Chapter 2
Understanding the Assumptions of Major Models of Disability Theory

*Everything is vague to a degree you do not realise till you have tried to make it precise.*

Bertrand Russell.

2.1 Introduction

The Foreword introduced ABI through Durham’s personal experience. The co-author, Ramcharan, has been involved in funded disability research for 25 years. He was involved in research of the All Wales Strategy for the Development of Services to Mentally Handicapped People [sic] 1983 (see Felce et al., 1998) and co-directed the Learning Disability Research Initiative, a two million GBP strategy involving thirteen projects designed to support implementation of Valuing People (2001), a national intellectual disability government policy in England (see Grant & Ramcharan, 2007). Paul’s work for over a quarter of a century has melded an interest in the everyday life experiences of people with a disability (Ramcharan, Roberts, Grant, & Borland, 1996), and advocacy and voice (Goodley & Ramcharan, 2010). The interest in everyday lives and the everyday struggles faced by people with disabilities was a key basis upon which this exploration of the life experiences of people with ABI was both interesting and, at the same time, challenging. Durham’s work was, therefore, immediately of interest leading to both his supervision of her Ph.D. and his contribution to this volume. Both share the passion to seek to change lives for people whose struggles are grounded in their social circumstances as much as their biology.

Chapter 2 provided a review of Websites, books and blogs written by people with ABI, supplemented by a consideration of the information and resources most readily available to people with ABI.

The period over which mending bodies and re-establishing basic skills take place can be variable. One guide to TBI suggests written by a neuropsychologist using ‘psychological tests’ suggests that
research on these tests indicate that for two years following a head injury, there is evidence of improving scores. After this period...I can no longer see large changes in scores (http://www.tbiguide.com/getbetter.html)

More importantly, many people with ABI recount this as an early inpatient response to the question of how long it would take them to get better. From the perspective of the professional (the outsider), this time frame is ‘golden’ insofar as the greatest recovery is presumed to happen within this time, and it attracts the greatest professional input designed to mend bodies and re-establish basic skills. It is analogous to the ‘golden hour’, directly after a traumatic injury when there is greatest likelihood that prompt treatment will prevent death. Although recognising its limitations, we shall for brevity, therefore, use the term ‘golden period’ to refer this two-year period, or thereabouts, directly after the person acquires their brain injury.

We also use this term to contrast with the views of people with ABI. As shall be seen, from the perspective of the person with ABI (the insider), this period is far from golden—it is the ‘dark hole period’—the time of greatest pain, loss and despair as Durham has found in her continued engagement with people with ABI over the years.

Depending on the cause of the brain injury, for example, a car accident or a fall causing broken bones some people with ABI are hospitalised. Others suffer brain injury and it is not diagnosed, and/or they are not hospitalised. Some spend a short time, others months or years in hospital depending on their injuries and/or severity of the brain injury. Except for people with severe brain injury, at some time during the ‘golden period/dark hole period’ of medical and rehabilitative attention, most people with ABI go home to their communities where they have to mend their ‘fractured lives’. Examples of information and resources that are typically available for people with ABI and their families have been examined, but from what source does this information come? Upon what assumptions is it based? This is the question that preoccupies us in the following three chapters.

We show that many of the categories of understanding in the information on Websites are drawn from what might collectively be termed a biopsychosocial model encompassing a majority medical model input. We also argue that this more formal academic engagement around ABI has significant blind spots, that it is preponderantly negative, that it predisposes to only certain professional interventions and that in so doing it misses solutions to the everyday support required once a person moves home from hospital or rehabilitation. By exploring the underlying theory, models and information, this review seeks to re-frame the approach on sound alternative assumptions, and to further inform and populate the methodological tool Keys to the ABI Cage that is used in this study.

In the first section of this chapter, some of the theoretical frameworks around disability are discussed and two broad categories are identified, the body-object view of ABI and the body-subject view of ABI. The dominance of the body-object view, it is argued, is not inconsequential. The results of such a view continue to objectify people, to obfuscate any interest in the complexity of their everyday lives
and, as a result, to miss what is most important—the person behind the theory and behind the actions consequent to the theory when applied. The remainder of this chapter will then examine features and assumptions of the body-object view, including research into ABI, leaving a focus on building the body-subject view for the chapter to follow.

2.2 Differences in Perspectives of Disability

Man has become less rational than his own objects, which now run ahead of him, so to speak, organising his surroundings and thus appropriating his actions,
Jacques Baudrillard.

As already mentioned, it is all too easy to slip into a view that damaged brains produce damaged emotions, damaged behaviour, damaged communication, damaged interaction…damaged people…disabled people. The following introduces philosophies and ways a person with ABI can be viewed.

2.2.1 The Body-Object Model

‘The body is our general medium for having a world’
Maurice Merleau-Ponty, *Phenomenology of Perception*.

The roots of the distinction upon which we draw in this volume have a significant past, lying in broader philosophy, at least since the Enlightenment.

Naturalism and idealism as competing epistemologies have been in contention since Schelling, Kant and the later phenomenologists starting with Husserl who questioned Descartes proposition about the measurement of the object world through science. The competing traditions pit the pursuit of the factual world in the capacity of science to intercept, define and hence find meta-theory, against the idealist view that the reality of external objects cannot be subject to proof. The idealists’ world is mediated by our consciousness, and it is only through such consciousness and intention that the world comes into existence.

In this way, even the hard fact of a ‘stone’ is not, for the idealist, defined through its scientific properties, its physical properties, chemistry and origin (igneous formed from fire and sedimentary formed from the compacting of layers). Rather, the stone may be the object of an aesthetic interest, and it may be a weapon in certain circumstances, evidence of the likelihood of a particular presence such as oil or gold, and so forth. In this way, the stone exists only by the intention of its use, by the conscious intention of the actor.

From one point of view, what is important for the purposes of this volume would be the external and defined fact of acquired brain injury. From another point of
view, what is important is how we come to know acquired brain injury through consciousness and experience. The result of our epistemology is consequential to our understanding of the world, our ontology and, more importantly to the choices we make in intercepting and working upon that world. As Merleau-Ponty (2002) argues ‘to understand is to experience harmony between what we aim at and what is given, between the intention and the performance—and our body is the anchorage in the world’ (Merleau-Ponty, 2002, p. 167).

According to the French phenomenological philosopher Merleau-Ponty (2002), the view we have of the body plays a foundational role in the way we understand and engage with the world. He wrote of difference between the ‘body-object’, as determined and predicted by medical science, as the outsider’s perspective, and the ‘body-subject’, as the body as we experience it, the body that gives meaning to the world around us, as the insider’s perspective. An outsider or etic (Pike, 1954) description of an observed behaviour or belief often holds a different perspective or philosophy to that of an ‘insider’ (emic) (Pike, 1954). Just as body-object proponents rely upon Cartesian dualism and the separation of the body as an external object from its observation, so the body-subject proponents see object and subject as one and the same, i.e. as people see things, so they are.

However, even within the bifurcated category, body-object or body-subject, which is used to structure this and the following chapter, there are many different philosophies, ‘models’ or belief systems that have evolved, define and fundamentally affect the way in which the individual with ABI is viewed and treated. Perception of ABI is dictated by the dominant belief, model or ‘lens’ through which the individual, the medical or rehabilitation professional, family member, friend or the general public views, considers, assesses, or judges the person with ABI. These different beliefs can affect the way outsiders regard and behave towards the person with ABI.

Disablement models that developed in the twentieth century ‘defined the meaning of terms we use every day, and that do not always exert a positive effect upon the people to whom such terms refer’ (Masala & Petretto, 2008, p. 1242). So before reviewing the ABI literature, it is essential to discuss the place of theoretical systems in research. As a researcher, do such frameworks dictate the approach and limit what I want to observe or measure? Should a theory be used as an apparatus to interpret a person’s world? Or should we be looking in our data for the ways in which people themselves construct their own realities and mould something out of these accounts? These questions are not inconsequential because they have a bearing upon how interactions take place between people, one party to this interaction being a person with ABI. It is, therefore, also relevant to the method employed in any study of people with ABI including the present study.

Below, we demonstrate the points made above by exploring and considering varying theoretical views of disability and their corollaries and consequences.
2.2 Differences in Perspectives of Disability

### 2.2.2 The Moral Model

The first and oldest model of disability is the moral model. In this view disability is a defect caused by a moral lapse or sin—...it brings shame to the person with the disability, (Olkin, 1999, p. 25)

“Macbeth: How does your patient, doctor?

Doctor: Not so sick, my lord, as she is troubled with thick-coming fancies that keep her from rest.

Macbeth: Cure her of that! Canst thou not minister to a mind diseased, pluck from the memory a rooted sorrow, raze out the written troubles of the brain, and with some sweet oblivion antidote cleanse the stuffed bosom of that perilous stuff which weighs upon her heart.

Doctor: Therein the patient must minister to himself.”

—William Shakespeare, Macbeth

People with disabilities have been recognised as ‘different’ and treated according to such differences for many centuries. Recognition and veneration through the ages, of ‘gifted’ savants with prodigious abilities beyond the population at large (Treffert, 2014) and, since Athenian times¹ (Penrose, 2015) a consistent recognition and support for those disabled in the military service of their country, represent but a small minority of cases resulting in ‘positive regard’.

More often than not the effect of such ‘difference’ has resulted in treatments that have produced troubled lives, impoverishment and a life quality for which none of us would choose to queue. Through the ages, people with disabilities have, inter alia: been seen as ‘possessed’ or ‘children of the devil’ (leading to exorcism, bloodletting and being burnt at the stake); subject to infanticide (and death); treated as freaks (leading to fair game for circus sideshows, commodification and humiliation); perceived to belong to the class of ‘moral degenerates’, (such as prostitutes, criminals and beggars who have traditionally attracted the interest of the corrective services); argued to be a threat to the national gene pool (leading under a eugenic argument to both mass murder in Nazi concentration camps and to enforced separation of males and females in institutions); rated as ‘unemployable’ (leading to their occupancy of poor houses and later institutions); and, latterly, accepted to be legitimate beneficiaries of welfare (having to declare their disability to access additional support services), (see e.g. Thompson, 2010; Metzler, 2013; McClimens & Richardson, 2010; Nielson, 2012; Bogdan, 2014).

For most of history, humanity has perceived the trouble as lying with the person with a disability whether by possession, incapacity to work, moral degeneracy and

¹Penrose, in his interesting comparison between the Athenians and Spartans, shows how much more sympathetic the Athenians were, than the Spartans. He argues that “…in Sparta, the failure to recognise the disability caused by impairment was a harsh form of prejudice...The Athenians allowed disabled veterans and others to be exempted from military service and to collect a pension, whereas no consistent record of exemption is extant from Sparta’ (Penrose, 2015, p. 522).
more recently in their biology. How might we better understand this sad history, through which the morality of public and Government views have separated, labelled and denigrated one significant group of humans? One way is to consider the links between Government, economy, knowledge and public sentiment (McClimens & Richardson, 2010).

The lack of engagement of Governments and people with disabilities prior to the middle ages meant that the treatment of people with disabilities was likely to be a product of community sentiment. Such sentiment would have been diverse across regions, but would almost inevitably have included systems of religious belief on the one hand and economic security on the other. Given the unpredictability of agrarian modes of production and technology, capricious climates and insecure tenancy, the economic circumstances were often highly testing.

The confluence of living on the edge of survival, alongside religious views of possession might, in the absence of other options have led to people with disabilities being left to die or to infanticide or exclusion, e.g. being treated as possessed. The very survival of people with disabilities was, therefore, at issue and exacerbated by very low levels of medical proficiency. Often, the family mediated the experience of relatives with a disability by controlling interaction with the rest of the community. Families, it should be noted, have consistently been a vital support mechanism through the ages. But for people with disabilities, life was tough and, for many, all too short.

The emergence of new nation States in Europe in the middle ages saw the protection of land for the nobility, giving rise in 1325 to Prerogativa Regis (in the prerogative of the monarch) in which land was held for ‘idiots and natural fools’ for the land-owning classes, though no provision was made for those without land. In the absence of such support from families, people with disabilities were likely to be driven to vagrancy, prostitution or shelter in the monasteries from which they were ‘sent to beg “cap in hand”’—the source of the term Handicap—for charity’ (Ramcharan, 2016).

The moral model of labelling views the person with a disability as being responsible for both disability and the treatment accruing given the adopted moral position. The religious model has, in the past, been an extreme model where disability is viewed as punishment by God, or a supernatural force and was common in the Middle Ages and particularly during the Inquisition. It was often seen as resulting from their immoral actions the person or those of their parents. Although the moral model of viewing ABI can be seen as ignorant, some insiders privately still hold onto this perception (Durham, 1997). This influences well-being and self-efficacy for people with ABI. Some outsiders behave towards insiders, people with ABI, as if they are being punished by God, or because they had ‘asked for it’ by engaging in reckless behaviour, driving dangerously or taking drugs, for example (Durham, 1997).

It was not until the Elizabethan Poor Laws in the UK in 1601 that the roots of welfare can be identified. The landed gentry now operated in smaller identified areas termed parishes. Since taxes were essential for parishes to thrive, it became necessary to identify the ‘impotent poor’, i.e. those unable to be economically productive.
The resultant laws represented the first recognition of the State’s responsibility to support the deserving poor. To be deserving of ‘alms’ or handouts, it was, therefore, necessary to be defined or to self-define as disabled, a welfare model that lasts in some shape or form to the current day. By doing so, the government social policy and administration of disability separated people with disability from the population at large providing a serviced existence for those eligible.

The alms offered from the earliest times were not enriching but based on the principle of less eligibility, i.e. that they would not match the level of wages for employment (Claeys, 2000). Furthermore, this ‘economic model’ distinguished between the ‘employed, unemployed and unemployable’ (Scull, 1989, p. 219). In this model, the person’s inability to work and the consequences of this for the individual, employer and Government are established as a basis for social policy. This model was used primarily by policymakers to assess distribution of benefits and to counter fraudulent claims, but this model can lead to confusion and lack of coordination in disability policy. Another important dimension of this model is that by declaring themselves disabled, the person effectively declares themselves unemployable, the result of which means they are more likely to be confined to the financially disadvantaged sectors of society or, later, institutions.

More particularly, from a social policy perspective, the person with ABI is seen as a victim of circumstances, deserving pity and the recipient of charity due to the tragedy of their disability. The emergence of the Poor Laws in the UK, for example, demonstrate how the tragedy/charity model of the 1800s involved the transfer of the responsibility of giving alms from the Church to the government. Workhouses run by local governments housed the unemployable and in some cases the unemployed. The charity model views the disabled including those with ABI as having a tragic, negative and miserable existence. Through raising money and resources, somehow the suffering and sadness of the disabled person’s lives would be reduced (Oliver, 1990, p. 1; Swain & French, 2004). This model lasted for nearly two centuries, although both the Enlightenment and industrialisation played a significant role in once more changing the living circumstances of many people with disabilities.

The advancement of science as the Enlightenment unfolded, heralded longer working hours and progressively harder manual labour in the industrial sector, as well as the growth of bureaucracies and more ‘brain work’. Agriculture was increasingly mechanised and people moved in droves to cities to provide industrial labour. States too, were changing. Having established the place of alms or welfare, there was now a gradual extension of suffrage, i.e. voting rights. The Poor Laws in the UK from 1834 reflected this widening suffrage and the need to cater for more than just the landed classes led to a focus on the interests of the wider citizenry. Since all men would vote\footnote{In the late eighteenth century, the western USA and some northern European countries gave women the vote. The full right to vote in Australia came with Federation in 1901. In the UK, it was not until 1928 that women had the same voting rights as men and in Switzerland, not until 1971.}, it was necessary to appeal to all groups including people with disabilities.
While the workhouses provided temporary and low-quality housing for those temporarily out of work, people with disabilities and mental illness posed a problem for Governments and were expensive to house on a continuous basis. For example, as Richardson (2005) argues

Capitalism therefore sought to remove, control and discipline those who would not or could not conform to new working practices by introducing new secular controls… Between 1720 and 1825, 150 hospitals were built in England to cater for the rising numbers of sick poor (p.71).

These asylums were seen to be placed where the concentration of residents allowed scientific discoveries to be applied more systematically. The seminal work of Seguin and later others on how education could achieve change in the behaviour and abilities of people with disability was revolutionary. While the emergence of modern medicine and psychiatry saw medical staff placed in control of such asylums, Dykens (2006) argues that Seguin’s idea of the training school which through education delivered people with disabilities back to community life was adopted quickly but that...

..over time these schools changed dramatically. With the realization that students were not being cured, schools became less educational, larger and more custodial...institutions became places to keep persons away from a less forgiving and accepting society, (2006, 185).

McClimens and Richardson (2010) posit that up to and during the mid-1900s many people who had disabilities either died when they were young or lived their lives hidden away in institutions or their homes. In the first half of the twentieth century, both the moral and the early medical models were firmly entrenched in western culture and people with disabilities remained segregated from society (Mackelprang & Salsgiver, 1999). ‘Segregation was considered a caring policy in a society which did not care about disabled people…. but World War 1 produced hundreds of thousands of people with disability—who took on the role of the worthy poor’ (British Broadcasting Corporation, 1999, cited in Mackelprang & Salsgiver, 1999, p. 7).

Large institutions situated ‘around the bend’ (and out of sight, the source of this euphemism describing the insane) now operated to cure and to train the lunatics and mental defectives, at least those who did not remain with their families. Bracken and Thomas (2001) argue that in some ways, having been given positions of leadership within the institutions, that psychiatry was borne out of the institutions, rather than the other way around.

The early period in the emergent leadership of the medical profession was also influenced towards the end of the 1800s by Mendel and Darwin in relation to heredity and Binet in relation to intelligence. It may have seemed at the time that the

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(Footnote 2 continued)
Prior to that age restrictions applied (making their voting numbers smaller than men) and various property or rate paying requirements which prevented their suffrage.
potential of biological science was limitless and that, almost inevitably, the source was individual deficit or pathology. Consequently, the eugenics movement argued that people with disabilities were weakening the national gene pool. Separation of the sexes in the institutions and mass sterilisations followed and continued in some places up to the 1960s (Stubblefield, 2007).

However, the most egregious of the eugenics policies under Nazism saw many hundreds of thousands of people with disabilities gassed in the concentration camps. The repercussions of the Second World War for disability cannot be underestimated. The 1948 Universal Declaration of Human Rights emerged in large part as a response to the experience of Nazism. Not long after, Goffman’s (1961) work on asylums and Barton’s (1959) on institutional neurosis changed public sentiment and pointed to the regimentation, Spartan conditions and cruel treatment experienced in the asylums. While survival rates improved, inmates’ experiences are widely recognised as being extreme and catastrophically damaging. Not surprisingly the latter half of the twentieth century has seen deinstitutionalisation and resettlement in the community under a series of ‘community care’ initiatives hand-in-hand with normalisation theory.

While normalisation proposed (Wolfensberger 1973; 1983) that people should lead as normal and socially valued lives as others in society, it remained difficult to establish among such diversity what represented a norm and, indeed, what was socially valued. More fundamentally, the welfare model continued. To be able to qualify for welfare payments, people had to declare themselves as a person with a disability in order to access services. That many of these policies were exclusive and segregated meant a ‘parallel’ existence for those so labelled. Thus, while being on a disability register accorded them rights to welfare, it also separated them into a system of off the shelf disability—only services which kept them segregated from the community, leaving the exhortations of normalisation unfulfilled.

Normalisation had observed the application of a host of stereotypical labelling over the ages: ‘perpetual child’ ‘an object to be pitied’ ‘brave but pitiable’, ‘objects to raise money for’; ‘a menace or threat to society’ or ‘people to be feared’ (Wolfensberger, 1973). People with disabilities have often been portrayed as deviant in the literature, films and television. Bogdan and Biklen (1993) suggest that most monsters are in fact persons with disabilities. Mary Shelley’s Frankenstein published in 1818, for example, portrays such monstrosity as a reflection of the potential of the possibilities of science. People with disabilities have been perceived as: ‘sick’, ‘needing special treatment for which they should be thankful’, a ‘burden to society—they never quite fit in’, ‘ugly and sexless’, ‘incompetent’, ‘freaks’ ‘cursed by God’, or in terms of disability was a ‘gift or test from God’ (Gill, 1993, pp. 12–15).

It is easy to see that the fundamental view held by persons within society will lead to actions that reflect such views. People act rationally, but do so in a way that reflects the premise upon which that rationality is based. The perception of the person with a disability being a menace or threat would lead to the persons so labelled being distanced from society. The view that the disabled person’s body and biology are broken and need to be mended would lead to the primacy of the medical professions in their lives. For the person on the receiving end of such views, the effect of such labels cannot but affect their own self-concept and their reaction to it.
2.2.3 The Medical Model

For too long a time—for half a century, in fact—psychiatry tried to interpret the human mind merely as a mechanism, and consequently the therapy of mental disease merely in terms of technique. I believe this dream has been dreamt out. What now begins to loom on the horizon is not psychologized medicine but rather those of human psychiatry.

—Viktor E. Frankl, Man’s Search for Meaning

The emergence of the medical model alongside the large institutions noted earlier had established a significant medical leadership by the turn to the twentieth century. Rollin (2003) usefully reviews a plethora of treatments for those illnesses recognised by the profession in the UK at the time. Rollin argues dominant treatments to be abstention and ‘cold turkey’ for alcoholics, hypnotism for the neuroses (i.e. neurasthenia, a ‘ragtag’ of symptoms causing lassitude and, hysteria) and ‘moral treatments’ for the insane designed as ‘palliatives for symptoms’. Such palliation was likely to encompass systems of physical restraint such as padded cells and straitjackets, chemical restraints available at the time and a number of exploratory approaches such as music, cycling, ‘hypodermic injection of brain extract’, 3 Indian hemp 4 and opium. 5

Rollin asserts ‘The composite picture of psychiatry in Britain at the end of the Victorian era and a little beyond is chiefly one of unremitting gloom’ (2003, p. 298). Certainly, the effect on inmates would have been nothing short of catastrophic to their lives and freedoms. The early testing of treatments seems to have been based upon trial and error more than science, and institutional inmates were the guinea pigs for new treatments. A more systematic approach to the classification of diseases and to treatment was to emerge in the two decades that followed.

Bracken and Thomas (2001) point to the seminal work of Karl Jasper’s highly influential General Psychopathology, first published in 1913, and to its phenomenological backdrop. Jaspers built his work on the seminal phenomenological writings of Edmund Husserl who had argued that by the process of ‘bracketing out’ surrounding contextual issues, it was possible to access the phenomenon at issue.

Unlike the vast majority of major phenomenological writings that came later, Husserl, who had started as a scientist, maintained a Cartesian view of the world in which mind and matter remain separate. Most later writings in phenomenology posited that the subject and object world were one and the same, that ‘as I see things so they are’. This latter position allows an explanation of the meaning of behaviour in terms of the contextual social, environmental and other factors, making these central to understanding explaining human behaviour and the impact on the person. But Husserl’s adoption of a Cartesian position was to have a profound effect on Jasper’s work.

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3Lancet 3 February 1891.
4BMJ, 4 July 1890.
5BMJ, 18 March 1893.
In Jaspers’ view, the bracketing out of contextual factors led to a focus upon the ‘form’ rather than ‘content’ of the individual psyche. So, for example, hearing voices is not of interest in terms of content of those voices but, rather, that there is no stimulus (form) that accounts for the voices. In many ways, phenomenological reduction here ironicises the patient’s experience. That is to say, although the medic uses their experience as reported, the model of ‘science’ is still used to judge whether there are grounds for hearing such voices. In the absence of such grounds, the conclusion is that the cause must be organic and, indeed, faulty.

Despite this, Bracken and Thomas say that Jaspers’s comprehensive work on ‘form’ established the groundwork for the Diagnostic and Statistical Manual used in the USA to date. More importantly, the underlying assumption of form is that it is disordered individual cognition that must be addressed—that the fault lies in the biology of the individual. Importantly, in making a case for a new direction for mental health they argue that,

Both supporters and critics of psychiatry agree that the discipline is a product of the European Enlightenment and the movement’s preoccupations with reason and the individual subject. Although a critical, postmodern position does not mean rejecting the Enlightenment project, it demands acknowledgement of its negative as well as positive aspects. It means questioning simple notions of progress and advancement and being aware that science can silence as well as liberate, (Bracken & Thomas 2001: 724).

As shall be seen, it is these silences that are those being attended to through this study.

The traditional medical model, therefore, places the source of the problem with the person with the disability and stresses the importance of finding a cure or, by taking a moral position on what is ‘acceptable’ behaviour, helping the person be more ‘normal’ (Mackelprang & Salsgiver, 1999; Olkin, 1999). Disability was seen as a medical problem, as a defect or failure of a bodily system and as such is inherently abnormal and pathological. The goals of intervention are cure, amelioration of the physical condition to the greatest extent possible and rehabilitation…persons with disability are expected to avail themselves of services offered to them and to spend time in the role of patient or learner being helped by trained professionals, (Olkin, 1999, p. 26).

More importantly, the engagement of the medical profession with what is now termed ABI was about to take on a particular urgency. The links between the emergence of medicine and the Great War 1914–1918 cannot be underestimated as the crowds of injured returned from the fronts in Europe, ‘the earliest disability policies of the twentieth century around ABI were entrenched in a medical model primarily focused on the physical restoration of individuals who had suffered some sort of physical trauma or impairment as a result of war’ (Blessing, Golden, & Bruy’ere, 2009, p. 2).

Prior to the twentieth century, there was a high mortality rate of people suffering from ABI but improvements in care made during World War I reduced the death rate (Boake & Diller, 2005). As argued below, the Second World War also produced significant leaps forward in classifying and treating such head injuries.
Even more recently the Iraq and Afghanistan conflicts, blast injuries caused by war have led to significant new research into brain function (Belanger, Kretzmer, Yoash-Gantz, Pickett, & Tupler, 2009; Jones, Fear, & Wesseley, 2007).

The medical or biomedical model of disability has had dominance in the public’s perception of disability. The medical model has regarded disability as a defect or sickness that must be cured through medical intervention. It focuses on, for example, training the body to walk and limbs to work again, in order for the person to be able to accomplish everyday tasks; therapy to assist speech; and training to be safe, inside and outside the safety of home or a rehabilitation hospital.

Although ABI does not feature in the early disability literature, it was perhaps seen in those times as manifested in physical impairment and mental impairment. It was not until the mid-twentieth century that it began to have an identity of its own. After 1948, under World Health Organisation auspice the International Classification of Diseases (ICD) and a significant number of reclassifications have taken place since. Similarly the USA, which also had its own history of classification, launched the Diagnostic and Statistical Manual (DSM) with an additional focus on clinical use in 1952, at the same time WHO published ICD-6. This new classification drew on classification work by the Veteran’s Administration working with World War II veterans. A vital turn at this point was the move to a biopsychosocial model on the basis of the work of Adolf Meyers who saw mental disorders as individual reactions to biological, psychological and social factors.

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) which complements the ICD classification plays a similar role in grounding the biopsychosocial model. While the recognition of ABI as a medical issue first and foremost came at the turn of the twentieth century, it was not until much later that it was formally incorporated within a disability model. In 1980, the World Health Organisation described:

Impairments as any loss or abnormality of psychological or anatomical structure or function; disability as any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being; and a handicap as any disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfilment of a role that is normal for that individual. (WHO, 1980, p. 14)

Looking at the history of professions and their legitimacy, it may be that the capacity of medicine to work on the brain and the injured body together gave the category of ABI a life of its own. In a useful editorial of the American Journal of Psychiatry, for example, Yudofsky and Hales (2002) speak of three classifications addressed by psychiatry (mood, affect, thought and behaviour), neurology (motor and sensory) and neuropsychiatry (attention, alertness, perception, memory, language and speech, intelligence, cognition and motivation). People with ABI may fit under the disability or handicap classification, but it was not until 1993, at a meeting on ABI held in Oxford (UK), that the International Brain Injury Association was formed to encourage global exchange of information, to support research, provide training and to advocate for brain injury (International Brain...
Injury Association, 2011). But the move to clarity around the classification of brain injury has been slow.

ABI itself has really only recently been adopted in the DSM and ICD classifications. Wortzel and Arciniegas (n.d) review this history. The DSMIII (American Psychiatric Association, 1980) spoke of ‘post-concussional syndrome’ but not traumatic brain injury or head injury; traumatic brain injury like acquired brain injury however when using initials TBI and ABI DSM II-R (American Psychiatric Association, 1987) identified only ‘head injury’ as an etiologic factor for delirium and organic personality syndrome; DSM IV (American Psychiatric Association, 1994) and DSM IV TR (American Psychiatric Association, 2000) use the term ‘head trauma’ in narratives describing delirium, amnestic disorder, dementia, cognitive disorder (not otherwise specified) and personality change. DSM V (American Psychiatric Association, 2013) TBI and neuropsychiatric sequelae are detailed and criteria for diagnosing an injury event as TBI are offered. This is considered within a framework of neurocognitive disorders and includes a long list of behavioural disturbances (delusions, hallucinations, mood disturbance, affective lability, agitation, disinhibition, wandering, apathy) and the co-occurrence with neurocognitive symptoms (depression, irritability, fatigue, headache, photosensitivity, sleep disturbance).

Wortzel and Arciniegas (n.d.) usefully summarise the DSM approach. In this model, they use the preinjury, injury and post-injury time frames to consider the focus of rehabilitation professionals in four key areas.

- **Cognition**—including impaired arousal or attention, slow processing, memory disturbance, communication issues, apraxia, visuospatial and executive dysfunction.
- **Emotion**—incorporating pathological effect, depression, anxiety, irritability and anger, agitation and aggression;
- **Behaviour**—including disinhibition, apathy, sleep disturbance, fatigue and headaches;
- **Sensorimotor function**—including pain, visual problems, dizziness/vertigo and seizures.

The classifications in the DSM as described above perhaps give a clue about the focus of the current model. It remains unclear whether this approach is biopsychosocial in that many of the social aspects of lives are ignored. First, even were the focus to have a social dimension, this seems to be likely to be in the hands of the medical and rehabilitation staff to establish and to work upon. Secondly, the model is based on a normative framework of cognition, emotional behaviour and sensorimotor function. This means some interpretation is required to assess what is (the person presenting) and what ought to be (the ‘normal’ person). Thirdly, the focus on what ‘ought to be’ implies efforts to use all medical and rehabilitative efforts to achieve this norm, a largely de facto biomedical approach. Fourthly, the body-object approach—the biomedical model—imposes power differences between professional and client (Sherry, 2006; Smart, 2009).
There may be important weaknesses and limitations of the Biomedical Model which are less visible and rarely acknowledged, but have far greater implications...prejudices and discrimination towards people with disabilities has developed not in spite of but because of it, (Smart, 2009, p. 4).

The ‘golden period/dark hole period’ of which we spoke in the introduction to this chapter, that two-year window in which such change is taken to be possible, therefore establishes a focus premised upon pathology. In this volume, as will be seen, life after that ‘golden period/dark hole period’ now needs to be similarly transcended to engage with the latter end of a ‘recovery model’, that is, with re-engaging in everyday life.

2.2.4 The Social Model

Some models have sought to provide grand or all-encompassing theories around disability. In recent years, the social model of disability has posed a significant challenge to the medical model as a global theoretical framework for understanding disability (Barnes, Oliver, & Barton, 2002). The social model thesis separates the impairment from disability.

Impairment—lacking part of or all of a limb, or having a defective limb organism or mechanism of the body.

Disability—the disadvantage or restriction of activity caused by contemporary social organization which takes no account of people who have physical impairments and thus excludes them from mainstream social activities. (UPIAS, 1976, quoted by Oliver, 1990, p. 11.)

Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (UPIAS, 1976 p. 4)

In this model, the impairment is seen as a characteristic, feature or attribute that affects an individual’s mind or body function as a result of an injury, genetic make-up or disease. In contrast, disability is seen as socially constructed. Society is built for the able-bodied, and so it discriminates against people with impairments. It creates disadvantage through attitudes and culture (e.g. negative images in the media) that reinforces stereotypical views of incapacity, inaccessible environments (e.g. homes, businesses, transport, workplaces, education) and organisations that do not question discrimination nor provide accessible environments. Since these barriers are socially produced, they are subject to socially produced solutions.

But there are some limitations to the social model. For example, Shakespeare and Watson (2001) argue that the social model has not so much as replaced the medical model but has simply placed a higher emphasis on addressing disability as a social issue. They go on to explore the background to British academic and political debates over the social model and argue that the time has come to move beyond this position. Three central criticisms of the British social model are
presented and focus on the issue of impairment, the impairment/disability dualism and the issue of identity. It is suggested that an embodied ontology offers the best starting point for disability studies, and some signposts on the way to a more adequate social theory of disability are provided.

Indeed, the impairment/disability distinction remains unresolved and fails to establish an embodied ontology (i.e. the disability identity itself). In reflecting this embodied ontology, common identity and action through disability pride has been proposed (Morris, 1991), while intersectionality, the combination of excluded identities (disability, ethnic minority, LGBTI among others) has been a focus for others (Caldwell, 2010). Looking at the history of labelling by others, as discussed above, the embodied ontology or body-subject view is potentially hugely important. Shakespeare (2006) suggests that the way forward lies in a combination of the medical and the social model and new ways of thinking. The issue of impairment, the impairment/disability dualism and the issue of identity are included in the criticisms of the British social model and echo the breakdown of Shakespeare’s relationship with the UK disabled people’s movement as disability studies became too reliant on political rhetoric and ideology (Shakespeare & Watson 2001). Shakespeare states that ‘there is no qualitative difference between disabled and non-disabled people because we are all impaired in some form, some more than others’ (2002, p. 27).

However, the very act of saying the word ‘disability’ may not be helpful. If there is no qualitative difference, as Shakespeare suggests, then why is it we still recognise a group of people with disabilities versus the rest of society? The issue is borne out in the tone and focus of disability studies literature. Longmore (2003), Garland-Thomas (1997a) and Sherry (2006) argue that the social model of disability focuses upon physical disabilities, while cognitive impairments such as brain injury are overlooked. Chappell posits that ABI is marginalised within the social model and states ‘some of the arguments emanating from within the social model are assumed to refer to all disabled people, when in reality they do not’ (1998, p. 212).

Oliver (2004) acknowledges five common criticisms of the social model (of which he was the main architect): it ignores or is unable to deal adequately with the realities of impairment, it ignores the ‘pains’ (Oliver, 2004, p. 8) of both impairment and disablement, it is unable to incorporate other social divisions, disabled people are viewed as ‘other’ (Oliver, 2004, p. 9) and it is inadequate as a social theory.

More recently, the social model has generated a number of radical critiques posing various alternative terminologies around people with a disability. Abberley (1999) asserts ‘a liberative theory’ of disability requires the posing of values counter to the classical sociological and revolutionary consensus, the assertion of the rights of the human ‘being’ against the universalisation of human ‘doing’ (p. 14). Finkelstein (1980, 1993) argues that ‘the predominant factor contributing to the disablement of different groups is the way in which people can participate in the creation of social wealth’ (Finkelstein, 1993, p. 12).

Oliver (1990) posits that the comprehensive materialistic account of the creation of disability places ideology at the centre of arguments about disability. In the
above models, the assumptions underlying the role of the State/society and the body-object, even though not a medical model, are no less likely to have huge ramifications on the persons so-defined.

The problems of many of these attempts to distinguish groups of people with disabilities are that they rely on prior meta-theoretical categories. Moral classification supports the treatment of people as sinners; medical classification establishes the grounds for medical intervention; the social model establishes the grounds for access while failing to explore limitations to the accessibility argument for some. The arguments around ‘embodied ontologies’ are vital for they fire off the quotidian narratives of day-to-day life and experience, and the collective and synthesised narratives these represent.

For example, Nussbaum (2001) argues that over time people adapt to deprivations which despite best attempts, they fail to escape. In such circumstance, there is an ‘adaptive preference’ to a life denuded of the potential many of us would continue to fight for, leaving the person ‘satisfied with their lot’. Bourdieu’s seminal work on the ways in which societal structures rub up against human agency is useful to this debate on ontology, disability, identity and adaptive preference (e.g. Bourdieu and Wacquant, 1992; Bourdieu, 1994). It was established earlier that the principle of less eligibility in which welfare is always lower than employment income and that many of the services to people with disabilities run parallel to generic services for the population as a whole. Each of us brings a number of capitals to bear in our struggle to flourish, and this is true for all humans.

In the absence of additional support from family or others, the economic capital wielded by people with disabilities under a welfare model is likely to be severely limiting; in services that are often still closed, social capital for people with disabilities is limited to those in closed services. Such capital does not afford an expansive network of reciprocal support out of which to build a flourishing community. Moreover, the person has very little symbolic capital (power) given their place within the systems of power (field) operated by staff within such settings.

The structure of State welfarist policy, therefore, bears down upon the person in such a way as to limit the extent to which their combined capitals, their habitus, can be used in pursuit of their life’s ambitions. Over any protracted period, such limitations produce a way of being, what Bourdieu terms a ‘disposition’ which is reflected in the ways in which people act. This establishes their ontological view of the world and of their identity. In the face of additional discriminatory, hectoring and rejecting behaviours by the community, people with disability begin to embody their social practices as what they have come to expect from the world. Such embodied practices may come to reflect Nussbaum’s adaptive preference behaviours in which the loss of hope that there can be change for the better is exemplified in limited personal choices and ways of being.

For people with ABI, the challenge to the person’s ontology and identity can be particularly important. From the start, there is an additional potential struggle with the embodied practices of life’s disposition to date, compared with the need to establish one that is new. It is, therefore, absolutely essential that from the start those interactions, those services, those relationships in the person’s life are formed
to establish the embodied practices of inclusion and of dignity. It was one of the necessary features of this research to draw upon what we know about people with ABI to structure the research approach to do no harm at minimum, but to work in an inclusive way that treats participants with dignity.

2.3 Recapitulation

In this chapter, we have summarised a number of assumptions underlying major models of disability and demonstrated that in all disability theory models there can only but be assumptions. It has been seen that such assumptions are the basic premise upon which social action is based: assume possession by the devil, then treat such possession; assume biological cause, then address the biological cause; assume social exclusion through inaccessible environments, then create ones that are accessible. Two further points are necessary to make in relation to the discussion above.

First, since the introduction of welfarist models disability theories may have characterised differences across a range people with disabilities, but the administration of disability under welfare policy still means that to access services, it is necessary to declare or be declared as a person with a disability. This is true even under the radical National Disability Insurance Scheme in Australia in which access to those assessed as having ‘significant and enduring’ disabilities makes available individualised funds that, at least theoretically, can be used to purchase services of people’s choice.

It should be noted at this point that at any one time 19–20% of the population of any country may have disabilities, more in countries where there has been conflict. Many of these people live full lives, are employed, home owners and live in relationships of their choice. So, not all people with disabilities are registered for the provision of disability services. Systems of rationing, therefore, still mediate those who are ‘deserving’ and those who are not. For those that are, lives are dictated by the availability of health and social care services and by other defined rights to services.

For many years, such services have almost inevitably been segregated and run parallel to the policies and services available to other citizens (e.g. in terms of schooling and employment) maintaining the long discrimination between those who work, as independent from those who are deemed to be unable to do so. Redefining people with disability as ‘citizens’ with rights to a minimum level of outcome or in some other way that affords them as humans a fundamental right to a good life could have huge impacts. This relates to the second point.

In all the models considered above, the medical model has perhaps provided a classificatory system that separates out ABI most. As shown above, many of the arguments within the social sciences seek broader theoretical formulations of disability that are all inclusive. Importantly, also all the models reviewed take the behaviour of others as a predicate to the theory of disability. Having defined the
disability, the consequences of mundane interactions are seldom linked back to the theory itself. Disability theory has as yet to systematically explore the behaviours of professionals or members of the community as the subject of understanding. So, for example, what would be the point of making roads and buildings accessible if those around still treat you with disdain? Of what use would it be to mend a body if the professionals treat you in an undignified manner? Even if psychiatry grew from phenomenological roots, even if social constructionism reflects the social model, the everyday experiences and interactions of people with disabilities have been subservient to broader theoretical formulations and this remains a yawning gap, a blind spot, the ‘tiger hidden in the foliage’.

It is now time to focus on the everyday and mundane life experiences of people with ABI. In phenomenological terms, a move to the lifeworld (Lebenswelt) rather than that of the bracketing Husserl recommended is required, an engagement with the natural attitude (Schutz & Luckmann, 1973), and the inter-subjectivities of everyday life and experience are necessary. But, as already established, to do so requires at the very least to ensure the approach does no harm and takes into account as much as is known about people’s experiences in such a way as to engage in a research process that is at once positive, based on dignity and which helps participants to engage with the reconstruction of ontologies, identities and embodied practices, of hope. This study seeks this path.

Nevertheless, there is knowledge from each of these perspectives that is useful. In what follows, we seek to draw upon the collection of body-object knowledge in Chap. 3 and body-subject knowledge in Chap. 4 to further instruct us as to how the Cage should be populated. Once again, in these chapters we separate out these instructional findings into shaded Headwork boxes that inform Keys to the ABI Cage and to the processes used to engage people with ABI as research participants.

References


