak during the research timescale. The newspapers were very much interested in the ethical and legal issues surrounding this matter. Most articles of this type implied that voluntary assisted euthanasia may be a reasonable approach to ending a disabled person's life if the disabled person considered that their quality of life was not tolerable. Second, there were articles discussing people who had accidents or complex medical treatment which meant that their impairment or condition put them in a life or death situation. These articles normally emphasise the miracles of modern technology or the determination of the central character.

#### (11) Medical

These stories were always focused on the medical aspects of the disability or condition dealt with in the article; for instance, any medical advancement such as new drugs, therapy, equipment, surgery or other treatments. These stories concentrate on the disabled character's experience of pain from their impairment or condition. They often refer to the bravery of the disabled character.

## (12) Sensational

In these articles all the events and human feeling are exaggerated using very emotive and florid language. These articles give the impression that disability is an extreme experience in every instance.

# (13) Tragedy

This is any story that depicts the main character as a victim of or suffering from their disability or condition. The central character is usually somebody who was or was going to be successful in the non-disabled world or born to non-disabled parents who needed to change their lifestyle due to having a disabled family member.

# **Results, Analysis and Discussion**

In this section the researcher will examine in detail the types of macrothemes found in different newspapers and will present a quantitative analysis of the newspaper articles in terms of word counts. The qualitative analysis within the framework of language used, meaning, context and underlying motivation of the article writers. This analysis will be in many ways a semiotic process. All research and analysis will then be discussed in detail using sample articles.

## **Qualitative Analysis and Discussion of Print Media Data**

## (1) Brave/Determined

(a) <u>Content</u>: These articles are 'classic' in content. Without exception they deal with characters who are overcoming or have overcome adversity. This may be a born impairment, a disability, illness, or an

impairment resulting from an accident. The case studies will examine two prime examples in John Diamond and Heather Hills.

(b) <u>Language</u>: The language used in this macrotheme is often related to struggle, adversity, battling, fighting, courage and overcoming the odds.

(c) <u>Style</u>: These stories were always emotive in tone and language. The central characters are always built up to be extraordinary, despite their suffering. The aim of the story is to move the reader and present the character as an heroic figure.

(d) <u>Meaning</u>: The underlying meaning of this type of story is that disabled people are figures of admiration, sympathy and astonishment. However, all these emotive feelings are couched in patronising language and images.

# (2) Charity/Dependent

(a) <u>Content</u>: In these articles the central character is either dependent on the help of a charity or has been helped by the research of a charity. Also, there are a lot of articles about the newspaper raising money for charity.

(b) <u>Language</u>: The language used in these articles is very often patronising, implying that disabled people would not have the same quality of life if it was not for the help of these charities. Some of the words used are 'committed', 'fundraising' and 'remarkable'.

(c) <u>Style</u>: These articles are often written in a condescending way, where the disabled person is spoken about in a passive manner and where the charity, or even the newspaper, is seen to be the saviour.

(d) <u>Meaning</u>: The underlying emphasis in all these articles is that disabled people are passive recipients of help and need support from charities and from readers of the newspapers. This is very much about being 'the other'.

# (3) Children and Babies

(a) <u>Content</u>: In these articles all the central characters are children and babies, who are under the age of 16 and have been born with or acquired impairments or disabling illnesses. There are three key themes within this macrotheme: the age of the subject, the tragedy of the subject and the precariousness of their situation. They normally report a matter of extreme medical intervention. This macrotheme overlaps with the Medical, Tragedy and Brave and Determined macrothemes. However what distinguishes these articles is the focus on the children and babies involved, rather than their treatment or their surrounding circumstances. All the stories within this macrotheme are human-interest articles.

(b) <u>Language</u>: The language used in this macrotheme is emotive and often sentimental. Some of the most common terms used are 'tiny', 'fragile', 'fighter', 'battling', 'courageous' and 'defiant'. The language, when used in the context of a baby, is always about its remarkable ability to overcome adversity. In the context of older children the language normally relates to how they have made a conscious decision to fight or cope with their disabling condition.

(c) <u>Style</u>: All of these articles are written in a dramatic way. Most of them are not sensationalised, but are presented in a manner that focuses on the individual, family and sometimes, the medical team surrounding the child. The structure of the texts mirrors the narrative of a soap opera. The journalist is aiming to draw the reader into the child or baby's world. Also, they are aiming to play on the reader's sentimentality; they want to

'draw their heart strings'. These articles are well written and often quite moving. The tabloids are much more likely to run this type of article. If the same stories appear in the broadsheets, it is very much more factual and less sentimental.

(d) <u>Meaning</u>: There are three major underlying themes in these articles. First, that children and babies are immensely resilient and capable of remarkable recoveries or able to cope with extreme circumstances. Second, that medical science has advanced so much that even the most extreme disabling conditions need not be life threatening. Finally, that the parents of these children and babies are not only devoted, but are highlighting and meeting weaknesses in the system, such as the need for more child donors of organs.

## (4) Devoted Parents

(a) Content: This is a macrotheme that is unique to the print media survey. In all the newspapers surveyed there were a high proportion of items related to devoted parents of disabled children and adults. Most of these articles use the disabled child or adult as a narrative vehicle in order to focus on the 'plight' of the parents. Many of these stories concentrated on the sacrifice made by parents for their children or family members. In effect these stories were stories about non-disabled people dealing with disability. Very few of the articles presented the disabled person in a positive way. Most of the disabled people were seen directly or indirectly as burdens on their families or parents. This was brutally highlighted in the case where a mother 'murdered' her two children with cerebral palsy because of lack of services and support. The mother was treated with much sympathy within these articles and very little was said about the consequence of her actions on her disabled children. These articles gave an overwhelming impression that it was an understandable

crime and was 'for the best' reasons in terms of the quality of life that the children may have had in the future. In this case its representation of disability leaves one wondering if disabled children and adult's lives are valued as equal to non-disabled people's lives.

(b) <u>Language</u>: Once more the language used in these articles is quite emotive. The articles concentrate on words such as 'despair', 'desperate', 'burden', 'need', 'quality of life', 'commitment' and 'love'. All the positive language is used mainly for describing the role of the parents or family and very little towards the role of the disabled person.

(c) <u>Style</u>: There are two styles within this macrotheme. One concentrates on the human-interest approach in terms of the impact on the family or parents and the second style is focussed on the lack of services and support offered to parents and families with disabled members. The actual opinions, needs and wants of the disabled person are rarely mentioned in these articles.

(d) <u>Meaning</u>: The underlying meaning within these articles is that disability is a burden for parents and families and that society is not very supportive of them. Disabled people are mainly portrayed and represented as being passive recipients of their help and love. It is rare that the disabled person's perspective is highlighted in terms of what they think should happen. These articles indirectly or directly imply that the non-disabled person's needs and quality of life are being undermined by the disabled family members.

#### (5) Exceptional/Special

(a) <u>Content</u> These articles always focus on the extraordinary abilities of disabled individuals. Despite their impairments they have achieved major successes or are very special people in some aspect of their lives. These articles often deal with people who have become disabled and have

coped with their impairments, particularly by doing unusual things such as running a marathon after a major accident.

(b) Language The language used in these articles is always about achievement and success. Words such as 'exceptional', 'special', 'extraordinary', 'triumphant' and 'remarkable' are common. The disabled people are described in almost superhuman terms. In the disability movement these types of stories are known as 'supercrip' stories and actually bear very little relation to the everyday lives of disabled people. One important thing to write about the language within these articles is that if it is about an acquired disabled person it is described in terms of the special inner will of that disabled person. If it is about a born disabled person it is often described in terms of them being remarkable and rare. In this instance the language used is often very patronising. This indicates that the writer feels that born disabled people cannot normally be expected to achieve success whilst non-disabled people who become disabled often find an inner strength

(c) <u>Style</u> In these articles the overall style is a mixture of emotive, sensational, hyperbolic and patronising approaches towards explaining the central character's stories. Most often these stories are taken from a human-interest perspective and a lot of unnecessary personal detail is described. These articles tend to be mainly in the tabloids, but the broadsheets often have their own standardised version of the same article. It is quite clear that many of these articles are directly taken from press releases, because several newspapers run almost identical stories.

(d) <u>Meaning</u> In these articles the writer decides to portray disability as an extraordinary success, despite the impairments of the character. The underlying meaning is that it is 'remarkable' if you are disabled to be successful.

## (6) Fate/Miracle

(a) Content This macrotheme is made up of two distinct groups of articles, which are very often inter-related. First of all we have articles which are almost always about people who become disabled, but the outcomes have a positive social effect on that person's life. For instance, someone who breaks their neck after taking heroin and goes on to become a counsellor for drug addicts. In these stories the event of becoming disabled was represented as a turning point in that person's life. In most of these stories the 'fate' of the person is always positive. The second type of article within this macrotheme is that of 'miracles'. For instance, the case of the baby with a severe heart defect making a miraculous recovery after being in intensive care for many weeks. Most of these articles are about babies or children who are very disabled or thought to be terminally ill with an impairment, but somehow survive in a medically inexplicable manner. Even when these articles mention the term miracle, very few articles mention the intervention of God. These articles concentrate on the miraculous power of children and babies to overcome adversity.

(b) <u>Language</u> These stories are full of emotive language, such as 'miraculous', 'destiny', 'inexplicable', 'impossible', 'amazing', 'remarkable' and 'overwhelming'. The language used is suffused with the writer's own amazement at the facts.

(c) <u>Style</u> In these articles there are a number of different styles ranging from sensational to heart-warming. All the articles are written in such a way that the disabled person is central to the article, but the medical technology is often the star. In the 'fate' stories there is a repeated theme of 'But for the grace of God go I'. This is about the writer's recognition that fate deals everyone different cards and it is up to the individual to make the best of their hand. There is an underlying assumption that life should

be fair, but as we know from the material analysis of the actual world it is currently nothing of the sort.

(d) <u>Meaning</u> This macrotheme is interesting in that it draws upon a range of ideologies about faith, religion, destiny and the paranormal. These articles emphasise the mystery of life and try to explain it in terms of quasi-mystical metaphysics. There is a real underlying theme of 'bad things happen for a good reason', particularly when it is about becoming disabled. This is of course a rationalisation, but it makes the outcome more acceptable and familiar. This is an interesting way of normalising the otherwise unacceptable.

### (7) Idealisation

(a) <u>Content</u> All of these articles depict the life of their disabled characters as being 'perfect' or 'near perfect'. Most of the articles are about disabled people who have overcome their impairment to achieve unusual things, such as climbing major mountains when they were amputees. These stories do not refer to the person's impairment or disabling condition when it could be appropriate. This is similar to the macrocategory Idealisation.

(b) <u>Language</u> These articles do not have a set pattern of language, but they do use many exaggerative terms, such as 'extraordinary', 'brilliant', 'special', 'remarkable', 'one-of-a-kind' and 'historical'. All of the characters are described as superhuman, despite their disability.

(c) <u>Style</u> These articles are usually quite sensational in their style - very much 'shock and horror' or 'would you believe it?' These stories are always human-interest based, with little reference to the problems faced by the disabled character unless it is also to their 'superhuman' ability to overcome them.

(d) <u>Meaning</u> The overall meaning within these articles is that nothing is impossible no matter what your impairment or disabling condition is. These articles idealise disabled people or their achievements when their achievements may be seen as being relatively ordinary if they did not have an impairment or disabling condition.

### (8) Incidental

(a) <u>Content</u> In these articles the writer's only mention of the impairment or disabling condition is as a matter of fact, rather than the central theme of the story line. These articles tend to be well written, factual, with any arguments well balanced, allowing the readers to reach their own conclusion rather than be swayed by the writer's opinion. Disability in these articles is not the central topic of the narrative. These articles normally deal with issues that are related to disability, such as service provision, the NHS and ethical and legal issues around treatments and consent.

(b) <u>Language</u> The language used with these articles is not emotive. There are no identifiable word patterns as these articles use a much more factual and pragmatic approach to their subject matter. Language tends to be guided by an overriding need to supply a 'message'.

(c) <u>Style</u> The journalists who write these articles use a more objective approach, where the facts and arguments are analysed on their merits. The reader is able to make a more informed decision, rather than being led into an opinion.

(d) <u>Meaning</u> The meaning in these articles gives a real sense of acceptance of the fact that impairment and disabling conditions are part of everyday life. None of these articles make disability the central theme, and all of them describe the disabled character as a person first, rather than highlighting their impairment or disabling condition.

### (9) Legal/Ethical

(a) <u>Content</u> These stories are focussed on the legal arguments around life and death issues relating to disability. During the study, the cases of Diane Pretty and Ms. B were in the headlines. In terms of newspaper reportage, these became exemplary for many other cases, which were less reported. The content of these articles was always centred on three components of the issue: the ethical pros and cons of assisted suicide; the arguments relating to euthanasia; the morality of allowing someone to suffer. There was very rarely any discussion relating to a disabled person's right to life and the necessary facilities and services that would be required for them to life in comfort and with dignity.

(b) <u>Language</u> The language used in these stories is very often emotive, speaking about 'every person's' right to die, the relief of suffering and misery and the quality of life. There is very rarely any positive language relating to disability. There is also quite a lot of legal jargon used, which is not very well defined, therefore the articles appear authoritative without any real substance or explanation.

(c) <u>Style</u> The style of these articles is often pseudo intellectual. In the broadsheets the arguments are better set out and more exploratory. The broadsheets tend to offer a more balanced argument. However, the emphasis is often on the right to die rather than the right to live. In the tabloids they often set out why the disabled person ought to be allowed to die, then go onto justify this conclusion.

(d) <u>Meaning</u> There is a dichotomy between the broadsheets and the tabloids. In the broadsheets, there is a serious attempt to engage in a national debate on assisted suicide and euthanasia. Most of the broadsheets lean towards the right to die whilst noting that this has wide ranging implications on how decisions are made and what legal

safeguards need to be put in place. In the tabloids, the arguments are more trite. In these articles the emphasis is on misery and suffering in the context of quality of life. Tabloids take a much more human-interest approach and turn it into a personal tragedy and not a national issue.

### (10) Life and Death

(a) Content: These articles are very stark and dark. They often depict disability and impairment as a choice between life and death, which is normally in the disabled person's hands. It is worth noting that during this study there were two high profile cases (Ms B and John Diamond) where disability was constantly discussed in terms of life or death and disabled people's right to die by choice.

(b) <u>Language</u>: The language used in these articles is emotive. Words such as 'dire', 'helpless' and 'crippling' are used.

(c) <u>Style</u>: There are two styles within these articles. The first one relates to the debate about euthanasia and the right to die. The second style is based on asking the reader to sympathise with the plight of the victim.

(d) <u>Meaning</u>: There are two underlying meanings within these articles. One is that having a disability may warrant people the right to die because of their impairment. The second is that disabled people are objects of pity and sympathy.

### (11) Medical

(a) <u>Content</u> In these articles medical technology and breakthroughs are central to the narrative. Disabled people who are being treated or using the technologies are secondary to the theme of the article. These articles are in three subgroups: new surgical techniques; new drugs; new

equipment. The overall thrust of these articles is of the wonderment of medical science. These articles gush over in detailing the incomprehensible facts of this modern science. The writers of these articles are completely taken up by the science involved rather than the human implications of its application. This may be because most of the articles were written by the science correspondents of the newspapers.

(b) Language In this macrotheme the language is extremely medicalised and jargonised. They use technical terms, which are not often explained. The language is positive in terms of the benefits to the disabled person, but no account is taken of the disabled person's feelings about any particular procedure or drug. What is important in these stories is the medical language and not the human language. There is a real sense that the writers of these articles are genuinely pleased that disability might become a thing of the past. This is particularly true when they deal with issues around hereditary impairments or genetic defects. When these articles do address the issue of eugenics, it is very often in the interests of what is best for all humanity, rather than recognising the value of diversity.

(c) <u>Style</u> There are three main areas within this macrocategory. One is a very matter of fact scientific approach. This is where the article deals with the nuts and bolts of the medical science involved, rather than the human-interest aspect of the story. The second style of story is more human-interest centred and deals with the impact of the medical science on the actual life of the disabled person. The final type of style is where the writer is almost painting a futuristic picture of what might be possible with the medical science under discussion. This often relates to ridding humanity of genetic and long-term impairments or disabling conditions. For instance, a more reliable and earlier test for Down's syndrome. (d) <u>Meaning</u> These articles have two or three underlying themes in their meaning. First, that medical science is able to 'cure' or overcome most disabling conditions. Second, that it is a good thing that medicine intervenes with disabled people's lives almost without question. Finally, that disability needs to be eradicated wherever possible, even if this means diversity becomes restricted. There is a subtext, which implies that we should strive for a 'perfect' human race. This is an extremely political message and one which humanity has struggled with for thousands of years. However, with new medical technology some people are more or less consciously accepting this as a reasonable aim.

### (12) Sensational

(a) <u>Content</u> These articles are all written in a highly charged manner. The writers aim to shock the reader, or are nauseatingly sentimental or didactically elicit righteous indignation. These articles have very few facts relating to the disabled person. However, they tend to extrapolate consequences to a remarkable level. All of these articles concentrate on the human-interest aspects of the disabled character's impairment, in many instances in a ghoulish manner.

(b) <u>Language</u> These articles are full of hyperbole; words such as 'shameful', 'pitiful', 'exceptional', 'heroic', 'doomed, 'defiant'. The language always exaggerates the consequences of..... on the person's life, when it is clear that this may not be the case. All these stories take a very negative perspective on impairment and disabling conditions. There are a few articles that sensationalise remarkable recoveries.

(c) <u>Style</u> The style of these articles is always one of exaggeration and emotive language, the facts lost behind a mass of clichés. These articles do not only appear in the 'tabloids', but also in the broadsheets. Most of these articles are written from press releases. These are noticeable

because there is a commonality across newspapers in the headlines and the quotes that they use.

(d) <u>Meaning</u> These articles promote the idea that disability is extraordinary and unusual. They also promote the idea that disability is a negative experience or a life changing experience. None of the articles take a pragmatic view of either the impairment of disabling condition. Disability is always extraordinary.

### (13) Tragedy

(a) <u>Content</u> Most of these articles are written about adults who have become disabled, either by an accident or severe illness. Some of the articles are about people who were born disabled and the severe consequences their impairments have had on their lives. These articles always focus on the negative outcomes of having an impairment or disabling condition. All these articles are human-interest stories whereby the central thrust is related to the 'tragic' events or illness, which changed the central character's life. In the articles that feature born disabled persons there is often an underlying note of pathos.

(b) <u>Language</u> In these articles the language is very direct, using mainly emotive and sentimental terms, such as 'despair', 'unfortunate', 'desperate', 'helpless', 'horrific' and 'terminal'. The language is loaded to elicit the reader's compassion. The headlines of these articles are always graphic in sensationalising the content of the article, such as 'Brave little soldier fights back against IRA bomb'.

(c) <u>Style</u> All of these articles are written in a human-interest manner, where the events are described often in gruesome detail. It is reasonable to suggest that these articles are voyeuristic. The newspaper is inviting the readers to take an interest in the gory details of these accidents or events in the name of honest reportage.

(d) <u>Meaning</u> The underlying themes within these articles are as follows. First, becoming disabled is a 'tragic' event. Second, being born disabled or with a disabling condition is 'tragic' for the parents or family. Finally, it is 'tragic' for people who become disabled and do not receive the necessary support. This is not raised when the subject is a born disabled person and so, by default, having an acquired impairment is more 'tragic' than a born impairment.

#### **Quantitative Analysis and Discussion of Print Media Data**

In this section there will be analysis of all the disability related words in all the newspaper articles. The process of identifying these words was similar to that of the word counts in the macrocategories. First, all the words of all the articles were counted and the criteria of language, meaning and context were applied. This was in essence a semiotic process. Due to the number of words involved this was a more difficult process and perhaps more subjective. However, there was an 83% agreement of disability words between inter-raters. In this analysis the words with more than 3 mentions will be considered important. As there are so many disability words in each macrotheme, this seems a reasonable cutoff point.

#### Word count methodology

In this section I will discuss and analyse the word counts of the macrothemes from the newspaper articles. The methodology used for this part of the study was as follows: All words in all articles were counted in Atlas.ti. Then disability related terms were identified in terms of language, meaning and context. This was in essence another form of semiotic analysis. The criteria used were any words which had a disability meaning or context. Two inter-raters were used to affirm the disability related words with an 81% agreement. There was total agreement in all

words with a count above one. A Cohen's Kappa test was not applied to this part of the research because there were over 270,000 words in the articles. Each inter-rater read 20% of articles. Therefore 40% of articles were reassessed independently.

### (1) Brave/determined

This macrotheme makes up 3.9% of all articles. There were six articles designated to this macrotheme. Only articles that appeared in tabloids were within this macrotheme, since the tabloids published twice as many of these articles than the expected count. The absence of these articles is also noticeable in the broadsheets. The reason for this may be that the tabloids are more concerned with human-interest items and are more likely to dwell on the personal aspects of any issues relating to disabled people's lives. The sample article was published by The Daily Express on 3<sup>rd</sup> March 2002. This article deals with a young army cadet who lost his hand and eye in a suspected bomb blast. This story was covered by all the tabloids in the study. The headline in this article was 'COURAGE: Stephen is to sky dive with the Red Devils to raise money for groups which helped him recover'. Another notable headline, which relates to this story, is from The Sun on the same day. This read, 'My brave little soldier will never surrender'. These headlines are typical of the reportage of this story. Within all the articles there are numerous references to his bravery, determination and 'will to live'. The central character, Stephen, is depicted as a superhero. No doubt Stephen is a determined person, however these articles focused on his injuries, rather than the problems he faced after the accident in terms of education and employment. It is clear that Stephen would have survived despite his injuries and made a full recovery even if he was not usually a resilient personality, therefore these articles gave a misrepresentation of a disabled person's life.

# Figure 72: Brave/Determined Sample Article (page 1 of 4)

# Brave/Determined Sample Article (page 2 of 4)

# Brave/Determined Sample Article (page 3 of 4)

# Brave/Determined Sample Article (page 4 of 4)

#### Word count analysis of Brave/Determined macrotheme

In this macrotheme word count there are 131 words that are disability related, with 22 words with three or more counts. The top count is 'hospitals' followed by 'award' and 'pride'. These articles tend to deal with disabled people who have become disabled and overcome their impairments. Many of the words in this macrotheme are related to overcoming adversity and fighting back. In this macrotheme disability is portrayed as a human struggle. Many of the words are medicalised, therefore disability is once more related back to health and illness, rather than social discrimination.

### (2) Charity/Dependent

This is a very interesting macrotheme as there was only one story which was designated to it. There were many articles relating to charity, but most of them had other primary themes. The sample article comes from the Observer newspaper on 26<sup>th</sup> March 2000. This article concerns Louise Clifford, who is the disabled daughter of the PR tycoon Max Clifford. Louise has severe rheumatoid arthritis. Louise works for the charity, Scope. The article concentrates on Louise and Max's commitment to charity work and their mutual commitment to PR. This is neatly illustrated by: 'She insists she didn't set out to follow in his footsteps, though: I questioned whether I should be doing something a bit more caring like teaching or counselling, but then again that would be a bit of a cliché as well because you come up through the medical route and get to know hospitals and doctors and counsellors inside out.' It is interesting that there are not more articles related to charity. However, most of the charity-related articles fall into Medical or Tragedy. Also many articles relating to children and babies have a charity content.

# Figure 73: Charity/Dependent Sample Article (page 1 of 4)

# Charity/Dependent Sample Article (page 2 of 4)

# Charity/Dependent Sample Article (page 3 of 4)

# Charity/Dependent Sample Article (page 4 of 4)

#### Word count analysis of Charity/Dependent macrotheme

There are 34 disability related words in this macrotheme, with only three having counts of 3 or more. These are 'disability', 'disabled' and 'medical'. Most of the words in this macrotheme are either medicalised or related to discrimination. It is interesting to note that articles relating to charity work almost always fall into the medical type or the civil tights type. This is very much reflected in the type of words used. For instance, medical stories use specific clinical words, such as 'arthritis', 'rheumatoid' and 'counselling', whereas discrimination articles use words such as 'rights', 'discriminatory' and 'restricts'. This is an interesting dichotomy in how journalists perceive the world of charities. On the one hand, charities are impairment specific organisations and on the other, they are campaigning organisations fighting for the civil rights of disabled people. From the work with the Focus Groups, disabled people concur that these are the two main types of charities and that disabled people are not involved in their management.

### (3) Children and babies

This macrotheme represents 3.3% of the total number of stories with 5 articles designated. All five stories were in tabloid newspapers. This was twice the expected count. This may be because all of these articles are directly human-interest stories. It must be noted that many other macrothemes included articles concerning children and babies. However within this macrotheme the complete focus is on the issue that has a child or baby involved. The sample comes from The Mirror newspaper on 14<sup>th</sup> March 2001. This article is about a little girl with cerebral palsy, called Maria, who has received help from a charity to pay for adaptations to the house. The newspaper paper takes vicarious credit for this success, due to its intervention. This article is heaping praise onto the work of charities in helping disabled people, rather than questioning why disabled people

and their families need to apply to charities and do not receive this help from the government. All of these articles depict children and babies as 'helpless' and 'needy', requiring the public's sympathy and support. There is no discussion about disabled people's civil rights in terms of getting the services and adaptations they may need. These articles perpetuate the idea that all disabled people are dependent on the non-disabled community in order to have a good quality of life. These articles underpin the Charity model of disability and propagate the notion that disabled people are objects of 'sympathy' and 'pity'. As will be seen from the Focus Group discussions, this is not how disabled people wish to be seen.

# Figure 74: Children and Babies Sample Article (page 1 of 2)

# Children and Babies Sample Article (page 2 of 2)

#### Word count analysis of Children and Babies macrotheme

In this macrotheme word count there are 71 disability related words with 7 that have three or more counts. The top two counts are for 'hospitals' and 'charities'. Many of these words are medically related or have health related meanings. All these articles concentrate on the impairments of the children and babies involved. Many of the words are emotive, such as 'battle', 'suffers' and 'trauma'. In all the articles the journalists depict these children and babies as if the children and babies have a conscious will to live. There is a real emphasis on their innate ability to survive. There is also a strong emphasis on the 'suffering' of the experience. Once more this portrays disability as a negative scenario.

### (4) Devoted Parents

This macrotheme makes up 7.2%, with 11 stories designated to it. There was no difference in distribution between the tabloids and broadsheets in terms of observed count and the expected count. The Daily Mail and The Daily Telegraph both had three articles each. The Observer was the only other newspaper to have more than one. The sample article comes from The Daily Telegraph, 8<sup>th</sup> March 2002. This article is headed, 'The bravest face of all'. This article is about the 'despair' and 'stress' of parents who had a baby, named Samantha, with Goldenhar syndrome. This is a condition where the facial features are different from the standard face. In this instance the baby had a missing ear and a small chin. The article concentrates on the parents suffering in not having a 'normal' child and their continuing quest to get the best treatment for Samantha to make her look as normal as possible. One of the key themes is the conflict between how many operations and how much pain they were willing to put Samantha through to make her look 'acceptable'. This is a key representation of disability because it raises the issue that being 'different' is always sociably unacceptable and that the pain imposed on the child is

worth going through in order to be more socially acceptable. The parents perspective is about changing the child rather than supporting her through difficult social reactions to her impairment. Goldenhar is not normally life threatening. This article once more raised the complex relationship between medicine and disability. In this case Samantha was born with severe symptoms, but the central theme of the article is how devoted the parents are and not how society can accommodate people who look very different from the 'norm' and what services may need to be developed in order to support them. This article emphasises the need for continuous medical intervention, not only on health grounds, but also in terms of aesthetics. This is a very complex mixture of reasons. The fundamental message of this article carries a negative perception of disability.

# Figure 75: Devoted Parents Sample Article (page 1 of 3)

# **Devoted Parents Sample Article (page 2 of 3)**

# **Devoted Parents Sample Article (page 3 of 3)**

#### Word count analysis of Devoted Parents macrotheme

In this macrotheme word count there are an enormous amount of disability words; 615 to be exact. This is the highest count of any macrotheme. 129 of the words have counts of three or more. There are three types of words in this macrotheme. The first are medical terms such as 'operation', 'diagnose' and 'surgery'. In these articles the emphasis is on the medical issues. Secondly, there are words directly related to specific impairments, such as 'Downs', 'Palsy' and 'Hutchinson'. These are always portrayed as burdens on the parents. Finally, there are words relating to negative emotions and sacrifice, such as 'strong', 'despair' and 'devotion'. Outside these types are other negative words relating to disability, such as 'depression', 'disbelief' and 'disrupted'. All these words are used in a negative context. The overall tone of these articles is that disability is a disruptive, painful and depressing experience for parents. Most of these articles are about children and babies with disabilities and very little mention is made of the disabled person. It is as if journalists perceive that the parents are the victims of an unfair life experience.

### (5) Exceptional/Special

This macrotheme represented 9.2% of all articles. 10 of the 14 were in the broadsheets with only four in the tabloids. Five of the stories were in The Daily Telegraph, with no other newspaper having more than two. One of the reasons for this distribution is that during this study, John Diamond died of cancer with severe disabilities. John Diamond was a very famous broadsheet journalist and therefore many articles were written which recognised his achievements. In addition there was a very important court case of a little girl named Lucy, who had become disabled because of a hospital accident. This case will be used as an example. This article comes from The Guardian on 8<sup>th</sup> March 2002. The headline is '£4m award to high IQ child victim of hospital blunder'. Lucy developed a

severe form of cerebral palsy when she experienced anoxia at birth through hospital incompetence. Her parents took the hospital to court and won a £4m award. The money was granted in order to ensure Lucy was cared for all her life. Lucy was described as follows; 'Lucy is fully selfaware and is an extremely intelligent little girl whose mental powers have not been impaired'. The QC in this case said, 'without her disability, she could have entered one of the highest-earning professions'. Over £400,000 of her award was related to loss of potential earnings. This is an interesting Social Representation of disability, which is actually at odds with itself. Here we have a highly intelligent child who may or may not be successful, depending on many other factors in her life. The assumption is that because of her physical impairments she will not achieve that potential success. There is a contradiction in the representation of this case, which is that many intelligent non-disabled people are successful and many are not. But there is the assumption that this child would have been successful were it not for her impairment. The case did not consider if Lucy might rather be an unemployed hippie for instance. This is a real instance of society trying to compensate for an impairment, which did not need to be acquired, therefore acquired impairments have more 'value' and need to be compensated for. In addition, the fact that Lucy was very intelligent and 'exceptional' made compensation even more imperative. No discussion in any articles devoted to Lucy made an attempt to analyse what happened if Lucy had not been 'exceptional' and 'intelligent'.

# Figure 76: Exceptional/Special Sample Article (page 1 of 2)

# Exceptional/Special Sample Article (page 2 of 2)

#### Word count analysis of Exceptional/Special macrotheme

In this macrotheme word count there are 360 disability related words with 129 with three or more counts. The top two are proper names – David Blunkett, a blind person who is also Home Secretary and John Diamond, a famous journalist who died of throat cancer after having a speech impairment for three years. Both of these men were depicted as being exceptional and special in many articles which describe the overcoming of their impairments to achieve. The Blunkett and Diamond articles may have slightly skewed the words used in this macrotheme. However, overall when these articles speak about disabled people they are depicted as extraordinary on the basis that they have overcome their disability and achieved something special in society. From the work with the Focus Groups, disabled people do not see themselves as exceptional or special, but would like to see themselves as exceptional or special for reasons that are not disability related.

#### (6) Fate/Miracle

This macrotheme represented 6.6% with 10 articles designated to it. There was no difference between numbers in the broadsheets and tabloids from the observed counts and the expected counts. No one newspaper had more than two articles within this macrotheme. The sample article for this macrotheme is a little quirky. This article was in The Daily Mail on 13<sup>th</sup> March 2000. The headline reads, 'A soccer debut for the boy who tackled the odds'. This article is about a young boy named Justin, who had an amputated leg and was banned from playing football using his artificial leg by the Football Association. As the article says, Justin was 'destined to be thwarted in his ambition'. However, his parents saved money to buy a special artificial leg that met FA rules and now Justin is allowed to play junior league football. Throughout the article is the underlying theme that fate was in Justin's favour. This is an

interesting case of Fate/Miracle because it combines the two concepts of fate and miracle. The article implies that it's a miracle for a one-legged person to be a footballer and also implies that he was destined to be a football player. Most of the articles in this macrotheme in other newspapers deal with Fate/Miracle in a much more religious or metaphysical way. But with Justin it's more a matter of what he was 'born to do'.

# Figure 77: Fate/Miracle Sample Article (page 1 of 2)

# Fate/Miracle Sample Article (page 2 of 2)

#### Word count analysis of Fate/Miracle macrotheme

In this macrotheme word count there are 33 words with more than two counts, which are disability related, out of 196 identified disability related words. The words with most counts are 'treatment', 'Parkinson's' and 'patients'. This is because a large proportion of newspaper articles are medically focused items. During the study there were many articles relating to new treatments for Parkinson's and for spinal injuries. This would account for their high counts. Also, there were a huge number of articles about the journalist John Diamond, who died of cancer of the larynx. However, it is noticeable that most of the disability words, particularly in the top 33 words, have negative connotations, such as 'injury', 'problems' and 'danger'. It is clear that disability is seen to be a perilous state of affairs. However, in the Fate/Miracle macrotheme, redemption often highlights groundbreaking treatments or spiritual experiences. This is definitely a means of making extremely complicated scientific knowledge into common knowledge by using the concepts of metaphysics and self healing in layman's language. Therefore disability once more becomes mystified and so outside common knowledge.

### (7) Idealisation

This macrotheme has produced five articles with no newspapers having more than two items of this nature. This macrotheme made up 3.3% of all articles analysed. There is no significant difference between tabloids and broadsheets. There were two key themes for these stories. Firstly, the death of John Diamond the newspaper reporter, and secondly the engagement of Sir Paul McCartney and Heather Mills. Heather Mills is a former model who lost part of her leg in a road accident. Many of the articles about John Diamond are also found within the Life and Death macrotheme and Tragedy macrotheme. Therefore, this section will analyse a story about Heather Mills from the Sun newspaper on 16th March 2000. This story is typical of many like it, whereby Heather Mills is portrayed to be the perfect partner for Sir Paul, despite her impairment. In this article the relationship and her achievements are built up into an idealised picture. For instance, 'Paul was impressed by Heather's bravery in continuing her modelling career, and gave £150,000 to her campaign for limbless war victims.' The article continues in a very sycophantic tone and makes out that there are no problems with her impairment and that Heather Mills is a champion of disabled people. However, when the Focus Groups mentioned Heather Mills, all the disabled people had a much lower opinion of her contribution to the liberation of disabled people.

# Figure 78: Idealisation Sample Article (page 1 of 2)

# Idealisation Sample Article (page 2 of 2)

#### Word count analysis of Idealisation macrotheme

In this word count there are 156 disability related words with three or more counts. This word count is very unusual because almost all the word counts within this macrotheme are about the journalist John Diamond, who died of throat cancer. The top count is for 'cancer'; followed by his name. All of the other 21 words are related to the treatment and the death. However, all these articles concentrate on John Diamond's achievements as a journalist and writer. Also, they highlight his strength of character, facing up to a terminal illness. This is very much about idealising a fellow journalist and ignoring the fact that John Diamond wrote about his deep depression and utter despair at times.

Many of the articles written by John Diamond discuss the prejudice against people with impairments. These articles were mainly when he was unable to talk anymore. However, the journalistic world did not want to discuss matters of discrimination and attitudes to disability, but rather portray a disabled colleague as a brave fighter, with a unique sense of humour. From the work with the Focus Groups, it is clear than many disabled people feel that ordinary disabled people are worthy of the same adulation. Becoming disabled when you are famous, such as the cases of John Diamond or Christopher Reeve, brings with it the Social Representation, which to all intents and purposes ignores the everyday reality of their impairments. This may be because 'heroes' or 'supermen' cannot be flawed. In common knowledge disability and impairment equates to imperfection.

#### (8) Incidental

This macrotheme represents 11.8% of all articles in the study with 18 articles assigned. There is a notable difference between the tabloids and the broadsheets from the expected count. The broadsheets have 12 articles compared to 6 from the tabloids. The expected counts were 8.8%

and 9.2% respectively. This indicates a difference in approach of the types of newspaper in terms of stories that involve disabilities, but are not the central purpose of the article. There are two sample stories within this macrotheme, which are very different but illustrate the differences between types of newspapers. The first article is from The Mirror and is dated 8<sup>th</sup> March 2002. This was headed, 'Mum: Girl killed my baby son'. This story is about a teenage mother who blamed her three-year-old daughter for drowning her baby son in the bath. However, she was charged with murder. The baby son had Spina Bifida. It is very important to know that no major reference was made to her son's disability. It was a case of suspected murder. However, it is interesting that the newspaper did not question why the mother might have murdered a disabled baby. The case continues.

The second example comes from The News of the World, 11th March 2001. The headline is, 'Disabled Tim joins world's high-flyers'. This is a very positive story about a disabled pilot taking part in the London to Sydney air race. This makes a big deal of the pilot's disability, but is very 'feel good' in terms of personal achievement and raising money for charity. This story is very much within the Social model of disability, whereby disabled people are able to achieve given the right support and opportunities.

# Figure 79: Incidental Sample Article 1 (page 1 of 1)

# Figure 80: Incidental Sample Article 2 (page 1 of 1)

#### Word count analysis of Incidental macrotheme

In this macrotheme word count there were 213 disability related words, with 40 with more than three counts. The highest counts were for 'disabled' and 'brain'; followed by 'disease', 'doctor' and 'patient'. This may not appear very positive at first sight. However, all 213 words in this count were used in an appropriate way, relating to disability, without negative overtones. These articles often discussed discrimination, advances in medicine and the lived experience of people with impairments. They were very often related to law and politics. This is why words such as 'litigation' and 'Thatcherism' appear. These articles are generally focused on the disabled person, rather than the medical or health professionals. Most of these articles used disability to discuss legal or moral issues. This is the only macrotheme with the word 'zombie' in it. This is worth noting, if only for humour.

#### (9) Legal/Ethical

These articles made up 7.9% of all articles. 10 of the 12 articles were published in broadsheets and only two were in the tabloids. The tabloid expected count was three times this number. One possible reason for this is that broadsheets deal with more social and political issues in an indepth manner. The Daily Telegraph and The Independent both had three articles of this nature. The sample article is from The Guardian, published on 6<sup>th</sup> March 2000. The headline says, 'Disabled child care: Case of the week'. This article discusses the legal aspects of a hospital not sharing information relating to a Downs syndrome baby. The parents took the health authority to court because they would not have wished for a disabled baby. Therefore they were arguing that the hospital should pay compensation for the 'burden' of bringing up a 'handicapped' child. This ruling relates to The Abortion Act in which the mother was given the right to terminate a disabled foetus. This article raises complex legal and

ethical issues relating to a disabled person's right to life and to a mother's right to choose. There is no dispute that the parents have a right to terminate a disabled foetus should they so wish. However, there is the question of valuing disabled people's lives. If parents are properly informed about the potential and the possible services that are on offer, some parents may choose to continue with the pregnancy. This is definitely one Social Representation where information, knowledge and communication underpin the final outcome. If disability was not seen as a burden or hard work, but seen in terms of diversity, people, including the medical profession, might have a more open-minded approach.

# Figure 81: Legal/Ethical Sample Article (page 1 of 2)

# Legal/Ethical Sample Article (page 2 of 2)

#### Word count analysis of Legal/Ethical macrotheme

In this macrotheme word count there are 176 words which are disability related, out of which 42 have three or more counts. The top three counts are 'disabled', 'motability' and 'disability'. These articles tend not to be about the disability itself, but tend to relate to treatment or outcome, using words such as 'treatment', 'ventilator' and 'rehabilitation'. Many of these words are used in the context of professional negligence or ethical dilemmas. During this study there were two high profile cases of Miss B and Diane Pretty. Both were women who had become disabled and wanted the right to die. This means that within the word count, there are words such as 'rights', 'tribunal' and 'controversy'. The words within this macrotheme are quite different to those in others because most of them are used in a legal context.

#### (10) Life and Death

This macrotheme represents 13.8% of all articles with 21 articles designated to it. There is no noticeable difference between tabloids and broadsheets in terms of their observed count and expected count. No one newspaper stood out in terms of the number of articles within this macrotheme. The Daily Mail had four articles. The issue of life and death was a major preoccupation of all newspapers. Many other articles, which were not designated to this macrotheme for various reasons, also dealt with life and death issues. Newspapers appear to promote the idea that disability equates to life and death issues more often than not. This is particularly true when they deal with stories relating to acquired disabilities. These articles give the impression that having a disability is somehow of itself life threatening.

This macrotheme is a complex one and therefore two contrasting sample stories have been selected, both from the Daily Mail on the same day, which was 7<sup>th</sup> March 2002. During the period of this study the case

of Miss B came to the attention of the press. Miss B was a social care worker who became paralysed from the neck down and was on a ventilator to keep her alive. Miss B was totally lucid and not with brain damage. However, Miss B was determined to die, by asking the medical professionals to turn off her ventilator, which would result in certain death at that time. This case went to court, but Miss B died before any final judgement was made. Her death was partly due to her refusal of other treatments. Her case raised many problems. The first sample article, which is headed 'The Case for Life', deals with the 'unbearable quality' of life that Miss B might have if she lived. This article was sympathetic with her plight and quoted the poet Arthur Hugh Clough's dictum, 'thou shalt not kill, but needst not strive, officiously to keep alive'. In this case the medical professionals were being asked to break their Hippocratic Oath to preserve life at all costs. In contrast, in the same newspaper, there was an article by a woman with severe disabilities who had also wanted to die at a certain point in her life. Unlike Miss B, she learnt to live with her impairment and became important in helping other disabled people in India. These two stories contrast the different stances on the Social Representation of disability; on the one hand, the tragedy and on the other, the inspiration. Disability is often connected with death and at the very best with a poor quality of life. However as we will see from the Focus Groups, this is not how disabled people perceive their lives.

# Figure 82: Life and Death Sample Article 1 (page 1 of 1)

# Figure 83: Life and Death Sample Article 2 (page 1 of 3)

# Life and Death Sample Article 2 (page 2 of 3)

# Life and Death Sample Article 2 (page 3 of 3)

#### Word count analysis of Life and Death macrotheme

In this word count there are 320 disability words with 99 having over three counts. The top counts are 'hospital', 'die', 'cancer' and 'doctors'. Once more articles about John Diamond are primarily responsible for the emphasis on this word count. However, the case of Miss B is very significant as well. This is highlighted by some of the words such as 'euthanasia', 'paralysed' and 'Butler-Sloss' (the judge who presided over the Miss B case). All of the words with more than three counts have a negative overtone and emphasise that disability is about a negative experience, complex medical decisions and ethical issues. Most of the words used in the macrotheme are highly emotive and are used to paint a bleak picture of living with impairments.

#### (11) Medical

This macrotheme represented 20.4% of all articles with 31 articles designated. There was no difference between the tabloids and the broadsheets in terms of observed counts and expected counts. The broadsheets published 16 articles and the tabloids 15. The Daily Mail had most articles with seven. The Times had six. It is noticeable that other tabloids had very few articles of this nature. The Daily Telegraph had the next highest count with four articles. Most of these articles were very 'scientific' in nature and attempted to explain or discuss medical advancements or problems that might be related to disability. All the newspapers seem to be fascinated by medical jargon, failures and unique treatments. These articles were written in a matter of fact manner with the pretensions of real or scientific knowledge. The sample article comes from The Times on the 15<sup>th</sup> March 2001. This article reported advancement in the treatment of Parkinson's disease. The headline in itself is an interesting representation of the macrotheme. The headline reads, 'Parkinson's Progress'. The article discussed the development of a number of new treatments for Parkinson's disease. None of these treatments have been entirely successful and the article focuses on the risks that medical advancement involves. In all the articles in this macrotheme, disabled people are not the central theme. It is the medicine that is the central subject. Science correspondents generally write these articles and therefore the human-interest component of any article is secondary. From all the articles in this macrotheme there is a clear message that medical science is very good, if sometimes dangerous, and is capable of 'curing' disabled people or 'improving' their quality of life. This is meant to be a positive representation of disability, but as we see from the Focus Groups data, disabled people often see medical science as a threat to their lives rather than a help.

# Figure 84: Medical Sample Article (page 1 of 1)

#### Word count analysis of Medical macrotheme

In this macrotheme word count there are 436 disability related words, which is the highest overall count of any macrotheme. There are 149 words with three or more counts. This is also the highest count in all of the macrothemes. Most of the words are directly linked to medicine. The highest counts are 'treatment', 'disease', 'health', 'hospital' and 'patients'. There is no doubt that these articles directly connect disability and impairment with illness and health. This is very much promoting a Medical model of disability, which is not apparent as a major theme in the storyboard stories. First, technical medical terms such as 'Alzheimer's', 'eczema' and 'botulinum' are noticeable. These are used in a matter of fact way. Second, there are words relating to treatment such as 'drugs', 'physiotherapy' and 'diagnose'. These words litter the word count and are used mainly to describe what is happening to the disabled person rather than considering what the disabled person wants. Finally, there are words relating to outcome, such as 'deadly', 'information' and 'suffering'. Most of these words have negative undertones. Many of the words in this macrotheme are hyperbolic. Nearly all the words within this macrotheme portray disability as a negative experience and show that medicine is attempting to remove the incidence of impairment wherever possible. From the work with the Focus Groups, disabled people clearly feel that the words used about disability are often medicalised and negative.

#### (12) Sensational

This macrotheme was unexpectedly low in numbers. It represented 1.3% of all articles with only two articles. Both were from The Sun newspaper. The researchers expected a much higher count here, however many of the Sensational type articles fell into other more appropriate macrothemes. Therefore the Sensational macrotheme was a component of other macrothemes, such as Brave/Determined and

Exceptional/Special. A separate macrotheme was maintained because these two articles explicitly emphasise the influences of disabilities on the central character. The sample story is from The Sun on the 9<sup>th</sup> March 2000 and is headed, 'Broken face of Diana's guard'. This is an article about Trevor Rees-Jones, who was the bodyguard of Princess Diana of Wales, who survived the car crash in Paris, where the princess died. Trevor Rees-Jones received major injuries in the accident, mainly to his face and head. These injuries are ghoulishly documented in detail in the article with pictures of the x-rays with captions, such as 'nose damaged beyond recognition'. The article also details the remarkable work of the surgeon who reconstructed his face. This article says that the physical impairment has become minor compared to the psychological trauma. It is very interesting that this article plays down the facial disfigurement of what was a 'handsome' man and emphasises the psychological aspects. Once more as we will see from the Focus Groups study, it becomes clear that society has a problem with facial disfigurement.

# Figure 85: Sensational Sample Article (page 1 of 2)

# Sensational Sample Article (page 2 of 2)

#### Word count analysis of Sensational macrotheme

There are 45 disability related words in this macrotheme with only two with three or more counts, which are 'blind' and 'remarkable'. Most of the words in this macrotheme are emotive verbs, such as 'shattered' and 'maimed'. There are also a lot of emotive adjectives, such as 'deadly', 'horrible' and 'incredible'. It is clear that the journalist is attempting to incite high emotions in the reader. Many of the words used are descriptions of extreme emotions, such as 'shocked', 'stunned' and 'terror'. This language takes disability outside everyday life. In addition there is another underlying theme of exceptional words, such as 'remarkable', 'incredible' and 'amazingly'. With such a small sample it is not clear if this is unusual for newspapers. However, it is clear from the context of the articles that disability only falls into the macrocategories of either Brave and Determined or Tragedy. From the work with the Focus Groups, it is clear disabled people consider this is a rather naïve and inaccurate portrayal of their lives.

#### (13) Tragedy

This macrotheme makes up 10.5% of articles with 16 articles designated. 11 of these articles were published in tabloid newspapers. This was above the expected count of eight. This may be because tabloid newspapers are more interested in human-interest and emotive stories. The sample story comes from the Daily Mirror newspaper dated 15<sup>th</sup> March 2001. It reports the story of Karmel, a young woman in her mid twenties, who was diagnosed with Multiple Sclerosis. The article is headed, 'I won't let MS beat me'. In the first few words of the article it can be seen that the overall tone is going to be tragic. The second line reads, 'To the vivacious 25-year-old it sounded like a death sentence'. This is a very emotive statement. The article continues with a very dark description about how Karmel felt about her new disability. The article says Karmel was 'freaked out, distraught, in deep depression', whereas before she was 'bubbly', 'successful' and 'ambitious'. 'MS has made her a virtual recluse'. Despite this rather tragic report Karmel has come to terms with her impairment and was intending to run the London Marathon. Karmel has come to terms with her disability, but the article does not emphasise this aspect of her story. The reader is left with the sense of loss and tragedy instead of a feeling that disability is part of everyday life. The language used within the article is very negative. Words such as 'stricken', 'mortified' and waiting to 'deteriorate' are used to highlight the negative aspects of becoming disabled. When the article discusses Karmel's new positive attitude it is still tinged with a hint of sadness and is put in the context of a heroic fight against impairment. Whereas Karmel is reported as saying, when speaking about her marathon run, 'It gives me a goal to reach, to prove that there is life with MS'. This is set against the background of how she was diagnosed, which means the positive aspects become lost in the perceived tragedy of the situation. It is clear from all the articles in this macrotheme that disability, particularly acquired disability, is generally a negative life experience, rather than just a change in the type of life someone has. There is a strong underlying message that disability is a tragic event that merits society's sympathy and understanding. All of these articles deal with the human drama of impairment and do not address how disabled people can be supported in order to live as 'ordinary' and 'normal' life as possible. It is in the nature of journalists to make a drama out of a crisis. As we will see from the Focus Group material, most disabled people lead reasonably ordinary lives if they receive the right support and financial assistance.

# Figure 86: Tragedy Sample Article (page 1 of 4)

# Tragedy Sample Article (page 2 of 4)

# Tragedy Sample Article (page 3 of 4)

# Tragedy Sample Article (page 4 of 4)

#### Word count analysis of Tragedy macrotheme

In this macrotheme word count there are 292 disability related words, with 79 having three or more counts. The top counts are for 'brain', 'patients' and 'autism'. Many of the words are very negative, such as 'catastrophic', 'devastating' and 'stricken'. Disability is written about in technical terms with an overwhelming tone of disaster and fear. It is interesting to note that autism is very much seen as a tragedy, rather than another complex psychological problem. 'Autism' and 'autistic' are mentioned 34 times in this macrotheme. This is not present in the same numbers in other macrothemes. This may be because there is still a worldwide mystery and confusion surrounding the nature of autism. Autism demonstrates non-disabled people's fear of the unknown and unexplained.

#### **Summary Discussion Print Media Survey**

The print media survey identified some of the Social Representations of disability that were not present in the storyboard data. However, there was a definite degree of overlap, but using different narrative forms. Newspaper articles represented disabled people as macrothemes of Brave/Determined, Charity/Dependent, Exceptional/Special, Idealisation and Tragedy. These macrothemes correspond reasonably well with the same type of macrocategories in the storyboard data. In the newspaper articles these representations are much more florid in style. This is most likely because they were written by professional journalists. However, the semiotic message and key language are extremely similar. All these articles reinforce the language, images and representation found in the storyboard stories. Of course it is not possible to suggest a causal link between the Social Representation identified in the storyboard stories and the same type of stories in the print media. It is reasonable to suggest

that journalists – be they non-disabled or disabled – have assimilated some of the current Social Representations of disabled people, which are present within society and therefore reproduce them in their work. It would need a much more systematic and wider analysis to determine if there was a causal link between these sets of representations. These Social Representations may be thought of as a form of Moscovici's concept of propagation. Propagation in the media maintains the status quo of Social Representations within society and it is likely to be a dialectical process whereby ordinary people influence the way journalists write and at the same time journalists influence the way people think. Shakespeare (1997) observed that there is an integral link between high profile newspaper stories and awareness of certain disability issues within the general public. This was mainly discussed in the context of genetic engineering.

It is very interesting that even professional writers rely on basic stereotypes of disabled people and in most cases do not challenge them. In actual fact in the case of John Diamond they actually perpetuate the Exceptional/Special and Brave/Determined representation of disabled people. This is particularly interesting as John Diamond was one of their own colleagues, whom many of them would have known very well. However, when he became disabled their representation of him went from hard-nosed journalist to brave and exceptional disabled journalist. This indicates that there is an underlying idea that becoming disabled makes a person different.

Within the print media survey the study has identified certain Social Representations which are not found in the storyboard data. These are Children and Babies, Devoted Parents, Legal/Ethical, Life and Death and Sensational. These are very much based on human interest or sensationalism. It appears that if one believes the media all disabled people are children or babies with devoted parents. Of course this is the

researcher being cynical. However, an important point must be made: disabled people are often portrayed in a child-like or dependent manner. These are not active, responsible members of society. Disabled people are the subject of medical experiments or victims of some tragedy. The key focus of all these articles is not the disabled person themselves, but the people around them. Therefore the disabled person only becomes the secondary narrative object. The focus is often the sacrifice or the commitment of non-disabled people in order to 'improve' the quality of life for some unsuspecting disabled person.

There are two important macrothemes, Legal/Ethical and Life and Death, which do not appear in any storyboard stories. In the Legal/Ethical articles disability is seen to be a complex medical and moral issue. This research was undertaken with a backdrop of the case of Miss B and Mrs Pretty, who both wanted to die because of their impairments. These issues were not discussed in the storyboards. In the newspaper articles relating to these cases there was a strong leaning towards the right to die. This may be thought as propaganda in terms of disability being 'not a nice thing'. Very few newspaper articles gave a balanced argument.

The Incidental macrotheme articles are different from the macrocategory Incidental stories in that the disabled person is a subsidiary or vehicle to discuss another major topic, such as a medical advancement or discovery. This is the same for the Medical macrotheme articles as well. In terms of the Fate/Miracle macrotheme, this differs from the Fate macrocategory in the storyboards because the concept of miracle is ever present. This is, in a way, a form of propaganda, as it implies there are solutions to impossible problems.

The newspaper articles tend to portray disability very much as a life or death issue in a medical framework; whereas the storyboard stories are much less focussed on this theme. In many ways it appears that the newspapers are lagging behind popular thought. This may be because the general public have more direct contact with disabled people in their everyday life and therefore understand the issues in more detail. Journalists are in part driven by the need to make human interest copy, which will help to sell their boss's newspapers. Therefore sensational stories in whatever form are very commonly used. It is the opinion of the researcher that newspapers do not have a major influence on how disabled people are socially represented in society, but they are part of the complex matrix of how people obtain, analyse and disseminate knowledge or assumed knowledge.

# Chapter Four: Focus Groups: What disabled people

say...

# Introduction

This chapter is different in that it is concerned with how disabled people view non-disabled people's perceptions of them. This section will offer an outline of the differing Focus Groups, an explanation of the methodology, results and analysis. There will be a discussion of what the disabled people actually said. Primarily direct quotations will be used and abstracts from contemporaneous notes. These data are much more ethnographic and will be compared to other more empirical data.

In this section I will examine the nature of Focus Groups, the history of Focus Groups and how they can be applied to special audiences, such as disabled people. I will contextualise this application of Focus Groups with their use in qualitative research.

#### Nature of Focus Groups

Focus Groups typically have common characteristics or features. These points relate to the make up of the Focus Groups. They are groups of people whose members have a common characteristic, i.e. disability in this case, which come together to take part in structured discussions (Kreuger 1994) which provide the researcher with quantitative or qualitative data. Ideally Focus Groups should be made up of between 6 and 12 people. Two factors need to be taken into consideration when thinking about Focus Group size:

(a) The group must be small enough for everyone to get a reasonable share of the participation, in order to share their insights.

(b) Large enough in order to ensure a diverse mixture of opinions.

In this research there were other factors to take into account. First, because all of the participants were people with disabilities, all venues needed to be disability friendly, such as with wheelchair accessible rooms, toilets for disabled people and support workers available. Second, in terms of the actual Focus Group process, it was important to ensure that there was appropriate communication equipment and support available. For instance, when the group had deaf members sign language interpreters had to be employed. About one in three group members had medium to severe communication problems, such as deafness, speech impairments or memory problems. This meant that each Focus Group needed to be structured differently according to the members' needs. The groups included a number of people with learning disabilities, which meant the level of language was adjusted in order to enable them to understand fully. The researcher led all the Focus Groups with the help of two or three non-disabled facilitators. This automatically changed the Focus Groups from the classic model. As is clear from the methodology, the Focus Groups were meant to be one hour in length, but because of communication problems, many groups overran. In the opinion of the researcher, the interaction between group members was as high as groups with no communication problems; it just took longer.

Focus Groups need to be undertaken in a series, with a similar mix of participants. This allows the researcher to detail patterns or trends across groups. This also safeguards against unexpected problems, such as one member of the group being overbearing or someone making a very provocative remark and therefore destroying the whole of the group discussion. As a result it is very important to plan a series of Focus Groups within a reasonable time scale so that external factors such as newspaper or news stories do not overly influence the key components of the prospective discussion. In this research the Focus Groups were undertaken with the backdrop of Miss B, the woman who broke her neck and wanted the doctors to let her die and the engagement of Heather Mills and Sir Paul McCartney. This meant one or two Focus Groups focussed on legal and ethical issues, while others concentrated on how disabled people need to be, to be properly disabled.

It is important in Focus Group research that participants have some form of homogeneity. In terms of this research, because of the range and types of disability and the range of skill levels, it was difficult to maintain a complete balance within certain groups. It was decided that one group would be run entirely for learning disabled people and this allowed us to have an internal homogeneity. In theory researchers have said it is better for Focus Group members not to know each other before the group. This is because it is thought that familiarity inhibits disclosure. In recent years researchers have questioned the need for this approach, particularly in community based studies. In this research it was a mixture of unknown and familiar groups. This is because participants were often users of common services such as day centres or residential homes. In order to maximise disclosure any non-disabled support workers who were familiar with participants were asked to leave the room, by the Focus Group leader, when sensitive topics came up. This meant that group members felt a much higher level of confidentiality and felt they would not be victimised for what they were about to say. This is an important point for disabled people who are dependent on non-disabled people for support. Many disabled people feel unable to criticise or question non-disabled people's perceptions of them; for they fear that the non-disabled people will be upset or withdraw their help.

Focus Groups have a rather narrow purpose, that is to determine the perceptions, feelings and the manner of thinking of the Focus Group members. Focus Group members cannot be truly representative of the target population. However they can provide important insights into some of the thinking within that target population. Focus Groups are not designed to generate consensus or make decisions. They are designed to identify the range of opinions, attitudes and feelings within this target group. This is in contrast to other group processes, such as brainstorming, nominal groups and delphic processes. These types of group are primarily used to reach solutions.

The role of the researcher or moderator within the Focus Group is absolutely crucial. They have several functions within the group, including moderating, listening, observing, redirecting and analysing. The analysis is usually by an inductive process. This means that preconceived theory and hypothesis are not being directly tested, but the actual Focus Group discussions inform the researcher about what conclusions they can make. The topics within any Focus Group must be well determined prior to each group. These usually take the form of well-defined, open-ended questions, which the researcher has developed over a period of time. These questions are known as the 'questioning route'. The questions are arranged in a natural and logical sequence. It is important that the researcher must not impose or allow Focus Group members to impose a feeling that the group must reach consensus. Conflicts within Focus Groups must be managed, without members feeling undermined.

Focus Groups can be used in conjunction with many other quantitative and qualitative approaches, such as interviews, questionnaires and surveys. In this instance the Focus Groups have been used as a form of triangulation. The Focus Groups within this study are 'reality checks' with the actual lived experience of disabled people compared to the Social Representations of non-disabled people. In addition the study is using the Focus Groups to elicit disabled people's own Social Representations of disability. This multi-method technique has become a valuable tool in identifying Social Representation (De Rosa, 1987)

At the heart of the validity of Focus Group data is the intense relationship between the researcher and the Focus Group members. The researcher is able to probe for the most in-depth and truthful responses (Mariampolski, 1984: 21). Validity can be measured in two ways. First, 'face validity', i.e. do the responses appear valid? Second, 'predictive validity', i.e. can we predict people's ideas and behaviours (Krueger, 1994: 32). In this study a combination of both is used.

## **History of Focus Groups**

Focus Groups are not a new idea. The earliest published work was by Robert Merton and his collaborators, who used Focus Groups to examine the effectiveness of wartime propaganda (Merton et al., 1956; Merton, 1990). Soon after the Focus Group technique was taken up as a market research tool by Paul Lazarsfeld and others (Lazarsfeld, 1986). For many years Focus Groups disappeared from the tool kit of Social Sciences. This was primarily because Merton and his colleagues published very few papers and because social psychologists became increasingly quantitative. This was the influence of the American School of psychologists and sociologists. Also, in the 60s and 70s social psychologists developed other qualitative techniques centred on participant observation and individual interviews. For many years Focus Groups remained the domain of market research and were used as a form of group interview. One of the reasons that Focus Groups became popular within the marketing community is that the original research was undertaken in the field of communications research, which used stimulus

materials, such as storyboards in order to initiate discussions (Morgan, 1984). Market researchers were interested to see how consumers responded to 'concepts'. This was a very psychodynamic approach and drew on Psychoanalytical Theory. This technique allowed market researchers to tap into the underlying or unconscious desires, needs and thoughts of their consumers.

In the late 1930s social scientists began to explore the value of nondirective interviewing to improve the quality of information gained. This was as a result of serious concerns surrounding the accuracy and validity of information retrieved from one-to-one interviews with closed questions. In 1931 Stuart A. Rice was one of the first senior social scientists to express major concerns. He wrote:

A defect of the interview for the purposes of fact-finding in scientific research, then, is that the questioner takes the lead. That is, the subject plays a more or less passive role. Information or points of view of the highest value may not be disclosed because the direction given to the interview by the questioner leads away from them. In short, data obtained from an interview is as likely to embody the preconceived ideas of the interviewer as the attitudes of the subject interviewed. (Stuart A. Rice, 1931 p.561)

During the 1930s and 1940s psychologists such as Roethlisberger and Dickson (1943) and Rogers (1942) began to lay foundations of nondirective interviewing, which led Merton to develop what we now know as Focus Group techniques. Many of the key components of Focus Groups were set out in the classic work 'The Focus Interview' (1956 and 1990 by Merton, Fiske and Kendall).

Over the years Focus Groups have widened their scope from assessment of brand popularity to how people perceive particular institutions or organisations (Bellenger, Bernhardt and Goldstrucker, 1976, Coe and Machachlan, 1980). Since the late 1980s Focus Groups have entered the political arena. They have been used to assess the understanding and popularity of particular social and economic policies. The present Labour Government has used Focus Groups more than any other party in British politics. They have often been used to discuss controversial issues, such as entering the Euro zone or asylum seekers. When this technique is well administered and the data analysed carefully and appropriately, Focus Groups are able to reveal feelings and attitudes that may be quite deep seated in people and may not be expressed in everyday situations. Therefore Focus Groups are a very powerful tool when addressing taboo type subjects, such as disability.

# Methodology

#### Introduction

The study set up a number of Focus Groups made up of disabled people with physical, sensory and learning disabilities, in order to obtain a reality check on their actual lived experience of non-disabled people's reactions to them. Also, it allowed the study to ask disabled people what Social Representations they thought were present in society. In this section the author will detail the administration of the Focus Groups, the subject profile and the materials used.

#### **Administration of Focus Groups**

The Focus Groups were set up by the author and a facilitator during the period of May 2000 to October 2001. There were 11 of the groups in total, made up of 97 disabled people with varied impairments. The Focus Groups lasted one hour and were in an informal discussion format. The minimum group size was eight and the maximum group size was 17. The groups were briefed about the object of the session (see briefing notes in

Appendix 3). Once the group had understood the task the researcher gave them a set of five questions to read and then a free flow discussion was facilitated around each question. The researcher only directed the discussion if it became too personal for the individual. This only happened twice. The questions asked were as follows:

- 1) What do non-disabled people think of disabled people in general?
- 2) What do you think non-disabled people think of you?
- 3) How do you think newspapers portray disability?
- 4) What key words do you think non-disabled people link with disability?
- 5) What do you think about other disabled people?

The Focus Groups were all flip charted and detailed notes made and written up. One of the groups was filmed in its entirety and its transcript was analysed in detail. All groups were given the opportunity to tell personal experiences and to widen the discussion. This often meant that the Focus Groups took longer than one hour and all of them wanted to discuss disability in the context of television.

# **Profile of subjects**

There were 97 subjects made up of 45 men and 52 women. They ranged in age from 19 to 63. Out of the groups 39 were born disabled and the rest had acquired disabilities later in life. The subjects were obtained through contacts with local and national disability organisations. The organisations were as follows: Scope, Capability Scotland, Royal National Institute of the Deaf, Royal National Institute for the Blind, The Nottingham Coalition on Disability and the Disability Rights Commission. The sample was a convenience sample, however within the 97 subjects, 53 had different impairments or conditions. There were 9 people from black or minority ethnic communities. All subjects were paid expenses by the host organisation.

# **Results, Analysis and Discussion**

This section will concentrate on the outcomes of nine Focus Groups with disabled people. The aims of these Focus Groups were threefold: to discover how a range of disabled people felt about how non-disabled people perceived them and what attitudes, representations and beliefs they thought non-disabled people used; to understand how disabled people thought they were portrayed in the print media and what language they found appropriate and inappropriate to describe their lives; to discuss whether they felt that non-disabled people treated people born with disabilities differently from those with acquired disabilities.

The purpose of these groups is to provide supporting and background data, which the study will be able to use to correlate with the storyboard material and the newspaper articles. This will allow the research to compare actual lived experience with the representations of disability presented in the subjects' stories and newspaper articles. This will act as a form of triangulation. This multi-method technique is strongly recommended by researchers such as De Rosa and Wagner because Social Representations are composed of many facets and no one technique can be assured of illustrating its makeup.

#### **Focus Group themes**

This section summarises the major issues and themes that arose out of the discussions. These are outlined below

#### 1. Fear of difference

In all Focus Groups this was the central theme. Participants thought that non-disabled people made assumptions based on ignorance rather than experience and knowledge. All participants said that in their experience non-disabled people who had social contact with disabled people seemed more comfortable. This introduced the idea of people having a comfort zone relating to disability. The importance of 'difference' became a central concept. One participant said:

...they look at me, teenagers make fun of me, because I look different they think I'm 'different'.

Many others reported staring, looks of disgust and total avoidance. As one young man who had a stroke put it:

People live in fear of catching a disability, wouldn't drink out of the same cup, might catch a brain haemorrhage!

All the Focus Groups reported a generational difference in how nondisabled people responded to their disabilities. Older people appear to feel pity and sorrow, whereas, younger people were more accepting. However, the fear component was universal. All the groups felt that nondisabled people constantly made assumptions based on hearsay, 'old wives tales' and mis-information from friends, family and the media. One woman participant said:

They hear stories in the pub, make up most of it. They fantasise about how awful it is.

So the relationship between fear and fantasy is strong in the eyes of the disabled participants. Facts about disability appear to be more difficult for non-disabled people to obtain because their social contact with disability is systematically limited by the way disabled people are excluded from mainstream education, employment and leisure activities.

In terms of the initial typology of the Social Representations of disability gained from the analysis of the storyboards, fear played a major part in the Medical/Illness stories and the Sad/Lonely stories. Therefore, disabled peoples' lived experienced is being reflected in these stories.

#### 2. Language and Portrayal

This was a much-heated part of all the discussions. Participants felt that television only portrayed images of disability and that the print media was only concerned with sensationalism in terms of tragedy, miracles or heroics. One participant said:

Disabled people are not shown to be ordinary people doing ordinary things on telly, in the papers if a disabled person achieves something, their disability is the real topic of the story not their achievement.

Every group listed numerous words that offended them. 'Handicapped' was the word most people hated the most. They all said that words such as 'cripple' or 'invalid' are still regularly used in their presence or earshot. They all felt that language influenced the way people behaved towards them. As one person said:

You can't be beautiful and a cripple in their eyes.

This opened up the discussion around beauty and ugliness and how disability was associated with weakness and disgust. A man who was in a car accident summed this up:

Superman was all handsome and strong until he fell off that horse.

This was a reference to Christopher Reeve, the actor who starred as superman until he broke his neck in a riding accident. There were strong feelings that disability was mis-represented in the printed press because horror and tragedy sells newspapers. One young woman with cerebral palsy said: People love death and destruction, it makes their lives seems seem better. (sic)

From the initial analyses of the print media material, there seems to be some truth in this assertion. The disabled people were not certain who influenced whom in terms of wanting this type of negative story. Do the media lead the public or do the public shape the media? Most participants concluded it was a two-way process.

#### 3. Born versus Acquired disability

There was clear consensus that non-disabled people did distinguish between born and acquired disabilities, but only after they knew that information. One man said:

When I tell people I was a farmer before I crashed my car, they become more normal with me

The born disabled participants felt most strongly about this issue. One commented:

We are like aliens to people, people think we are different in every way. I don't know what its like to walk, but I'm still a person.

Another said:

I realised my anger was not at having short arms, it was at being treated like shit because I had short arms.

All groups felt that young acquired disabled people received better services and more opportunities to lead a 'normal' life than born disabled people or old people with acquired disabilities. They thought this was about the way society values different people. In addition, there was an issue about becoming disabled as a child, when you were more likely to be treated like a born disabled person. The cut off point for this distinction seemed to be in the early teens. This is almost certainly related to educational provision, i.e. if you stay at a mainstream school or not.

# 4. Group Identity

All the groups felt that being disabled gave them an additional identity, particularly when around other disabled people. They felt that disabled people empathised with each other and were willing to help each other more. However, they did feel that the disability movement was not truly representative of 'normal' disabled people. One man said:

I'm an Arbroath supporter first then a dad then disabled [said with a huge grin]

So multiple identities for disabled people are very important. No one in any group thought of themselves as disabled first and foremost as a descriptor of their identity. So it is very interesting that most non-disabled people use the disability as the primary identity when meeting disabled people. As one woman said:

Shop assistants don't see me, they see my wheelchair.

This is an issue which has come up in many storyboard stories in the study where the whole story is based on that character's impairment. Also the newspaper articles tend to over concentrate on the impairment. This issue covers all the story types except the No Mention/Incidental Mention stories.

# 5. Professional Attitudes

This relates to the Focus Group participants' experience of medical professionals, mainly doctors, social workers, care workers and teachers. All groups thought that doctors viewed disabled people as a challenge and potential 'guinea pigs'. One woman said;

If they [doctors] can't cure you, they think they may as well experiment on you.

This was a very harsh feeling which many participants subscribed to. All the Focus Groups thought that doctors and nurses were trained to see disability as a problem to be solved and not part of someone's being. Many participants felt that social workers and care workers wanted to 'do good' but were patronising. Every Focus Group thought people were not trained enough in disability issues by disabled people themselves. The born disabled participants thought that their teachers had low expectations for them and therefore they felt they never reach their full potential until after school, if at all.

This is a very interesting component of the research whereby the stories written by different professionals, namely doctors and care workers, have been analysed. Doctors were the only people to see disability as Fate and care workers wrote Brave/Determined stories or Special/Exceptional stories. It is clear that this is an important area of investigation in terms of the Social Representations of disability as these professionals may be using emancipated representations instead of the hegemonic representations.

# **Summary Discussion of Focus Groups Data**

It appears from these narrative data that disabled people experience all the Social Representations that this study has identified in the storyboard data and the print media survey. From a research point of view, this is very reassuring because actual experience appears to match research interpretation. Therefore the focus groups have been a form of 'reality check'. Five key themes come out of the focus groups in relation to the rest of the study data.

Firstly, disabled people experience their lives as being represented as different, extraordinary or unfortunate by non-disabled people. Very few disabled people in the focus groups mentioned positive imagery of themselves. However, very few disabled people found this depressing. What they expressed was a resolution to the situation presently within society. They feel discriminated against, but interestingly they somehow rationalise this discrimination in the context of the fear of the other. Therefore it is in part a collective - or even social - internalisation of the representation of disability among disabled people. It is outside the scope of the study to offer concrete evidence for this assertion. However it appears from the focus groups discussion that this was an important underlying theme.

Secondly, the focus groups reaffirm that disabled people experience non-disabled responses to them as being based on fear or assumed knowledge. Disabled people discuss in detail how little non-disabled people know about their real lives, rather than what is assumed. This amounts to non-disabled people propagating fantasies about disability, such as 'they have no sexual feelings' or that they need constant help.

Thirdly, disabled people find that newspaper portrayals of their lives are completely distorted in terms of the medicalisation of impairment. This is actually what the data suggest, however a more comprehensive study is needed to affirm this.

Fourthly, the focus groups offered an insight into what disabled people thought of themselves. This was in many ways the most interesting aspect of the focus groups discussion, although not the central purpose of this research. There was a real dichotomy between born disabled people and acquired disabled people. Most born disabled people have come to terms with their lifestyle and needs. They attempt to lead as normal a life as possible, with appropriate help. People with acquired disability had one main problem which was they had a non-disabled life to compare with. This generated a number of mental health problems, which they had to deal with. They did not feel a bereavement or loss in the usual sense, but they felt that life was unfair. This is an understandable and rational position. However, those that came to terms with their impairment were leading an active life. This is very important in terms of the Social Representations of disability because positive images of disability are not often seen in the media. This leads to the researcher's final point that all disabled people in the focus groups complained bitterly about the misrepresentation of disability in television and film. It is clear that disabled people are not yet part of mainstream popular culture. Disability is still reified in this context. Many researchers, including Shakespeare (1997) and Darke (1998) have demonstrated that televisual and cinematic images are possibly the key factors in changing, developing and maintaining Social Representations of disability alongside actual direct experience of disabled people.

The focus group findings underpin the outcomes of the storyboards and the print media survey. There is still much research needed to identify the relationship between different means of knowledge development and communication of knowledge. However, this study hopes that this is an initial attempt to start this process.

# Chapter Five: What is the whole story?

# **Overall Discussion**

It is the purpose of this chapter to draw together the evidence from each of the methodologies used in this research, in order to identify key commonalities and contrasts across the research data. In addition it will discuss the strengths and weaknesses of the research findings and discuss the development of future methodologies which may improve and update the present understanding of the Social Representations of disability.

It is the opinion of the researcher that the use of Social Representation Theory has enabled this study to uncover and elicit some of the feelings, ideas and fears of non-disabled people relating to physical, sensory or learning impairments. In contrast to attitude theories which are based on functional or individual responses to disability, Social Representation Theory allows methodology which attempts to examine the inner or unconscious thoughts of non-disabled people. In the past, despite all the attempts of deception by attitude theorists, what they have uncovered is primarily at the level of conscious thought. Social Representation Theory and its developing methodology allows the researcher to delve into the inner world of fantasies and fears surrounding disabled people and their meaning within society. This is not only at an individual level, but at a group level as well.

The use of the storyboard technique offered a small but significant insight into the imaginations of non-disabled people when confronted with images and information about disabled characters. It became clear from the consequent stories written that non-disabled people's Social Representations could be reliably distinguished into the twelve macrocategories outlined in this research. However, these twelve macrocategories can be related back to the commonly used models of disability, the Medical model, the Charity model and the Social model. The first group is made up of Social Representations of disabled people in which disabled people are 'special' people. This group would include the macrocategories such as Brave/Determined, Exceptional/Special and Happy/Idealisation. These stories can be related to the Charity model and in historical terms are connected to the 'deserving poor'. These Social Representations are used by charities to raise money and they allow nondisabled people to contribute to the lives of disabled people from a safe distance. It also allows them to assuage responsibility and in turn their guilt and fears of disability. This enables non-disabled people to have a feel-good factor and supports their general assumptions that their quality of life is better than that of most disabled people. This is very much an ingroup, out-group phenomenon. It also neatly ties up with the understanding of non-understanding of the other.

The second umbrella group of Social Representations of disability relates mainly to the Medical model. This group includes Sad/Lonely, Tragedy, Medical and Support/Dependence. From the storyboard stories it became clear that medical professionals and ordinary people use these types of representations. It was much less common among charity workers. The Focus Groups provided experiential and anecdotal evidence for this finding. It is clear that medical professionals concentrate mainly on the functional and structural outcome of impairments. It is most likely that medical professionals only meet disabled people in an institutional or professional scenario. Therefore their training and experience will bias their perspective, even if they have relatives or friends with disabilities. Ordinary people often use this type of representation because disability is considered to be reified knowledge and therefore must be set in a pseudo-scientific framework. This point is further supported by the overwhelming medicalisation of disability in the print media. Once again disability is understood to be a negative life experience. From the work with the Focus Groups, disabled people say that despite the practical and social problems they might encounter, that they feel having an impairment and disability is not inherently equated with a lower standard or quality of life. It is important to note that the disabled people in the Focus Groups emphasise the importance of non-disabled people's reactions to them rather than the lack of services and facilities provided for them. This underlines the importance of understanding the Social Representations of disabled people held by non-disabled people. From the work with disabled people in this study it is clear that the medicalisation of disability is not primarily in terms of medication and treatment. There is a real 'social wish' to expunge impairments from everyday life. This may be related to non-disabled people's need for normality. Disabled people's normality is actually no different but is mediated via the limitations of their impairment. Therefore disabled people experience the same world in different ways.

The third umbrella group can be thought of in terms of the Social model. The macrocategories within this group include Incidental and Fate. The storyboard stories within this group always put impairment or disability in their social context. This is mainly manifested by the discussion of discrimination, prejudice and practical problems in an appropriate way. Although this group makes up under 25% of the overall Social Representations, it is, however, significant to note that many non-disabled people appear to understand that disability is not only about impairment but also its social consequences. It is also worth noting that many of these stories were written by younger people. This is encouraging because perceptions about disability and knowledge of disability may be becoming less reified and more that of common

knowledge. It is an assertion of this research that the Social Representations of disability identified although not exhaustive are the primary Social Representations present in British society at this moment time. This research proposes that the in hegemonic Social Representations are ones closely related to the Charity model, with those related to the Medical model being the emancipated Social Representations. These two sets of Representations make up the bulk of non-disabled people's Social Representations of disability. The polemic Social Representations can be seen in the context of the Social model in terms of Incidental macrocategory stories.

It is clear that none of the models of disability, nor the Social Representations of disability identified within this study, fully explain, describe and express the experience of disabled people within society. However, the Social Representations offer a new insight to the underlying psychological feelings and thoughts that non-disabled people have about disabled people. It may be useful to develop a representational model of disability which encapsulates all aspects of the Medical, Charity and Social models, in terms of the Psychological Theory of Disability, relating not only to non-disabled people, but disabled people also. This would help mitigate some of the social and political weaknesses of how disability is explained and perceived. Disability is not only a medical, environmental or social issue, it is also a psychological issue. This would lead to a more integrated approach to disability especially in educational, employment and social interaction.

In terms of the print media survey, it is clear that although there may be different Social Representations portrayed and manufactured, the same themes recur as in the storyboards. However, the print media seems much more obsessed by medicine and tragedy than all the storyboard subjects. This may be because scientific 'miracles' and human suffering sell newspapers. The storyboard subjects do not appear to reproduce the same type of storylines as the ones that appear in the print media survey. This links very well to Moscovici's analysis of the media (1976). It appears that in terms of disability the media operates within a narrow spectrum of the Social Representations of disability. This spectrum can be explained in terms of Moscovici's concepts of propaganda, propagation and diffusion. These concepts can also be related back to the models of disability. In terms of propaganda, the macrothemes of Medical, Legal/Ethical, Sensational and Devoted Parents characterise this group.

It must be noted that there are distinct differences between the Social Representations elicited by the storyboard technique and those found in the print media study. These differences were all identified within the Focus Groups. Although Focus Group members did not name macrocategories and macrothemes developed in this study it became clear that in their actual experience and language they were referring to the same Social Representations within the study. One Social Representation that was noticeably absent was disgust. Many disabled people in the Focus Groups have experienced disgust at their impairment from non-disabled people. However it is the opinion of the researcher that this representation was sublimated by subjects in the storyboard process, by subjects writing about Tragedy and Sad/Lonely. In the media there are rules about descriptions of people. Disabled people in their everyday lives seem to experience reactions of disgust by non-disabled people. For instance, moving from a table near to them in a restaurant. This may be a coincidence but it was reported by nearly all the disabled people in the Focus Group. In the Focus Groups embarrassment was a key feature but it was not reflected in the Social Representations found. This was interesting because it may mean that non-disabled people deny some of their own fears about disability. In the print media study the emphasis was on the non-disabled carer rather than the disabled person. The nondisabled carer was often portrayed as the real 'victim' rather than the disabled person. This is a form of egocentric thought. Devoted parents were a high priority in the media. In the opinion of the researcher all parents should be devoted whether or not their child is disabled. The media was very much ghoulish in their interest in the medical detail of particular impairments, for instance babies with 'impairments' at birth. Difference was seen to be strange and freakish. This is not much different from the time of John Merrick (the elephant man). It is now just more subtle and wrapped up in the guise of informing the public of medical advancement. The media has not fully recognised that disability is a political issue as well a social issue.

The research has shown that there are occupational differences in the Social Representations depicted. It is reasonable to assume that this is a function of differential knowledge bases, training and experience. Unexpectedly, medical professionals did not see disability in purely impairment terms but in terms of social consequence i.e. the Sad/Lonely macrocategory or the Tragedy macrocategory. This may be because most of the sample were of younger medical professionals who are being trained to see impairment in social terms. This is an important step forward. Charity workers appear to remain patronising and altruistic in their Social Representations of disabled people. In this case the altruism is often tainted with self satisfaction. 'Ordinary' people appear to have a reasonably wide range of Social Representations of disabilities and seem to understand that disabled people are people. However they do emphasise the practical problems such as physical access rather than having integrated education. This offers some hope of future developments.

There are three key findings of this study. Firstly non-disabled people have in general different Social Representations of born disabled people as compared to their Social Representations of acquired disabled people. A prime example from the storyboard study is that born disabled people are Sad/Lonely or Support/Dependence whereas acquired disabled people are often Medical, Tragedy or Brave/Determined. Born disabled people are very much Exceptional/Special if they are 'successful'. In the print media born disabled people must be Brave/Determined or Exceptional and people with acquired disabilities need to deal with life and death issues or are tragic and in pain. Fate runs throughout both groups. In the case of born disabled people fate is seen to be the 'cards' you've been dealt, in acquired disabled people it is seen to be an unjust turn of events. However this is used for emotive media reportage despite any material facts. Secondly, there is a noticeable difference in how male and female disabled characters are portrayed in both the storyboards and media study. Male characters are portrayed as active but frustrated and angry or Exceptional/Special. Women disabled characters are more passive, accepting of their situation and grateful. This is an interesting gender difference in perception of how disabled people cope with their impairment.

Thirdly, it is significant that non-disabled people cannot resist making disabilities or impairments the central theme of their stories or articles when images or information are presented about disability. It is therefore reasonable to infer that non-disabled people become preoccupied by people's impairments and disabilities and find it difficult to see beyond them. However there is a minority of people who are beginning or have come to terms with the fact that disability or impairment only constitutes part of a disabled person's persona. This makes the researcher optimistic about the future.

This study begins to elucidate some of the key underlying thinking and feeling processes that non-disabled people and disabled people undertake when considering disability. Although in the context of this study the research cannot make any firm conclusions, there are a number of indicative findings. First of all there does seem to be a reasonably stable typology of Social Representations about disability. This study has not produced a definitive list, however the researcher believes it has identified the primary Social Representations. Further research is needed to unpack some of the Social Representations and test more precise hypotheses. For instance, there is some indication that different occupational groups have different Social Representations of disability. This was highlighted in particular by the comparison between ordinary people, medical professionals and charity workers. These differences may be attributable to different knowledge bases, training and life experience. A wider selection of occupations who deal with disabled people, such as Social Workers, therapists and residential care workers, may reveal more detailed information on the nature of their Social Representations and representations which are not apparent from this research.

It is clear from this study that non-disabled people and disabled people have very different Social Representations of born and acquired disability. This aspect of Social Representations needs to be studied much more closely because it has immense impact on social policy development, particularly in employment, education and health. It is clear from all the data that born disabled people and acquired disabled people are represented differently. From the Focus Groups it became clear that born disabled people were automatically shunted into a segregated system in terms of education, employment and housing whereas people with acquired disabilities were more often than not able to retain a notion of their 'normality' and were not segregated in the same manner. Acquired disabled people were not always seen to be of 'the other'. Otherness in Social Representations needs to be investigated in much more detail. This may be undertaken by detailed interviews of disabled people and their experiences. Also it may be possible to undertake an ethnographic study within a segregated service such as a residential home in order to determine what Social Representations are circulating within any one institution.

It has become clear that there is a complex inter-relating process between non-disabled and disabled people's life experiences and the information that they reach and digest in the print media. It is important to note that the print media has some representations which were not present in the storyboard stories. This suggests there is another psychological and social driving force present in the production of newspaper articles. This fits in very well with Moscovici's concepts of propaganda, propagation and diffusion. In simple terms journalists and/or their newspaper bodies have political and social agendas which they want to promote, maintain or disparage in whatever way they see fit. A more long-term analysis of print media may present other Social Representations which this study has not yet found.

The Focus Group material presents many new opportunities to discuss the real life experiences of disability. It is clear that born and acquired disabled people have very common experiences of Social Representations, but at the same time encounter different Social Representations based on the origins of their impairments. These differences and commonalities should be examined more closely by direct observation and analysis of interaction such as the waiting room scenario whereby a non-disabled person is sat next to a disabled person and a conversation ensues. This may reveal much more detailed information about how Social Representations are created in linguistic and behavioural form.

It is the opinion of the author that the primary contribution of this research to the development of Social Representation Theory and to psychology as a whole is that it makes an initial attempt to understand and study the thinking and emotional processes which lie behind the Social Representations held by society of disabled people. This moves the research from concentrating on the disability per se to how it is perceived and represented in everyday life. This is very different from attitude research which focuses on the disability itself. This research will hopefully open up a new field of study whereby the experience of impairments is investigated in terms of its psychological effects, not only on disabled people, but also in terms of non-disabled people's experience of disability in the framework of Social Representations.

# Conclusions

This study has explored the many complex and subtle perceptions of disability by non-disabled and disabled people. From this work the researcher hopes that the following points can be made:

- That Social Representations of disability within society are stable, but not finite. The representations develop in relation to changes to knowledge, culture and communication.
- 2) The use of Social Representation Theory is an important psychological tool in understanding people's perceptions of disability and impairments because it focuses on the social component of individual and inter-group representation processes.
- 3) The use of multi-methodologies to determine a set of Social Representations is essential to corroborate and pin down the key

components of any Social Representation. This was very important in this study because the storyboard materials were based on imagination and the print media studies were based on assumed facts. The Focus Groups were based on lived experiences. The overlap between these data outcomes was quite significant in qualitative terms and with some statistical underpinning. It is clear that the living experience of disabled people is represented by the Social Representations defined in this study. These Social Representations may change. However it may be possible now to track their development.

- 4) It has become clear that non-disabled people have different Social Representations of born disabled people to those of acquired disabled people. This is characterised by the underlying implication that acquired disabled people are essentially 'normal' because they were non-disabled before and that born disabled people are actually different. This is an important psychological perception of impairment and is reflected in the treatment and services offered to born and acquired disabled people. For instance, acquired disabled children rarely go to segregated schools.
- 5) There is a noticeable difference in the occupational groups. This is most likely a consequence of knowledge base and training. Ordinary people appear to have a much wider range of Social Representations of disability than charity workers and medical professionals. This is an encouraging sign. It appears that the media has little or no impact on people's Social Representations of disability outside their normal schema of thought. The media will have some influence but it is not reflected in the evidence of this study.
- 6) There is an indication that images of disabled people produce more emotive and elaborate storylines than written text about disabled

people. This may be because disability is often associated with visual difference and aesthetics.

7) All of the Social Representations identified in this study both in the storyboards and in the print media study were independently identified by the disabled people in the Focus Groups. Therefore it is reasonable to deduce that these Social Representations of disability have a real material valence within society. This is an important finding because it allows disabled people and other professionals to focus their training, service developments and academic work in a more strategic way.

There is much detail within this study which merits further research, such as the relationship between Social Representation Theory and Aesthetic Theory. The researcher considers that the development of a representational model of disability could resolve many of the conflicts between disabled people and their non-disabled peers. This would demand both parties to understand each side's perspective. However the underlying fear relating to disability must be tackled by integration and education. As I said at the beginning of this thesis I was puzzled as a child by non-disabled people's reactions to me. I hope as an adult that I have begun to help to understand the underlying reasons for people's responses to disability. I hope this study enables other researchers to take a fresh and innovative approach to disability research.

# **Appendix 1: Sample Storyboard Pack**

# WHAT'S THE PROJECT FOR?

The aim of this research project is to investigate how people use language and imagination in story writing based on photographic images. Each subject will be presented with one storyboard, made up of four photographs. There are twelve possible storyboards. You will be asked to complete one of them. Each storyboard will be of a different character. Subjects will be told a few sentences about each character's background. The storyboards will be made up of images of men, women, and people of different races, cultures, disabled people and people with a variety of different occupations. You will be asked to write a story using the photographs and the accompanying information. Most subjects will have different sets of storyboards. Subjects will not be expected to write more than one A4 side per storyboard. This task will that no longer than 25-30 minutes to complete. The researchers are not concerned about grammar or spelling, but only interested in the imagination and language used as well as the themes people develop. The stories are expected to be fictional in nature. Any writing style is acceptable. The stories that a re submitted will be held in confidence and anonymously. You will get an opportunity to discuss the project with a researcher after completing the task. If you feel at this point that you do not wish to submit your material, you are entitled to withdraw it without any further obligation.

The benefit of this research is to see how people use language with images in relation to their imagination. This will allow new educational and training material to be developed. The benefits to the subjects are:- (a) to have fun; (b) to have an opportunity to be creative; (c) to be part of the development of new educational techniques; and (d) to take half an hour away from the humdrum of their working day. There will be no financial remuneration. Payment is in terms of a good conversation piece! You will be pleased to know that the researchers will be eternally in your debt.

Subjects will be asked separately for their first name, sex, age, and occupation. This information will be held in confidence and within the regulations of the Data Protection Act. Thank you for agreeing to take part.

# Participants Consent Form.

I agree to take part in the experimental procedure investigating language use and photographic images, and understand that any story material produced by myself will be anonymous and confidential. all material produced will be kept according to the ethical guidelines laid down by the British Psychological Society, the University of Cambridge Psychology Ethics Committee and the Data Protection Act.

I am aware that the procedure will take about 45 minutes to complete. I retain the right after the debriefing session to withdraw any written material from this research project.

Name of Participant:

Age:

Sex:

Occupation:

Ethnic Origin (self defined):

Signature of Participant:

Date:

# HINTS & TIPS ON USING THE STORYBOARDS.

- Look at all the photographs in the storyboard before starting to write. The photographs do not follow any kind of story sequence as such, but are designed to stimulate you imagination. Your story should, however, include events or scenes that relate to all the photographs.
- Use your imagination. Your story should be fictional but please use your own life experience as well.
- Think about the central character. Imagine their background, family life, lifestyles, interests, hobbies, feelings, sense of humour, health, worries, likes and dislikes, work experiences, education, politics, opinions, and any other factors that make people individual.
- Use the photographs to think of what is happening in the life of the character. Where they are? Who are they with? What relationships do they have?
- Write the story in your own style.
- Have fun completing the task.

# Storyboard C:

This is Eve. She was born with brain damage which affects the way she learns. Please use the following photographs to write a story about Eve.





The Social Representations of Disability

Michael Devenney



# Appendix 2: Inter-rater Reliability: Cohen's Kappa Calculations

		Int	er-r	ate	r A:									
	Macro- cat:	1	2	3	4	5	6	7	8	9	10	11	12	Total
	1	З												3
	2		1											1
	3			З										3
	4				2			1						3
Jer	5			1		З								4
2	6						2							2
sea	7							2						2
Researcher:	8								2					2
_	9								1	3	1			5
	10									1	3			4
	11											3		3
	12		2										2	4
	Total	3	3	4	2	3	2	3	3	4	4	3	2	36

#### **Inter-rater A:**

K = (29-3.08)/(36-3.08) = 0.79

#### Inter-rater B:

		Inter-rater B:													
	Macro- cat:	1	2	3	4	5	6	7	8	9	10	11	12	Total	
Researcher:	1	3													3
	2		2												2
	3	1		3											4
	4				2										2
	5			1		2									3
	6				1	1	2								4
sea	7							3							3
Ses	8						1		2						3
-	9									2					2
	10								1	1	2				4
	11											3			3
	12									1			2		3
	Total	4	2	4	3	3	3	3	3	4	2	3	2		36

## Inter-rater C:

		Inter-rater A:													
	Macro- cat:	1	2	3	4	5	6	7	8	9	10	11	12	Total	
	1	3													3
	2		2												2
	3	1		3											4
	4				3										3
ler	5		1			2									3
10	6				1		2								3
sea	7							2							2
Researcher:	8								3						3
-	9									3					3
	10								1		2				3
	11											1	1		2
	12		1					2		1			1		5
	Total	4	4	3	4	2	2	4	4	4	2	1	2		36

$$K = (27-2.94)/(36-2.94)$$

= 0.73

## Mean Kappa:

K = 0.76

# **Appendix 3: Focus Groups Briefing Schedule**

All the Focus Groups were personally briefed by the author with the help of two non-disabled assistants. All the Focus Group participants were informed of the following items:

- 1) The focus of the research being undertaken was to investigate the nature of non-disabled people's Social Representations of disabled people. This concept of Social Representations was explained in layman's terms and all questions about the concept were answered as fully as possible. Before the Focus Groups proceeded, all participants were asked if they understood the nature of the research and the basic concept of Social Representations. All Focus Group members were comfortable to continue.
- The Focus Groups were informed of the structure of the Focus Group procedure and all were given fifteen minutes to discuss the Focus Group questions amongst themselves without any facilitation.
- 3) After fifteen minutes the facilitators initiated a more structured discussion of the questions.
- 4) All Focus Group members were informed that this procedure was in confidence and anonymous.
- 5) All Focus Group members were asked permission if the author was able to quote particular statements anonymously. All Focus Group participants gave their permission.
- 6) At the end of the structured questions the facilitator invited any other comments which might be relevant.
- 7) All Focus Group participants were offered access to professional counselling or other help of there were issues that were brought up in the Focus Groups that they wished to discuss further. Five

participants requested some further help. The facilitator ensured that appropriate advice and counselling was followed up.

# Appendix 4: A Brief Summary of the Disability Discrimination Act 1995

#### Part I Definition of disability

Defines the definition of disability under the act and who is protected under it.

#### Part II Employment

This section prohibits discrimination of disabled people in employment and requires the employer to make 'reasonable adjustments' for a disabled person or employee if they are at a substantial disadvantage in relation to a non-disabled person.

# Part III Provision of goods, services and facilities & selling or letting of premises

Makes it unlawful to discriminate in the provision of goods, facilities and services. Currently discrimination occurs if a disabled person is treated less favourably for a reason that is related to that person's disability and this treatment cannot be justified. Further stages will be implemented in October 2004.

#### **Part IV Education**

Education is excluded from Part III of the act but there are specific exceptions. The Employment part of the Act covers Education. There are also requirements under the Act for educational bodies to provide information for disabled people.

#### Part V Transport

Under this section of the Act the Secretary of State has powers to establish minimum access criteria for new transport vehicles which will be phased in over time. Transport vehicles such as buses, trains and aeroplanes are excluded from part III of the Act, though transport infrastructure such as railway stations and airports are covered.

#### Part VI National Disability Council

This section of the Act set up the National Disability Council; whose purpose was to advise the government on disability issues. The National Disability Council has already been superceded by the Disability Rights Commission.

#### Part VII Supplementary issues

Covers:

- Codes of Practice
- liability of employers
- assistance for people suffering discrimination

#### Part VIII Miscellaneous

Includes the issues of government appointments, regulations and interpretation.

#### Schedule 8 Northern Ireland

Sets up the provisions by which the DDA is extended to cover Northern Ireland; this includes the setting up of the Northern Ireland Disability Council.

### **Appendix 5: Additional Sample Stories**

These stories are not discussed within the main body of the thesis, but are useful examples to support the main points made within the thesis.

### Figure 87: Additional Sample story 1: Brave/Determined Macrocategory (page 1 of 1)

# Figure 88: Additional Sample story 2: Exceptional/Special Macrocategory (page 1 of 2)

# Additional Sample story 2: Exceptional/Special Macrocategory (page 2 of 2)

### Figure 89: Additional Sample Story 3: Fate Macrocategory (page 1 of 3)

#### Additional Sample Story 3: Fate Macrocategory (page 2 of 3)

#### Additional Sample Story 3: Fate Macrocategory (page 3 of 3)

### Figure 90: Additional Sample Story 4: Happy/Idealisation Macrocategory (page 1 of 3)

# Additional Sample Story 4: Happy/Idealisation Macrocategory (page 2 of 3)

# Additional Sample Story 4: Happy/Idealisation Macrocategory (page 3 of 3)

### Figure 91: Additional Sample Story 5: Happy/Idealisation Macrocategory (page 1 of 1)

# Figure 92: Additional Sample Story 6: Incidental Macrocategory (page 1 of 1)

# Figure 93: Additional Sample Story 7: Medical Macrocategory (page 1 of 2)

#### Additional Sample Story 7: Medical Macrocategory (page 2 of 2)

# Figure 94: Additional Sample Story 8: Medical Macrocategory (page 1 of 3)

#### Additional Sample Story 8: Medical Macrocategory (page 2 of 3)

#### Additional Sample Story 8: Medical Macrocategory (page 3 of 3)

# Figure 95: Additional Sample Story 9: Medical Macrocategory (page 1 of 3)

#### Additional Sample Story 9: Medical Macrocategory (page 2 of 3)

#### Additional Sample Story 9: Medical Macrocategory (page 3 of 3)

### Figure 96: Additional Sample Story 10: Sad/Lonely Macrocategory (page 1 of 1)

### Figure 97: Additional Sample Story 11: Support/Dependence Macrocategory (page 1 of 3)

### Additional Sample Story 11: Support/Dependence Macrocategory (page 2 of 3)

# Additional Sample Story 11: Support/Dependence Macrocategory (page 3 of 3)

# Figure 98: Additional Sample Story 12: Tragedy Macrocategory (page 1 of 4)

#### Additional Sample Story 12: Tragedy Macrocategory (page 2 of 4)

#### Additional Sample Story 12: Tragedy Macrocategory (page 3 of 4)

#### Additional Sample Story 12: Tragedy Macrocategory (page 4 of 4)

### Figure 99: Additional Sample Story 13: Disability (non-disabled) Macrocategory (page 1 of 2)

# Additional Sample Story 13: Disability (non-disabled) Macrocategory (page 2 of 2)

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