THE GREAT DIVIDE:

ABLEISM AND TECHNOLOGIES OF DISABILITY PRODUCTION

by

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This thesis is dedicated to:

Julia Pastrana,

posthumously.

Julia was born in 1832 and was a short statured woman. Due to her differently appearing body Julia worked in circus and freak shows until her death in 1860, aged 28 years. Julia's 'act' was billed as the 'Ugliest woman in the world'. Her name became synonymous with monstrosity. Death did not release Julia from the violence inflicted upon her – a Professor Sokoloff mummified her body and Pastrana became a public spectacle for another hundred years.

Julia Pastrana is remembered and acknowledged as one of our disability martyrs. This dissertation is an offering of recompense for the injustice done to her.

KEYWORDS

Ableism; Cyborgs; Disability Theory; Ethics; Embodiment; Legal Disability; New Technologies; Normalcy; Ontological Formations; Personhood; Science Studies; Theology; Wrongful Life.

ABSTRACT

Subjects designated by the neologism 'disability' typically experience various forms of marginality, discrimination and inequality. The response by social scientists and professionals engaged in social policy and service delivery has been to combat the 'disability problem' by way of implementing anti-discrimination protections and various other compensatory initiatives. More recently, with the development of biological and techno-sciences such as 'new genetics', nanotechnologies and cyborgs the solution to 'disability' management has been in the form of utilizing technologies of early detection, eradication or at best, technologies of mitigation. Contemporary discourses of disablement displace and disconnect discussion away from the 'heart of the problem', namely, matters ontological. Disability - based marginality is assumed to emerge from a set of pre-existing conditions (i.e. in the case of biomedicalisation, deficiency inheres in the individual, whilst in the Social Model disablement is created by a capitalist superstructure*). The Great Divide* takes an alternative approach to studying 'the problem of disability' by proposing that the neologism 'disability' is in fact created by and used to generate notions and epistemologies of 'ableism'. Whilst epistemologies of disablement are well researched, there is a paucity of research related to the workings of ableism.

The focal concerns of *The Great Divide* relate to matters of ordering, disorder and constitutional compartmentalization between the normal and pathological and the ways that discourses about wholeness, health, enhancement and perfection produce notions of impairment. A central argument of this dissertation figures the production of disability as part of the tussle over ordering, emerging from a desire to create order from an assumed disorder; resulting in a flimsy but often unconvincing attempt to shore up so-called *optimal* ontologies and disperse *outlaw* ontologies. *The Great Divide* examines ways ‘disability’ rubs up against, mingles with and provokes other seemingly unrelated concepts such as wellness, ableness, perfection, competency, causation, productivity and use value. The scaffolding of the dissertation directs the reader to selected sites that produce epistemologies of disability and ableism, namely the writing of 'history' and Judeo-Christian renderings of Disability. It explores the nuances of ableism (including a case study of wrongful life torts in law) and the phenomenon of internalized ableism as experienced by many disabled people. The study of liberalism and the government of government are explored in terms of enumeration, the science of 'counting cripples' and the battles over defining 'disability' in law and social policy. Additionally another axis of ableism is explored through the study of a number of perfecting technologies and the way in which these technologies mediate what it means to be 'human' (normalcy), morphs/simulates 'normalcy' and the leakiness of 'disability'. This analysis charts the invention of forearms transplantation (a la Clint Hallam), the Cochlear implant and transhumanism. *The Great Divide* concludes with an inversion of the ableist gaze(s) by proposing an ethic of affirmation, a desiring ontology of impairment.

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ABBREVIATIONS

ABS - Australian Bureau of Statistics

ADA - *Americans with Disabilities Act* 1990

AI – Artificial Intelligence

AL – Artificial Life

ANT – Actor-Network Theory

AT - Appropriate Technology

CI - Cochlear Implants

COH – Cochlear Limited

CRS – Commonwealth Rehabilitation Service

D-P-W – Devotees, Pretenders and Wannabees

DDA - Commonwealth *Disability Discrimination Act* 1992

DSA - Commonwealth *Disability Services Act* 1986

DSM – Diagnostic and Statistical Manual of Mental Disorders

FDD – Factitious Disability Disorder

HGP – Human Genome Project

ICD-10 - International Classification of Disease (10th Revision)

ICFDH - International Classification of Functioning, Disability and Health

ICIDH - International Classification of Impairments, Disabilities and Handicaps

J – Justice (title – Officer of the Court)

NRT – New Reproductive Technologies

SRV – Social Role Valorization

TA - Technology Assessment

U.S. – United States of America

WB – Wrongful Birth

WHO – World Health Organisation

WL – Wrongful Life

STATEMENT OF ORIGINAL AUTHORSHIP

The work contained in this thesis has not been previously submitted for a degree or diploma at any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

Signed: ___________________________________

Date: ____________________

ACKNOWLEDGMENTS

The writing of a doctoral thesis bears many similarities to embarking on a monastic journey. The *Rule of St. Benedict* for instance requires the inquirer's request for entrance into the monastic life be rejected three times to ascertain the seriousness and perseverance of the postulant. Engagement as a PhD candidate involves a similar persistence and initiation into a world of personal and intellectual self-discovery. Many times over my three years as a candidate I have experienced self-doubt about my capacity to complete the task and have been visited by 'demons' insistent upon interrogating my *bona fides*. A PhD in progress has a double life – one that is private and another that is public.

So I start my acknowledgements by focusing on the private domain. Since I started researching this PhD in February 1999 until its completion in January 2003 I have moved house four times. I have carried four pregnancies, resulting in three miscarriages and one live birth – my daughter Revati on the 1st July 2001. I have also had two bouts of pneumonia. My first acknowledgements then are to those people who sustained me over this time – Denise my partner and our daughter Revati who brings my intensity down-to-earth.

Over to the public domain: I would not have ever considered postgraduate study if it was not for the encouragement and passion of my undergraduate legal studies lecturer Dr Adrian Howe (La Trobe University/ now at the University of Central Lancashire). There are some books that leave an indelible impact on the reader – I acknowledge Owen Wrigley's (1996) *The Politics of Deafness* as a work that continues to challenge and provide inspiration. I would like to thank the students of my 'Political Sociology' class at Queensland University of Technology (2001) as well as the students of 2001 and 2002 in the course 'Disability, Theory and Philosophy' at Griffith University for providing me with the opportunity to test out and clarify my ideas. My deepest appreciation to Gail Pritchard who undertook the proofing and copy editing of the final copy.

It is often said that a supervisor leaves their imprint in some shape or form on their students work. This certainly was correct in my situation. I would like to thank Dr Gavin Kendall for his encouragement, support and willingness to let me have a freedom to develop my own ideas. Without the influence of Gavin's work I would not have had exposure to the world of science studies and Actor Network Theory. Additionally I thank Dr Trevor Hogan (La Trobe University/Sociology) and Dr Jayne Clapton (my Associate Supervisor, Griffith University/Human Services) for providing me with excellent feedback on the Clint Hallam case study. Similarly I acknowledge the encouragement provided by Bronwyn Statham, one of the Editors of the *Griffith Law Review* to submit an earlier version of a chapter portion to their journal. The development of ideas for chapter 3 on theological issues and disability would not have been possible without the assistance of Dr Elaine Wainwright from the Brisbane College of Theology. Over the past two and half years I have been supported both academically and personally by Dr Shelley L. Tremain (University of British Columbia/Philosophy). Shelley and I have never met in the flesh – but I thank her for the considerable time spent working with me to clarify difficult concepts. My thanks also to Alison McCallum, Research Officer School of Humanities, Queensland University of Technology for guiding me through the bureaucratic paper work and ensuring that all was well. I would be remiss if I did not mention the support of Dr Nicholas Buys, (Griffith University/Human Services) to complete this thesis as well as his role in providing me with gainful employment.

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DIVISION ONE: BODIES OF KNOWLEDGE

Chapter 1 - Introduction

The telling of stories is a significant medium for the communication of ideas and values of culture as well as the transmission of the 'memory' of a body of people; a form of anamnesis that makes connections between the past, present and the future. Stories help us make sense of the world and the way in which we interpret the 'nature' of things and interpolate ways of difference. Sometimes these stories are explicitly named and actively exchanged, whilst others are more mundane, somewhat insidious - passing on in a multitude of remnants, connected, disconnected, contrary and multiple, eventually taking on the status of being considered a naturalized state of affairs, part of an *a priori* objective form of social ordering.

The focal concerns of this doctorate relate to matters of ordering, disorder and constitutional compartmentalization between the 'normal' and 'pathological' (c.f. Canguilhem, 1978) and the ways that stories about wholeness, health, enhancement and perfection are told. *The Great Divide* is for all intents and purposes a story (stories) about the creation and production of a certain kind of difference known under the contemporary neologism 'disability'. As such, the stories are not finished, they are ongoing, they are highly contestable and the scripts are therefore necessarily partial. I have not set out to provide stories that speak of coherency or indeed conspiracy. Rather, just as the neologism 'disability' is elusive and catheretic, patterns of disorder and incongruity become the order of the day. This dissertation will demonstrate that the neologism 'disability' easily evades capturing and enumeration. I am in agreement with Barbara Altman (2001) who argues that disability's inherent complexity leaves such a phenomenon empirically indefinable unless such stories of ‘disability’ are reduced to a focus on a specific (contained) aspect of lived experience. Uncritical stories and namings of disability are in a deconstructed sense, stories of *disability fabrication* – stories that seem to objectively tell us how ‘disability’ and its kindred twin ‘impairment’ are to be framed and thus understood. Undeniably a significant amount of storytelling that masquerades as disability is not really about impairment or disablement at all – the ‘real’ story being told is about ableism – the ways our bodies *should* be or at least strive to become. The ableist story unfolds as a comportment of living from our early years as a child and into adulthood, creating a code that helps each of us to make sense of the contingencies and exigencies of living.

Statement of Purpose

The project of *The Great Divide* is to dispute the self-evidence of categories/entities of disability and impairment and open up dialogue that presents a ‘difference’ called disability in a contextualised, problematised and fluid fashion. Argument within this dissertation views the production of disability as part of the tussle over ordering, of a desire to create order from an assumed disorder, a flimsy but often convincing attempt to shore up so-called *optimal ontologies*. I am interested in the ways ‘disability’ rubs up against, mingles with and provokes other seemingly unrelated concepts such as wellness, ableness, perfection, competency, causation, productivity and use value. The project of this dissertation is to invert the usual gaze employed in the study of disability, namely empirical observations via ableist prisms of those bodies considered as aberrant or pathological, in order to examine the ways disability is known by continually returning to, and thus focusing our attention on the practices and formations of ableism. In other words, the enduring inquiry throughout this work is “what does the designation ‘disability’ tell us about what it means to be ‘able’ and the corresponding nature of practices and epistemologies of ableism?”

Approaches and Scaffoldings

This doctorate is firmly entrenched in explorations of governmentality in a Foucaultian sense - that aspect of biopower that is hungry to unearth, make visible, classify and enumerate the population. The importance of systems of calculations and ordering make it possible for a number of relations to shape and bring into existence different spectrums of being human. For example, the differentiations between ‘young’ and ‘old’ people, people who are ‘diseased’ or people who have an ‘impairment’ and so forth. The emphasis on the biological population is also an emphasis on the multiple, intimate points of contact between regulatory technologies and a heterogeneous body of subjects. Michel Foucault (1976) refers to this mode of organising, managing and above all regulating ‘the population’ (considered as a biological species entity) as ‘biopolitics’. In order for a biopolitical power to be able to regulate and impel subjects in a particular fashion, it must organise the bodies of subjects (both individual and collective) in such a way that a manageable and functional corpus of knowledge may be produced from those subjects. That corpus of knowledge and its corresponding networks of interest and organisation are known throughout this thesis as the processes and practices of ableism.

The Great Divide is a cartographic journey into the world of the production(s) of disability as well as the battlegrounds, the fights, the wars that seek to ensure the line of defence, the de-militarised zone, (to extend the military metaphor) between notions and epistemologies of ableism and disability are maintained, to remove grey zones that foreground hybrids, reduce uncertainties and enact ‘outlaw ontologies’ (Wrigley, 1996). The unfolding and writing of the doctorate was also a journey - albeit less cartographically dependent - for there were no roadmaps, only the remnants of foundations (e.g. existing disability studies scholarship) on which to pitch the author's tent in order to ponder, discern, gather resources (literature outside of the purview of disability studies) and journey onward and a-round-ward (occasionally in circles). After many years of being immersed in disability studies literature I sensed that there was an element of inquiry missing from critical analysis. It seemed that the 'disability problem' was frequently expressed in terms of attitudinal barriers (incorporating social, political and legal) that resulted in social exclusion. Biomedicalism and/or social organisation were targeted as being the cause(s) of these mindsets (Bickenbach, 1993; Oliver, 1990; Oliver, 1991; Oliver, 1996) toward impairment.

If this were simply the case, the solution would be to initiate some kind of program of awareness, positive and affirmative disability training aimed at inculcating more inclusive appreciations of disability. Certainly since the United Nations International Year of Disabled Persons (IYDP) in 1981, many countries have embarked on this task. The measure of the long-term success of these programs is debatable. It is true that a number of western countries instigated legal and social policy reforms in the 1980's and 1990's aimed at providing a better quality of life for disabled people. It is also true that with the increasing influence of economic monetarism 'conservative' government in many Western nations have reneged from or weakened social programs. As a Canadian disability activist remarks "goodwill is no substitute for freedom" (Snow, 1996). In the early days of pondering this thesis journey – the question, the subtext that directed my research, was related to the nature of unfreedom – the aspect of disablement that even in so-called 'good' social policy times – dented the shine – and continued to provoke disquiet. This disquiet revealed itself in conditions where an alternative construct of impairment was being proposed – in the simple settings of daily disability life: of a Para

Olympian suggesting that her spinal injury was the *best thing* that happened to her, a mother feeling blessed to have given birth to a Deaf child, a devotee who desires another because of the nature of their impairment or a man with Tourette's Syndrome who rejoices in his frenetic creativity.

In this doctorate I aim to explore that which is 'unhinged' when disability becomes *too* delightful. My inquiry moves into the realm of ontological matters – that level of speculation that concerns the state of being human (subhuman) and post human. That is not to say that this work does not tune in to or mediate the specific stories of people who identify as 'disabled'. Rather the stories and first person narratives of disabled people run like a thread throughout the textual chatter and exploration. The stories of our lives, the urgency of issues underpinning our lives are firmly imprinted in struggle and passion of the language of the text. Whilst the dissertation is not strictly phenomenological in orientation – within specific discussions such as those related to case studies concerning wrongful life, elective disability, cochlear implants and the forearm transplant of Clint Hallam, 'spaces' are opened (albeit momentary) for this to happen.

In the time honoured tradition of an explorer (maybe in contrast with a researcher?) I decided to move onward with some sketchy landmarks (or just images) but no predetermined path. My 'rule' of doctoral writing was to keep an open mind, utilise a range of resources and resist any attempts to identify a delimited 'big bogeyman' of disability, a grand theory of disability oppression. I did not want to fall into the trap of arguing that disability is merely a form of social oppression created by the forces and needs of capitalist production (Abberley, 1987; Priestley, 1998; Union of Physically Impaired Against Segregation [UPIAS], 1976). Rather, in the writing of this dissertation

I aimed to visit specific sites of subordination to see what these sites suggested about the formation of the neologism ‘disability’ and also the neologisms ‘able’ and ‘ableism’.

The sequencing of the chapters reflects this movement in interest and depth and from epistemology to practice (specifically legal and social policy). The structure of the dissertation contains a number of ‘anchor points’ on a journey, in a conversation framed by stories of desolation, burden and despair and alternatively counter stories of subversion, recripping™, decripping™, delight and elation over the difference of ‘disability’. I have organised the chapters around three divisions: *Bodies of Knowledge, Practiced Bodies* and *Desiring Bodies* to establish an axis between what may appear to be disparate themes. Whilst these divisions are not self-contained they exist to provide shape to the thesis as a whole. All chapters and their various sections feature specific sites in the government of impairment and the regulative formation of disablement. Each chapter has been written as a ‘stand-alone essay’ on specific themes. However the task of producing a doctorate necessitates that the body of work as a whole has a kind of unity. This dissertation presents a systematic exposition of the character of epistemologies of ableism – its endurability, contradictions, incoherency and capacity to reformulate itself when confronted with practices of resistance on the part of individuals with aberrant bodies. Irrespective of the site of subordination under discussion what becomes quickly evident within my argument is that unless ableist configurations of disabled bodies as *inherently* negative (or for the more philosophically inclined, *ontologically intolerable*) are confronted, reckoned with and exposed then the *Great Divide*: the partitioning of (human) life into either productive or useless (redundant) bodies will be maintained and reproduced.

Challenges

Before moving on to provide a synopsis of each chapter I want to make mention of some of the challenges in writing about a type of difference that is continuously being deconstructed but simultaneously is in need of precision in order to gain a clarity about various differentiations between actants. Throughout the work I have engaged in a constant struggle over the issue of language and reductionism. For instance, I speak of impaired people or people who are impaired – in a way that sometimes in the text reads like I am referring to a category of beingness that is self-evident and fixed. In fact the delimitation of impairment is far from being self-evident and discrete – but workability calls for some *signifiers of containment*. On occasions when I have become restless and lapsed from this strategy I have, for clarification purposes, spoken in terms of a person who is 'referentially' disabled or impaired to indicate that from the perspective of subjectivity I am referring to an individual who identifies as having a disability/impairment. Another semantic relationship that creates a quandary is that between so-called able-bodied people and people with a disability. Again the same caveats and rules apply. I want to emphasise here that one's positioning within these two arbitrary and artificial camps is more dependent on their ontological and epistemological stance and less on their corporeal and mental states. For instance, a person may be bodily impaired (there you see it: reductionism!) but may be ontologically of an ableist persuasion i.e. a great supporter of the disability as deficit approach. Alternatively, an individual assumed to be able-bodied (and aren't we all, unless…!?!) may in fact embrace an affirmative approach to disability.

Portions of the dissertation may be hard work for the reader. Some of the difficulties will be due in part to unfamiliarity with the content and argument. More likely the strain may stem from the fact that the work is multidisciplinary – spanning a range of epistemologies and linguistic styles – theological, sociological, science studies, and legal reasoning and case law. I have not made any attempt to regularise the language and stylisation between and within each chapter. I am aware for instance, that the sections related to theological and legal themes *do assume* to some extent a working knowledge of the respective disciplines.

An early reviewer of a draft of this doctorate suggested that it maybe more 'politic' to restrict the purview of disablement to that of physical impairment rather than disability (in general). I have chosen not to do so – when I refer to the 'disabled body' that expression is inclusive of physical, sensory, intellectual and emotional impairments. As a philosopher of disablement I have made a decision to refuse the specificity of impairment in a study of meta-concepts and neologisms of disablement and ableism. This refusal or resistance is for a number of reasons. Impairment specificity can lead, as Iris Marion Young (1990) points out; to a 'scaling of bodies' that additionally begets the question as to the criteria for the establishment of hierarchies. Like Randall Kennedy (2002) remarks when writing about 'niggers,' I do not wish to take on the role of an 'accountant of atrocity'. The debate about which group of disabled people is worse off is not only divisive, it is also redundant as the 'lived body' is far more complex and contextualised than mere diagnostic determinism would suggest (Turner, 1992; 1993). My refusal of specificity however should not be seen as a denial of difference between impairments, nor a disregarding of embodiment or some kind of disability relativism. Throughout this work I have used the 'stories' of disabled people in support of my inquiry. Because I have not used a specific impairment 'type' throughout this work, it does not follow that my analysis does not extend to those groupings. Rather, the voices of disabled people are used anecdotally and demonstratively in order to link practice back to its theoretical underpinnings.

Finally, I am aware that orthodox writing conventions dictate that to speak authoritatively through writing, “one must speak from nowhere and no body” (Rhodes-Little, 1996, 1). I have consciously resisted such an accreditation technique. I have a body that is raced, sexed and deemed impaired and my work can be situated within an identifiable personal and scholarly journey. It is for this reason that I have adopted a narrative in the first person and because writing is a conversation and a thesis a dialogue, I also describe the reader in terms of ‘you’ and ‘our’ to denote some re-cognition of a collective investment in the enterprise at hand.

Chapter 2 provides an outline of the methodological and epistemological assumptions engaged for this work and states the dissertation’s relationship to existing literature, matters related to terminology and conceptual frameworks and my knowledge standpoint. This thesis involves the capacity to represent ‘disability’ in ways that may erase or authorize the lived experience of disablement. Whilst this dissertation broadly adopts a poststructuralist approach to research, the work is also firmly engaged in a process of meta-alternation, drawing upon a range of methodological approaches to suit the topic under discussion. The utilisation of a mixture of sources, methodologies and disciplines is a particularly original aspect of the doctorate. It is unusual to find a work that draws upon literature from medicine, industry design, science, biblical scholarship, sexology, media, history, policy studies and law and relates that vast body of work to the matter of disablement and ableism. Methodologically this vast body of knowledge has been harnessed for an engagement in an analytics of *imaginisation* in order to cultivate a kind of critical thinking, an attitude of problematisation. As Morgan (1986: 334) fittingly summarises, this approach "… encourages us to understand and grasp the multiple meanings of situations and to confront and manage contradiction and paradox, rather than pretend that they do not exist".

Chapter 3 is concerned with the question of the discursive practices of 'disability' as a site of struggle (Foucault, 1984a). The specific interest of the chapter relates to historical and theological constructions of anomalous bodies. My exploration begins with an investigation of the challenges of undertaking 'histories' of disability. In recent years the scholarly world has witnessed a flowering of publications that aim to write disability back into history. As I point out in the chapter, histories are important because they can 'tell us who we are' and explain 'what we might become' in this present and future moment. The chapter proposes and develops a scaffolding of genealogies of disability in Western thought as a template for further historical studies. One of the salient features of accounts of 'disability' within historical material is the uneven way 'disability' marks out bodies considered different and the variability of connotations given to that (impaired) difference. Nonetheless I have tracked key genealogical convergences in the form of three broad formations of inquiry into the disability question, namely "*What is it?*", "*Who are You?*" and the twenty-first century preoccupation of "*Do you wish to be?*" within Western philosophical traditions.

The second focal concern of the chapter relates to Judeo-Christian renderings of disability. You may ask what business has theological concerns in a social science, critical legal studies thesis? On two fronts I believe that it is fundamental for disability studies scholars to engage in the work of theological deconstruction and reconstructions. The first rationale is fairly straight forward: the disability services sector (business) has been dominated to a greater or lesser extent depending upon location, by community services operated or auspiced by churches, charities and missionary organisations drawing upon various theological charisms. The second rationale is that whilst the 17th century enlightenment rejected many of the knowledges of the churches preferring a secular rationality – much of liberal humanism is underpinned by theological worldviews about social ordering, fate and fortune. Section 3.2 navigates through various 'victim theologies' (to borrow a phrase off Lane, 1992b) and then moves on to an analysis of attempts by some theologians to reconstruct more 'helpful' readings of disability within the theological canon. The final sub–section of this chapter is a case study – examining the biblical figure of Moses.

Chapter 4 provides an analysis of the politics of ableism and disability hatred. As such it provides a significant contribution to the field of disability studies by the development of a sustained and dedicated examination of the formation of ableism and its specific impacts on the lives of disabled people. The chapter is divided into three sections, with each component building upon the other. People with disabilities remain one of the most researched heterogeneous groups in the Western world. Such an emphasis produces scholarship that contains serious distortions, gaps and omissions regarding the production of disability and the social and discursive context in which understandings of disablement are formed. Disability, often quite unconsciously, continues to be thought and written from the perspective of the Other (Marks, 1996: 70). This chapter overturns this traditional preoccupation and shifts our gaze by concentrating on what the study of disability tells us about the production, operation and maintenance of ableism. Firstly, the reader is introduced to the concept of ableism, its insidious hiddenness and indelible reach.

As part of this project of exposing ableism - the second task of the chapter is to tease out the strands of what I refer to as '*internalised ableism*', an attitude of psychic thinking that produces a docile disabled body that becomes complicit in inaugurating practices of ableism. In order to assimilate into the norm, the individual *referentially* disabled is required to embrace, indeed to assume an 'identity' other than one's own – and this subject is repeatedly reminded by epistemological formations and individuals with hegemonic subjectification of their provisional and (real) identity. The experience of impairment within an ableist context *can* and *does* effect formation of self – in other words 'disability *is* (becomes) me', but that 'me' does not need to be enfleshed with negative ontologies of subjectivity. This section presents an original contribution to thinking through the processes of internalised ableism outside of a narrow psychological paradigm by drawing upon broader philosophical schema at play. Finally, as part of a commitment to make the necessary connections between theory and practice, the third focal concern examines the ethos of ableism and its enactment in the arena of law, in particular tort liability law. My case study relates to a strand of development known as wrongful life litigation. This form of legal reasoning proposes that non-existence is preferable to existence with impairment.

Chapter 5 is titled *Governing 'Disability' in the Spirit of the Enlightenment*. This chapter explores the mechanisms of governing disability within the Australian and International context. I first examine the tenets of liberalism that inform processes of governmentality in particular the ethos of freedom so attractive to exponents of liberal rights discourses/strategists. The chapter then moves on to a discussion of the 'in-vogue' management practice of mutual obligation to highlight the limitations of liberalism's inclusivist ethic. As part of our inquiry into the techniques of managing disability Chapter 5 also considers the roles and relationships between practices of enumeration (the counting of cripples), epistemologies of biomedicalism and the way in which these networks converge to shape the ground of what it means to be 'human' as well as 'aberrant'. I develop the concept of the '*enumerative passport*' to denote those documents (and badging) necessary for the right-of-passage though services and welfare support. The use of an *enumerative passport* can make a contribution in speaking about the enactment of practices of disablement/ableism in a shorthand way in daily (policy) life. In the day-to-day the production and management (disciplining) of disability (and the disability business) is operational zed through the adoption of social role valorisation theory (SRV) within disability policy and human services. The final section of chapter five brings together our investigations into the government of disability so far, by looking at the way understandings of disability are produced in law and the way patterns of convergence and resistance take place over various formations/formulations of disability. Specifically the chapter examines the emergence of new ways of defining (legal) disability along the lines of 'immutable impairment' in contrast with 'voluntary' or 'elective' disability. These rival ways of framing disability were put to the test in a series of decisions that the U.S. Supreme Court handed down in 1999.

Chapter 6 is concerned with the ways that various technologies mediate and produce how disability, impairment and normalcy are known. The opening section sets the scene and introduces debates about the nature of technology, its relationship to science, matters of 'progress' and actors in a network of association. Here I consider the works emerging out of the appropriate technology movement, Heideggerian and Foucaultian thought and science studies in general. Rather than holding to a simplistic view that technologies are inherently dangerous or implicitly beneficial, this work attends to ways technology is engaged, its disjunctures and constructed boundaries.

Having discussed various philosophies of technology, the next section considers technological possibilities for people with impairments. In this section I explore the kinds of dynamics and impulses that are generated when productions of disability are coupled with the technological apparatus. Consideration is given to the promises of technologies and the possibility of eugenicism. Argument is provided to support the proposition that the vast majority of 'new' technologies simply *morph (simulate) ableism* and therefore can be reckoned as applications enforcing visions of normalcy. The chapter concludes with two contemporary case studies of morphing: Clint Hallam's Wayward Hand (the world's first forearm transplant) and the selling of the Cochlear Implant (to cure deafness). The final section looks to the future and considers the prospects that posthumanism or transhumanism have for the liberation of disability.

Chapter 7 marks a turning point in the doctorate's focus on negative ontologies of disability by shifting our attention to matters affirming disability, by marking out sites of resistance to technologies of ableism. As the reader commences the final chapter they should be well and truly cognisant of the fact that people with disabilities have had to live under the enormous weight of negative figurations of disablement. Yet it is all the more extraordinary that disabled people have not yielded to this repression, adopted a 'lie down and die' approach but have often resisted docility and engaged in transgressive figurations of disability. The placement of concepts such as 'desire' and 'disability' within a single context almost appears to be an oxymoron. Chapter 7 examines the relevance or otherwise of Foucaultian 'desire' in its consideration of 'disability' as oppositional ontology and engages in a project of alternative formulations. Discussion opens with a brief survey of various philosophical treatments of the desire question in order to assess their usefulness to this undertaking. Next, I signal some of the quandaries that may emerge in applying desire and disability in the same context. The final section moves into an analysis of conflicting practices of *reading* desire and disability, in the form of the pathologisation of desire by disability devotees.

The Great Divide is a work in progress – it is a provisional form of research, a rewriteable doctorate (actually I hope not!!). My aim is to contest the injurious notion that disability is *inherently* negative and foreground the culpability of the practices of ableism in enshrining this view as a naturalised state of affairs. *The Great Divide* beckons each of us to unthink hegemonic disability and re-cognise the possibility of another way – ontologies of affirmation.

Chapter 2 - Methodological and Epistemological Assumptions

> Theory is sociology's self-consciousness, its awareness of its own corrigible authorship. Writing does not end interpretation, with definitive clarifications and definitions removing all doubt as to meaning. Clarifications must be clarified - the hermeneutical circle. To theorize is to listen to sociological writing write, and in so doing to recognize that science - and thus society - could be written differently. (Agger, 1998: 188).

> … do we position ourselves on the side of colonizing mentality? Or do we continue to stand in political resistance with the oppressed [sic], ready to offer our ways of seeing and theorizing, of making culture … This choice is crucial. It shapes and determines our response to existing cultural [also hegemonic] practice and our capacity to envision new, alternative, oppositional aesthetic acts. It informs the way we speak about these issues, the language we choose. Language is also a place of struggle. (hooks, 1990: 145).

2.1 Methods

The central concepts underlying this doctorate are Michel Foucault's notions of governmentality and practices of normalisation (Foucault, 1977a; 1988a (Orig. 1981); 1991). In particular, the way technologies of self induce a particular understanding of desire or a dis-ease about the particularities of corporealities. This kind of desire or dis-ease makes it impossible to envision 'disability' as anything other than absence or negative ontology. Throughout this work I am interested in the ways individuals with disabilities respond to the compulsion towards ableist normativity and the way that compulsion also shapes the binarism of disability and able-bodiedness. My project of *speaking otherwise* about 'disability' and ableism is an attempt to unsettle hegemonic understandings of disability, to create a movement of *aggiornamento*, to open up an ecstatic 'space' where the flowering of positive spectrums of the 'disabled self' can be foregrounded. This chapter outlines specifically the methodological approaches and epistemological assumptions adopted throughout the work.

The Objects and Research Question

The object of this doctorate is the exposition of the ways disabled or corporeally ambiguous bodies are known and the effects of that knowing on the formation of 'disability' and 'abled' subjectivities. Having said that, part of the exploration of the object is to ask a number of related and associated questions:

- What place (and there are multiple) has the 'disabled' body occupied in the Western imagination, and in the symbolic productions of Western culture over the past two thousand years?

- In what ways has the imaginary of 'disability' shaped the delimitation of 'humanness' and its constitutive outside?

- How have these various positionings (often contrary) effected the formation of 'disabled' subjectivities at the level of function, structure and institutions?

- How have these various positionings effected the formation of 'abled' or 'able-bodied' subjectivities at the level of function, structure and institutions?

- Is it possible to develop counter-stories (or oppositional discourses) based on affirmative ontologies of disability?

These questions are broad sweeping and act as a template or scaffolding from which to guide the focal concerns of each chapter. For reasons of space and purview, I have delimited the thesis topic, by restricting my focus to three main centres of interest:

    - *Bodies of knowledge* – three strands: (1) theological and (2) genealogies of disability history and (3) epistemologies of ableism;

- *Practiced Bodies* – the ‘disability’ question and its relationship to governmentality, sites of law and new technologies;
- *Desiring Bodies* – an exploration of the dynamic of desire and ‘disability’.

Methodological considerations

By necessity, the task of exploring the ‘disabled body’ means that such writing is epistemologically interdisciplinary, utilising legal, sociological, philosophical and anthropological traditions. More particularly, this doctorate draws (directly and indirectly) significantly upon the works of Michel Foucault, Judith Butler, Wendy Brown, Nikolas Rose, Bruno Latour and Owen Wrigley. All these theorists provide useful ‘tools’ for the development of a transgressive understanding of ‘disabled’ embodiment.

The trans-disciplinary nature of the doctorate has resulted in a style of *meta-alternation*, based on the proposition that the analysis of different subject matter requires different methodological frames of reference to be adopted, especially when the focus relates to the physical sciences. Whilst this approach may initially seem somewhat eclectic to the reader, the utilization of a mixture of sources, methodologies and disciplines is a particularly original aspect of the doctorate. *Meta-alternation* should not however be confused with the usage of methods on a whim or another kind of arbitrariness. Each method has been carefully selected as an approach that is ‘best’ suited to the focal concerns of the enquiry. The rest of this section is a summation of methods utilized within this work.

Actor Network Theory and the Social Construction of Technology

I have utilised a number of methodological approaches from science studies such as *Actor Network Theory* (Akrich, 1989; 1992; Callon et al., 1986; Latour, 1988; 1992;

1993; 1999; Law, 1991; 1992; 1994; 2000; Star and Griesmer, 1989) and those outlined by Pinch & Bijker (1987), namely the *Empirical Programme of Relativism* (EPOR) and the *Social Construction of Technology* (SCOT) modes of analysis, especially in those chapters related to questions of technological development, processes and practices.

Actor Network Theory (ANT), sometimes known as the sociology of translation, is concerned with studying the operation, diffusion and workings of power. However unlike pluralist or 'elite' theories (see Dahl, 1961; Mills, 1956) ANT requires that the researcher suspend any hypothesis that may explain modalities of power and adopt a posture of openness that may position the researcher to identify various networks of association and convergences of actors. John Law (1992) explains:

> …Instead we should start with a clean slate. For instance, we might start with interaction and assume that interaction is all that there is. Then we might ask how some kinds of interactions more or less succeed in stabilising and reproducing themselves: how it is that they overcome resistance and seem to become "macro social"; how it is that they seem to generate the effects such power, fame, size, scope or organisation with which we are all familiar.

The focus of ANT is the identification of heterogeneous networks. Networks are made up of not just human actants, but machines, texts, epistemologies, sentiments beings and other material forms.

A 'sociology of technologies' as developed in Pinch and Bijker's (1987) work on artifact stabilization and technological closures provides extra fortification of the ANT approach. *Artefact stabilization* refers not only to the (final) choice or design of a technological apparatus but also the dominant 'meaning(s)' given to that artefact. *Artefact stabilization* is achieved through various mechanisms of closure that can be grouped into two kinds, namely *rhetorical closure* and *closure by re-definition of the problem*. *Rhetorical closure* draws attention to the existence of contestable meanings over the nature and purpose of an artefact and closures of representation. Rhetorical closure involves a cessation of controversy, with the dominant actors (inside and outside of the medical/scientific community) that institute a fixed meaning and 'disappear' any problems associated with the device. This process involves mobilising allies across networks of association to assist with inducing a particular thematic spin or representation. As Pinch and Bijker remark, "… in technology, advertising [and media] can play an important role in shaping the meaning which a social group gives to an artefact" (1987: 427). *Closure by re-definition of the problem* often occurs when there are perceived concerns about technological practices and artefacts. Instead of responding to alleged 'problems', the meaning of either the artefact or its application is translated to constitute a solution to another problem.

In order to guard against technological determinism or essentialism the use of the abovementioned science studies methods enables an exploration of networks of association that link laboratory/biotechnological practices to other domains, whilst at the same time attending to the engagements, disjuncture and constructed boundaries that disrupt what might otherwise appear to be a seamless web of non - associated linkages. This is especially important with regard to discussions of the role of technological stakeholders, the failure/success process and questions of compliance and consensus.

Poststructuralist and Foucaultian methodologies

The doctoral research utilises a *poststructuralist research methodology* in the belief that this theoretical approach can be a useful tool for the exploration of difference and the corporeality of 'disability'. Such a research methodology is well known and used by scholars both in Australia and internationally (Dean, 1994; Fairclough, 1993; Fairclough, 1995; Kendall and Wickham, 1999). My choice of methodology is further enhanced by engaging with feminist insights into questions of method, epistemology and subjectivity (Braidotti, 1994; Smith, 1988; Stanley, 1990; Weedon, 1997).

I have adopted a Foucaultian *genealogical approach* to archaeological research (Foucault, 1984a; 1984c; 1994 orig. 1970). The use of a Foucaultian research methodology provides '*reading strategies*' to foreground discourse "in operation, in a specific historical context [and] see whose interests its serves at a particular moment" as well as unmask such things as discursive manoeuvres and recuperative strategies (Weedon, 1997: 108). As Stuart Hall (1997: 6) puts it:

> …[Discourse] examines not only how language and representation produce meaning, but how the knowledge which a particular discourse produces connects with power, regulates conduct, makes up or constructs identities and subjectivities, and defines the way certain things are represented, thought about, practiced or studied.

The danger otherwise is to continue to reproduce dominant discourses that represent people with disabilities as passive victims lacking agency. As such, this doctorate is one way of asserting resistance; it is a 'transgressive' piece of writing (research), which seeks to "interrupt existing ideologies and exploitations of disability"[1] (Fine cited in Zarb, 1992: 133).

Discourse analysis is a primary method of epistemological 'interruption'. As Foucault (1980a: 52) explains, "the exercise of power perpetually creates knowledge and, conversely, knowledge constantly induces effects of power". Foucault once suggested that his work should be used as "little tool boxes" and this doctorate takes up that offer (Morris, 1979: 115). Amongst other things, Foucault's method of discourse analysis

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[1] The position adopted is often referred to as an "Emancipatory Research" perspective. Morris (1992: 158) provides a good summary of this framework: "A new research paradigm … must be based on: empowerment and reciprocity; changing the social relations of research production; changing the focus of attention away from disabled individuals and onto disablist structure".

enables an examination into the way 'disability' is put into discourse, acknowledging that the terrain of discourse is itself a site of struggle and competition (Foucault, 1976: 11; Foucault, 1984a: 110). Throughout this doctorate the use of discourse analysis makes transparent the sometimes bloody (but often hidden and little alluded to) battles of over meaning (and limitations) of the neologism 'disability'. Foucaultian discourse analysis can assist in revealing ways 'disability' and 'ableism' comes to be produced, encoded and exhibited. Discourse analysis can be undertaken in a threefold manner. Firstly, by examining at the *textual* level the way 'disability' is put into specific narratives – be they historical or theoretical; secondly, at a *discursive* level, it is possible to reveal patterns (uneven as they may be) related to the representation of 'normative' corporeal ontologies and inquire into what has been excluded, minimised, been disqualified or has been considered marginal (Foucault, 1980b: 82); Thirdly, at the level of the *social*, such analysis enables the operation of *sovereign power* in the form of ideology and hegemonic technologies to be revealed exposing liberalism's figuring of the sovereign 'individual' as a fabrication[2].

In order to name the violence – epistemic, psychic, ontological and physical, experienced by people whose bodies have been marked as corporeally intolerable or ambiguous, the extrication of discursive formations can reveal the concealed 'gaze' of the 'underlying subject' of discourse: the pursuit/conformation of the phantomological body of the liberal self[3]. I want to show that there is an intrinsic link between the productions of sovereign selves, ways relationality and embodiment are understood, the figuring of

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[2] Once understood as fictitious or imaginary, the whole of the liberal rights project begins to unravel. It is questionable whether it is possible to deliver substantive 'justice' to people whose bodies' don't/won't/can't fit a particular kind of human self/citizen.

[3] I argue that the figuring of 'disabled' bodies reiterates the 'truth' of the 'essential' 'normative' body that is masculinist and ableist. 'We' (all of us regardless of how we are positioned) learn from a young age about the kinds of bodies that lack or transgress, including the consequences of such 'uncivility'.

‘disabled’ bodies, as Othered and the production of practices of ableism. The task of poststructuralist methodologies is not to look for coherent patterns that can contribute towards a broad universalist explanatory narrative of disablement, rather the challenge of this doctorate (and poststructuralist methodologies) is to log, to document, to discern “… the innumerable accidents and myriad twists and turns of human practice …” that continue to produce and mediate conceptualisations of ableness and disablement (Prior, 2002, 66). In chapter 3, section 3.2.4, a re-reading of the Hebrew Bible call of Moses and in chapter 6, section 6.3 on the case of Clint Hallam I have departed from a specifically Foucaultian form of discourse analysis. In these sections, I have adapted methods better suited to the subjects’ disciplinary base, e.g. biblical exegetical analysis (see Brenner, 1997; Brenner and van Dijk Hemmes, 1993) and media content analysis (see Berelson, 1952; Holsti, 1969; Kellehear, 1993).

Of particular interest is Foucault’s analytics of power that employs the analysis of ‘dividing practices’[4] that facilitate techniques of surveillance that “function ceaselessly …[wherein]… the gaze is alert everywhere” (Foucault, 1977a: 195). It is the role of technician’s ‘gaze’ operating within the context of biomedical realism that classifies, monitors, modifies and documents the ‘unruly’, transforming us into “subjected and practiced … ‘docile’ bodies” (Foucault, 1977a: 138). Taking on board the conceptual tool of the gaze, this doctorate inverts the usual gaze employed in the study of disability, namely empirical observations via ableist prisms of those bodies considered as aberrant or pathological. Instead, my methodological engagements aim to shift the gaze, to invert it, to examine the ways disability is known by continually returning to and thus focusing our attention on the practices and formations of ableism.

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[4] Foucault (1983: 208) defines such ‘dividing practices’ as situations where “the subject is either divided inside himself [herself] or divided from others”.

The enduring question throughout this work is "what does the designation 'disability' tell us about what it means to be 'able' and the corresponding practices and epistemologies of ableism?" In other words, the orientation of this doctoral work is towards an *extrapolation of the governing of 'disability'.* I am using 'governing' in the Foucaultian sense of 'conduct'. Mitchell Dean (1999: 11) explains:

> Government is any more or less calculated and rational activity, undertaken by a multiplicity of authorities and agencies, employing a variety of techniques and forms of knowledge, that seeks to shape conduct by working through our desires, aspirations, interests and beliefs, for definite but shifting ends and with a diverse a set of relatively unpredictable consequences, effects and outcomes.

In line with these focal concerns, the ***objects*** of my investigation are those texts (documents and devices) concerned with the discursive ***practices*** of governing 'disability'. For instance:

- Reports –
    - Government policy
    - Governmental agency discussion papers
    - Legal discourse – statutory & case law, bills of parliament
    - General policy and research papers by a range of stakeholders
- Books –
    - Scientific/ Technological types
    - Social sciences orientation (incl. Disability studies)
    - Autobiographical
- Devices –
    - Campaigns & Activism
    - Marketing material – selling products ~ ontological productions
    - Documentaries
    - Electronic discussion lists

Methodological praxis:

The practice of research engagement is essentially unobtrusive involving reading and textual analysis via a range of *exegetical and hermeneutical* techniques (Kellehear, 1993). To analyse both documents and devices in terms of the production and governing of ‘disability’ I have adopted the framework outlined by Kendall and Wickham (1999: 26) by way of *functional* working objectives:

TABLE 1: Working Objectives

- to ***chart*** the relation between the sayable and the visible;
- to ***analyse*** the relation between one statement and other statements;
- to ***formulate rules*** for the repeatability of statements (or, if you like, the use of statements);
- to ***analyse the positions*** which are established between subjects … in regard to statements;
- to ***describe 'surfaces of emergence'*** - places within which objects are designated and acted upon;
- to ***describe 'institutions'***, which acquire authority and provide limits within which discursive objects may act or exist;
- to ***describe 'forms of specification'***, which refer to the ways in which discursive objects are targeted. A 'form of specification' is a system for understanding a particular phenomenon with the aim of relating it to other phenomena.

The central concern of this doctoral research is *theory* - in particular the theorization of ‘disability’. As such, it represents a work-in-progress not a form of theoretical foreclosure (Slee, 1997). Any ‘conclusions’ should be regarded at best as tentative. The importance of theory and its engagement within social policy debates cannot be minimised. As Donna Haraway (1991b: 187) puts it:

> We need the power of modern critical theories of how meanings and bodies get made, not in order to deny meaning and bodies, but in order that they have a chance for a future.

So it is my hope that this doctorate can contribute to practical debates and acknowledge that the very act of theorizing about ‘disability’ is a form of action (Foucault, 1984b; Shakespeare, 1996).

Delimitations:

In this research no surveys, interviews or 'real time' observations of scientific (laboratory) practices have been carried out. With the exception of Chapter 3, the timeframe and focus of the thesis was on post World War II liberal democracies in the West (e.g. Europe, North America and Australasia).

2.2 Dissertation's Relationship to Disability Studies Literature

This section represents a survey of this doctorate's relationship to existing Disability studies literature. It should not be considered as a formal literature review. In keeping with a poststructuralist approach, a review and critical analysis of the literature is integrated throughout the work as a whole (Kellehear, 1993).

Theological Literature

Dominant understandings of Christian theological traditions have positioned people deemed corporeally ambiguous as representing the sinful, irredeemable, mortal side of human ontology. In other words, people with disabilities represent a kind of 'fallen' or incomplete creation. Additionally, 'disability' has been equated with notions of sin and irrationality, or alternatively it has performed as symbol of the 'suffering servant' - a virtuous human who is made 'whole' in the next life. With these themes in mind I am in agreement with feminist theologian Nancy Eiesland who argues that " … 'disability' has never been religiously neutral, [it is] … shot through with theological significance" (Eiesland, 1994: 69). Indeed, within mainstream Western theology, both traditional and modern, 'disability' has embodied a moral discourse that oscillates around a number of diffuse and seemingly contradictory themes:

- ‘disability’ as an undesirable, negativised state of ontology acting as a sign of punishment or evil incarnation;
- the disabled body as a ‘conduit’ body/’damaged’ object (a vehicle or vessel of theological showing) - marked out either as the object of divine action or as a challenge to divine ‘perfection’; and
- ‘disability’ as a form of impurity, as ‘matter out of place’ creates ambiguities about competence, exemptions and inclusions within religious practice (Fontaine, 1996: 289 - 295; Rose, 1997: 397).

It is not surprising then, that Christian theology is perceived in philosophical, sociological and feminist works related to embodiment, as the source of ambivalence and even hatred towards the body and corporeal differences attributed to ‘sex’, ‘race’ and ‘disability’. It is this legacy that set in train the foundations and justifications of persecution, marginality and oppression of people with ‘disabilities’ (DeVries, 1994: 127; Rose, 1997: 396). Despite the churches involvement in charities servicing people deemed ‘poor’ and its substantial investment in ‘disability’ and human services, there has been a paucity of material critically examining the relationship of theological precepts to the construction of ‘disability’. It has only been the mid – 1990’s that a ‘disability’ focus within theological studies has emerged. Chapter Three’s discussion of Christian theology forms a fundamental component of the thesis as a whole as mainstream culture continues to read and appropriate visual and textual images of biblical people with ‘disabilities’ within secularised cultural productions. Critical studies can be divided into two streams – scriptural: exegetical/hermeneutical and systematic theology.

Work in the area of systematic theology has been slow coming. Earlier attempts to develop a transgressive theology of ‘disability’ have been stalled by epistemological frameworks that continue to render ‘disability’ as a brokenness wherein faith in divine activity induces possibilities of ‘post-corporeal’ salvation. Recent shifts in theologising of ‘disability’ have engaged in a reformulation of the divine as the ‘disabled god or Christ’. Whilst approach has varied in focus, often the transgressive potential of the analysis has floundered as the figuring of god as ‘disabled’ is based on an *a priori* negative ontology of ‘disability’, although the exposition of this new symbolic formulation has been divergent and conflicting (Cooper, 1992; Eiesland, 1994; Habel, 1998).

Exegetical work has focused on foregrounding texts of ‘terror’, by way of techniques of deconstruction as well as reclaiming alternative celebratory scriptural images of ‘disability’ (Alison, 1997; Ashley, 1985; DeVries, 1994; Eiesland, 1994; Eiesland and Saliers, 1998; Fontaine, 1996; Grant, 1998; Habel, 1998 (1981); Harriman, 1996; Rose, 1997; Stiteler, 1994; Webb-Mitchell, 1994). Developments within feminist theological biblical hermeneutical studies suggest that earlier attempts at exegesis involving the foregrounding of ‘positive’ roles/views of people with ‘disabilities’ have their limitations. In discussing the sexing of texts, Cheryl Exum (1994 [1981]: 76) sums up this concern well: “one [cannot] … simply pluck positive images out of an admittedly andocentric text, separating literary characterizations from the andocentric interests they were created to serve”. The critique of a ‘surface reading’ of texts has led to exciting developments in biblical intertextuality, narratological studies and poststructuralism (Aichele and Bible and Culture Collective., 1995; Bal, 1988; Beal, 1992; Beal and Gunn, 1997; Brenner and van Dijk Hemmes, 1993; Carrette, 1999; Exum, 1996; Fewell, 1997; Kristeva, 1982; Kristeva, 1995). Such methodological approaches can be appropriated and transposed when examining theologically ‘disability’ from the prism of positive ontologies.

Epistemologies of Disability

The terrain of epistemologies of 'disability' broadly replicates the mappings and demarcations found in the disciplines of the social sciences. For the purposes of this summary, the typology adopted by Riddell should suffice in describing the range of approaches: essentialist perspectives[5], social constructionist[6], materialist[7], postmodernist[8] and 'disability' movement perspectives (rights discourses) (Slee, 1997: 409 - 410). Elsewhere I have reviewed and critically appraised the dominant 'alternative' model for conceptualising 'disability', euphemistically known as the 'social model of disability' (Campbell, 1998). In the last five years new epistemologies of 'disability'[9] have emerged broadly influenced by ***postmodernism*** (Corker, 1998; 1999a; 1999b; Fawcett, 1998; Grosz, 1996; Karpin, 1999; Radford, 1994; Skrtic, 1995; Thornton, 1997a), ***Foucaultian methods*** (Allan, 1996; Campbell, 1999; Casling, 1993; Hughes and Patterson, 1997; Law, 1994; Lunbeck, 1994; Mirzoeff, 1995; Munford and Sullivan, 1997; Shildrick, 1997; Sullivan and Munford, 1998; Wrigley, 1996), ***literary theory/cultural studies*** (Davis, 1995; Ingstad and Whyte, 1995; Meekosha, 1998; Mitchell and Snyder, 1997; Thomson, 1997a; Thomson, 1997b; Thomson, 1997c; Woodill, 1994) and ***geographical studies*** (Gleeson, 1995; 1999; Imrie, 1996). With the exception of works by John Law (1992), Stuart Blume (1994; 1997) and Ingunn Moser (2000) there are few disability epistemologies that explicitly utilize and extend Foucaultian notions into Latourian and

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[5] Inclusive of ontologies based on the biomedical, rehabilitation, therapeutic models. Some aspects of normalisation theory could be grouped under this category.

[6] Includes approaches using sociological approaches allied to labelling theory. Goffman's work would come under this purview.

[7] Primarily a U.K. sociology based 'social model' of disability utilising a Marxist/neo-Marxist analysis.

[8] A newly emerging currently divergent field – based on feminist body theories (e.g. Grosz, Butler), Foucaultian and Derridean methodologies and other practitioners of discourse analysis.

[9] These new epistemologies arose in response to the lack of treatment by the 'social model' of the corporeal and discursive aspects of 'disability' production.

Actor-Network Theory (ANT). Within this dissertation I have undertaken an analysis based on a fusion of Foucaultian methods and ANT.

Science Studies

The literature relevant to this thesis relates to the philosophy of technologies, biomedical ethics and methodological approaches such as Actor-Network Theory. I will restrict my summation to those works related to philosophical and ethics issues. Despite the high level of engagement that people with 'disabilities' have with a multitude of technologies few writings can be found that subject this engagement to critical analysis, beyond mere questions of functionality and economics (Pell et al., 1999; Roulstone, 1998)[10]. If we exempt the literature relating to euthanasia, writings interested in new biomedical technologies dominate (Franklin and Ragoné, 1998; Hughes, 1996; Lippman, 1993; Newell, 1999; Rowland, 1998; Silvers, 1998a; Spiewak and Wild Yard, 1999 (Dec); Wolbring, ND; Zimmerman, 1991). However, if we delve further and restrict our search of the literature to critiques of technological applications, in particular 'perfecting' technologies, the flow of works reduces to a trickle (Crouch, 1997; Henk and Have, 1995; Law, 1991; Law, 1999; Lysack, 1997; Parens, 1998a; Parens, 1998b; Tenner, 1996; Thornton, 1993; Wrigley, 1996).

The newly emergent field of science studies, particularly the work of John Law (1991; 1994; 1999; Law and Hassard, 1999) provides useful tools that can be deployed to critically interrogate the relationship of technologies to ontological understandings of 'disability' (Berg and Mol, 1998; Clarke and Fujimura, 1992a; Fujimura, 1992; Fujimura, 1996; Latour, 1993; Pickering, 1992; Pinch and Bijker, 1987; Star and

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[10] The 'will to technologise' has been particularly subject to challenge predominantly in the field of Deaf studies.

Griesmer, 1989). Of course this conversation needs to occur within a broader framework of an inquiry into the nature (or philosophy) of technologies in order to ensure that the thesis' research concerns do not lapse into a kind of technological essentialism. Consideration then is required of the philosophy of technology literature and the contestations therein relating to questions of technology's delimitation and purpose, actors, practices and effects (Coyne, 1999; Drengson, 1995; Feenberg, 1991; Feenberg and Hannay, 1995; Heidegger, 1977 (Orig.1953); Hickman, 1990; Hindmarsh et al., 1998; Kyle, 1993; Latour, 1993; Latour, 1996; Mackey and Mitcham, 1983; Pickering, 1992; Pitt, 1995; Zerzan and Carnes, 1991; Ziman, 1984; Zimmerman, 1990).

'Disability' Culturalism

By placing 'disability' at the *speaking centre* of our analysis, not just in terms of subject/object relations but also based on an *affirmative ontology*, a 'space' can be opened for the foregrounding of an eroticisation of 'disability', read as a positive unfolding of difference. Known euphemistically as *'disability' culturalism*, the literature concerning this ontological enclave is minimal and patchy. We can include some selective autobiographical/biographical material as a starting point. These works are often phenomenological in orientation (Bauby, 1997; Kuusisto, 1998; LaSpina, 1998; Mairs, 1987; Mairs, 1996; Sacks, 1984; Sacks, 1989; Williams, 1996). Another cluster of literature covers celebratory cultural representations in performance, visual arts, aesthetics, literature and media (Corker, 1999a; Duffy, 1997; Kuppers, 1999; VSA Arts Gallery, 1999). Only a handful of works tackle 'disability' as ontologically positive 'head on', either by way of discussion of the notion of 'disability culture'/pride[11] or the appropriation (and re-inscription) of traditionally pejorative language and imagery

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[11] A distance adult eduction course '*Celebrating Differences: Disability Culture'*, through the New York New School for Social Research is an example of such a project online.

(Australian Association of the Deaf, ND; Brannon, 1995; Campbell, 1999; Corker, 1999a; Linton, 1998; Martin, 1997; Wrigley, 1996). Many of the recent developments within '*disability culture'* mirror some of the pathways of the cultural politics of other liminal identity groups such as queer nation and black pride[12]. This dissertation makes a significant contribution to epistemological and ontological explorations of the ways 'disabilities' mediate 'desire' and incite a movement towards a transgressive aesthetic.

2.3 On Matters Relating to Terminology

'Ontology'

I am using ontology not in an essentialist sense, but rather to denote ways of Being that are inscribed, fabricated and shifting. In other words, this approach emphasizes the linkages between the formation of Being (self/subjectivity) and culture. (C.F. Butler, 1997b: 3-4).

'Disability'

Like many other themes within social theory, 'disability' as a signifier may be understood in terms of *catachresis*[13]. That is, there is no literal referent for this concept, for as my thesis will demonstrate, as soon as we discursively interrogate 'disability', its meaning loses its fixity, generality and ultimately collapses[14]. However, terminology as discourse is important and requires certain justifications, clarifications and elaborations. Throughout this thesis, I have intentionally used the neologisms 'disabled body', 'disabled subject', 'disabled citizen', 'referentially disabled', as a way of reframing ontological positions of 'disability'. From this perspective, I argue that the citation

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[12] The re-embracing of 'nasty words' like '*cripple*' *a lá* '*queer*' is a case in point.

[13] I am indebted to Gayatri Spivak who understands that the catachrestic process induces a continual discernment of meaning, providing a crisis of possibility not impossibility. (See Spivak, 1990a; 1993).

[14] Yet 'disability' endures as a category.

‘disability’ invokes a reading of corporeal differences, particularities, and unintelligibilities within the context of culturally delineated normative and ableist (benchmark) bodies.

In this way I argue that the signifier ‘disability’ is *always in need* of problematisation – it is a conceptual formation that is highly contextual, historical, contestable, multiple, changeable and fluid. Rather than maintaining a notion of ‘disability’ as a mere difference that may by default valorise the subject[15], thus instilling hierarchical and binary orderings, disabled subjectifications when situated within poststructuralist traditions explain the inscribing and marking of those bodies from the viewpoint of an analytics of power. So, like sexed and radicalised bodies, the once ‘inessential’ body of the ‘disabled’ subject within critical social theory can be inserted into the continuum of subordination and the art of government in neo-liberalism.

The ‘disabled body’, then refers to the figuring and representation of bodies deemed intolerable or ambiguous. Central to this signification is the materiality and embodiment of ‘disability’, in which incogitant assumptions concerning bodily difference bring an ontology of ‘disability’ into existence. One should not confuse the use of such terminology with ‘real’ people with disabilities and the subject positions in which our identities are constituted.

Another concern is the question of how we are to ‘name’ privileged subject positions in ways that foreground dimensions of agency without falling into developing power elite theories. In other words, how do we talk about ‘who’ is doing what to ‘whom’? In her discussion about the boundaries of normativity, Thomson (1997a: 8) introduces the notion of the ‘normate’ to designate “the social figure through which people can represent themselves as definitive human beings” and uses the ideas of Erving Goffman (1986; 1990) to profile the type of individuals fitting such a subject position. The effects of a ‘normate’ designation are problematic. Thomson’s theorization conflates a ‘severely ableist’ disposition with the privileged speaking position of what she calls ‘normates’. But this rendering is misleading, for not all severely ableist individuals can be deemed privileged ‘normates’. Ableism also infects the sexed, classed and radicalised bodies of those anchored on the periphery and are not merely restricted to those within the so-called ‘normate’ profile.

I argue that Margaret Thornton’s neologism of the ‘benchmark’ is more theoretically tenable because of its conceptual linking of subjectivity with power. According to Thornton (1996: 2), a ‘benchmark’ is used to delineate a hegemonic viewpoint that coincides with the interests of white, middle class, heterosexual, ableist men. Such hegemonic views project a particular way of seeing the world and certain figurations of the body as ‘natural’, as species typical functioning.

‘Strategic Essentialism’

In keeping with the poststructuralist project of deconstructing the citation ‘disability’ this dissertation argues that there is no such entity/being as a ‘disabled person’, in contradistinction from that other referential category, a ‘person with an impairment’. The visceral and somatic occurrence of ‘impairment’ is not in doubt here. Rather, this doctorate is an attempt at developing greater conceptual clarity regarding the relationship between the concepts of ‘impairment’ and ‘disability’. Whilst impairments have many

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[15] So much of the traditional charity model is based on such assumptions. I am reminded of the ‘brave’ child or adult who transcends personal tragedy or the Para-Olympian designed as a ‘super-crip’, who is still ‘disabled’ yet different.

sources of causation (organic, social-environmental, political), not all impairments transmogrify into that signifier known as ‘disability’. Likewise, not all disabled subjects experience ‘impairment’ in the usual way that term is understood.

As I will discuss in Chapter Five, the government of liberalism demands ontological designation of its subjects, what I call an ‘enumerative passport’. In other words, for individuals with particular needs related to impairment to access legal protections, medical treatment and indeed ‘social roles’ some kind of designation(s) is/are required. However there is always a tension between using a designation such as ‘disabled person’ asserted *instrumentally* in order to advance liberal rights-based access to social goods or resources and the *actual* incorporation/interpellation of that ‘identity’ via technologies of self within the being-ness of the individual concerned.

As Thomson (1997a: 140) points out “there is always a gap between the subjective experience and the cultural identity of having a disability”. Vigilance is required to guard against the danger of conflating the discursively produced ‘subject’ with an embodied ‘individual’. Paul Smith (1988: 34) reminds us: “there is no such thing as a ‘subject’ before the accession to language … As soon as it is proposed that the ‘subject’ is the effect of a given signifying practice, it must then be claimed that the interpellation is various …[and not necessarily reductionist]”. We say then that the workings of liberalism mean that in the day-to-day reality of persons with impairments that some kind of ‘strategic essentialism’ is adopted in order to become visible and agents of resistance (Spivak, 1990b).

'Ableism'

I define 'ableism' as: a network of beliefs, processes, and practices that produce a particular kind of self and body (the corporeal standard) which is projected as the perfect, as the species typical and, therefore, as essential and fully human. It is important to mention here that there is no intention on my part to develop a 'grand theory of ableism' for I argue that there is no one single source or agent of subordination. Rather, the phenomena of ableism whilst engaging key sites of power formations such as law and medicine, usually involves the fluid convergence of particular networks, actants and environments at specific locations and points in time in order to produce and defend various discursive formations and subjectifications of 'disability'.

2.4 Knowledge Standpoint of the Researcher and the Ethics of Research

As a researcher I am both the subject and object of my research and therefore it is necessary to be upfront about my own speaking position and representational politics. My position as a researcher with a 'disability' demands that this thesis be undertaken as a contribution to the oppositional project wherein subjugated knowledges are insurrected. Subjugated knowledges are:

> a whole set of knowledges that have been disqualified as inadequate to their task or insufficiently elaborated … knowledges located low down on the hierarchy, beneath the required level of cognition or scientificity. (Foucault, 1980b: 82).

Traditionally, research on 'disability' has been seen by many people with 'disabilities' as oppressive and alienating. The material relations of research production has meant that 'able-bodied' researchers, writing from a position of ableist normativity, have made people with 'disabilities' the object of their gaze. In effect, research has come to represent a violation of our experience, bearing little relationship to our daily struggles (Oliver, 1992: 105). The asymmetrical relations of research production and the positionality of the researcher have only recently been recognised as an important concern. Yet in other areas of the social sciences the implications of positioned-research have been acknowledged for some time. Stuart Hall articulates some of the issues concerned when he declares

> … we all write and speak from a particular place and time, from a history and a culture which is specific. What we say is always 'in context', positioned … representation is possible only because enunciation is always produced within the codes which have a history, a position within the discursive formations of a particular space and time (Hall, 1990: 222).

The voice of people with 'disabilities' has been absent or marginalised within 'disability' research. My task then as a researcher with a 'disability', is to open up 'spaces' for the absent and silent subject and repressed phenomenological experiences. My own positionality does not however, automatically render this inquiry 'authentic'. Several poststructuralist writers argue that no experience is pre-theoretical and therefore it is always in need of ongoing deconstruction and interpretation (Alcoff and Gray, 1993; Shakespeare, 1996; Weedon, 1997). Whilst subjugated knowledges can inform social theory, Joan Scott reminds us of the problematics of an experience-based paradigm:

> [it is] not individuals who have experience, but subjects who are constituted through experience. Experience in this definition then becomes not the origin of our explanation, not the authoritative (because seen or felt) evidence that grounds what is known, but rather that which we seek to explain, that about which knowledge is produced. (Scott, 1992: 26)

The combined role of disability activist and researcher can create its own tensions. For instance, the dual natures of accountability to one's own constituency and the academy (Shakespeare, 1996: 117). The act of asserting a 'disabled' subject position presents a conundrum, for the very specificity of such a positionality shores up the 'disabled'/'able' binarism. Nonetheless, it is critical that people with 'disabilities' "come out of the closet" and engage in research production. As Deborah Marks (1996) points out, when 'able-bodied' people run courses or conduct research, there is always a risk that colonization of the 'Other' will occur. Reflecting upon her position, Marks states:

> My fear is that I will be positioned in relation to disability in the way that men have been positioned in relation to feminism. Despite adopting the language of poststructuralism, the course [or research] risks slipping into an examination of 'Others'. (Marks, 1996: 70)

The challenge of resisting engagement in acts of colonisation through the development of scholarship that *speaks otherwise* about disablement is pursued in Chapter Three.

Chapter 3 - Historical and Theological Incursions Concerning Anomalous Bodies

The purpose of this chapter is to ground the study of discursive formations of disability and ableism within a broader historical and theological context of responding to ambiguous and anomalous bodies. Shifts and contestations within theology and history over the ways disability and notions of ableness are known can contribute to an increased understanding of the government of disability in the contemporary moment including possibilities for the disruption of ableist impulses. The first section of the chapter studies the production of histories of disablement. The second focal topic engages the deconstruction of Judeo-Christian formulations of ableism and disability.

3.1 Doing a History of Disability? – Problematisations

In tandem with the rise and development of disability rights movements in the Western world and corresponding increase in identity-based ‘pride,’ so-called ‘histories’ of disability have emerged. My own BLS Honours thesis written in 1998 contained a chapter on the history of disability. In fact during the mid to late 1980’s a proliferation of histories from ancient to contemporary times were written (Baynton, 1996; Bolderson, 1991; Cocks and Edith Cowan University. Centre for Disability Research and Development., 1996; Cocks and Stehlik, 1996; Deutsch and Nussbaum, 1999; Gleeson and Australian National University. Urban Research Program., 1998; Kent and Quinlan, 1996; Klages, 1999; Longmore and Umansky, 2001; Lunbeck, 1994; Martindale and Martindale, 1985; Safford and Safford, 1995; Solinger, 1998; West and Milbank Memorial Fund., 1991; Wright and Digby, 1996). One of the earliest attempts at a ‘universalised’ Western history, aptly titled *‘Corps Infirms et Sociâetâes’* was published by Henri Stiker (1982) in French although the English version took another eighteen years to see the light of day (1999)[16]. The interest in the history of disability in many ways echoes similar scholarly developments in the maturation of identity politics by other marginalized groups such as women and people of colour. The erasure or objectification of liminal or subaltern populations from mainstream historical projects has provoked variously what I would call ‘reclamation movements’. These movements aim is to find and ‘recover’ the disabled person, woman or ‘black’ person formerly hidden in history and place them at the speaking centre of historical narratives. This section of Chapter Three explores some of the problems and challenges in undertaking histories of disability within an ontological and historical prism. I first discuss some of the merits, limitations and problematical aspects of writing the disabled subject back into history. Then I present a genealogical map or schema if you like, of ‘moments’ of disability formation or subjectifications in western historical discourses.

3.1.1 Writing ‘In’ Disability – Problematisations

> The purpose of history, guided by genealogy, is not to disclose the roots of our identity, but to commit itself to its dissipation. It does not define our unique threshold of emergence, the homeland to which metaphysicians promise as return; it seeks to make visible all those discontinuities that cross us. (Foucault, 1977b: 162)

> It is through memory that we frame our sense of individual, group, and national identities, give meaning to our life history, and understand our social past. Our individual memories, however, are constantly supplemented, altered and mediated by the circulation of representations and articulations of the past that constitutes collective memory. (Darian-Smith, 1994: 137)

What may seem for some a straightforward task of recovering stories of people, incidences and events in order to write a history of disability, is in fact a highly complex

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[16] I might add here that the burgeoning of histories since the late 1990’s has been produced by American publishing houses. The consequences of this are that in Australian universities it is easier to find out about American disability history rather than our own Australian story.

and contentious task, fraught with dangers, disclaimers and requires continual narratological clarifications. I would argue that the majority of 'histories of disability' have been and to a lesser extent continue to be, written from the knowledge standpoint of ableism, in otherwords 'disability' as Otherness. In this way we can speak of majority histories as doing history 'from above', with the 'voice'(s) of the ableist narrator mediating what can be known of the disabled subject. I would like to put the case in stronger terms – narratives logging *disability are in the main stories* of the colonisation of aberrancy written by the colonisers[17]. In the twentieth century context, histories of disability services and philanthropy have been misrepresented as histories of disabilities as if people with disabilities have been and are totally and solely bonded to the service paradigm.

And what of so-called histories from 'below'? Is the task of the emancipatory historian or social science practitioner to seek out stories by 'the disabled' in an attempt to present a more authentic account of things?[18] There is a danger is pursuing this line as well. For as long as the interpretative lens of historical discourses remains wedded to an understanding of disability as inherently negative or ontologically intolerable, it does not really matter if the narrator identifies as disabled. Ableist formations of disability continue to be uncritically reinscribed into the narrative. The authorisation of subject formations of disability always occurs within the context of dominant power configurations. Even seemingly positive imagery is circumvented by the funnelling of acts of resistance into narrow positionalities of 'hero', 'survivor' and 'brave heart'. This is not to suggest that histories from 'below' are not useful, rather we need to be vigilant

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[17] Those considered 'able-bodied', having a 'benchmark' body. This group usually holds to the view that disability represents a blot on humanity.

[18] In the late 1990's is has become popular to use first person studies, i.e. biographies of disability within faculties of literary and film studies. One get a sense that the telling of one's own stories somehow automatically renders the 'voice' and the 'facts' more authentic, uncontaminated and truthful.

about identifying the discursive formations from which certain narratives arise. Indeed, for such a frequently studied group, it is difficult to find the 'voices' and subjugated knowledges of the 'disabled' subject. We have, more often than not, been erased[19]. The dominant view of a history of people with 'disabilities' is as a 'history of catastrophe'[20], narrated within universal themes of degradation[21] essentially being teleological in orientation. Acknowledging this paucity a number of recent works have emerged that seeks to uncover historical characters and positive role models of disability[22].

There can however be limitations to such an approach. Commenting on a similar trend within feminist biblical studies theologian Cheryl Exum (1994, 76) remarks: "… one [cannot] … simply pluck positive images out of an admittedly andocentric text, separating literary characterizations from the androcentric interests they were created to serve". This holds true when dealing with the figuration of the disabled subject. For even 'positive' images are the products of various networks of association coming together within the context of fluid ableist discursive formations. There are instances at certain periods and locations in Western history where it is just might not be possible to find what we contemporaries might consider positive representations of the disabled subject simply due to the overwhelming hostility towards aberrancy. Instead, an emancipatory hermeneutics must wrestle with questions related to the control of symbol production and

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[19] Elizabeth Grosz (1996: 62) highlights a classic example of this problem. In her study of conjoined twins she notes that she could only find two written accounts of such a bodily experience from the perspective of those with living as conjoined subject(s).

[20] I have borrowed this expression from quite a different context, namely Judaic studies. David Roskies (1984) documents the motif of catastrophe being an enduring reality in the lives of Jewish people in 'good' and bad' times. Without suggesting any relativism here, Roskies sentiments resonated with my understanding of the recorded lives of disabled people in Western history.

[21] See Errol Cocks' *History of Services* (1996). Whilst containing his work to the history of the "West", Cocks goes on to deduce universal themes in the treatment of people with disabilities. Similarly, Margaret Winzer's title of her piece is telling: *Disability and Society Before the Eighteenth Century Dread and Despair*, (1997). Such grand narratives are not only incorrect, but misleading, erasing voices of resistance and other ways of inscribing 'disability'.

[22] One interesting work for children profiles seven dozen people throughout history with various physical or intellectual disabilities an attempt to redress this imbalance (Kent and Quinlan, 1996).

"… of necessity, read against the grain. It must step outside the text's ideology and consider what andocentric agenda these narratives promote" (Exum, 1994, 79). The critical questions when studying historical documentation become:

1. What ableist interests does this positive presentation of disability/aberrancy promote?
2. What is it about their characterisation that people considered as 'disabled' during that period might wish to identify?
3. What is it about their characterisation, which makes the dominant symbol makers want to manipulate them into symbolic capital?

As reflective practitioners, we need to continually ask ourselves - whose history is being written? One important concern that I have not addressed until now relates to what could be rather crudely referred to as the 'object of study'. For as the focal concern of this dissertation will conclude, the signifier disability is in many ways discontinuous for the domain of 'disabled bodies' is 'leaky'[23], elusive defying intelligibility. It becomes methodologically flawed and vacuous to insist on a developmental, trans-historical delineation of the disabled subject. Is the 'object of study' – disability as a construct, or a history of aberrant bodies – known during the period under examination as 'disabled' or persons considered 'disabled' using contemporary formulations?

Post Enlightenment[24] narrations of history for instance, are based on the flawed presupposition that history is essentially developmental and progressive. A history of 'disability' contained within Post - Enlightenment discourses re-presents and constitutes that 'history' through a prism of unity that in effect buffers up a hegemonic organic conceptualisation of 'disability'. As Canguilhem (1978: 72) reminds us, such a 'history'

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[23] The notion of 'leaky bodies'"I believe captures this sense of inscription throughout history. The boundaries of bodies are shifting, unstable and multiple. I am indebted to Margaret Shildrick who developed this concept *in Leaky Bodies and Boundaries: Feminism, Postmodernism and (Bio)ethics*. (1997). In any case, Foucault's genealogical method is concerned with earthing absences and discontinuities rather than the search for origins. (Foucault, 1984c).

[24] For example, Kant's 1784 essay: *Idea for a Universal History with Cosmopolitan Purpose.* A good outline of this problem is contained in *On the Possibility of Writing a Universal History* (Fukuyama, 1995).

presents an "… illusion of retroactivity according to which [disability] was already given - although unnoticed - in nature." Instead of seeing 'disability' as a pre-given, it may be more useful to speak of bodies that transgress, those that represent corporeal ambiguity. 'History' read from the perspective of problematisation, that is the way 'truth' and 'falsehood' about corporeality is produced, reveals a myriad of discontinuities and overlaps.

Renowned historian Arthur Marwick in response to the question 'what is the use of history?' remarked "imagination boggles, because it is only through knowledge of its history that a society can have knowledge of itself. As a man [sic] without memory and self-knowledge is a man adrift, so a society without memory … and self-knowledge would be a society adrift" (Marwick, 1970, 13). Marwick's assertion raises other pertinent issues. I have already briefly alluded to the fact that dominant presentations of disability histories proceed along the lines of catastrophe. To be sure historical records bear testimony to many painful and tragic events in the lives of peoples deemed 'disabled'. And whilst acts of subordination and hostility towards people with disabilities need to be uncovered and recognised – there is also a danger that the citation and recitation of 'stories of tragedy' reinforce the notion of disabled people as passive victims[25]. To counteract this possibility what is needed at the same time are histories of resistance, histories of the 'uppity crip' who usurps attempts at repression. Such a reorientation of histories of disability in this way are important to contemporary realities where (collective) 'memory' can act as a strategic tool for social change including the use of historical characters as mentors for the present[26].

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[25] This concern has arisen in the writing of holocaust histories. C.f. Roskies (1984). See also Chakrabarty (1998) on the politics of 'minority histories'.

[26] Elizabeth Bredberg (1999) is another scholar with a keen interest in the potential and challenges of writing disability history.

3.1.2 Genealogies of Disability in Western Thought

> Among abusive expressions relating to the body, habits, learning, occupation, or nationalities, that of calling a deformed man by his right name, such as "the blind", "the lame," etc., shall be punished with a fine of 3 panas … If the blind, the lame, etc., are insulted with such ironical expressions as "a man of beautiful eyes," "a man of beautiful teeth,", etc., the fine shall be 12 panas. Likewise when a person is taunted for leprosy, lunacy, impotency and the like. Abusive expressions in general, no matter whether true, false, or reserve with reference to the abused, shall be punished with fines ranging above 12 panas, in the case of persons of equal rank. (Kautilya, 1960)

> We are the failures of modern medicine, the "cases" whose births could not be foreseen and for whom there are no known cures. We testify against the omnipotence of medical science and represent a frightening truth. We are feared and hated and viewed as hopeless patients in all of our daily environments. (Connors, 1985)

A striking feature of accounts of 'disability' in the literature is the unevenness in the way 'disability' is inscribed on bodies considered different. It is possible however to point to key genealogical themes, three broad formations of inquiry into the disability question, namely "**What is it?**", "**Who are you?**" and the twenty-first century preoccupation of "**Do you wish to be?**" within the Western philosophical tradition. This section maps some of the characteristics of each of these genealogies.

The trajectory of 'disability' within the ancient world is characterised by a search for the limits of human subjectivity and the nature of social roles within the polis, summed up by the conundrum: "What is it?" (Figure 1). Both Plato[27] and later Aristotle in *Politics*, advocate the destruction of newborns with deformities: "There should certainly be a law to prevent the rearing of deformed children" (Aristotle, 1998b: Bk 7, Ch 16: 1335b19). Three hundred and fifty years later, Philo of Alexandria (Philo Judaeus) in *De Specialibus Legibus III* argued vigorously against the widespread practice of 'infanticidal' killings, pleading compassion (Philo, 1993: XX: para.113-119).

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[27] *The Republic* (370 BC), Book 5, para. 460.

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Figure: 1 “What Is It?’

Conjoined twin ‘types’ as depicted by French Renaissance surgeon Ambroise Pare.

Source: http://zygote.swarthmore.edu/cleave4b.html

Yet, the figuring of 'deformity' should not be understood in the modern sense, for the fluidity of its meaning in *Generation of Animals* is extended by Aristotle to include all women:

> … just as the young of mutilated parents are sometimes born mutilated and sometimes not, so also the young born a female are sometimes female and sometimes male instead. For the female is, as it were, a mutilated male … (Aristotle, 1998a, 2.3, 737a26-27)[28]

The monstrosity of the female sexed body was considered by Aristotle (and no doubt other intellectuals of his time) as a natural *anomalia*[29] not as an aberration[30]. Rather, the disabled body was inscribed as a recalcitrance of nature, "necessary for the very perpetuation of the species" (Matthews, 1986: 23). This very marking of bodies contributed to the distinction within Western philosophy between 'essential' and 'inessential' corporeality[31].

However not all representations of the 'disabled' body were infused with inessentiality. In the case of adults [males] deliberative agency was beyond question. Plato in *Laws* is emphatic: a man who is deformed[32] in body is "perfectly comely, in respect of their eminent uprightness of character, his language would never be thought of out of place" (Plato, 1934: Bk IX, 247). Similarly, historian Martha Edwards (1997: 37 - 38) draws attention to a speech by Lysias *'On the Refusal of a Pension'* in which physical disability did not in itself class an individual as *ordunatous* (unable). As Edwards points out the

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[28] An elaboration of the theme of this passage can be found in G. Matthews (1986) *Gender and Essence in Aristotle*.

[29] Gk: meaning unevenness, asperity, e.g. anomaly.

[30] It was not until 1909 that deformities were considered as "inborn errors of metabolism". (C.f. Canguilhem, 1978: 171).

[31] The intersection between the sexed and disabled body, resulting in the denial of women's deliberative capacity resurfaces in the nineteenth century through the figuring of sexed differences as disability in law (Silvers, 1998b: 92 - 93).

[32] An alternative rendering is 'physically ugly'.

very constituting of 'disability' was not related to aetiology, rather to "the community's understanding of people's roles - what they were supposed to do" (1997, 35). It is not surprising then, to read that Marcus Sergius, a Roman general during the Second Punic War (218 BC) returned to battle as a double amputee, fitted with iron hands (Disability Social History Project, 1998).

The conundrum "What is It?" is best represented in the figure of the 'monster'[33], who as Foucault (1997a: 51) puts it "combines the impossible and the forbidden" and disturbs the "juridical regularities". During the 14th and 15th centuries in Europe, the figuring of the 'monster' or 'freak' was unstable and multiple. This period can be characterised as a time of ambivalence and uncertainty about the liminality of human corporeality. As such the 'monster' conjures up mystery, sublime, prodigy, awe as well as repulsion. Monstrosity was ennobled in images (albeit in a later period) imputed to Julie Pastrana, known as the ugliest woman in the world (Figure 2)[34].

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[33] The *Webster's New Twentieth Century Dictionary* indicates that 'monster' derives from the Latin '*monstrum'* meaning "any occurrence out of the ordinary course of nature, supposed to indicate the will of the gods, a marvel a monster, from *'monere'*, to admonish to warn" (1165).

[34] An exploration of the theme of monstrosity is beyond the parameters of this chapter. However I refer the reader to a number of significant works: Jeffery Cohen (1996) provides an interesting analysis of the relationship of concepts of monstrosity and culture. Equally feminist scholar Rosi Braidotti'a article 'Mothers, Monsters, and machines' (1997) argues for the linkage between the topos of women as a sign of abnormality and the formation of concepts of monstrosity.

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Figure 2: ‘The Non-Descript Monstrosity’

Julia Pastrana reinscribed as the ugliest woman in the world.

Source: http://bullseyedesigns.com/sideshow/people/hairy/julia_pastrana.htm

In regard to what was termed 'leprosy', the Church instigated "the office at the seclusion of lepers" who were ritually pronounced 'dead' (Turner, 1987: 63), whilst the 'mad' (*la folie*) embarked onto ships, *Narrenschift*, cast out, in search of reason (Foucault, 1967). Such expulsion culminated in extermination with the introduction of the so-called detection manual, *Malleus Maleficarum* (The Hammer of Witches) in 1487. Thousands of corporeally abject individuals were rendered noxious, unknowable, then tortured and killed (Winzer, 1997).

At the dawn of the Enlightenment, philosopher John Locke in *An Essay Concerning Human Understanding* (1689)[35] was trying to grapple with the unspeakability and corporeal ambiguity of 'changelings'[36]. Were they human, beast or something in between? :

> Shall a defect in the Body make a Monster; a defect in the Mind, (the far more Noble, and, in the common phrase, the far more Essential Part) not? Shall the want of a Nose, or a Neck, make a Monster, and put such Issue out of the rank of Men; the want of Reason and Understanding, not? (Locke, 1979: Bk 4, Ch 4, 571-572).

Earlier in the same work, Locke examined the constituting of subjects deemed 'idiots' and 'mad Men'[37] and concluded that an 'idiot' is deprived of 'reason'; whereas a 'mad Man' has not lost the faculty of reasoning, rather they "put wrong ideas together, and so make wrong Propositions, but argue and reason right from them" (161).

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[35] The relevant sections are Book 4, Chapter 4 "*Of the Reality of Our Knowledge*", S.S. 14 - 16; and Book 2, Chapter 11 "*Of Discerning etc*", S.S. 12 - 13.

[36] 'Hybridity Theory' posited that such entities were the offspring of bestial activity, therefore called 'monsters'. Martin Luther believed such beings to be "a mass of flesh with no soul, because they were possessed by the devil" (Weir, 1984: 28).

[37] It is interesting that Locke separates the words 'mad Men'. Does this suggest that his usage in the adjectival form, means that the subject position 'madman' (noun) is not yet a fixed entity?

Whilst the inquiry into "What is It?" persisted[38], within various Enlightenment discourses there emerged a new emphasis, particularly in the nineteenth century, encapsulated in the question "Who are You?" (Foucault, 1978). A new form of 'truth – production', under the gaze of the physician located 'deficiency' in the individual. The Enlightenment ushered in a new spirit of optimism where rationality and the autonomy of the knowing subject gained ascendancy, "linking will, authority and the use of reason" (Foucault, 1997b: 411). Such sentiments held out promises of the perfectibility of the body. Reconstituted as machine[39], the body was marked and measured in terms of efficiency, classification, ranking and value (Bickenbach, 1993, 62; Foucault, 1977a, 170 - 194; Radford, 1994, 9; Thomson, 1997c, 11). Corporeal ambiguity came to represent anomaly and degeneracy, that which breached a new ordering of civilization and the new fixity of personhood. 'Disability' was transmogrified into the Enlightenment's 'recidivist element'[40] - an ontology of failure[41], hopelessness requiring surveillance, repair and management (Figure 3).

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[38] The era of the freak show was 1840 - 1940. Weir (1984: 21) reports "as late as the 1939 World's Fair in New York, there were "incubator-baby sideshows" displaying premature and deformed infants for the curious public who paid to see …".

[39] Fritz Lang's 1927 film "*The Metropolis*" provides an excellent portrayal of this shift towards viewing the body as an extension of the machine. Paul Henri Thriy, Baron d'Holbach (1723-1789) describes the body as a machine (Solomon, 1988: 10).

[40] John Radford (1994) in "*Intellectual Disability and the Heritage of Modernity"* expands on this theme and relates the quest for rationality with broader themes such as modernity's relationship to the Holocaust.

[41] Physicians such as Philleppe Pinel (1745 - 1826) influenced by the philosophical works of Locke and Condillac, adopted a moral treatment based on psychological factors rather than biology. See Porter (1997) Chapter 16.

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Figure 3: 'Medical Repairs for the Deficient Body?'

Source: (Markova and Farr, 1995: 16)

Whilst work on the body became a predominant response to the question “who are you?” increasingly the ‘psych’ professions played an important role in exploring the interior life of the ‘disabled patient’ in order to assist the assimilation of their soul into a normate state of being (Rose, 1991; Rose, 1996). The incitation towards the interiorisation of disability can be seen not only in the therapy room of the specialist but also filtered into the medium of popular confessional media forums. Not unlike the freak shows of old – disabled (weird) people are prompted to ‘tell’ the ‘truth of living with a disability’. The desire to know, to ask who are you? becomes in effect a source of pleasure. As Foucault puts it “[…we have] the fascination of seeing it and telling it, of captivating and capturing others by it, of confiding it in secret, of luring it out in the open” (1976, 71). So both within the popular and the specialist realms confessional discourses have become commonplace.

A recent shift in genealogical themes of disability can be captured in the question “Do you wish to be?” or maybe “can I be that which is different from what I am – post human or transhuman?” Like the other two themes there are many layers of meaning to this question which relates to the validity of ‘life’ / ‘existence’ with an impairment either before or after birth (as an adult). I have located this theme in the early twenty first century so as to differentiate it from that Enlightenment concern of cure, restoration and elimination. With the advent of prenatal diagnostic technologies, euthanasia movements and the increasing use of tort liability litigation (in the form of wrongful life/birth claims) the contemporary moment beckons this new problematic at both the individual and social levels. Hughes (2000) identifies the particular nuances of this shift in charting the rise of the new molecular medicine (originally considered a suspect branch of research) which has created new kind of aestheticization of lifestyle and in turn an *aesthetic invalidation* of people with disabilities.

This critical moment is given expression in the visual and imaginings of extropic art in the iconic visualisation of the new *übermensch*: Primo 3m+ (see Figures 16a and 16b), whose bodily 'design' is reputed by its makers to be "more powerful, better suspended and more flexible – its body offering extended performance and modern style" (Vita-More, 2002). We may ask that in the event of Primo 3m+ coming to birth, are disabled bodies cast further into the wilderness of matter out of place? It is difficult to comment more about the patterns and disjunctures related to this genealogical theme as this analytical writing is being produced (is a product of) and is immersed in the playing out of that formation "Do you wish to be?" Keeping these limitations in mind, Chapters Five and Six of this dissertation provide greater consideration of aspects of this 'new' turn particularly in relation to new technologies and their production(s) of new ascriptions of disability and normalcy.

In this section I have attempted to engage critically with some of the difficulties and problematisations in writing histories of disability and the ways those histories are predicated on the basis of pre-existing ontological formulations. In an attempt to reconnect and make more explicit the link between histories (the telling of stories) and ontological framings of disability I have sketched out (albeit briefly) three major genealogical formations of inquiry into the reading of disability in western thought. In the next section I examine another body of thought that has shaped ways of knowing disability – this time in the realm of the spiritual, specifically Judeo-Christian renderings of disability.

3.2 Deconstruction: Judeo-Christian Renderings of ‘Disability’

3.2.1 Abusive Theologies of Disability

> To speak of disability, handicaps and illness is to speak of the weakness of our human condition. No-one born into this world is free from human frailty – whether it be physical, emotional or spiritual. Each of us must personally come to terms with this frailty. (Pope John Paul II, cited in Australian Catholic Bishops' Committee for the Family and for Life, 1997).

Orthodox malestream understandings of Christian theology have positioned women's bodies[42] and others deemed corporeally ambiguous as representing the sinful, irredeemable, mortal side of human ontology, perpetually caught up in a vortex of immanence rarely capable of sanctified transcendence and sanctification. Whether we are ‘religious’ or ‘secular’ in outlook, abusive theologies of ‘disability’ influence our beliefs about creation, perfection, holiness and wholeness, theodicy and suffering. ‘Disability’ in particular has been equated with notions of sin and irrationality, or alternatively it has performed as symbol of the ‘suffering servant’, a constant reminder of the imperfectability of this world, wherein the subject is valorised as a patient patient, docile and passive. In this sense I agree with feminist theologian Nancy Eiesland (1994: 69) when she states " … ‘disability’ has never been religiously neutral, [it is] … shot through with theological significance". Indeed within mainstream Western theology, both

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[42] I have already made reference in the previous history section to Aristotle's belief of woman as a mutilated male. This theme is extended in the work of Margaret Miles (1989).

traditional and modern, ‘‘disability’’ has embodied a moral discourse that oscillates around a number of diffuse and seemingly contradictory themes[43].

- ‘disability’ as an undesirable, negativised state of ontology acting as a sign of punishment or evil incarnation;
- the disabled body as a ‘conduit’ body/ ‘damaged’ object (a vehicle or vessel of theological showing) - marked out either as the object of divine action or as a challenge to divine ‘perfection’; and
- ‘disability’ as a form of impurity, as ‘matter out of place’[44] creates ambiguities about competence, exemptions and inclusions within religious practice (Fontaine, 1996: 289 - 295; Rose, 1997: 397).

It is not surprising then, that Christian theology has been perceived in philosophical and feminist works related to embodiment, as the font of flesh denying misoanomalia that renders Othered bodied to the netherworld. This theological belief system sets in train the foundations and justifications of persecution, marginality and oppression of people with ‘disabilities’ (DeVries, 1994: 127; Rose, 1997: 396)[45]. At the extreme, there is an argument that Christian theology is dependant upon the various modes of ‘ableism’, in

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[43] These themes are mirrored within general historical roles of people with disabilities in the West (Cocks and Stehlik, 1996):

- Non human (animalistic)
- A menace
- An object of pity
- An object of ridicule
- A burden of charity
- An unspeakable object of dread
- A child (in perpetuity)
- Holy Innocent
- A diseased organism; and
- As dead or dying.

[44] Anthropologist Mary Douglas (1984) coined this phrase.

[45] In the American context mainly of the mainstream churches lobbied to be exempt from coverage under the *Americans with Disabilities Act* 1990.

the form of dualisms such as whole/broken, sinner/ saved, perfection/chaos to promote its redemptive ethos. I argue that such a view is simplistic, narrow and selective[46].

The next sub - section will navigate through and visit some sites of what theologian Nancy Lane terms 'victim theologies' (Lane, 1992b) and then moves onto an analysis of attempts by some theologians to deconstruct and reclaim more 'helpful' readings of disability within Scripture and the broader theological canon. The final sub –section of this chapter is a case study – examining the biblical figure of Moses (the father of Israel). In this sub-section I argue that the re-telling of the Moses saga with 'disability' at the speaking centre can provide a different understanding of leadership and mentoring.

However, before moving forward I would like to comment on the justification for including theological content in this thesis. There are two compelling reasons. Firstly, Christianity and Western culture have irrevocably influenced (and continue to impact upon) contemporary literature of disability (Miles, 1995; Mackelprang, 1996; McKennis, 1999; Morad, Nasri & Merrick, 2001; Hedayat and Pirzadeh, 2001). Secondly and by no means insignificantly, the *raison d'etre* for provision of services to people with disabilities relates directly to and emerges from the benevolent mandate of religious organisations. For example, *UnitingCare Australia* (the National Body for Community Services in the Uniting Church) and *Catholic Welfare Australia* (a commission of the Australian Catholic Bishops' Conference) are the two largest providers of human services including disability services, throughout Queensland. Both organisations construct, manage and deliver services within the authority and auspices of the theological foundations of their respective churches.

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[46] Cusack (1997) also rejects this dominant approach in her study of medieval Europe arguing that many people viewed disabled people as having a privileged status as recipients of God's grace.

3.2.2 Reading the Holy Books in a Different Key

The subject of bodies has always played a central role in both the Judaic and Christian traditions. For Christians in particular, the moment of salvation is bodily. As Rogers (1999: 240) puts it: " [for] Christians, bodies are no more or less than a means by which God catches hold of and sanctifies human beings. In short, bodies are made to be saved". The Judeo-Christian tradition contains ambivalent (and mainly negative) approaches to people whose bodies rupture the assumed order of things. Such ambivalence it is argued is somewhat unremarkable, as the ancient world as a whole, the Hellenist and Roman, were "… paranoid about pollution … purifications and cleansings" (Martin 1995: 139). Both the Hebrew Bible (referred to by Christians as the Old Testament)[47] and the Christian New Testament include texts of terror[48] and texts of transformation[49] with respect to 'disability'. For instance, one of the more 'in your face' prescriptive exclusions can be found in Leviticus 21: 17 - 19:

> …No one of your offspring through their generations who has a blemish may approach to offer the food of his God. For no one who has a blemish shall draw near, one who is blind or lame, or one who has a mutilated face or a limb too long, or who has a broken foot or a broken hand, or a hunchback, or a dwarf, or a man with a blemish in his eyes or an itching disease or scabs or crushed testicles …

Yet further on in the same passage the writer emphasises that this exclusion is not total: "… He may eat the food of his God, of the most holy as well as of the holy…" (Lev 21: 22). What are we to make of this exclusionary differentiation? Whilst still unsatisfactory, because the norm of ableism is left intact, we can stake a claim for inclusion into the

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[47] Unless otherwise noted, Scripture references are taken from the *New Revised Standard Version* (NRSV) of the Bible.

[48] Lev 21: 17 - 24; Deut 27: 27, 28: 29; Ex 20: 5; Num 5: 1 - 2; Isa 59: 10; Mt 9: 2, 15: 14; Jn 9: 1-3; Lk 5: 18 - 26, 6: 39; Heb 9: 14;2; Cor 12: 7 - 10; Acts 3: 1 - 10.

[49] Lev 19: 14; Deut 27: 18; Is 43: 1 - 10; Ex 4: 10 - 16;

community of Israel - at least on the terms set by the priestly [ableist patriarchal] cult (Webb-Mitchell, 1994: 55).

A striking feature of accounts of ‘disability’ in both biblical and theological literature is the unevenness in the way ‘disability’ is inscribed into the body of God, church and believing communities. Rather than acting as an apologist for the tradition, using feminist methodologies we can seek to recover subjugated/hidden knowledges about ‘disability’ in the Judeo-Christian tradition. A critical reading of scripture may enable us to reclaim texts previously considered problematic or irrelevant. We can be adventurous and tease out new and multiple textual interpretations and reconstruct a new biblical vision of ‘disability’. As biblical scholars David Clines and Cheryl Exum (1993: 13) argue “ … every new way of looking at our familiar texts is to be eagerly seized upon and tested for all its worth … [There are] no automatically inappropriate angles of vision upon our texts”. With that perspective in mind, let’s briefly look at Deuteronomy 27: 18:

> ‘Cursed be anyone who misleads a blind person on the road.’ All the people shall say , ‘Amen’.

Following the methodologies of Elaine Wainwright (1995: 135) and Mieke Bal (1988: 2) it is possible to read this verse in a different key, or ‘against the grain’ and when such a strategy re-assigns the character of the person with a disability from the margins of the text to a more central positioning, the significance of this single verse becomes apparent[50]. Set within the context of the giving of the Deuteronomic law code by Moses it becomes clear that persons with visual impairments (and by extension other ‘disabilities’) are an integral element of Covenantal life and the continual performance of

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[50] Louis Althusser’s (1979: 21 - 28) strategy of *symptomatic reading*, reading the text against itself is a similar approach.

its requirements[51]. When approached this way the foregrounding of ‘blind’ bodies in the Covenantal drama is no accident of specificity. We may even employ our biblical imagination[52] by imagining blind (or other persons with ‘disabilities’) playing a leadership role on the spiritual journey and begin to tell new and liberating stories (Jantzen, 1998: 61, 67; Schussler Fiorenza, 1992: 26). So ‘the blind person on the road’ stands as a metaphor of inclusion, envisaged as part of a larger communal ethos[53]. Read alongside the text of the prophet Isaiah 43: 8-10 it is clear that God’s message is not just of so-called ‘inclusion’ but liberation from the margins to a place of centrality in salvation history[54]:

> Bring forth the people who are blind, yet have eyes, who are deaf, yet have ears! Let all the nations gather together, and let the peoples assemble. Who among them declared this, and foretold to us the former things? Let them bring their witnesses to justify them, and let them hear and say, “It is true.” You are my witnesses, says the LORD, and my chosen servant whom I have chosen, so that you may know and believe me and understand that I am he. Before me no god was formed, nor shall there be any after me.

In order to shift the disabled subject from the periphery of New Testament Scripture to its speaking centre two major obstacles need to be negotiated and reconciled. Firstly, a number of texts[55], sometimes called the healing narratives, mistakenly conflate the question of ‘sin’ with ‘disability’, thus re-instilling a negativised ontology and

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[51] Dumbrell (1984) provides a useful outline of the meaning of ‘covenants’.

[52] This capacity to imagine/re-imagine has been identified as a key tool of transformation by feminist theologians. On imagination and spirituality, Sandra Schneider’s offering is useful (1986: 15 - 16). Sallie McFague (1993), *a la* Foucault, also reminds us that metaphors are a way of ‘knowing’ ontologies not just a way of communicating.

[53] Mc Clintock Fulkerson (1994: 111) reminds us of the necessity to continue narrating i*mago dei* in the story of the outsider.

[54] This theme is reiterated in what could be understood as an early example of ‘disability’ vilification codes in Lev 19:14 which speak also of justice “You shall not revile the deaf or put a stumbling block before the blind; you shall fear your God…”.

[55] A narrow reading of these texts continues to present ongoing problems of relationality between the church and disabled people whose ambiguous and inscribed ‘unwell’ states continue to endure (Fontaine, 1996: 288). Fontaine, herself has problems coming to grips with the conceptual distinction and assumes a conflation between disability and illness, which is not necessarily one and the same thing. Many disabled people argue that we/they are not sick but whole and well with a disability. See also Wendall (1996).

provisional salvation. Secondly, I argue that conceptualisations of ‘suffering’ need to be demarcated away from associations with virtuosity. In terms of the ‘big picture’ the reworking of disability’s positionality and signification within the holy books requires new questions be raised about propositions concerning *imago dei*, creation, atonement and theodicy.

Sin, Healing and Disability

A number of key New Testament passages conflate sin/evil with the acquisition of disability (by definition an incomplete creation[56] and thus devoid of sanctity), and forgiveness/faith with healing/wholeness (perfection imaged in the divine)[57]. Before treatment of these themes can occur we need to briefly re-visit similar themes in the Hebrew Bible in order to fully comprehend the dominance of somaphobia with Platonic – Christian theology and how this perspective has become an interpretive lens for reading the creation stories in the *Book of Genesis*. Benedict Ashley's work on *Theologies of the Body* (1985: 108) identifies "... the resurrection, image [creation], and death themes [as] the principal ones through which the Bible interprets our bodily existence in its original beauty, its ruin, and glorious restoration". It is at this level of formulation that the task of deconstruction is necessary, for the creation stories in Genesis have been theorised in terms of a completed (static) state of 'original uniformity', a perfectibility which prefigured diversity. The 'fall out', deviations and the turmoil induced by 'sin' and 'evil' are then a *perversion* of the essence of the Divine plan (DeVries, 1994; McFague, 1993; Rose, 1997).

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[56] According to one theologian, ‘defects’ are about an unfinished creation. (Alison, 1997: 85).

[57] Jn 5: 14; Mt 9: 2, 15: 14; Lk 5: 18 – 26.

Such a rendering of the story of creation has created and continues to create particular problems for people with bodies deemed 'volatile', ambiguous or 'disabled'. Dawn DeVries (1994: 135) explains:

> Although we have no experiential knowledge of a world without 'disability', the view of creation as a finished act invites the view that 'disability' is not part of the essence of God's creation but rather a perversion of it. 'Disability' therefore, is either willed or allowed by God[58], not as a part of the original good plan of creation but rather as the punishment for sinful deeds: 'disabilities' are necessary evils.

In fact I argue that this dominant discourse about creation has produced patterns of thought and structures that create and maintain ableism[59], and (re)produce its constitutive outside [60]. To endorse such a theological understanding is to give credence to the belief that humans with so-called disabilities are not imaged in the Divine. The reckoning of *imago dei* has been as site of contestation for feminist theology (Daly, 1973; Harriman, 1996; Jantzen, 1998; Johnson, 1993; McFague, 1982; Moody, 1996; Radford Ruether, 1983; Schneiders, 1986). It is these kinds of analyses that need to be deployed to interrogate the dominant Patristic theology, which argues that the 'essential' male, 'able-bodied' body more closely represents the image of God than does the image of a disabled person. Such occlusion, by inference suggests that people with 'disabilities' are incapable of a (mature) relationship with/to God (Cooper, 1992: 175; Eiesland, 1994: 72; McClintock Fulkerson, 1997: 107).

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[58] Adele McCollum (1994: 123) points to the enduring presence of Calvinist Providence, which understands 'disability' as God foreseen - as a purposive, though elusive act of God.

[59] Feminist theologian Elshout (1994: 101) transposes a schema developed by Mary Daly (1978: 130 - 133) - the seven characteristics of the 'Sado-ritual Syndrome' to draw together the implications of the creation - sin nexus: obsession with purity, erasure of responsibility, inherent tendency to spread disease [replication/contagion], women as token torturers, fixation' upon details, acceptable and normative [child destruction, abortion, euthanasia] and legitimation by 'objective' scholarship [the ableist expert knows best].

[60] The marking out of corporeal foreclosures produce an "exclusionary matrix by which subjects are formed thus requir[ing] the simultaneous production of a domain of abject beings, those who are not yet 'subjects', but who form the constitutive outside to the domain of the subject" (Butler, 1993: 3).

Within ancient Greek culture, especially in the genre of the tragedy, the notion that disease is of divine origin is typical (Prioreschi, 1992). However Martin (1995) documents perspectives at odds with this dominant assumption. Citing the Hippocratic author of a text titled *The Sacred Disease*, he notes that the author refutes this 'basic' understanding of divine linkage. Instead, according to Martin (1995: 154), the Hippocratic author " … does not so much refute [the belief] outright and attribute the disease to other, 'natural' sources as argue that all diseases are divine in the sense that all disease is part of natural process, which include divine processes". In other words, to hold that disease is divinely ordained does not imply that the diseased person is despoiled by a god.

Despite this argumentation, the early Christian communities believed that disease (and by extension, disablement), was caused by the "invasion of hostile, cosmic, personal agents" (Martin, 1995: 164). The Gospels of Matthew and Luke attest to the connection between disease and pollution where the 'unclean' are at the mercy of divine healing. In contrast, the Gospel of John does not associate demonic activity with the experience of disease or disablement. The Johnanine assertion weakens the conflation of 'sin' with 'disability'. In John 9: 1-3, Jesus gives sight to a blind man:

> As he walked along, he saw a man blind from birth. His disciples asked him, "Rabbi, who sinned, this man or his parents, that he was born blind?" Jesus answered, "Neither this man nor his parents sinned; he was born blind so that God's work might be revealed in him".

Within this short passage, the message is that not only is the man's blindness *not* the result of sin (and that the search for a cause or purpose is futile), but that the blindness is an *opportunity* or occasion for the performance of a divine work. Despite this rather positive reading, according to dominant theologies[61], the only 'hope' out of a conundrum called disablement, is transformation towards the divine through healing, restoration to wholeness. Although not intrinsically problematic, the impulse towards a theology of healing becomes a problem when disability *qua* disability is seen (assumed) to be in need of restoration. Such theologies of healing move from an *a priori* assumption that impairment in its materiality needs to be restored or at least ameliorated. For a theology of healing to be emancipatory, theological and biblical presuppositions need to be unhinged from positioning disabled bodies as broken. A contrasting and 'alternative' healing theology attempts to respond to the 'harms' (effects) produced by relations of corporeal subordination and scaling. As Rogers (1999: 238) argues within the context of a discussion concerning sexuality, any re-positioning involves asking:

> [t]he question is, *which* bodily things ought Christians to believe? Are some bodily forms … irredeemable, or can God sanctify them? Which bodily forms we revere has a lot to do with what sort of society we are, what our external boundaries and internal organs are in the *social* body.

It may be more fruitful in the long run to engage in the development of a theology of difference. Even some feminist theological reclamations have not escaped the compulsion to figure 'disabled' bodies as ontologically negative. The metaphor of 'disability' is used as a device to impute brokenness, a negative space, albeit patriarchally created. The problem is as Barbara Patterson (1998: 126) reminds us is that the 'healed' body is still inscribed as "... one that mirror[s] the bodies of those with institutional power, in other words, able-bodied men". The bodies of people with 'disabilities' produce a double restoration imperative - firstly in terms of ourselves the compulsion to be 'healed' and 'cured' (passive receivers); and secondly, for the able-bodied 'giver' who performs redemptive 'good works', acts of kindness and charity on us. John Sandford

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[61] Even so-called 'progressive' theologians are guilty of this kind of orientation. (C.f. Macquarie, 1995; Moltmann, 1998).

provides a small oppositional voice on the relationship of healing to sickness (and maybe disability). Because this is a rare example of thinking differently about this matter I quote extensively. He suggests that:

> … a person may find healing *through* sickness rather than *from* it. The insight, courage and fortitude that come through prayer are all a part of healing. They may or may not be accompanied by a cure … It is possible to know wholeness in the midst of illness if one has reached a place of honesty and humility about oneself … (Sanford, 1977: 46).

Consider the piece by Valerie Stiteler (1994: 120)[62] who rightly castigates Elly Elshout's conflation of the disabled body with pain and disappointments[63] (I might add suffering here). Yet Stiteler, on the previous page (119), made the same referential mistake herself when re-interpreting Genesis 2: 21 - 24, she concludes: " ... in order to create woman, God *disabled* man (a perfect creation). Woman was created in *brokenness and disunity*. The creation of woman is our first scriptural image of disability" (my emphasis).

What is really being said here, what is the *readable silence* between the text[64] and who is speaking and for whom? It would seem that this analysis is still constructed within a framework of a negative ontology, which continues to denote 'disability' as lack, as undesirable. The challenge is then, to develop a feminist theology of 'disability' that begins to mediate the tensions of patriarchal erasures (death-making) and the nurturance of a figuring of 'disability' that affirms ambiguity and pain without taking flight into despair.

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[62] It is not my intention to single out Stiteler solely for criticism; in fact her contribution to the feminist roundtable on 'disability' is quite exemplary. Carole Fontaine's (1996- updated version) piece within the same dialogue I believe is more problematic exposing the author's own ambivalence toward 'disability '/illness.

[63] Elshout uses disability as a metaphor to reflect the "social reality of the differences and conflicts of women's experiences" (Elshout, 1994: 103).

[64] Isherwood & Stuart (1998: 80) remark " … what is read is not what the text says but what it does not say". See also Kristeva (1995) on the subject of linguistics and the bible.

Transformative suffering?

> God and suffering belong together, just as in this life the cry for God and the suffering experienced in pain belong together. The question about God and the question about suffering are a joint, a common question. (Moltmann, 1998: 49)

At the outset I want to say that I am uncomfortable with needing to discuss the question of 'suffering' and 'disability' because the two issues are not *inherently* connected. The enduring legacy of the 'personal tragedy' approach (c.f. Oliver 1990) to impairments make this linkage 'real' and constantly foregrounded within disability discourse, when its very correlation is not necessarily obvious in the impairment under exploration. Theologian Donald Senior (1994) in remarking on his experiences of pastoral care with disabled people notes "people with disabilities have never thought of disabilities as suffering". Yet the narratological voice and perspectives of disabled people are diminished and may even be dismissed within mainstream and etic[65] studies as the theme of 'suffering' constantly re-occurs in much of the discourse around theology[66], 'disability' and God. The imposition of a nexus between suffering and disability has proved quite 'dangerous' to the lives of so many people with 'disabilities' in terms of spiritual solace and in the arena of welfare discourses and policy development.

The theme of 'suffering' is extremely complex and it is difficult to do justice to such complexity within the confines of this sub-section. However, I argue that the concept of 'virtuous suffering' is the flip side (the ethical twin) of the 'disability' - sin conflation, and as such ties implicitly into questions concerning the doctrine of God/Christ and theodicy. At the level of praxis and more explicitly, church pastoral practices, a belief in the

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[65] This anthropological term refers to 'outsider' perspectives in contrast with 'emic' or 'insider' views.

[66] This is especially so in contrast with the 'secular' literature. Maybe it has something to do with the so-called 'redemptive' aspects of 'suffering? I'm not sure.

virtuosity of 'suffering' has resulted in churches acting as agents of terror and abuse[67]. The reign of such abusive theories according to Patricia Wismer has exacerbated the 'suffering' of women (and others Othered), "often adding a spiritual dimension where there would not otherwise have been one" (Wismer, 1995: 140). Nancy Eieland's (1994: 72 - 75) analysis supports this view; she adds that the linking of virtuous 'suffering' with divine testing has promoted an acceptance or resignation to injustices and incarceration under the guise of adherence to Christian obedience[68].

We need to unpack the practical implications of a glorified and redemptive vision of 'suffering' in order to later on develop alternate and transgressive feminist understandings. Helen Betenbaugh and Marjorie Proctor – Smith (1998: 284) provide a synopsis of this traditional patriarchal ableist vision with devastating clarity:

> God is testing you; be faithful/hold on and there will be some great reward for you or some great work that God has in mind for you. You're being purified; one day you'll be one of the saints. This is your cross. Be grateful, take it up, and follow Jesus. You've done all your penance with what you've paid in advance. Now you have carte blanche to sin all you want to - You've paid in advance. Your 'disability' is really a blessing in disguise; look at what you're doing now! God never gives us a greater burden than we can bear.

This assumed conflation of 'suffering' with 'disability' gives rise to the theodicy question - why does God allow 'suffering'? We can add an additional question - what image(s) of God is/are being constructed? And two sub questions - Can God be said to 'suffer'? What kinds of relationality and inter-subjectivity between God's self - humankind - the cosmos are being imbued? Although Christian texts such John 9: 1-3 break the nexus

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[67] As Foucault (1976; 1991) points out it is these very pastoral practices that produce power that is pastoral power.

[68] In a similar vein, Webb-Mitchell (1994: 59) cites a passage from a pastoral care piece by H. Sigerist: "Disease is suffering and it is through suffering that humanity is completed by God's saving grace". In a rather disappointing article by John Macquarie: (1995: 30) concern is expressed about the possibility that the problem might be *even more oppressive* if the *victims* of handicap could no longer expect to find any *consolation* in a religion's faith (emphasis added)".

between 'disability' and ‘sin’, we are still left with a particular post Enlightenment obsession with the need to 'know', to rid ambiguity and therefore ambiguous bodies from creation and to have evil and rationality explained (and thus ultimately controllable) (Hauerwas, 1990: 40).

3.2.3 Alternative and Oppositional Theologies

Feminist theologies of suffering and relationality

In this next section I move onto a consideration of debates within feminist theologies around the themes of ‘suffering' and 'relationality' that may prove useful for refiguring a theology of 'disability'. I introduce a methodological and epistemological framework from which to center and drive this exploration, and to nurture a new 'text' responsive to multiple and even self-contradictory voices. A 'synthetic' theology that emerges, as Greeve Davaney (1997: 210) puts it "through the combining of disparate elements to form a coherent, if only for the moment wholes that are ourselves". I am choosing to use and adapt Jane Korpas’ (1994: 224 - 229) five principles of transformative theological anthropology, namely:

- An orientation towards a holistic (non-Cartesian) corporeality,
- intentional multi-dialogical - affirming the formative role of culture [and 'disability'] on the sexing of persons.
- the re- visioning of the autonomous subject transfigured as inter - subjective.
- didacticism - a refusal to separate theologising from ethics; and
- the figuring of creation and human persons in process; a transforming unfinishedness - our bodies and the world become a scene of endless re-writing.

Suffering:

Whilst there are a range of perspectives and contestations around the meaning and significance of ‘suffering' within feminist theologies, there is general agreement that classical formulations of ‘suffering' as redemptive are both faulty and offensive. Many feminist scholars are emphatic, arguing that suffering is never redemptive and hitherto suffering can never be redeemed. Elizabeth Johnson (1993: 261) concurs, arguing women’s experiences of degradation results in a "suffering that bears marks of affliction ... which take possession of the soul and marks it with a brand of slavery”. What is not at issue is the existence of ‘suffering’ *per se*, disagreement occurs over its theorisation. In other words, the way suffering is understood such as the meaning/interpretation given to such a phenomena. 'Radical suffering', according to Wendy Farley

> … is present when the negativity of a situation is experienced as an assault on one's personhood as such ... This assault reduces the capacity of the sufferer to exercise freedom, to feel affection, to hope, to love God ... In radical suffering the soul itself has been so crippled[69] [sic] that it can no longer defy evil. The destruction of the human being is so complete that even the shred of dignity that might demand vindication is extinguished. (Farley cited in Johnson, 1993: 249).

The role of the storyteller as a moral exemplifier then becomes problematic, unless there is an awareness that "the passage into speech of the wounded storyteller is always circumscribed by concealed dynamics of gender and race", as well as ableism (Graham, 1998: 225). We need to ask, where is the incitement to 'tell' coming from? Who are the interpreters and hearers? Narratives of ‘suffering' without some form of discursive interrogation run the risk of reinforcing individualised and privatised understandings of 'experience', leading to the possibility of the creation of a gulf between the 'speaker' and 'hearer'. One strategy to avoid this pitfall has been developed by Mujerista theologies,

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[69] A good example of an unintended (I hope) use of the metaphor 'crippled' to impute a negative ontology.

which emphasise 'struggle' (*la lucha*) over 'suffering' and communitarian engagement rather than an individual focus (Korpas, 1994: 226).

The feminist theological project has begun to reclaim and transmogrify the interpretation of ‘suffering' in the Christian context. Part of the reclamation is to ground theological inquiry into pain and 'suffering’ and to develop an 'epistemology from the broken body' and create new symbols that summon forth the mystery of God (Johnson, 1993: 254; Kyung, 1990: 39). Rita Nakashima Brock (1988), Elaine Graham (1998) and Patricia Wismer (1995) are three feminist theologians who have embarked on this project.

Rita Nakashima Brock (1988) in *Journeys By Heart* provides an alternative to classical formulations of ‘sin' and 'atonement'. Her claim that sin is socially and historically produced by way of destructive forms of relationality enables a re-examination of the construction of 'suffering', 'illness' and 'disability'. Nakashima Brock's (1988: 76) analysis closely parallels a theoretical development in the social sciences referred to as the *social model of disability*[70]:

> Sickness is oppression or possession by hostile forces that seek to destroy a person in body, psyche, spirit, and/or community. Sickness points to the social and relational dimensions of individual disease. Sickness reveals brokenheartedness and produces suffering. Brokenheartedness, as I use it, is a metaphor for both political oppression and sickness and the damage to the self from complex forms of destruction in our culture. In using the image of brokenheartedness I want to point to that which draws our attention to the large, relational dimensions of sickness that rest in economic, political and environmental factors.

Such an analysis, taken in conjunction with her problematisation of Patristic formulations of atonement, exposes the asymmetrical foundations that foster fear, paternalistic charity and ambivalence towards the abject, in this case people with disabilities. As Nakashima Brock (1988, 56) concludes "We are encouraged to believe our own suffering has been

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[70] The model is discussed in section 5.2.2.

taken away by someone else's suffering and by a cosmic transaction within the divine life".

Elaine Graham in *'Only Bodies 'suffer'* (1998) critiques sociologist Arthur Frank's notion of the storyteller as a moral exemplifier. As an alternative, she develops an oppositional understanding of 'voice' based on the work of French feminist philosopher Luce Irigaray who implores all women to speak in the active voice and undertake the task of *speaking otherwise*. This movement from passivity to activity, not getting 'stuck' but journeying through 'suffering' is imbued with rich theological significance. Engaging Luce Irigaray's concept of 'divine becoming', Graham postulates that the apprehension of our own active voice, redeems "... one's capacity to connect with others, thereby forging a moral sensibility grounded in communicative inter-subjectivity" (Graham, 1998: 257). The locus of 'divine becoming' is the body wherein divine transcendence and immanence merge. A return towards the body, engaging the spiritual and the corporeal in a constant state of unfinishedness ensures that divine transcendence remains intimate. For Graham, Irigaray's analysis is profoundly Christocentric: "A birth into transcendence, that of the other, still in the world of the sense ('sensible') still physical and carnal, and already spiritual" (lrigaray, cited in Graham, 1998: 269).

Patricia Wismer's (1995) *For Women in Pain* is an exposition of a feminist theology of 'suffering'. Her analysis is not merely restricted to a critique of traditional pastoral approaches[71] to 'suffering', rather Wismer maps out the tensions in feminist discourses around this theme. Two 'voices' are identified - the dominant 'suffering never again' position and emergent relational theologies which postulate that 'suffering is part of life'.

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[71] Wismer (1995: 143 - 146) identifies five responses: masochism, cheap forgiveness, apathy – escape from sin, the miracle mentality and the easy-fix response.

The tensions between these two approaches, Wismer argues do not need to be reconciled, rather it is in the tension that it is possible to acknowledge that "… suffering can never be justified and suffering must be accepted as part of life" (1995: 148). The analysis shifts into formulating a theological anthropology for women in pain, based on the five principles of embodiment, relationality, the re-visioning of 'virtue', the overhauling of the doctrine of original sin (influenced by Nakashima Brock) and the healing erotic power of grace (150 – 156).

Relationality:

I want to conclude this section by briefly examining recent feminist theologies of relationality. Influenced by the process-relational thought of Alfred North Whitehead the writings of Sallie McFague (1982; 1993; 1994; 1997) and Catherine LaCugna (1991) offer a significant contribution to a re-visioning of 'disability' within Christian theological discourses.

Sallie McFague's writings exploring an embodied ecological theology are vast. I am interested in teasing out two themes that have not received as much consideration. In her recent book *Super, Natural Christians*, McFague postulates a theology of 'radical touch': " ... a model of being and knowing that begins with touch ... will insist on being bonded to skins, fur, feathers, to smells of the earth, to the intricate and detailed difference in people and other life forms" (1997: 102). If we stay with this notion of 'touch' for a moment, expand and extrapolate – I believe we can go further and examine differences in human 'sensory surfing'. People with disabilities due to their occupation of different social and physiological 'spaces' offer a different insight into perceptibility[72]. Our

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[72] Consider the new emerging scholarship related to the theme of spatiality and the production of disability. (Butler and Parr, 1999; Gleeson, 1999).

bodies are a prism from which to read the world. An engagement with a theology of ‘touch’ may provide new insights into ways the divine is incarnated into different and ambiguous bodies[73]. McFague in advocating for a reincarnated Christian theology argues that bodies do indeed matter: “… whatever else salvation means, it starts with the needs of bodies, all the wonderful, various, strange, and beautiful bodies on our planet” (1994: 142). McFague continues with an exploration of 'space' and 'place', a critical component of a theology of embodiment. A future meditation of 'space' as understood in this context may present possibilities for the renegotiation of the exclusion of many people with ‘disabilities' from social, textual, philosophical and divine spaces[74].

Catherine Mowry LaCugna's *God for Us: The Trinity and Christian Life* (1991) proposes a new understanding (appreciation) of the doctrine of the Trinity that may have a significant flow on effect in the development of a theology of 'disability'. LaCugna (1991: 243) argues that “... trinitarian theology is *par excellence* a theology of relationship. God to us, we to God, we to each other". It is on this basis that she proposes an ontology of relation which is "the modality of all existence" (250). LaCugna's analysis has the potential to subvert the binary oppositions of 'self' and 'other', through her deployment of the concept of 'heterocentric communitarianism' (257).

LaCugna’s work is strongly influenced by the thinking of British realist philosopher John Macmurray (1891-1976). Macmurray rejected the modernist notion of self as possessive and rationalist. Instead he argues that personhood is not atomistic, rather relational. This ‘thick’ concept of self permeates all interpersonal and interpersonal relations. As Macmurray (1995, 17) puts it: “…the self is constituted by its relation to the Other – it

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[73] On matters related to sensibility, presence and visibility see Corker (2001).

[74] A recent edited multi-disciplinary collection explores these issues (Butler and Parr, 1999).

has its being in its relationship". The heterocentric nature of relationality takes four forms. The individual is firstly directly acquitted with the other; second, they do not *see* the other as an object; third, there is respect for the other as 'free' and equal; and finally the individual doe not act towards the other as an object (Roy, 1989). LaCugna's notion of heterocentric communitarianism adopts the stance that each person is a steward toward another: "…the Self seeks to do what is right in reference to the Other" (1991, 257).

Following on from this discussion, LaCugna's appropriation of the 8th century doctrine of *perichoresis* to characterise the Holy Trinity may prove fruitful. The re-fashioned perichoresis:

> … means being-in-one-another, permeation without confusion. No person exists by him/herself or is referred to him/herself; this would produce number and therefore division within God. Rather, to be a divine person is to be by nature in relation to other persons. Each divine person is irresistibly drawn to the other, taking his/her existence from the other, containing the other in him/herself, whilst at the same time pouring self out into the other (LaCugna, 1991: 271).

Like Macmurray's conceptualisation of personhood, LaCugna envisages the Trinity as being the ultimate form of a heterocentric prism. The font of Christian theology then, contains the wisdom of a belief system that challenges dominant notions of otherness as alienation and subordination. Such an understanding of relationality has profound implications for the revision of concepts such as integration and the refutation of dualist/hierarchical ableism[75]. In embracing perichoresis, the 'I' of able-bodiedness must become transformed into the relational 'you and I' where mutuality is achieved through an affirmation of 'difference' and not necessarily sameness. Whilst LaCugna can be accused of lapsing in occasion into a universalised essentialism[76] (e.g. the notion of a common creation), her explorations in this area are worthy of further consideration and

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[75] 1 am reminded of Lacan's notion of the Möbius strip, which has not inside or outside.

[76] See Jone's (1997) critique of LaCugna.

refinement, especially where her argument pertains to an alternative Christology of the Cross.

The Disabled Christ – Opportunities and Problems

I wanted to conclude this sub-section with a discussion of contemporary developments in theologising ‘disability’ and more specifically the divine, namely the ‘Disabled God or Christ’. Whilst this conceptualisation seems to have been eagerly received by practitioners working in the area of disability and church, the new formulation of the divine as disabled is not without its divergent and conflicting interpretations. The effectiveness of the neologism ‘disabled God’ is dependent upon the way ‘disability’ is conceptualised. In other words the salience of this concept becomes linked to matters of ethics and ontologies of disability. Any notion of ‘disabled God’ based on negative ontologies of disability ultimately becomes a defeatist project as a negative positionality is a problematic ground for emancipation.

Keeping that formulation in mind let us proceed. Early works by Norman Habel (1998 [1981]) and Burton Cooper (1992) speak of the ‘disabled God or Christ’ and are based on what I will call ‘crucifixionist theologies’. For Habel this invigorated symbol of Christ is based on transposing the Hebraic figure of the ‘suffering servant’ in Isaiah 53 onto the crucifixion action and extrapolating the crucifixion process/experience to that of disability. Whilst the image of Christ as the ‘suffering servant’ fulfilled, is a powerful and commendable kind of symbolism, one needs to ask whether we can conflate this symbolism with ‘disability’, or are we talking about two different and distinct issues? Again, Habel incorrectly without qualification conflates ‘suffering’ with the experience of ‘disability’.

Burton Cooper's (1992: 179) work on the 'disabled God' has been influenced by the work of German theologian Jürgen Moltmann (1981), especially his understanding of the 'crucified God' who suffers with us and also the process philosophy of Whitehead. Published in 1991, Cooper's analysis was innovative; however I believe that the strength of his analysis is reduced by his constant attempts to reduce the naming of God as 'disabled' to mere metaphor. In his opening paragraph Copper states: "I am persuaded that by thinking of God as disabled – metaphorically, of course – we can deepen our understanding of the nature of God's creative and redemptive love "(1992, 173). We can ask what is the problem (theologically) of conceptualising God as 'disabled' literally? What conceptualisation of 'disability' is Cooper using that results in him 'hitting a brick wall' with his proposed re-conceptualisation of God? Like Habel, Cooper also bases his formulation around the crucifixion moment, imbued with the image of the 'suffering Christ'. I quote:

> God suffers with the disabled person; God gives reality to the world of that disabled person. In this way, we approach once again the image of the disabled God. God is disabled in the sense that the reality of the disabled enters into God. God feels the world in the same way the disabled person feels the world. To call God disabled reminds us of the concreteness of God's loving presence in the world. (Cooper, 1992: 180).

Aside from universalising the experience of 'disability' and aligning that experience with 'suffering' there is something about Cooper's declaration that makes me uncomfortable the more I read it. Again I am not sure whether it is the subtle imputation glimpsed when I read the text 'against the grain' that insinuates a distancing of 'real' as against empathetic 'disability' with Christ. I don't get a sense that this text is really saying it is okay to have a 'disability'. Cooper's lingering negative connotation of 'disability' is exposed in his argument that figuring God as 'disabled' enables a re-conceptualisation of power, in particular God's power (180). He first suggests that a belief that God's power is unlimited reflects an ableist perspective. Where I have difficulty with Cooper's framework is that his analysis is juxtaposed with a 'disabled God's' power as limited (or more correctly self-limiting). Leaving aside the vexed question as to whether God's power is self- limiting or not, the problem of Cooper's proposal is that textually the work speaks from within a prism of an ableist understanding of wholeness. Whilst initially seeming liberating, Cooper's work ultimately falls victim and indeed is 'held hostage' to the false binaries that 'disability' signifies a sorrowful inability whilst to be 'able' signifies possibility.

Any entrée into the subject of the 'disabled God' would not be complete without a discussion of what has now become a canonical text in the inquiry, Nancy Eiesland's work *The Disabled God: Towards a Liberatory Theology of Disability* published in 1994. By way of comparison with Habel and Cooper, I would suggest that Eiesland's theology reflects a significant maturing of argument. For a start, her analysis moves beyond and breaks the nexus between suffering and 'disability', primarily because Eiesland's theoretical framework is not based on the crucifixion moment, rather it is the motif of Christ's resurrection which becomes central (94). Her strategy of change is to develop transformed religious symbols that invoke new images of 'wholeness' (92, 93).

The following passage is from the Christian New Testament of Luke 24: 36-39:

> [36] While they were talking about this, Jesus himself stood among them and said to them, "Peace be with you." [37] They were startled and terrified, and thought that they were seeing a ghost. [38] He said to them, "Why are you frightened, and why do doubts arise in your hearts? [39] Look at my hands and my feet; see that it is I myself. Touch me and see; for a ghost does not have flesh and bones as you see that I have."

Reading Luke with disabled subjectivities at the speaking centre, Nancy Eiesland transfigures traditional imaging of God:

> In the resurrected Jesus Christ, [the early church] saw not the suffering servant for whom the last and most important word was tragedy and sin, but the disabled God who embodies both impaired hands and feet and pierced side and *imago dei*. (1994: 99).

For Eiesland this image of the risen Christ symbolises a God of corporeal ambiguity, a dis-orientation if you like:

> The power of the disabled God is the seemingly inherent contradiction this God embodies … God appears in the most unexpected bodies… (1994: 100).

Later on this sense is reinforced:

> The disabled God embodies the ability to see clearly the complexity and 'mixed blessing' of life and bodies, without living in despair. This revelation is of a God for us who celebrates joy and experiences pain not separately in time or space, but simultaneously (Eiesland, 1994: 102-103).

The strength of Eiesland's analysis is that it speaks to the multiple realities of disability whilst avoiding the tendency towards romanticism or lapsing into a formulation based on negative ontology.

However, Eiesland's presuppositions become problematic in their reliance upon the raw physicality portrayed in the Lukan text and the image of the broken tortured body. In arguing that the primary symbolism of the 'disabled' God is physicality, Eiesland not only invokes a kind of Cartesian dualism that falsely splits 'mind' and 'body'; she also ignores the question of 'disability' as an ontological signifier. That is, the signifier 'disability' has little to do with the (real) body; rather its ascription is related to cultural rules about the kinds of states of being that are anomalous or whole. Still, Eiesland's symbol of the *imago dei* as signifying ambiguity warrants consideration. Such a formulation of the 'disabled' God enables a participation in the divine through a desiring image of 'disability' devoid of associations with suffering and sin.

3.2.4 Reinscribing Disability into Scripture - Moses' Mouth - New Ways of Mentoring

> Former Indonesian President Mr Abdurrahman Wahid, said disability could not be an obstacle to leading an active life. These words of the President, who is himself blind and in the presence of the First Lady (Sinta Nuriyah Abdurrahman Wahid), a quadriplegic, must have carried a powerful message (Subramaniam, 2000).
>
> But who is Wahid? Is he a severely disabled man who may be easily manipulated? Or is he a skilled politician who adroitly negotiated with numerous political factions to win the election? (Schriner, 2000).

There have been some spectacular inroads into developing transgressive theologies of 'disability', spoken with a 'D (Disabled[77]) voice' – however we need to recognize that there is still much more creative thinking to do. As Isherwood and Stuart (1998: 92) remind us there has been and still exits:

> … a failure on the part of the Church to examine its own ablebodiedism [sic] fuelled by a tradition which has not constituted the disabled person as a historical moral agent and which therefore always locates the abled-bodied at the speaking centre.

The question of 'who' is at the speaking centre I believe is critical in developing new theologies about 'disability'. As a test we need to ask – does the theological argument presented speak with a 'D voice' or an 'A (Ableist[78]) voice'? It seems a futile exercise to continue undertaking new theological epistemologies without a corresponding shift from a negative ontology of 'disability towards an engagement with a celebratory positive ontology of 'disability'. I cannot over emphasis this. At the end of the day if we remain with a belief that 'disability' is a negative state of being, then our theological strategies, however compassionately driven, are really only compensatory. Another challenge is that the neologism 'disability' is itself a hurdle to the development of any systematic theology. Maybe it is more practical and methodologically honest to dispense with an

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[77] Where the subjugated knowledges of disabled people are at the speak centre.

[78] A normative position that regards disablement as ontologically negative.

orientation towards systematisation and develop local, specific and multiple theologies of ‘disability’. It pays to be cautious about any universalising claims about ‘disability’.

Former Australian Prime Minister Paul Keating was rumoured to have once said that ‘anyone could become PM, except maybe a cripple’. Leadership, of the political kind has typically been seen as exhibiting characteristics of maleness, whiteness and ableness. When individuals with disabilities have become successful leaders portrayals have viewed such ‘success’ occurring *in spite of* ‘disability’. The election to the Indonesian Presidency of Abdurrahman Wahid is a case in point. The Hebrew Bible’s narrative of the call of Moses (Exodus 4: 10-17) challenges such contemporary readings by highlighting that Moses’ disability was *intrinsic* to his call to lead the people of Israel. Disability biblical scholarship is still in its infancy and orientated towards identifying texts of ‘terror’ and grasping at texts of ‘transformation’ in order to rescue both Judaism and Christianity from allegations of anti - disability bias and institute valued roles.

This Case Study uses the hermeneutical tools developed by feminist Hebrew biblical scholars Athalya Brenner and Fokkelien van Dijk-Hemmes in their book *On Gendering Texts* (1993) to present a different reading of Exodus 4: 10 – 17. Rather than falling into the trap of positive text plucking, Brenner’s and van Dijk-Hemmes’ use of a narratological model of textual ‘voice’ can enable the reader to assess the transformatory potential of certain biblical moments. By re-assigning the character of the person with a disability from the margins of the text to a central position it becomes possible to read text in a different way: against the grain. This ‘double reading’ of the text still pays attention to the text but does so in a way that ruptures or destabilises a fixed meaning. This approach to the text looks to what is excluded or repressed and opens the way to counter reading and story telling. As Jantzen (1998, 61) puts it "… in the undecideability … created [there] opens the possibility of thinking otherwise".

This section then, engages a critical eye beyond a mere surface reading of Exodus 4 by offering parallel readings of the narrative from the position of an Ableist (A) voice and an alternative, often subjugated position of the Disabled (D) voice. Part of this undertaking is not just to foreground a 'different' voice' (which is a task of merit), but also by running with multiple and counter interpretations/voices, the reader is better able to discern which voices have been audible. Such an approach I argue enables the reader to see whether so-called 'positive' texts really present a transformatory imaging of disability or merely recuperate the interests of an ableist ethos and spiritual worldview. I conclude that a transgressive, (D) Voice reading offers new ways of visioning leadership in the modern world and the capacity of people with disabilities to meet the obligations of citizenship. As Code (1998, 213-214) remarks on the subject of 'voice' in storytelling:

> …stories challenge the anonymous and universalist pretensions of dominant theories and afford rich opportunities for self-reflective theory making. Because they presuppose tellers and listeners, they are good candidates for shaping revisionary projects and transformational agendas… It presents loci for identification and differentiation, agreement and dispute, and presents them over a textured range of possibilities that are linked, yet contingent and available for assent or refusal.

The short passage from the book of Exodus, chapter 4: 10-17 is euphemistically subtitled in one commentary as *'Moses and His Mouth'* (Fretheim, 1991: 71 - 75). I have selected this scriptural text for two reasons. Firstly, Moses played and continues to play a significant role in the salvation history of the Israelites and the development of a theology of covenantal life (see Blitz, 2000; Neusner, 1987). Secondly, it strikes me that both within the traditions of Judaism and Christianity there is an absence of positive role models of people with disabilities. A few years ago whilst reading a paper discussing feminism and disability I came across a small exegetical paragraph on the call of Moses by Valerie Stiteler, which reoriented my reading of this narrative (Stiteler, 1994). With my imagination fired up and shaken up with a new way of conceptualising the 'Moses story' I contemplated the implications of undertaking a transgressive, insider reading of the text using the tools of feminist biblical scholarship and new literary criticism. The following textual divisions will assist our discussion:

TABLE 2: Exodus 4:10-17 (NRSV) – Reading In A Different Key

V10 The 'disability' problematic – the compulsion of internalised ableism

10 But Moses said to the LORD, "O my Lord, I have never been eloquent, neither in the past nor even now that you have spoken to your servant; but I am slow of speech and slow of tongue."

V11 God's refutation of ableist normativity – diversity, difference, disability all part of creation.

11 Then the LORD said to him, "Who gives speech to mortals? Who makes them mute or deaf, seeing or blind? Is it not I, the LORD?

V12 A new call to ministry – not in spite of 'disability', but because of it!

12 Now go, and I will be with your mouth and teach you what you are to speak."

V 13 – 16 God's response: Parallel readings - recuperation or collaboration?

13 But he said, "O my Lord, please send someone else."
14 Then the anger of the LORD was kindled against Moses and he said, "What of your brother Aaron the Levite? I know that he can speak fluently; even now he is coming out to meet you, and when he sees you his heart will be glad.15 You shall speak to him and put the words in his mouth; and I will be with your mouth and with his mouth, and will teach you what you shall do.16 He indeed shall speak for you to the people; he shall serve as a mouth for you, and you shall serve as God for him.
17 Take in your hand this staff, with which you shall perform the signs."

Earlier in this chapter I made mention that both Hebrew and Christian testaments contain texts of terror and texts of transformation. The exegetical enterprise is not just an exercise to naively pick out, in a de-contextualised manner positive images that may serve the disability cause. However useful the selection of positive images is just the start – we need to also engage a critical eye beyond a mere surface reading of the text to see whether the text really presents a transformatory imaging of 'disability' or merely recuperates the interests of ableism. So we begin.

V10 The 'disability' problematic – the compulsion of internalised ableism

> 10 But Moses said to the LORD, "O my Lord, I have never been eloquent, neither in the past nor even now that you have spoken to your servant; but I am slow of speech and slow of tongue."

From my own reading of verse 10, supported by the interpretations of Stiteler (1994) and Fretheim (1991), it is clear that the argument given by Moses to God as to his inability to take up the call is based on a negative view of 'speech disability'. Yet, most commentaries and textual translations either ignore that particular reading[79] or repress this understanding by recuperating the 'problem' as low confidence, clumsy speech[80]. As the passage progresses the text points to the role of Moses' speech impediment in leading God's people to freedom. So why has Moses' speech 'disability' become a readable silence in most exegeses of this passage? Is this another example of the 'submerged voice' of 'disablement' from underneath the dominant ableist view that controls symbolic literary production? (Brenner and van Dijk Hemmes, 1993: 8). Read from a place of 'disability', from a position of an 'outsider', I would suggest that Moses'

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[79] In my search I was amazed at the amount of commentaries that just skip over the introduction or become absorbed with details about sources.

[80] An example of a more 'modern' translation that shifts the meaning Exodus 4:10: "Moses replied, "I have never been a good speaker. I wasn't one before you spoke to me, and I'm not one now. I am slow at speaking, and I can never think of what to say." *The Contemporary English Version.* The only other passage about an inability to speak can be found in Jeremiah 1: 6 - 9 yet the focus of the dialogue is quite

hesitation maybe not be related so much to biological constraint, but rather to his own internalisation of 'disability negativity', what I will theoretically conceptualise as 'internalised ableism'. In other words, Moses' image of himself does not square with his image of the characteristics[81] required for leadership.

> **V11 God's refutation of ableist normativity – diversity, difference, disability all part of creation.**
>
> 11 Then the LORD said to him, "Who gives speech to mortals? Who makes them mute or deaf, seeing or blind? Is it not I, the LORD?

In this verse the Lord seems not to be so interested in buying into Moses' 'disability negativity', but instead adopts a 'so what' attitude. Moses is reminded that the Lord was not only involved in the creative process of 'disability', but that it is his 'disability' in particular that 'marks' him for the role to which he is invited. Unlike many of the passages in the New Testament, or for instance in Jeremiah 1: 1-6, there is no incitement to 'cure' here.

> **V12 A new call to ministry – not in spite of 'disability', but because of it!**
>
> 12 Now go, and I will be with your mouth and teach you what you are to speak."

A counter-reading would suggest then, that Moses is called not in spite of his 'disability', but *because* of it[82]. The text's speaking otherwise about 'disability', in the Lord's commissioning of Moses to lead his people to freedom, to embark on a journey unqualified in the salvation history of the Hebrew Bible is quite extraordinary. As Valerie Stiteler (1994: 121) remarks: "God's promise to use Moses' disability to save the

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different. Here Jeremiah points to his young age (and experience) as the reason for his lack of eloquence. God responds to Jeremiah's fear by 'curing' this problem, by 'putting words into his mouth'.

[81] The characteristics would include being male, ritually 'pure'. Bal (1988: 22) in the context of the Book of Judges refers to the judge/warriors as being "a hero of might".

[82] Again Fretheim (1991) and Stiteler (1994) support my reading. Fretheim states that "Moses' ineloquence is turned into an asset" (72), whilst Stiteler argues that Moses' speech patterns were essential for persuading the people" (121).

Israelites ignites images of the power and beauty of our disabilities". By privileging the voice of 'disability', we can have a textual reading that transforms our theological understandings of ministry, leadership in particular and inherent notions of 'competence'. Furthermore, the Churches understanding of charitable works and the corresponding roles of 'givers' and 'receivers' in the light of reading requires reassessment.

V 13 – 16 God's response: Parallel readings - recuperation or collaboration?

> 13 But he said, "O my Lord, please send someone else."
>
> 14 Then the anger of the LORD was kindled against Moses and he said, "What of your brother Aaron the Levite? I know that he can speak fluently; even now he is coming out to meet you, and when he sees you his heart will be glad.15 You shall speak to him and put the words in his mouth; and I will be with your mouth and with his mouth, and will teach you what you shall do.16 He indeed shall speak for you to the people; he shall serve as a mouth for you, and you shall serve as God for him.

For those of us raised with 'disabilities' (whether as children or as adults) we know only too well the struggle to remain afloat in an ableist world which floods us with symbolic representations of what it means to be fully human, that for a range of reasons are difficult, if not impossible to meet. A discomfort of 'disability' often becomes transmogrified into a kind of self-hatred that at a theoretical level I have termed 'internalised ableism' (See Chapter Four). Many people with disabilities will have little difficulty empathising with Moses' dilemma and plight as recorded in verse 13. The possibilities of leadership both within and without seem intractable – like with Moses sometimes those of us at the forefront of changing attitudes towards 'disability' get tired, believe we are 'incompetent' and become disenchanted – so – I know what he means, when Moses says 'O my Lord, please send someone else'.

Scriptural texts, as we know, are not written in one 'sitting' or indeed by a single 'author'. Instead texts emerge in the process of editing – the writing in and writing out of material. In some cases later editing is obvious whilst in others it is concealed. In verses

13 – 16 I argue that some kind of redaction has occurred – I don't have any 'proof', however it is possible to offer two parallel and discontinuous readings of this section. The exegetical approach developed by Athalya Brenner's and Fokkelien van Dijk-Hemmes (1993: esp. 1 - 29) is especially useful at this point of our analysis.

The maintenance of ableist normativity and an ableist reading of texts is dependent upon the status of the reader: are they reading from the subject position of the 'disabled body' or that of the subject position of the 'abled body'? These subject positions need not necessarily relate to the 'state' of our (real) bodies. It is possible with verses 13 – 16 to have a dual or parallel reading – to read and listen with a Ableist (A) voice or alternatively with a Disabled (D) voice. Whether one of these readings is privileged over the other is a matter of conjecture. A 'popular' reading of these verses, a reading with an A voice typifies what I will call the *integration imperative*. It is a jolly reading where the divine figure enshrines a form of community relationality based on collaboration and participation in mutual support[83] like in the case of Aaron helping Moses. Such a covenantal model of inclusion is good.

However when we approach a reading of the text from the 'underside', with a D voice a number of incisive questions emerge. In this section of the story what voice(s) is being filtered out (Brenner and van Dijk Hemmes, 1993: 11)? What reality is being displayed or hidden (Clines and Exum, 1993: 3)? The first thing that strikes me is the sharp contrast between the dialogue of the call (vv10 – 12) and the Lord's proposal (vv13- 16). I have already remarked that the call and commissioning of Moses is extraordinary – in fact it is profound and revolutionary! God is calling the abject, the Other – a person with a

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[83] Interestingly Stiteler (1994: 121) aligns herself with this interpretation, whilst Fretheim (1991: 73 - 74) sees the calling in and role of Aaron as less than ideal.

‘disability’ to take up a key leadership position – to take the Israelites to freedom! Such a subversive reading needs to be made more palatable to the leadership of the editors’ time: the character of Moses needs to be re-inscribed through the filters of the A-voice perspective by way of the process of recuperation.

We need to ask why is it at the very moment that God makes explicit that her/his choice of leader is based on the ‘disability’ of the person that the ‘full cup’ so to speak is ‘emptied’. Moses needs propping up. Recuperation is often an insidious process with its subtle changes masked. Linda Alcoff & Linda Gray (1993: 268) explain:

> … even when disruptive speech is not silenced by subsuming it within the framework of … discourse in such a way that it is disempowered and no longer disruptive … [disruptive speech can be] … channel[ed] into non-threatening outlets.

The call of Moses could be considered disruptive speech. Could the redactors be making Moses’ call less threatening by redirecting our gaze away from Moses towards his brother Aaron, who lends a hand? One inference of this sleight of hand is the figuring of Moses as a ‘claytons’ leader who really can’t lead without help from Aaron. Even though Moses appears to gain his ‘voice’ later in chapters 13 – 14 and Aaron’s role disappears one cannot help noticing when reading with a D voice that mention of Moses’ ‘disability’ also dissipates and is ultimately erased from the text and the whole salvation history story. All this begs the question both in the time of ancient Israel and in the contemporary moment– what is it about disability that makes it near impossible to imagine the person with an impairment being a leader, a mentor – and maker of history? How different the story (Judeo-Christian) may have been for western traditions had the impairments of Holy Father Moses been acknowledged and embraced.

The notion of disability as inherently negative and the preferability of ableism as a way of being human have a long, strong and entrenched lineage. In this chapter, I have mapped and undertaken a preliminary archaeological dig to expose the 'heart' of ableist sensibilities. And whilst such a legacy has shaped the ways we think of and speak about disability I also hope that I have in a small way prized open the cracks of historical and epistemological stabilisations releasing those gestures that disturb and disrupt the dominant line of disability as catastrophe and incompleteness. The time is ripe for the development of oppositional history and theologies of anomalous and diverse bodies, what I call 'brave' and counter-interpretations of disability. In the next chapter, these 'foundations' are extended by an analysis of the phenomena of ableism.

Chapter 4 - The Politics of Ableism and Hatred

> …the writings and experiences of people with disabilities, have convinced me that one of the best ways to improve our understanding of all discrimination, including race and gender discrimination, is by improving our understanding of discrimination against persons with disabilities. In particular, I wonder how different our views on race and gender discrimination might be if disability discrimination, rather than race or sex discrimination, had been our society's paradigm case of discrimination (Tong, 1999: 520 - 521).

> … we believe our duty is to extirpate ourselves from those horrid mixtures as forcibly as possible by not confusing what pertains to mere social preoccupations and what pertains to the real nature of things (Latour, 1993: 100).

So far this work has examined theological approaches to aberrant bodies as well as some of the challenges in undertaking histories of disability. This chapter moves on from these preoccupations, to shift our attention to those matters regarded as the focal concerns of the doctorate as a whole, namely the production and performance of the phenomena called ableism. My approach is three pronged. Firstly I explore the problem of speaking - thinking - knowing about the 'problem' of the Other (in this case persons we refer to as 'disabled people') and argue that it is necessary to shift the gaze of contemporary scholarship away from the spotlight on 'the disabled' to a more nuanced exploration of epistemologies and ontologies of ableism. As part of this project of exposure - my second task then will be to tease out the strands of what I have termed internalised ableism that produce a docile disabled body. Finally, as part of a commitment to make the necessary connections between theory and practice, I look at the ways an ethos of ableism plays out in the arena of law, in particular tort liability law. My case study relates to that development in tort law known as wrongful birth/life litigation.

4.1 Shifting the Gaze - Exposing Ableism

> The operation of foreclosure is tacitly referenced in those instances in which we ask: what must remain unspeakable for the contemporary regimes of discourse to continue to exercise power? (Butler, 1997: 139)

Typically literature within the social sciences and disability studies fields has concentrated on the practices and production of disablism, specifically by examining those attitudes and barriers that contribute to the subordination of people with disabilities in liberal society. Disablism is a set of assumptions and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities. As Susan Thomas puts it:

> Like sexism or racism, disablism can operate consciously or unconsciously, directly or indirectly, and may be acted out in social interactions between individuals or may be institutionalized and embedded in organizational structures. (1999: 40).

On this basis the strategic positions adopted to facilitate emancipatory social change whilst diverse, essentially relate to reforming those negative attitudes, assimilating people with disabilities into normative civil society and providing compensatory initiatives and safety nets in cases of enduring vulnerability. In other words, the site of reformation has been at the intermediate level of function, structure and institution in civil society and shifting values in the cultural arena[84]. As Harlan Hahn (1986) testifies there is a close link between the attitude of paternalism, the subordination of disabled people and the 'interests' of ableism:

> Paternalism enables the dominant elements of a society to express profound and sincere sympathy for the members of a minority group while, at the same time, keeping them in a position of social and economic subordination. It has allowed the nondisabled to act as the protectors, guides, leaders, role models, and intermediates for disabled individuals who, like children, are often assumed to be helpless, dependent, asexual, economically unproductive, physically limited, emotional immature, and acceptable only when they are unobtrusive (Hahn, 1986: 130).

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[84] The scaffolding of this analysis is contained in a four-tier framework: "The governing of disability in Australia" I developed within my honours thesis. It is contained in Appendix 1.

There is, as I probably don't need to explain, a proliferation of disability industries. Indeed disability is big business[85] - we, people with disabilities need to be serviced, classified, rehabilitated, treated, helped and studied. You can even have a career in disability without ever having to become disabled!

In fact people with disabilities remain one of the most studied heterogeneous groups in the western world[86]. Such an emphasis produces scholarship that contains serious distortions, gaps and omission regarding the production of disability and erases and at the same time re-inscribes an able-bodied voice/lens towards disability. Disability, often quite unconsciously, continues to be examined and taught from the perspective of the Other (Marks, 1996: 70). The challenge then is to reverse, to invert this traditional approach, to shift our gaze and concentrate on what the study of disability tells us about the production, operation and maintenance of ableism. For instance, in my own teaching I often ask students, what does the study of the politics of 'deafness' tell us about what it means to be 'hearing'? Indeed how the very conceptualisation of 'hearing' is framed in the light of discourses of 'deafness'. This re-orientation can be summarised in diagrammatic form (Figure 4):

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[85] For an interesting insight on the business of rehabilitation see: Albrecht (1992).

[86] This trend on primarily focusing on 'the disadvantaged' is not unique to disability issues. For instance in the Australian context there exists a great deal of scholarship about the formation of poverty and little on the formation of wealth and that group known as 'the rich'.

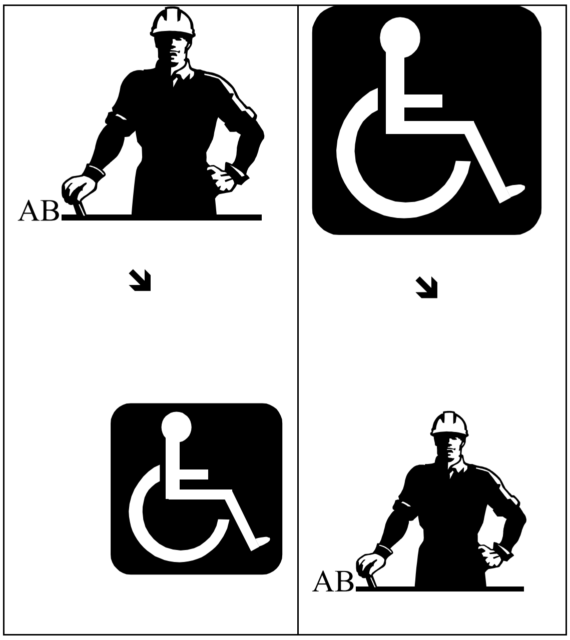

Figure 4: Inverting the Gaze

My pedagogical method of shifting the gaze finds agreement in the work of British scholar Tom Shakespeare. Shakespeare concludes, "… perhaps the maintenance of a non-disabled identity … is a more useful problem with which to be concerned; rather than interrogating the other, let us de-construct the normality-which-is-to-be-assumed" (1999: 28). This approach has similarly been adopted by U.S. scholar Simi Linton (1998: 13) who uses the concept of non-disabled strategically to re-centre disability: "Disabled is centered, and non-disabled is placed in the peripheral position in order to look at the world from the inside out …" in order to unveil the 'non-disabled/ableist' stance which in a different context Haraway exclaims " …cannot be said quite out loud, or it loses its crucial position as a pre-condition of vision and becomes the object of scrutiny" (Haraway, 1989: 152).

So what is meant by the term, the concept of ‘ableism’? For some the term ableism is used interchangeably with the term disablism. I argue however that these two words render quite radically different understandings of the status of disability to the norm. Furthermore, as a conceptual tool, ableism transcends levels of governance related to procedures, structure, institutions and values of civil society and locates itself clearly in the arena (at the level) of genealogies of knowledge. At the outset of our discussions, it is important to refute an essentialised understanding of ableism. It is not my intention here to propose ableism as another explanatory ‘grand narrative’, a meta - concept. In other words, I am not suggesting a universalised and systematized conception of disability oppression[87]. Rather, as I have maintained that by ableism I refer to

> … a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then, is cast as a diminished state of being human (Campbell, 2001b: 44).

Simi Linton commenting on a recent dictionary definition that defines ableism as a kind of discrimination in favour of able-bodied people adds that this also “includes the idea that a person’s abilities or characteristics are determined by disability or that people with disabilities as a group are inferior to non-disabled people” (1998: 9). Thomas Hehir provides us with a tangible and ‘cutting’ example of the way ableism reveals itself:

> … the devaluation of disability results in societal attitudes that uncritically assert that it is better for a [person] to walk than roll, speak than sign, read print than Braille, spell independently than use a spell check, and hang out with nondisabled [people] as opposed to other disabled [people] … In short, it is preferable for disabled [people] to do things in the same manner as nondisabled [people] (Hehir, 2002: 3).

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[87] As a conceptual tool, by ableism I am not referring to a system of oppression where a particular “enemy” can be identified and rooted out. Rather as my definition indicates, ableism refers to a convergence of networks that produce exclusionary matrices and ontologies. Indeed the players in the government of disability may change; other formations such as the use of regimes of law and medicine remain constant.

Linton (1998) however points out that unlike discourses of racism and sexism, there is little consensus amongst the general public (and I add scholars) as to what practices and behaviours constitute ableism. We can nevertheless, say that a chief feature of an ableist viewpoint is a belief that impairment or disability (irrespective of 'type') is *inherently* negative[88] and should the opportunity present itself, be ameliorated, cured or indeed eliminated.

Some of these definitions need to be teased out further. There are problems with simply endorsing a schema that posits a particular worldview that either favours or disfavours dis/able-bodied people as if each category is discrete, self-evident and fixed. Rather, I argue that my own formulation of ableism not only problematises the signifier disability but points to the fact that the essential core of ableism is the formation of a naturalised understanding of the characteristics of being fully human. Of course the semantics change in each disciplinary field. Such a naturalised body is spoken of in the world of techno-science as the 'species typical body', or in political theory as the 'normative citizen', in law as the 'reasonable man' and in theology as 'perfected creation' - all in all these signifiers point to a fabrication that reaches into the very soul that sweeps us into life and as such is the outcome and instrument of a political constitution: a hostage of the body (Foucault, 1977a). As such the figuration of bodies and genealogies within histories are irrevocably fused, as Foucault puts it

> We believe, in any event, that the body obeys the exclusive laws of physiology and that it escapes the influence of history, but this too is false. The body is moulded by a great many distinct regimes; it is broken down by the rhythms of work, rest, and holidays; it is poisoned by food or values, through eating habits or moral laws; it constructs resistances. "Effective" history differs from traditional history in being without constants. Nothing in man - not even his body - is sufficiently stable to serve as the basis for self-recognition or for understanding (Foucault, 1984c: 87).

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[88] Here it is important to acknowledge different degrees of degradation.

From this perspective, bodies are regulated through the use of disciplinary power, which produces the subjectifications of "ableness" and aberrancy (read: disabled). The creation of such regimes of ontological separation, appears disassociated from power, and are achieved through the use of three disciplinary techniques: hierarchical observation, normalising judgement and examination (Nettleton, 1995: 113 - 114). Bodies in this way become elements that may be moved, used, transformed, demarcated, improved and articulated with others (Foucault, 1977a: 136, 164). Indeed, this transformative process produces knowledge of the individual and the conditions of their existence. Their subjectivities are shaped by techniques that govern use, gesture, movement and positioning of the body (Foucault, 1977a: 152).

Central to regimes of ableism are two core elements that feature irrespective of its localised enactment, namely the notion of the *normative* (and normate individual[89]) and the *enforcement* of a *constitutional divide* between perfected naturalized humanity and the aberrant, the unthinkable, quasi-human hybrid and therefore non-human. This constitution provides the layout, the blueprint for the scaling and marking of bodies and the ordering of their terms of relation. Let's take each of these two elements separately and explore them more closely.

The corporeal Otherness of the 'disabled body' is integral to discourses of ableist normativity in order to establish the boundaries of 'normal' and 'pathological'. As Georges Canguilhem (1978: 69) puts it, "every generality is the sign of an essence, and every perfection the realization of the essence, … a common characteristic, the value of an ideal type". Inscribing certain bodies in terms of deficiency and essential inadequacy privileges a particular understanding of normalcy that is commensurate with the interests of dominant groups (and as we will see later, the assumed interests of subordinated groups). Indeed, the formation of the normate individual depends upon the self of 'disabled' bodies being rendered beyond the realm of civility, thus becoming an unthinkable object of apprehension. The unruly, uncivil, disabled body I argue is necessary for the reiteration of the 'truth' of the 'real/essential' human self who is endowed with masculinist attributes of certainty, mastery and autonomy - the perfectible God-made man. Marcel Detienne summarizes this system of thought aptly:

> [Such a] …system is founded on a series of acts of partition whose ambiguity, here as elsewhere, is to open up the terrain of their transgression at the very moment when they mark off a limit. To discover the complete horizon of a society's symbolic values, it is also necessary to map out its transgressions, its deviants (Detienne, 1979: ix).

Detienne's summation in the context in which I am writing, points to what we may call the *double bind of ableism* when performed within western neo-liberal polities. The double bind folds in on itself – for whilst claiming 'inclusion', ableism simultaneously always restates and enshrines itself. On the one hand, discourses of equality promote 'inclusion' by way of promoting positive attitudes (sometimes legislated in mission statements, marketing campaigns, equal opportunity protections) and yet on the other hand, ableist discourses proclaim quite emphatically that disability is inherently negative, ontologically intolerable – and in the end a dispensable remnant. As Judith Butler remarks in the open quotation to this section, this casting results in an ontological foreclosure wherein positive signification of disability become unspeakable – disability can't be thought of/spoken about on any other basis than the negative. To do so, to invoke oppositional discourses, to undertake acts of resistance; is to run the risk of further pathologisation, trivialisation, appropriation and recuperation by (and from within) hegemonic ableist networks. So to explicate ourselves out of this double bind we

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[89] In other parts of the thesis I also refer to this 'normate individual' as the 'benchmark body/man'. I use these characterisations interchangeably – they are one and the same in terms of composition.

need to persistently and continually return to the matter of disability as negative ontology, as a malignancy, that is, as the property a body constituted by what Michael Oliver refers to as, “the personal tragedy theory of disability,” A conception in whose terms disability cannot be spoken of as anything other than an anathema. On the personal tragedy theory, Oliver notes, “disability is some terrible chance event which occurs at random to unfortunate individuals” (Oliver, 1996: 32).

This is not to say that the experience of traumatic impairment such as spinal cord injury does not, at least in the initial stages, result in grief and anxiety. Rather those experiences of impairment in the early stages may be figured in terms of tragedy and crisis, in the longer term however, that experience is a catalyst for new understandings of embodiment and subjectivity (Seymour, 1998: 178). My argument is that insofar as this conception of disability is assumed within discourses of ableism, the presence of disability upsets the modernist craving for ontological security.

The conundrum disability/impairment is not a mere fear of the unknown, nor an apprehensiveness towards that which is foreign or strange (the subaltern). Rather, disability and disabled bodies are effectively positioned in the nether regions of ‘unthought’. For the ongoing stability of ableism, a diffuse network of thought depends upon the capacity of that network to ‘shut away’, to exteriorise, and unthink disability and its resemblance to the essential (ableist) human self. As Foucault (1994 orig. 1970: 326) explains:

> The unthought (whatever name we give it) is not lodged in man [sic] like a shrivelled up nature or a stratified history; it is in relation to man, the Other: the Other that is not only a brother but a twin, born not of man, nor in man, but beside him and at the same time, in an identical newness, in an unavoidable duality.

In order for the notion of ableness to exist and to transmogrify into the sovereign subject, the normate individual of liberalism, it must have a constitutive outside – that is, it must participate in a logic of supplementarity. Foucault can be excused for his rather constrained view of twin hood; however when looking at relations of disability and ableism we can expand his notion of symbiosis, an 'unavoidable duality' by further putting forward another metaphor, that of the mirror. Here I argue that people deemed disabled take on the performative act of mirroring in the lives of normative subjects. Uma Narayan's analysis of the formation of third world subjects and her understanding of the processes of mirroring explain this dynamic further:

> To be a Mirror is different from being a Face that looks back … with a range of expression and responsiveness that are responses of a Subject-in-Its-Own-Right. To be positioned as a Mirror is to be Put Out of Countenance, to Lose Face (Narayan, 1997: 141).

In this respect, we can speak in ontological terms of the history of disability as a history of that which is unthought, to be put out of countenance; this figuring should not be confused with erasure that occurs due to mere absence or exclusion. On the contrary, disability is always present (despite its seeming absence) in the ableist talk of normalcy, normalization, and humanness. Indeed, the truth-claims that surround disability are dependent upon discourses of ableism for their very legitimation. The logic of supplementarity infused within modernism's unitary subject, and which produces the Other in a liminal space, deploys what we may call a "compulsion towards terror:" a terror, ontological and actual, of 'falling away' and 'crossing over' into an uncertain void of dis-ease.

It is time then to turn our attention to that other core element of discourses of ableism, namely the necessity to establish and enforce a constitutional divide. The divide is at the levels of ontology, materiality and sentiency. In many respects, I have already begun talking about a constitutional divide, or at least a particular example of one, the normal and the pathological. However, here I wish to focus on the constitutionality of that divide and the mechanisms of ordering. Here my analysis is influenced by the proposals advanced by sociologist Bruno Latour in *We Have Never been Modern* (1993) and John Law's paper *Political Philosophy and Disabled Specificities*[90] (1999).

Latour's main proposition is that post-enlightenment modernity and atomistic man have never been modern, for the concept of modern delineates two sets of independent practices that must remain distinct in order for them to work/function. In recent times, Latour suggests, these practices have begun to be less clear and ambiguous. The practices that Latour speaks of are translation and purification:

> … 'translation', creates mixtures between entirely new types of being, hybrids of nature and culture. The second, by 'purification': creates two entirely distinct ontological zones: that of human beings on the one hand; that of nonhumans on the other (1993: 10 - 11).

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Figure 5: Purification and Translation

Source: Latour (1993: 11).

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[90] See also earlier works (Law, 1992; 1994b).

‘Translation’ is based on the notion that structures or networks are not axiomatic or self-contained. They are, as Law describes, “… like scaffolding on a building-site, but a site of struggle, a relational effect that recursively generates and reproduces itself” (Law, 1992: 5). The hybrid mixtures of translation are affected within networks that imply “transformation and the possibility of equivalence, the possibility that one thing …. may stand for another” (Law, 1992: 6). Latour (1993) uses the example of a chain flowing from the upper atmosphere, industrial strategies and onto the concerns of government and greenies. ‘Purification’ in contrast, engages in the creation of divides of ontological distinctions, which espouse a foundational (almost first cause) self-evidence. Here, Latour cites that partition between nature (as self contained), nonhumans and culture (created and driven by humans). This ‘modern critical stance’, as Latour calls it, acts as the ethos or template of modernity.

In the context of ableism, Latour’s schema proves helpful. For aside from ableism’s double bind, other perplexing, disjointed and seemingly contradictory movements occur. The devices of translation and purification can assist us to grapple with that which seems ‘unholdable’ and elusive. The fact is that the processes and practices of translation cannot be separated from the creation of that ordering category termed ‘disability’. In Chapter 6 “*Disabled Bodies in Process – the Nemesis of Technologies*” the practices of translation as they apply to the world of technoscience are discussed in detail. Without pre-empting that discussion, we can say that for many people deemed disabled their relationship with non-human actants has been profoundly cyborgical and hybridisable[91]. Such networks of association between human – non human (sentient beings and machines) I argue have always been and increasingly are pushing the boundaries of the practices of purification.

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[91] For example and not limited to: Communication and adaptive devices, implants and transplants.

Indeed Shildrick (2000) describes the fear induced by the disabled body as a body out of control because of its appearance of uncontainability. And whilst the practices of translation continue as an emergent property of relationality its dialectic (for want of a better word) remains concealed, hidden and unacknowledged. The practices of purification insist on this being the case – in this instance, ableism's constitutional divide posits two distinct and entirely clear ontological zones: disabled and abled (normate). Latour (1993: 11) explains

> …without the first set, the practices of purification would be fruitless or pointless. Without the second, the work of translation would be slowed down, limited, or even ruled out. … So long as we consider these two practices of translation and purification separately, we are truly modern – that is willingly subscribe to the critical project, even though that project is developed only through the proliferation of hybrids down below. As soon as we direct our attention simultaneously to the work of purification and the work of hybridization [translation], we immediately stop being wholly modern, and our future begins to change.

The challenge then is to look at the interactivity between the processes of purification and translation, or in Latour's words "to look … [at] the social construction of techniques and not a hypothetical 'social context'…" (Latour, 1992: 229), in particular investigate what this interactivity clarifies and obfuscates. Even though Latour (1993, esp 39- 43) claims that purification is not an ideology in disguise, I would assert that the existence of processes of purification creates a fabrication or a simulation if you like, of the conditions of naturalism[92]. In contemporary developments in high-tech and biotechnologies, it is occasionally possible to witness the glitches in the purview of purification, whether that is in the debates over transhumanism, xenotransplantation or the emergent of new 'life' in the form of artificial intelligences (A.I's).

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[92] Latour's discussion of whether relations are "conscious and unconscious, formal or informal, language and practice and illusion and reality" (1993: 40) is an important one. He concludes that moderns are not unaware of what they do, rather it is the holding steadfast to dichotomies, the divides, that makes possible the processes of translation. We can by analogy, argue that matters of intentionality or discourse and so forth, are not critical to the emerging technologies of ableism, but rather it is the act of holding stoically to the distinction between ableness and disabledness.

Later on, as if in anticipation of the reader's confusion, Latour points out the ultimate paradox of this modern constitutional divide is that whilst the proliferation of hybrids is allowed for, at the same time this constitution continues to deny the very existence of hybrid entities within its formulation (Latour, 1993: 34). Contemporary conditions suggest that it is not the event of denial that is operational; rather the 'place' or significance given to such ambiguous entities that disrupt the rather neat demarcation zones. Practices of purification continue to rein in (successfully or otherwise) the chaos created by increasing 'grey zones' along the continuum of human/nonhuman difference.

The fortunes of techno-science continue to disrupt the fixity of defining disability and normalcy especially within the arenas of law and bioethics[93]. The significance of the enforcement of a constitutional divide, from the perspective of our study of the practices of ableism, is that such orderings are not just repressive but they are ultimately productive; they tell us stories, they contain narratives as to 'whom' we are and how we 'should be'. In other words, as John Law rightly concludes: " … ethics will derive from ontology. And ontology, what there is, is being made at least in part in narratives" (Law, 1999).

In the closing pages of *We Have Never been Modern* (1993: 136 -137), Latour argues that as science creates new definitions of being human, these new formations do not displace the older versions rather humanism is redistributed. I am not entirely convinced of this emergent multiplicity and expansion of ontologies of humanness. In fact as we shall see in my chapter six discussion on transhumanism, contra Latour, Hayles (1999) argues that should sentiency be conceptualised on the basis of *informationalcy* this new rendering would amount to a profound shift in the theoretical markers used to categorise

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[93] These aspects are considered extensively in the later part of Chapter Five as well as Chapter Six.

all life (or what is 'life'). Rather, in the following chapters I attempt to show that in this moment there is a rallying of networks scurrying to squeeze new ontological formations of dis/ability into 'old' systems of ordering and thus attempt to avoid re-cognising an abundance of (post marginal, post peripheral) morphisms. Anthropomorphism becomes the catch cry of ableism. Whilst the journey into morphism connotes an axis of 'evil' as such a venture denies life to that constitutional divide implicated in an ableist worldview.

As Latour (1993: 137) rejoices:

> Morphism is the place where technomorpisms, zoomorphisms, phusimorphisms, ideomorphisms, theomorphisms, sociomorphisms, psyomorphisms, all come together. These alliances and their exchanges, taken together, are what define the anthropos. A weaver of morphisms - isn't that enough of a definition?"

4.2 Unravelling Internalised Ableism and the Docile Disabled Body

> Raised to know I was blind but taught to disavow it, I grew bent over like the dry tinder grass. I couldn't stand up proudly, nor could I retreat. I reflected my mother's complex bravery and denial and marched everywhere at dizzying speeds without a cane. Still, I remained ashamed of my blind self, that blackened dolmen. (Kuusisto, 1998: 7)

> The 'naturalness' of the notion of the abled-bodied liberal individual coupled with the negation of a disabled sensibility makes many disabled people queue for the chance to be anointed as 'people first', whilst simultaneously disavowing their previous embodied positions as 'gimps;' and 'cripples'. Ironically, disabled people who achieve 'people first' status are not achieving full normative status but are only legitimizing an able-bodied resemblance through their desire for normality. (Overboe, 1999: 24)

In Chapter Three I already alluded to some of the difficulties writing histories of disability, especially those histories that document acts of resistance by people considered disabled and those oppositional discourses of disability. This section will discuss another aspect of that challenge hitherto underdeveloped in disability studies scholarship, namely what I term *internalised ableism* or disabled self-hatred. My thinking with respect to these themes is informed by that large body of scholarship related to internalised racism within postcolonial and Afro-American studies (Fanon, 1967; Fanon, 1982; hooks, 1990; hooks, 1994a; hooks, 1994b; McClintock, 1995; Said, 1978; Said, 1993).

In my Honours year dissertation (Campbell, 1998), I first made the connections between epistemologies of ableism and the production of internalised ableism. The context was a discussion concerning Social Role Valorisation Theory (SRV) as articulated by Wolf Wolfensberger and the point of focus was an explicit strategy of discouraging/refusing contact/fellowship amongst persons with disabilities. This strategy of dispersal[94] is based on the belief that disabled people should not draw attention to ourselves/themselves; in other words, not 'stand out'. It is held that our/their value and self-esteem will increase (Szivos, 1992: 121) via 'mixing' (with Other people/able-bodied). This mitigation campaign has a familiar ring in the histories of other marginalized populations such as indigenous, coloured, gay and lesbian peoples. I argued in that thesis that the consequences of dispersal unfortunately are likely to produce internalised ableism because being in the presence of other people with impairments (especially those similar to one's own) would be seen as 'bad thing'. Writing in the context of Jewish women, Penny Rosenwasser defines what she terms 'internalised oppression' as

> … an involuntary reaction to oppression which originates outside one's group and which results in group members loathing themselves, disliking others in their group, and blaming themselves for the oppression – rather than realizing that these beliefs are constructed in them by oppressive socio-economic political systems (Rosenwasser, 2000: 1).

The key ingredients then, are a distilling of negative ontologies of human signification into the processes of subjectification, that act as regulatory norms; ultimately shaping and

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[94] See also Chapter 5.3.

inspiring technologies of self and the ways such technologies become mediated within a range of networks:

> Internalized oppression is not the cause of our mistreatment; it is the result of our mistreatment. It would not exist without the real external oppression that forms the social climate in which we exist. Once oppression has been internalized, little force is needed to keep us submissive. We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives. (Mason, as cited Marks, 1999:.25)

In other words, internalised oppression and in our case, internalised ableism means that in order to assimilate into the norm (real humanity), the individual *referentially* disabled is required to embrace, indeed to assume an 'identity' other than one's own[95] – and this subject is repeatedly reminded by epistemological formations and individuals with hegemonic subjectifications of their provisional and (real) identity. The desire to emulate the Other (the norm) is contemporaneous with a process of impairment disavowal, an attempt to establish and maintain a widen gap between that/those which are loathed and that which is desired. Such disciplinary techniques need not be coercive as Foucault points out individuals often "voluntarily" bring about subject-constitutional arrangements themselves by way of engaging technologies of the self that

> permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection or immortality" (Foucault, 1997d (orig 1982).

It is clear that the processes of internalisation are not straightforward and predictable. The formation of internalised ableism cannot be simply deduced by assessing the responses of individuals to Althusser's famous interpolative hailing "Hey you, there" (1979). Whilst a subject may respond to "Hey you there, crip!" – it is naïve to assume

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[95] I am not wishing to imply here that subjects have a true or real essence. In fact the subjects' formation is in a constant state of flux, multiplicity and (re)formation. However I argue that subjects (with disabilities) often feel compelled to fabricate 'who' they are – to adopt those postures and comportments that are additional to self.

that an affirmative response to this hailing repressively inaugurates negative disabled subjectification. In fact the adoption of a more positive or oppositional ontologies of disability by the subject in the question may unexpectedly enable in some way. As Susan Park (2000: 91) argues "what is at stake here is not so much the accuracy behind the hailing privilege, but the power of the hailing itself to instantly determine (or elide) that thing it is naming". Nonetheless, censure and the cancellation of the legitimacy of oppositional subjectivities remains common place as Cherney reminds us with respect to Deaf culture: "If abnormal [sic] bodies must be fixed to fit within dominant cultural views of appropriateness then the Deaf celebration of their differences must be read as an illegitimate model of advocacy". (Cherney, 1999: 33).

Foucault's (1976; 1980c; 1983) theorization of power as productive may provide some offerings from which to build a conversation about internalised ableism. I am not so much interested in the 'external'[96] effects of that power, but for the moment wish the concentrate on what Judith Butler aptly refers to as the 'psychic life' of power[97]. She describes this dimension:

> … an account of subjection, it seems, must be traced in the turns of psychic life. More specifically, it must be traced in the peculiar turning of a subject against itself that takes place in acts of self-reproach, conscience, and melancholia that work in tandem with processes of social regulation (Butler, 1997b: 19).

In other words, the processes of subject formation *cannot be* separated from the subject him/herself who is brought into being though those very subjectifying processes. The consequences of taking into oneself negative subjectivities not only regulate and continually form identity (the disabled citizen) but also can transcend and surpass the

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[96] Here I am not meaning to institute a false dualism of the internal versus the external, rather to point towards the interior life and away albeit momentarily, from matters of social policy and law.

[97] Foucault refers to this as the autonomous process of care for the self. (1988b: 50).

strictures of ableist authorizations. Judith Butler describes this process of the "carrying of a mnemic trace":

> One need only consider the way in which the history of having been called an injurious name is embodied, how the words enter the limbs, craft the gesture, bend the spine …how these slurs accumulate over time, dissimulating their history, taking on the semblance of the natural, configuring and restricting the doxa that counts as "reality". (Butler, 1997: 159)

Yet some philosophers such as Linda Purdy contend it is important to resist conflating disability with the disabled person:

> My disability is not me, no matter how much it may affect my choices. With this point firmly in mind, it should be possible mentally to separate my existences from the existence of my disability. Thus I could rejoice, for instance, at the goal of eradicating nearsightedness, without taking that aim as an attempt to eradicate me, or people like me (Purdy, 1996: 68).

The problem with Purdy's conclusion is that it is psychically untenable, not only because it is posited around a type of Cartesian dualism that simply separates being-ness from embodiment, but also because this kind of reasoning disregards the dynamics of subjectivity formation to which Butler (1997; 1997b) has referred. Whilst the 'outputs' of subjectivity are variable, I argue that the experience of impairment within an ableist context *can* and *does* effect formation of self – in other words 'disability *is* me', but that 'me' does not need to be enfleshed with negative ontologies of subjectivity. Purdy's bodily detachment seems to be locked into a loop that is filled with internalised ableism, a state with negativised views of impairment, from which the only escape is disembodiment, the penalty a denial is a flight from her body. My conclusion finds agreement in the reasoning of Jean Baudrillard (1983; 1988) who posits that it is the simulation, the appearance (representation) that matters. The subject simulates what it is to be 'disabled' and by inference 'abled' and that simulation in effect whilst morphing ableist imperatives – performs a new hyperreality of be-ing disabled. Disabled people by performing ableism unwittingly (maybe?) become complicit in their own demise – reinforcing impairment as an outlaw ontology.

Before proceeding any further, I need to stop and clarify this argument because my reasoning and your reading about subjectivity occurs always in context. Much of the discussion about 'disability *is* me' raises another seemingly related claim that I believe requires comment, albeit brief, namely the matter of immutability. In recent years claims for minority rights protections, especially within the Federal arena of law in the United States, have been based on immutability argument in opposition to cultures or identities of 'choice' (Currah, 1995). The argument suggests that when individuals or populations have an attribute that is inherent and unable to be removed (e.g. colour and race) that there is a stronger claim for civil rights entitlements than claims being pressed by groups where referentiality can be chosen or changed (e.g. the controversy of 'homosexual' orientation is an often cited example). Within this illusionary binary world of fixed or chosen corporeal attributions the status of impairment is not so clear. Impairment inheres within the body (or mind, cognition and so forth) however impairment despite being often characterised (etiologically) as 'permanent' is in a broader sense 'provisional'. Impairments exist in a state of constant deferral, being open to the interventions of psycho-medical regimes posting corrections, cures or indeed non-existence. The question of the settlement of disability, on the basis of post-immutability claims reappears with the emergence of a new epistemological knowing of disability, referred to as 'voluntary' or 'elective' disability, which will be discussed in chapter Five, section Four.

Butler's description of the process of injurious naming/speech finds expression in some of the debates about the linguistic naming of disability. For instance, in the United States and Australia the term 'people with disabilities' is preferred in order to emphasis personhood over impairment. Whilst in the United Kingdom a conscious decision has been made by advocates of the Social Model of disability to use the expression 'disabled people' in order to foreground the lived experience of people becoming disabled by incorporation of such an identity. One profoundly disturbing example of the 'carrying of a mnemic trace' can be found in media reports of disabled people requesting euthanasia as an 'out' to living with an impairment, a request only to be endorsed by euthanasia advocates who assume the 'naturalized' intolerability of disability. Ableism and internalised ableism even seeps into how we make sense of such a request. Because disability is seen as a problem in itself, the desire to commit suicide is often seen as natural when the requestor is disabled. Carole Cleigh, in a piece about women who 'completed suicides' using equipment designed by Dr. Jack Kevorkian, not only argues that the women she researched were disabled and not terminally ill, she also argues that the forces of ableism contributed to the naturalization of these suicide 'choices'. Cleigh (2001) concludes:

> One can easily imagine these people [women who completed suicides] expressing internalized oppression by telling a friend or relative that they no longer saw much purpose in life. Their suicide talk was taken seriously. But, unlike a nondisabled person whose suicide talk is taken seriously and then helped, thereby prevented from suicide, these people met with a particularly virulent form of ableism – the "better dead than disabled" variety.

In the case of disability subjectification, the internalisation of negative ontologies of disability not only contribute to the formation of a docile and readily pliable disabled body, but continue in a variety of ways to inhibit performances of disability acceptance and rehabilitation so demanded by the inclusivist impulses of liberal contract theory. Internalised ableism can mean the disabled subject is caught so to speak 'between a rock and a hard place' in order to attain the benefit of a 'disabled identity' one must constantly partake in a process of disability disavowal[98], aspiring towards normativity, a state of

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[98] Whilst acknowledging the early work on Fred Davies (1961) on the matter my approach is distinctive in that it moves beyond a symbolic integrationist, individualised perspective and adopts a stronger focus on ontological concerns within a philosophical and epistemological schema of ableism.

nearly ablebodiedness, or at a bear minimum at the least to effect a state of 'passing'. As Kimberlyn Leary (1999: 85) puts it:

> Passing occurs when there is perceived danger in disclosure. At its most extreme, it is a form of camouflage to sequester the self from expected trauma. Its represents a form of self-protection that nevertheless usually disables, and sometimes destroys, the self it means to safeguard.

The workings of internalised ableism by way of 'passing' are only possible when viewed more broadly, moving away from a focus on the impaired individual to the arena of relationships. For it is in the interactivity with the norm (such as an ableised able-bodied person) that another form of erasure is required. Ableist passing is not just about the person with impairment hiding their impairment or morphing their disability; ableism involves a failure to ask about difference, in this instance, disability/impairment. For internalised ableism to occur there needs to be an existing *a priori* presumption of *compulsory ableness* (or at least the aspiration of, illusion to). An example of 'passing' under these circumstances, would be the large of numbers of university academics with impairments who hide their impairment or disability status because of fears of stigma and tenure discrimination despite the facts that many argue that they and others would benefit from disability focused mentoring and networking arrangements[99]. My argument is sustained by an account given in Chapter Seven wherein amputee women undergoing rehabilitation are expressly discouraged from 'flaunting' their stumps to avoid such exposures causing distress.

Let us consider the case of a newly injured man with a spinal cord injury. As part of a case management plan, the rehabilitation client not only focuses on learning new ways of undertaking activities of daily living (ADL) he is also working on psycho-social

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[99] This conclusion is anecdotal and represents a summary some of the conversations within a recently formed network of academics with disabilities in Australia and New Zealand.

adjustment issues of living in an 'injured body' in a (non-injured) bodied world. As part of the recovery and restorative process, the young man is taught to emulate the norm, to like (read: accept) his body but not necessarily 'love' his disability, to embark on rehabilitation in order to nearly walk or to at least to 'come to terms' with non-walking. Vic Finkelstein's reflection on his own journey through rehabilitation is pertinent:

> The aim of returning the individual to normality is the central foundation stone upon which the whole rehabilitation machine is constructed. If, as happened to me following my spinal cord injury, the disability cannot be cured, normative assumptions are not abandoned. On the contrary, they are reformulated so that they not only dominate the treatment phase searching for a cure but also totally colour the helper's perceptions of the rest of that person's life. The rehabilitation aim becomes to assist the individual to be as 'normal as possible'. The result, for me, was endless soul-destroying hours at Stoke Mandeville Hospital trying to approximate to able-bodied standards by 'walking' with callipers and crutches. (Finkelstein, quoted in Oliver, 1993: 16 - 17).

Whilst successful rehabilitation may be measured in terms of personal care management, employment retraining and placement, the *benchmark* of successful inclusion is the acquisition of new skills for performing the part(s) of a disembodied abled self. My point here is that whilst there can be no denial of an injured body on the part of rehabilitation professionals and the injured client, a way out of the strictures of injury is to adopt and emphasize those aspects of self and subjectivity that are able to mimic the qualities of ableist personhood. The corporeality of the disabled body is constantly in a state of deferral, in a holding pattern, awaiting the day it will be not just repaired but made anew (cured). Until then, the conditions of fabrication, of mimicking the abled body are usually of the disembodied kind because it is assumed that a flight from the body will act as a distraction towards those assimilating qualities of social conduct and deportment. In time rehabilitation personnel will be able to re-create corporeal normalcy by way of rebuilding or morphing the injured body to a form that for all intents and purposes replicates the old (whole) form (see Chapter Six).

So far I have been talking about the consequences of a psychic internalisation of negative ontology norms. However, it is possible to make a distinction between these kinds of situations and the use of negative identities, or 'wounded attachments'[100] *instrumentally* in order to advance and engage with social injury claims (see Chapter 5.4.2). In Chapter Five I discuss the need for all people in liberal democracies to have what I term an 'enumerative passport' – a document, an authorizing classification that tells you and others 'who' and 'what' you are in order to pass through and negotiate access to goods and services, especially targeted funding and coverage under anti-discrimination legislation. In the case of 'impairment' or 'disability', whilst the disability rights movement and the discipline of disability studies continue to deconstruct and problematise formulations of disability, at the level of daily performance some kind of identity needs to be secured in order to function and be governed. Wendy Brown summarises the situation of the quest for rights and treacherous enforcement of identities:

> …rights secure our standing as individuals … they must be specific and concrete in order to reveal and redress … subordination, yet potentially entrench our subordination through that specificity; they promise increased individual sovereignty at the price of intensifying the fiction of sovereign subjects …they promise to redress our suffering … but only by fracturing that suffering – and us – into discrete components, a fracturing that further violates lives already violated by the imbrication of racial, class, sexual, [ableist], and gendered power. (Brown, 2000: 238).

As I will show in the following section in this chapter and again in chapter five, the very categories, classifications and definitions for the marking out of 'impairment' and/or 'disability' are predicated on negative ontologies and ableist conceptions. So the act of strategic essentialism (utilising labels to access social benefits) which might initially seem commendable and even viewed as an act of subversive resistance, also brings into itself acts of 'self-subversion', wherein passports of recognition become passports of unfreedom for it can be difficult to 'hold up the dyke' between negative ascriptions and

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[100] This phrase was coined by Wendy Brown in 1993. See (1993)

negative internalised incorporations (in other words, a little bit of negativity 'rubs off'). Tracy Strong explains this process more fully:

> Identity … does not consist of an active component, but is a reaction to something outside; action in itself, with its inevitable self-assertive qualities, must become something evil; since it is identified with that against which one is reacting. The will to power of slave morality must constantly reassert that which gives definition to the slave: the pain he [sic] suffers by being in the world. Hence any attempts to escape that pain will merely result in the reaffirmation of painful structure. (Strong, quoted in Brown, 1995: 69 - 70).

What started out as an attempt to not only gain benefits but potentially usurp the forces of enumeration and calculation in the governing of disability, often ends up becoming complicit, reproducing the constitutional ontologies and separations essential to the continued power of ableism. It should be clear now that such strategic essentialism is not without its dangers and pitfalls especially when the disability assignation carries with it the seeds of negative internalisation. The deployment of the disability signifier strategically cannot be undertaken without some incorporation of internalised ableism, be that at the level of consciousness or unconsciousness. People living with impairment face life with these two dynamics dilemmatically co-existing, sometimes jostling in tension, even when adopting outlaw and resistant subjectivities and lifestyles[101].

In the next sub-section of this chapter this problem of using pre-existing categories and epistemologies of disability that posit impairment as inherently negative are discussed in detail. The case study is drawn from that area of tort law known as wrongful birth and life actions.

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[101] I would like to acknowledge and thank my doctoral examiner Mike Michael for clarifying this point.

4.3 Case Study: Disability and Tortuous Liability – Wrongful Birth/ Life Actions

> Wrongful life and wrongful birth case law is plagued by folk demons and moral panics in the same way that increasing knowledge of human genetics brings with it inchoate fears of eugenic excess and monstrosity. (Mackenzie, 1999: 178).
>
> … the good advocate grasps at complex confused reality and constructs a simple clear-cut account of it … a case is very much an edited version [and] it is not just edited into a minimal account – a microcosm of the incident – it is an account edited with vested interests in mind … The good advocate is not concerned with reproducing incidents but producing cases, not with truth but with persuasion. (McBarnet, 1983: 17).
>
> It is understandable that a parent desires to have not only a healthy, but also a beautiful and intelligent baby: the best and the happiest baby in the world. At the same time, however, nobody can be sure that a healthy child will be a happy person, nor that a disabled person will necessarily be an unhappy person. (Marzano-Parisoli, 2001: 659).

Impairment, in particular impairments that are multiple and of a severe nature, requires extensive resources in order for the person concerned (and often, their families) to have full equalization of opportunities and a reasonable "quality" of life. The provision of supports and financial assistance from governments though the welfare system are becoming less available and when available considerable time delays are involved. As a last resort, many people with disabilities are looking towards the courts by way of case law for remedies that provide financial solutions.

The use of the law of torts is one area of civil law that is increasingly being tested in Europe, North America and Australia. This sub-section specifically relates that a specialized area of tort known as 'wrongful pregnancy, birth or life' actions. My approach to this case study is developed within the context of former discussions in this chapter related to ableism. In this sub-section I conclude that what is objectionable about the use of these tort categories is not the quest for compensation/financial support by families of people with disabilities and disabled people themselves; rather my objection relates to the processes of accessing law. The plaintiff and their legal team are required to 'trade in symbols', in particular trade in negative ontologies of disability in order to argue wrongdoing and claim compensation. Discussion begins with an outline of the fundamentals of torts, in particular wrongful birth/life actions, and then moves onto a consideration of legal reactions overseas and in Australia. The final part of this section looks at the broader philosophical and social policy impacts of using this particular area of tort law.

4.3.1 The Basis of Torts

Torts are civil 'wrongs' recognized by law as grounds for a legal action. These 'wrongs' result in an injury or 'harm' constituting the basis for a claim by the injured party. Whilst some torts have criminal penalties attached, the primary focus of tort law is to provide remedies for the damages incurred and deter others from committing similar 'harms'. The injured person may sue for an injunction to prevent to continuation of the tortuous conduct or for financial compensation (damages). Among the types of damages the plaintiff may recover are: loss of earning capacity, pain and suffering, and medical expenses deemed 'reasonable'. The assessment of damages includes both present and future expected losses. A number of elements need to be satisfied in order to test the validity of bringing a tort action:

a. The existence of a duty of care owed by the defendant to the plaintiff;

b. A breach of that duty;

c. A proximate chain of causation between the misfeasance[102] of the defendant and the "harm" suffered by the plaintiff; and

d. damages (Hersch, 1983: 134; Ossorio, 2000: 309).

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[102] Doing something in a way that falls short of a required standards and so amounts to negligence (Nygh and Butt, 1997: 261).

4.3.2 Fundamentals of Wrongful Birth and Life Actions

Two concepts that have gained a level of notoriety under common law legal systems are the torts of 'wrongful birth' and 'wrongful life'. For the sake of simplicity, 'wrongful birth' (hereafter referred to as WB) involves cases when the plaintiffs, the parents of the child with impairment, sue for wrongful birth on the basis of misdiagnosis or a failure to detect a so-called 'genetic defect'[103]. In this kind of action the 'wrong' or 'harm' is that the child herself constitutes a damage, in other words the birth of the child is a form of physical injury (Somerville, 1983). In the United States some State courts (twenty-four in total) have recognized a WB action whilst other States, notably Michigan and Georgia, have ruled them invalid[104]. Claims for WB actions are fairly established in Canadian jurisdictions (Nelson and Robertson, 2001: 103) the lead case being *Arndt v. Smith*[105]. In Australia this tort has been recognized by some State courts in a limited way (see, *Veivers v Connolly 1994*[106] in QLD and *CES v Superclinics (Aust) Pty Ltd 1995*[107] in NSW).

Whereas, the concept of 'wrongful life' (hereafter referred to as WL) involves an action brought by the child (or indeed adult) with impairment on the basis that the individual is born with a 'impairment'[108] due to the actions or omissions of a doctor or another party who owes a duty of care to the said child. Hersch (1983: 133) argues for a further division of wrongful life actions by proposing two classes, namely pre conception 'but for the doctors negligence the plaintiff would not have been born' and post conception

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[103] These cases are sometimes referred to as 'wrongful conception' cases, although his distinction is sometimes blurred (Weybury and Witting, 1995: 53).

[104] See Appendix 3.

[105] (1994), 21 C.C.L.T. (2d) 66 (B.C.S.C.); (1997), 148 D.L.R. (4th) S.C.C.).

[106] (1994) Aust Tort Reports 81 – 309.

[107] (1995) Aust Tort Reports 81 – 360. (CA NSW).

[108] The languages in these cases is often less civil – preferring more medicalized language such as 'defect', 'defective', 'abnormality'.

'but for the doctors negligence the plaintiff would not have been born impaired, or would have been terminated if the 'impairment' had been detected'.

Few jurisdictions in the United States recognize WL as a basis for action. In fact twenty-three state courts have rejected WL claims, whilst eight state legislatures have prohibited WL claims by statute. The lead case claiming a 'wrongful life' action is *Curlender v. Bioscience Laboratories*[109]. Whilst the English courts specifically rejected this basis for action in *McKay v. Essex Area Health Authority and Anor* (1982)[110]; the Italian Court of Verona[111] recognized this right in a limited way, as has the Cour de Cassation in France[112]. In the Australian context, courts have rejected 'wrongful life' actions based on following the English precedent established in *McKay* (1982). *Mc Kay* was applied in (NSW) *Bannerman v Mill (1991)*[113] and (QLD) *Veivers v Connolly (1994)*[114]. In March 2002 law firm Maurice, Blackburn, Cashman unsuccessfully attempted to test a WL action on behalf of three plaintiffs with impairments in the Supreme Court of NSW (see 'postscript' at the end of this section). Elizabeth Collins (1983-1984: 701) provides a summary of the fact situations characteristic of WL claims in the United States:

a. Dissatisfied life;
b. Incorrect sterilization procedures;
c. Unsuccessful abortions;
d. In cases of pre-conception negligence, parents are denied information on the possibilities giving birth to a child with impairment; and
e. Due to the post-conception negligence of a health professional, parents are denied the option of "avoiding" a child's birth.

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[109] 165 Cal.Rept. 477 (1980), appeal denied 2 Civ. 58192 (Sept.4, 1980)

[110] (1982) 1 QB 1166; (1982) *All ER* 771.

[111] (*Valentini c. Castaldini*, 15/10/1990).

[112] Exp Perruche c/ Mutualle d'assuance du corps sanitaire francais et al (Cour de Cassation, arret n. 457 P, Juris-Data n. 006884, 17.11.2000

[113] Aust Torts Reports ¶81 – 079.

[114] Aust Torts Reports ¶ 81 – 309.

The differences in legal reasoning between the two concepts I believe are significant[115], with WB actions claiming that the birth per se is wrongful (not the 'disability'), whilst the latter, WL invites the suggestion that life with an 'impairment' is inherently harmful – in other words, courts are asked to rule on whether life with an 'impairment' is preferable to the non-existence of life itself (Botkin, 1988; Butler, 1992).

4.3.3 Legal Reactions – the United States

In the United States of America Wrongful Birth/Life cause of actions are mainly negligence torts and as such is jurisdictionally the responsibility of state common law. In other words, the argument presented and relevant precedent followed in tort differs from state to state. This section makes no attempt to review tort law in this area on a state-by-state basis, rather in this section I wish to track and discuss key themes in legal reasoning by the courts. The earliest attempt to bring about a WL cause of action (not on the basis of impairment) occurred in 1963 in the case of *Zepeda v. Zepeda*[116] subsequently denied by the US Supreme court in 1964. Since that date a number of attempts, some successful, have been made to have WL cause of actions recognized by various state courts (see Appendix 3). It is worthwhile to examine, albeit briefly, some of the argument introduced by plaintiff to support their claim of WB/WL and the response to these claims by the courts.

The New Jersey Supreme Court in 1967 heard the first WL case based on 'impairment' as an injury or harm. In *Gleitman v. Cosgrove*[117], the WL cause of action was claimed in conjunction with a WB action by the parents. The plaintiffs sued Mrs. Gleitman's doctor

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[115] In section 4.3.4. I present argument by other commentators that suggest the difference between *WB* and *WL* is artificial or negligible.

[116] 41Ill.App.2d 240, 190 N.E. 2d 849 (1963), cert denied, 379 U.S. 945 (1964). In that case a child sued her own father because she was born illegitimately, and alleged harm on that basis.

[117] 49 N.J. 22, 227 A.2d 689 (1967).

for failing to inform her that the rubella she contracted in the early stages of her pregnancy would in all probability lead to foetal impairment thus denying her the obtaining of an abortion. The mother, Sandra, sued for the 'emotional distress caused by her son's birth defects'; and Irwin Gleitman the father, sued for the costs that would be incurred in caring for their child, whilst the child Jeffrey Gleitman, sued for his 'birth defects'. The court's reasoning was based on the presupposition that every child has the right to be born a whole, functioning human being, and because of the alleged actions of the doctor this right was being denied. On the basis of such reasoning, the Court proceeded to argue that since this right has been infringed, the plaintiff being born with impairment, that the harm was (an impaired) life itself, which would have been resolved by the intervention of a termination, but for the negligence of the doctor:

> The infant plaintiff is therefore required to say not that he should have been born without defects but that he should not have been born at all … but for the negligence of the defendants, he would not have been born to suffer with an impaired body. In other words, he claims that the conduct of defendants prevented his mother from obtaining an abortion which would have terminated his existence, and that his very life is wrongful … Ultimately, the infant's complaint is that he would be better off not to have been born (Gleitman, at 692).

Adding insult to injury, it becomes clear that the Court in *Gleitmen v. Cosgrove* held to a belief in the inherent intolerability of impairment and acted as a de facto mediator of the experience of the impaired person from an ableist perspective:

> It is basic to the human condition to seek life and hold on to it however heavily burdened. If Jeffrey could have been asked as to whether his life should be snuffed out before his full term of gestation could run its course, our felt intuition of human nature tells us that he would almost surely choose life with defects against no life at all (Gleitman, at 693).

Despite this argument, the Court rejected the cause of action brought by the plaintiffs on the grounds that the sanctity of human life in the end prevailed and on the basis of another argument, namely the difficulty in measuring damages:

> The normal measure of damages in tort action is compensatory. Damages are measured by comparing the condition the plaintiff would have been in, had the defendant not been negligent, with plaintiff's impaired condition as a result of negligence. The infant plaintiff would have us measure the difference between his life with defects, against the utter void of non-existence, but it is impossible to make such a determination. This Court cannot weigh the value of life with impairments against the non-existence of life itself. By asserting he should have not been born, the infant plaintiff makes it logically impossible for a court to measure his alleged damages because of the impossibility of making the comparison required by compensatory remedies[118]. (Gleitman, at 692).

The Californian case of *Curlender v. Bioscience Laboratories* (1980)[119] provides an early example of support for a WL cause of action by the courts. The plaintiff was born with Tay-Saches disease. There was no suggestion in this case the defendant caused the disease. Rather the plaintiff argued that the laboratory that incorrectly processed her parent's genetic tests were in part responsible for bringing her into the world (Chwang, 1997). The plaintiff argued and the court accepted that the she was seeking damages for her existence in an 'impaired' state rather than for her birth. The court recognized being born in an impaired state was cognisable at law:

> We construe the 'wrongful life' cause of action by the defective child as the right of such a child to recover damages for the pain and suffering to endured during the limited life span available to such a child and any pecuniary loss resulting from the impaired condition. (Curlender, at 489).

Despite the precedent decision in *Curlender*, Brenda McGiven (2002: 57) points out two other cases[120] during the same time frame that provide a significant US authority supporting a contrary view to the reasoning given in *Curlender*. The states of New Jersey, California and Washington[121] whilst denying a plaintiff a WL cause of action based on the comparing an impairment existence to non–existence, have recognized the cause of action in a more limited and prescribed way, namely the costs of medical and

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[118] See also another Californian case: *Turpin v Sortini*, 31 Cal. 3d 220, 643 P.2d 954, 182 Cal. Rptr. 337 (1982).

[119] 165 Cal.Rept. 477 (1980), appeal denied 2 Civ. 58192 (Sept.4, 1980)

[120] *Berman v Allan* 80 NJ 421; 404 A 2d 8 (1979) and *Azzolino v Dingfelder* 315 NC 103; 337 SE 2d 528 (1985).

[121] *Procanik by Procanik v Cillo* 478 A.2d 755 (N.J. 1984); *Turpin v Sortini*, 31 Cal. 3d 220, 643 P.2d 954, 182 Cal. Rptr. 337 (1982); *Harbeson v Parke-Davis, Inc.*, 656 P.2d 483 (Wash. 1983).

other support services. As Butler (1992: 884) argues these factors are “easily calculated and therefore should be awarded to the child who can prove these damages”. In *Procanik by Procanik v Cillo*[122] (1984) the New Jersey court held:

> Our decision to allow the recovery of extraordinary medical expenses is not premised on the concept that non-life is preferable to an impaired life, but is predicated on the needs of the living. We seek only to respond to the call of the living for help in *bearing the burden* of their affliction (Procanik, at 763 – my emphasis).

Wrongful life suits continue to be presented to various state courts with mixed success. Even when courts have recognized the high costs of rearing and providing medical care to children/adults with disabilities they have concluded that legislation (and not the courts) is the best mechanism to bring about policy change[123].

4.3.4 Legal Reactions Australia

In cases where no Australian precedent exists, the courts in Australia have turned to the decisions made by courts in the United Kingdom. Increasingly, though being weaker in authority, decisions made in higher courts in the US have had a persuasive influence in the absence of domestic cases. There has been a dearth of cases related to either WB or WL in either Australian state or commonwealth courts. Table 3 provides a summary of relevant cases to date. The lead case in terms of a WL cause of action can be found in the English case of *McKay v. Essex Area Health Authority and Anor* (1982)[124]. Because of Australian courts reliance on *McKay* for the development of domestic judgments I will provide an outline of significant point of reasoning. But before doing so, I want to refer back ten years to an earlier case heard in the Supreme Court in Victoria, *Watt v Rama* (1972)[125].

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[122] 478 A.2d 755 (N.J. 1984)

[123] *Taylor v Kurapati*, No. 204908, CA 1999 Mich. App LEXIS 170 (June 25); and *Etkind v Suarez*, S98G1978, 1999 Ga. LEXIS 627 (6 July).

[124] (1982) 1 QB 1166; (1982) *All ER* 771.

[125] [1972] V.R. 353.

Traditionally negligence law has deemed that a foetus has no separate existence (until it is born) apart from its mother and therefore is not legal person to whom a duty of care is owed (Hersch, 1983, 134). In *Rama,* Justices Winneke and Pape held that on the child's birth, the child experienced an injury such that *ex post facto* a duty of care was owed by the defendant (at 360). This judgment opened up the possibility for a cause of action to be brought on the basis of an injury suffered by a foetus *in utero* as a result of the negligence of a health care professional. In both Australian and English law the decision in *McKay* represents the most significant expression of judicial opinion of the matter of wrongful life causes of action. In *McKay* the appellant was a child who was born partially deaf and blind and experienced a range of other impairments as a consequence of her mother contracting rubella in the early stages of pregnancy.

TABLE 3: Wrongful Birth/Life Causes of Action in Australia

UK precedent (WL): *McKay v. Essex* (1982) ↓ ↓ *Bannerman v Mill* (1991) - NSW *Veivers v. Connolly* (1994) – QLD	**Post-Conception**: *Rama v. Watt* (1972) – VIC Ruled: ex post facto duty of care to a fetus
First case WB: *CES v Superclinics* (1995) – NSW **Most Recent WL:** *Edwards v Blomeley* (2002); *Harriton v Stephens* (2002) and *Waller v James (2002)* - NSW	**Duty to Disclose**: *Bolan v Friern Hospital Management Committee* [1951] 1WLR 582 *Howarth v Adey* [1996] 2 VR 535 *Rogers v Whitaker* (1992) 175 CLR 479

As in the US case of *Gleitman*, the mother had been tested for rubella and had been told that on the basis that her tests results were negative she could safely continue her pregnancy. The child sued the health authority arguing that the doctor was negligent for failing to advise the mother to have an abortion. Put another way the doctor was negligent for allowing her to be born. The plaintiff argued that her life with impairment was injurious and therefore sought damages. The court rejected this cause of action; Ackner LJ summarizes the court's reasoning:

> I cannot accept that the common law duty of care to a person can involve, without specific legislation to achieve this end, the legal obligation to that person, whether or not in utero, to terminate his existence, such a proposition runs wholly contrary to the concept of the sanctity of life. (McKay, All ER at 787).

Public policy considerations feature sharply in the underlying reasoning behind the judgment, particularly the discourse of 'the sanctity of human life' asserting the primacy of foetal rights over procreative rights. It was on this basis that the plaintiff was unable to access damages when in order to so involved an "evaluation between non-existence and life even in a flawed [sic] condition" (at 155). Whilst public policy considerations related to the sanctity of life were elevated in the judgment this elevation also extends to valuing living with impairment. The *obiter dicta*[126] of Lord Justice Stephenson who delivered the lead judgment reveals a concern with the possibility of endorsing negative ontologies of disability by giving assent to WL claims. To sanction a WL cause of action would be to accede to the assumption "… that a child has a right to be born whole and perfect or not at all" (Stephenson, at 1181). The implication being that such reasoning might suggest that life with an impairment is less valuable than a 'normal' child and therefore not worth preserving (at 1180)[127].

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[126] Loosely translated as "comments on the aside".

[127] LJ Griffiths agreed with LJ Stephenson adding that WL actions were premised on the belief that the child is "…better dead than alive" (Griffiths, at 1193).

A final comment on a possible duty by a doctor that acceptance of WL cause of action might imply. Both LJ Ackner (at 1187) and Stephenson (at 1181) are concerned that endorsement of a wrongful life action would impose an 'intolerable burden' on doctors "to advise abortions in doubtful cases" and raise the possibility of children suing their mothers for failing to abort them. Instead of focusing on the fear of doctors being sued, Robin Mackenzie argues that the framework of reasoning in *McKay* is flawed: "the duty in *McKay* could have been framed in terms of a duty to inform the mother of likely handicap in order that she might make a decision whether to continue with the pregnancy" (Mackenzie, 1999: 181). This may well be an alternative approach, however I argue that the concern in *McKay* is still valid – for there is a real possibility of increased litigation by extending the basis of actions of negligence, to say nothing of the rise in medical negligence indemnity insurances.

The *ratio decidendi* in McKay was applied in the New South Wales case of *Bannerman v Mill* (1991)[128]. The facts of the case are similar to *McKay* and involve the plaintiff whose mother contracted rubella early in pregnancy. Master Greenwood in applying *McKay* argued that a WL action was "not known at common law [and it is not] possible to assess damages in monetary terms" (Bannerman, at 88) dismissed the claim.

The case of *Veivers v Connolly 1994*[129] whilst strictly a WB action, can be included in this discussion of WL actions. Susan Veivers, who had contracted rubella and had not been tested by her doctor when she presented with symptoms, brought a WB action. Veivers argued that had she known of the existence of rubella she would have terminated the pregnancy. Her daughter Kylie who experienced intellectual and physical disabilities

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[128] Aust Torts Reports ¶81 – 079.

[129] (1994) Aust Tort Reports 81 – 309.

initially brought a WL claim. The plaintiff at the court hearing abandoned this cause of action as "it was conceded that, in Australia, there was no legal authority for such an action. The court relied on an English decision, *McKay v Essex Area Health Authority*." (Fitzgerald, 1995: 194).

Three children who were born with "severe" impairments brought about a WL cause of action in the NSW Supreme Court on March 11 2002[130]. Alexia Harriton, 20, was born after her mother contracted rubella. Keeden Waller, a 17-month-old IVF baby, inherited a clotting disorder that could have been detected with screening and Chelsea Edwards, 2, was born after a failed vasectomy. David Hirsch, a solicitor from law firm Maurice Blackburn Cashman representing plaintiffs Edwards and Harriton, said the complaint was about "having to suffer the disabilities arising from being born" (Crichton, 2001). A key theme running through the submissions on behalf of the plaintiff prepared by Hirsche is that is that the terminology of WL is misleading (2002). Argument by counsel relied extensively on the judgment of the Maryland Court of Appeal in *Reed v Comapgnolo (*1993)[131] that objected to the use of the terms WB and WL:

> These labels are not instructive. Any 'wrongfulness' lies not in the life, the birth, the conception, or the pregnancy, but in the negligence of the physician. The harm, if any, is not the birth itself but the effect of the defendant's negligence on the [parents] resulting from the denial to the parent's of their right, as the case may be, to decide whether to bear a child or whether to bear child with a genetic or other defect. (*Reed*, at 237).

Lawyers in the case prefer the concept of 'wrongful suffering' as this concept does not imply that no life is preferable to an impaired one (Crichton, 2001). Furthermore, proponents of WB torts argue that with the increasing success of WB claims greater financial support will be provided to the families to assist with the extra costs of

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[130] *Edwards v Blomeley* [2002] NSWSC 460; *Harriton v Stephens* [2002] NSWSC 461; *Waller v James* [2002] NSWSC 462.

[131] 332 Md. 226, (1993).

impairment. Hirsche argues that a better way is to accede to WL actions because the money is given to the child directly: it is, after all, the child who suffers the 'life with disabilities' and has need created by this. (Hirsch, 2002: 25).

4.3.5 Summary of Grounds for Rejection of Wrongful Life Actions

In drawing together the subsections related to legal reactions, the grounds are a summary of the reasons courts are generally are apprehensive about granting a WL cause of action:

a) The sanctity of life in any form is preferable to non-existence, i.e. not having been born at all.
b) There is a difficultly measuring damages by way of a comparison to a party in a position where the injury had not occurred, i.e. comparison in terms could have been before existence.
c) Any WL cause because of its significant social policy concerns should be left to the legislature.
d) There is a limitation in using "rights" discourses in arguing for a right not to be born or the right to be born "normal".
e) Extending torts to WL could result in an increase in claims from people with "less severe" impairments or other bodily differences.
f) The medical profession would be subjected to "litigation frenzy" and an overwhelming rise in insurance premiums.

4.3.6 Ontological Outputs, Philosophical and Legal Implications

In this final sub-section of the case study examining wrongful birth/life torts, I focus broadly on ontological, ethical, legal and social policy implication of some the cases and commentary discussed in my study.

Ontology

Elizabeth Collins (1983-1984: 690 - 691) points out that claims for wrongful pregnancy, conception, birth and life are substantially claims about the 'wrongful formation' of the human person. Even though the right to determine the form of a child has not been established by the courts, Collins (1983-1984: 691, 704) argues that this right is often implied in instances when 'impairment' is created – that is the 'choice' to continue to carry or terminate a foetus with 'impairment(s)'. Interestingly the right to 'choice' of form is rarely countenanced in instances where prospective parents 'choose' to create a child with a specific impairment such as Deafness. (C.f. Griffith, 2002a; 2002b; and McLellan, 2002).

Continuing the argument related to form, bioethicist George Smith advocates that notions of 'sanctity of life' be dispensed with and replaced with the notion that children have a 'right to a healthy and body' (Smith, 1981: 82). In the New York case of *Becker v. Schwartz*[132] (1978) the court noted the difficulty of defining the standard of 'a perfect birth' (Becker, at 812). The whole basis of WB and WL ultimately rests on a comparison of the preferability of life with 'non-impairment' in relation to that constitutionally separated category of 'impairment' (see section 4.1).

Throughout many of the cases surveyed disability/impairment continues to be described in terms of 'bearing the burden of affliction', 'suffering', and an 'arduous responsibility'. It is my contention that the discourses of burden and negative ontology occur in both judgments that favour and dismiss WB and WL claims and that the continued use of negligence law in the terms of injury and harm will reinforce the negative associations of impairment. My conclusion is supported by some of the debate in the courts and

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[132] 386 N.E. 2d 807 (N.Y. 1978).

commentaries about the terminology of WB and WL. In an attempt to escape the loop of ‘birth and/or life’ Robin Mackenzie (1999: 182) proposes that WL actions be reframed in terms of a ‘diminished life’ cause of action. Hirsch (2002) argued in the NSW Supreme Court (see *Edwards* [2002]) that the concept of ‘wrongful suffering’ is more precise. Both these proposals, whilst attempting to reduce the stigma associated with WL and WB (and therefore impairment), really do not significantly alter the terrain of disability-talk, they simply replicate (and again reinforce) the idea of impairment as ontological intolerable and inherently negative[133].

Ethical considerations

A number of WB cause of actions ruled in favour of the plaintiff by reasoning that it is important to curb negligent behaviour on the part of medical professionals especially in the usage and processing of diagnostic and genetic tests. These judgments encouraged to use and correct administration of tests in order to facilitate ‘choice’ on the part of parents and to reduce some of the costs of supporting impaired persons. Some these arguments however conflate the use of prenatal tests with technologies of termination. It is assumed that a ‘positive’ result would lead to the choice of abortion and opposed to the exploration of other options.

I have already mentioned that in *McKay* there was concern over the potential for increased litigation when doctors did not advise abortion when a ‘defect’ is indicated. Such litigation ‘phobia’ could lead to instances where medical professionals are coerced into termination procedures as a first response, thereby acting out eugenics by proxy.

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[133] A recent paper by Emma Ganderton (2000) proposes assigning values to life (+) and life with defects(-) [sic] where the assumption was that the more ‘severe the deformity’ the greater burden and therefore the less valuable a life.

The focus of WL actions has predominantly been in cases where the defendant is a member of the medical and allied health professions. It is seems to me that in time with the mounting pressure of costs and the increased use of rhetoric of ‘mitigated disability’ (see Chapter Five) that an action will arise where a child/adult with impairment sue their mother for acting negligently in not terminating their existence (*in utero*) after being made aware of a foetal ‘defect’. Put more strongly, a woman who resists the ‘desirability’ of prenatal testing or the compulsion towards selective termination becomes a pariah, a carrier of a criminalized (negligent) womb (c.f. Karpin, 1994; Maher, 1991; and Mason, 2000). Her decision to knowingly continue a ‘defective’ pregnancy would be characterized as a form of ‘negligent foetal abuse’ (Smith, 1981: 113).

Law and Social Policy

One of the ‘big picture’ questions not addressed in the cases or commentaries concerns the relationship of these novel tort actions and broader concerns related to the welfare state and the relationship between common law cases and the legislature. The narratives of families and individuals with impairment point to the extreme difficulties of providing support and assistance to a family member with significant impairment, especially in terms of financial burdens. Any access of the validity of WB and WL claims needs to include also a discussion of the role of the State in providing assistance to those in need.

What is clear from the cases is that governments are falling short in this respect and families are left with little option but to pursue remedies within an uncertain and often costly setting of the courts. A number of the US courts have rejected WL claims arguing that such decisions are best made by the legislature. In the Australian context, these arguments I believe have merit. There needs to be a public debate about the costs of disability, the responsibility of government (and community) to provide for people with long term high support needs. Finally, in what seems a light at the end of the tunnel, Brenda McGivern proposes that the focus of the claims, namely WB and WL can be bypassed by "avoiding the need to plead injury at all". She argues, "actions for losses associated with negligent acts, but in the absence of injury, have long been recognized by Australian courts in claims for pure economic loss. In these cases, and in this instance, it has been argued that the protected legal interest … is financial security" (McGivern, 2002: 59). We shall have to wait and see.

Postscript:

Since 'finalising' this case study, the law in Australia regarding wrongful life torts has been reaffirmed. On the 12th June 2002, Justice Timothy Studdert of the New South Wales Supreme Court delivered his judgment on the wrongful life cause of action brought in *Edwards v Blomeley*[134], *Harriton v Stephens* and *Waller v James*. After undertaking a comprehensive review of case law to date both in Australia and in other relevant common law jurisdictions, Studdert J determined that to award damages on the basis of WL would erode the value of human life, and harm the self-esteem of people with a disability. In reviewing the argument that non – existence was preferable to existence with impairment, the legal reasoning of the judgment provides solace:

> …There are many disabled members of society who lead valuable and fulfilling lives notwithstanding their significant physical handicaps [sic] … To all such persons the notion that non existence may be considered preferable to living within disabilities would surely be perceived to be offensive (*Edwards*, at para 75).

The judgment concluded with a summary of three public policy considerations for the inadvisability of WL claims that concur with the argument I have presented in this case

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[134] *Edwards v Blomeley* [2002] NSWSC 460; *Harriton v Stephens* [2002] NSWSC 461; *Waller v James* [2002] NSWSC 462. Justice Studdert heard all three cases together but delivered three independent judgements. Edwards would be considered the lead case.

study namely, the sanctity of human life and the impact that WL claims would have on the self worth of disabled people and "their perceived worthiness by other members of society" (at para 119[ii]). Finally, the court argued that recognition of this category of tort would expose treating doctors and mothers who decided to continue with a pregnancy to liability for a tortuous legal action.

In Chapter Four I have attempted to provide a comprehensive study and analysis of the texture, production and practices of ableism. This discussion has included an assessment of the merits of ableism as an explanatory tool, the processes of internalised ableism in the lives of disabled people and finally, an exploration of the operation of the ableist notion of disability as inherently negative, as ontologically intolerable in tort law. In the following chapter, the research shifts focus (slightly) by examining specific themes related to the governing of disability within a post-enlightenment, neo-liberalist framework. In particular, the research critically analyses the ways disability and ableness are mediated within the domain of the welfare state.

DIVISION TWO: PRACTISED BODIES

Chapter 5 - Governing 'Disability' in the Spirit of the Enlightenment

Chapter Five sets itself an ambitious task, the writing of a kind of genealogy of the governance disability at the level of ideas, regimes of governance, in particular the site of law. In visualizing a cartography of disability, I have adapted the schema developed by Wood (1995: 41) to assist in the project of navigating disability across various networks of association. The mapping scaffold contains four levels of input, namely genealogies of knowledge; cultural arena (values/political philosophy); function, structure, institutions: governmental arena law and social policy and finally level four, the procedure and techniques of power[135].

This chapter explores the mechanisms of governing disability within the Australian and International context. I first examine the tenets of liberalism that inform processes of governmentality, in particular the ethos of freedom so attractive to exponents of liberal rights discourses/strategists. The chapter then moves onto a discussion of the 'in-vogue' management practice of mutual obligation to highlight the limitations of liberalism's inclusivist ethic. As part of our inquiry into the techniques of managing disability this chapter also considers the roles and relationships between practices of enumeration (the counting of cripples) and epistemologies of biomedicalism and the way in which these networks converge to shape the ground of what it means to be 'human' as well as 'aberrant'. In the day-to-day, the production and management (disciplining) of disability (and the disability business) is operationalised through the utilization of Social Role Valorisation Theory (SRV) within social policy and programmes. Within the purview of

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[135] The mapping model is in diagrammatic form in Appendix 1.

this chapter's theme this section attempts to expose SRV's role in maintaining the fabrication of liberalism's inclusive dynamic and yet at the same time ensuring the continuation of disability as negative ontology and the preferability of so-called ableist existence. The final section of Chapter Five brings together our investigations into the government of disability so far, by looking at the way understanding of disability are produced in law and the way patterns of convergence and resistance take place over various formations/formulations of disability.

5.1. The Ableist Sovereign Subject of Liberalism

> … my sense (is) a) that the term 'subject' is best understood as the equivalent of what I call colligated subject positions and b) that the term 'individual' is ideologically designed to give the false impression that human beings are free and self-determining, or that they are constituted by undivided and controlling consciousness (Smith, 1988: xxxv).
>
> An able-bodied and competent person is thus a body with a set of given functions, skills and properties, which are steered by a central command unit – the consciousness – which is situated in the head. Agency, mobility, the ability to communicate verbally, to make discretionary judgments make decisions and implement them – is thus located in the body and in the self residing in that body (Moser, 2000: 205).

This section discusses the continuities and discontinuities of the formation of the Western self and foregoing concepts of 'personhood'– and how these notions relate to matters of citizenship, participation in governance and notions of perfectibility and 'worth'. It is not however meant to be an extended recitation of the 'self' within western philosophy[136]. Rather, my discussion will be confined to those elements of the liberal subjectification that build up a picture of a hegemonic sovereign self that is inherently ableist.

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[136] Literature here is vast. (Mackenzie and Stoljar, 2000; McCall, 1990; Ransom, 1997; Schneewind, 1998; Schrag, 1997; Strong, 1992)

Probably one of the most influential figurings of enlightenment 'man' can be found in the 1784 tract by Immanuel Kant entitled '*What is Enlightenment*?'(Kant, 1996). In that piece, Kant brought together an exposition of the relationship of full personhood to matters of reason and autonomy[137]. For Kant the essence of the enlightenment spirit could be summed up in the slogan *Sapere aude*! 'Have courage to use your own reason!' This quality supposedly offers the resolution (justification) of conflicts between knowledge and power. As Jane Flax (1992: 447) puts it

> … reason both represents and embodies truth. It partakes of universality in two additional ways: it operates identically in each subject and it can grasp laws that are objectively true; that is, are equally knowable and binding on every person …

Such truths contain the instructions of comportment; how to act in the world or as Foucault would express it, encode 'technologies of self.' The bearer of reason, the disembodied and universalised he-man can arrive at a 'view from nowhere'[138]; find authentic enlightenment by discerning the true [objective] nature of things. Matters of bodily locatedness and situated knowledges are easily sidestepped, reduced to the status of persona non-gratia. The universal reach of reason[139] gains potency when coupled to a self-assured individual autonomy. Reason as truth becomes discourse dependent and in turn generates notions of 'disability' and 'ability' (able-bodiedness). The human (adult) subject is assumed to be an independent centre of self-consciousness, who holds autonomy to be intrinsically valuable.[140] Neo-liberalism's normative (autonomous) citizen in the words of C.B. Macpherson (1964: 3) is a nominal 'possessive individual':

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[137] D'Agostino points out that whilst Kant maybe the precursor to this conception of autonomy, most liberal theorist such as Rawls, Habermas and Raz would be in agreement. (D'Agostino, 1998: 29)

[138] Coined by Thomas Nagel (1986).

[139] According to Kant, reason is universal in the sense that men may come to know the nature of things over time, thus giving birth to a developmental model of human be-ing.

[140] I am not convinced by the instrumentalist value of autonomy alone. For liberalism's autonomous sovereign subject invokes a certain moral personhood.

> free in as much as he [sic] is proprietor of his person and capacities. *The human essence* is freedom from dependence *on the will of others, and freedom is a function of possession* … Society consists of relations of exchange *between proprietors* (emphasis added).

This imaging of the neo-liberal subject insists that all people fit Macpherson's regulatory ideal. It is probably more correct to say that the thrust of shaping identity is geared towards a 'best fit', normalizing or morphed approach. The tool of comparison, of normativity is the 'benchmark man,' the normative citizen who is

> …the paradigmatic incarnation of legality who represents the standard against whom others are measured and who is invariably White, heterosexual, able-bodied, politically conservative, and middle class (Thornton, 1996: 2).

In turn, philosophical formulations of autonomy are often associated with particular conceptions of freedom. For the moment though we can say that autonomy is "the capacity to formulate and pursue plans and purposes which are self-determined" (Stainton, 1994: 21). On this basis, autonomy as a form of self-rule becomes problematic in certain stances for person's whose state of being differs from the norm[141]. John Law (1999) reminds us of the consequences and harshness of liberalism's formulation of legitimate personhood:

> … if a person measures up, or can be made to measure up, in these respects, then they become competent. If not, then they fail. All of which is, to put it mildly, a drastic divide. A divide, then, which resonates with the liberal concern with persons: but also operates as its dark side.

5.1.2 Autonomy as Freedom – a Recapitulation of Ableist Subjectivity?

Citizenship is a status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties with which the status is endowed. There is no universal principle that determines what those rights and duties

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[141] See also D'Agostino (1998).

shall be, but societies in which citizenship is a developing institution, create an image of an ideal citizenship against which achievement can be measured and towards which aspirations can be directed. (Marshall, 1963: 87)

Within contemporary Western, neo-liberal societies, freedom is held to be an inalienable and inherent right of the atomistic individual citizen. Indeed, the ethos of freedom is a foundation of the politics of our present, a mark and effect of justice and the other virtues of practice democracy —that is, a measure of a society's true worth, of the degree to which it is 'civilized'[142], and the extent to which it is 'advanced'. People who live in Western neo-liberal democracies are seduced into freedom, the utopian dream that holds within itself a promise, that is, the vision of an alternative way of living. For disability activists in particular, and for many of the other folk who live on the underside of liberalism, the ethos of freedom has performed as a source of emancipation which contains a promise to address 'social injury'. As Wendy Brown (1995: 7) reminds us, however, there is a paradox inherent to freedom: the incitement of freedom requires the very structures of oppression that freedom emerges to oppose.

In recent times, the practices of freedom have been moulded and codified into the apparatus of the welfare-state, citizenship and legal personality. In the terms of this apparatus, freedom is represented as autonomy, where this ideal encompasses the drive towards potential maximization, which invokes the performance of a choosing, desiring, and consuming subject. The 'free' citizen is one who can take charge of herself – to act

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[142] At least in the sense of 'negative' liberty and more recently 'positive' liberties encapsulated within human rights regimes. C.f. Duncanson (1994: esp pp 29-33) and Stainton (1994: esp. pp 9 – 16).

as her own command centre. Such techniques of self are not usually imposed but rather sought[143], as we are all enrolled into the task of self-appropriation and designation[144].

A drive towards self-mastery, may mean that it is not possible for some disabled people to be truly 'free' within the confines of liberalism unless some protectionist (paternalist) strategy or ethics of 'care' be employed. In any case, the sovereign subject will not be destabilized until we dismantle and refute 'autonomy'[145] as the basis for normative legal theory and revise the meaning of 'humanness' in terms of relationality. Indeed, Carole Pateman points out that to advocate for extension of 'citizenship' within the dominant understanding of autonomy and other characterizations is in effect to agree or acquiesce to the male stream meaning of the 'citizen' (Pateman, 1989: 197). Until we accomplish these theoretical and political tasks, we will be left with the task of managing or governing 'disability' in ways that that ensure its presence only minimally disrupts the truth-claims of legal discourse and its systematisation.

Under liberalism, production and governing of disability is facilitated, in part, through its taming into a mere logical and discrete etiological classification and ensuing ontological space. The performative acts of a 'logic of identity' reduce the disparity and difference of disabled bodies to a unity (see Foucault, 1980b: 117). In law, we find this logic of identity expressed in the ideal of impartiality, which is predicated upon the benchmark

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[143] Just as many of people of colour have experienced internalised racism by living within an environment of hegemonic whiteness, many of us with 'impairments' have had to wrestle with an *internalised ableism*, a view that suggests disability is *inherently* negative disallowing any prospects of 'pride'. By being denied access to celebratory representations, disability self-hatred often invokes the desire to 'pass' and assume an (albeit fabricated) ableist posture.

[144] In order to access goods and services and have coverage under 'disability laws', the individual is required to move towards a 'best fit' with the definitional parameters of what constitutes disability. This process of subjectification not only produces and reiterates of her own notion of self but also results in the reproduction of herself (ontologically) as a 'disabled subject'. The process of resisting such signification is fraught with danger. One consequence may be a de-legitimisation of bodily difference and a banishment to further peripheral zones of social life.

[145] For a good summary of the impact of 'autonomy' theory on 'intellectual' disability consult Stainton (1994).

legal subject. Although a great deal of feminist literature (Cheah et al., 1996; Grbich, 1992; Howe, 1994; O'Donovan, 1997) has critiqued this allegedly impartial figuring of the legal subject, that work has not addressed the ableist underpinnings of that subject. A more thoroughgoing analysis of 'legal man' would extend the reasoning of those feminist critiques to incorporate ableism as a key characteristic of rampant masculinist subjectivity. Without ableism, masculinist figurings would (we might say) 'lose their balls'.

The implications of classifying practices go even deeper than this sort of critique suggests. For the unruly, monstrous, and boundary-breaching qualities of disability must be tamed in ways that distinguish that category from other fluid and leaky categories (such as illness, poverty, and ageing) with which it is associated (see Shildrick, 1997; Shildrick and Price, 1998; Wendell, 1996). Corporeal slippages of the disability kind need containment, a civilized workability for procedural justice, and a regulated liberty that produces practices of normality, rationality, and pathology[146] . This regulated liberty is exemplified in the continued use of intelligence tests to separate the 'eligible' from the 'ineligible' within international and national[147] disability legislation (despite serious concerns about the validity of such tests)[148]. Nevertheless, disability is not only catachrestic, but is also contestable. Thus, I submit that matters, which should be regarded as ontological in character, are inextricably bound up with the politics of

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[146] Rose (1992), Canadian Law & Philosophy Professor's work on the bio-medical model and its convergence with law as 'gatekeeper' is useful here. Bickenbach (1993b) esp. Chapter 3, pp 61-92.

[147] For instance, Section 8(1)(b) of the *Intellectually Disabled Persons' Services Act 1986* (Victoria, Aus.) States that an assessment of eligibility be performed by use of "one or more standardized measurements of intelligence."

[148] In an early text, Scheerenberger (1983) points to some of the difficulties which arise when I.Q. tests are used to institute distinctions between "mild degrees of mental retardation [sic] and normality." The shifting of mental-age goal-posts has resulted in 50% of the white population in the United States being rendered "intellectually disabled." Scheerenberger writes that "even the most ardent advocates of mental tests did not want the percentage of mentally retarded persons to deviate significantly from approximately 2 or 3 per cent of the general population."

inclusion. Linton (1998: 10) adds weight to this conclusion when she suggests that insofar as "the term 'disability' is a linchpin in a complex web of social ideals, institutional structures, and government policies," many people have a vested interest in maintaining a tenacious hold on its current meaning, which is "consistent with the practice and policies that are central to their livelihood or their ideologies."

Let us consider what the embeddedness of disability implies for understandings of that category and the ways in which disability figurations are mediated in law. The working model of inclusion is really only successful to the extent that people with disabilities are able to 'opt in', or be assimilated (normalized)[149]. This model of inclusion assumes that the people who cannot, do not, or otherwise refuse to, 'opt in', will developmentally progress towards autonomy over time. Indeed, the governing of liberal unfreedom responds to the problem of what should be done with 'governing the remainder', that is, those who are identified as 'less than fully autonomous' (Hindess, 2000). Hindess identifies three approaches that are taken to governing 'the remainder'. They are: (1) a clearing away;[150] (2) the compulsion towards disciplinary techniques (for example, the normalization principle); and (3) targeting external causes by creating welfare safety nets. In order to institute such 'dividing practices' (Foucault, 1983: 208) of subjectivity, the aberrant subject may be extinguished (either before or after birth); be 're-appraised' (for instance, fabricated as a 'rehabilitated person'); become nearly able-bodied (via a morphed passing); or become benevolently transfigured into a 'deserving' welfare recipient *supra* the economy.

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[149] Commonly concepts such as 'integration' are construed in terms of assimilation. This is not surprising given the dominance of Social Role Valorisation Theory (SRV) or the normalization principle within human services.

[150] See Campbell (2000a) and (2000b).

Law plays an exacting and explicit role in this subjectifying activity of government. Legal intersections/interventions facilitate this subjectification by allocating and regulating populations into fixed and discrete ontological categories (such as disability, gender, sex, race) in order that the subjects assigned to those categories can be rendered visible and calculable (Foucault, 1976: especially 135 - 159; Foucault, 1994 orig. 1970). The fixity of disability (which is assumed to be a pre-given property of human bodies) within both legislative and case law not only establishes the boundaries of permissible inquiry it also establishes the legal fiction of 'disability' in the first place. It is this reification of disability (frequently based on bio-medical technologies and ascriptions) that reinforces the centrality of the ableist body and the terms of its negotiation. The formulations of disability often engaged by disability activists and enshrined in disability related law, in effect discursively entrench and thus reinscribe the very oppressive ontological figurings of disability that many of us would like to escape[151]. Alternative renderings of disability, if they are not able to 'fit' such prescribed 'fictions,' are barred from entry into legal and other discourses. Consider, for instance, the instructions given in a recent staff survey produced by the Equity Section of Queensland University of Technology (QUT) (2000). The QUT equity survey instructs:

> You should answer 'yes' to question 2 only if you are a person with a disability which is likely to last, or has lasted two or more years. Please note that if you use spectacles, contact lenses or other aids to fully correct your vision or hearing, you do not need to indicate that you are a person with a disability, and would answer 'no' (emphasis added).)(Equity Section Queensland University of Technology, 2000).

As we can see can see, defining disability in terms of what it 'is' and 'is not' performs an emblematic function that re-cognises the relationships between impairment and disability and civil society.

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[151] For comparisons in the area of gay law reform, see Morgan (1996)

5.1.3 'Governing the Remainder': Bound by Mutual Obligation

This sub-section is an exploration of Hindess' (2000) third category of governing the remainder through the creation of welfare safety nets. Of interest is the place of disabled people as fully endowed citizens. Australia's particular brand of welfare liberalism is characterized by a residual orientation[152] primarily reliant on paid employment with a sharply targeted (restrictive) safety net of benefits for individuals who for 'no fault of their own' are not in the paid workforce[153]. The residualist approach means that even those groups provided with assistance are positioned out-of-bounds of citizenry – they are, so to speak, 'remainders', euphemistically labelled welfare recipients[154]. Further study of governing through mutual obligation is critical as such strategies are closely linked to discourses about ontological differences and human valuing. The residualist position finds expression in the Federal Liberal government's welfare position based on a notion of 'deserving charity' rather than a neo-liberal 'rights' model:

> the principle objective of the social welfare system must be to ensure that people who are in genuine need receive adequate assistance, especially when circumstances beyond their control may prevent them from helping themselves [emphasis added] (Ruddock, 1994: 7).

When Shadow Minister for Social Security, Phillip Ruddock, explained this perspective further:

> [It] is to protect and care for those people who are genuinely needy and disadvantaged in our community. We remain committed to a welfare system that is a genuine 'safety net', not a 'hammock' nor a trampoline'. Proper targeting is essential to ensure this aim [emphasis added] (Ruddock, 1994: 12).

The reference to a 'trampoline' suggests that welfare's role is perceived as providing a 'stop-gap' rather than as a vehicle for substantive advancement. Ruddock's position,

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[152] Residual versus institutional welfare. Cf. Bryson (1992: 55 - 64).

[153] For an overview of Australia's welfare system from a Foucaultian perspective, consult Harris (2001).

[154] Whilst the rebirth of welfare contractualism offers the promise of entry to those formerly marginalized, into the polis and the attainment of citizenship, rights, entitlements and responsibilities can create new dilemmas. A condition of entry under contractualist welfare is by way of obligation, specifically mutual obligation. However, what is not clear is the basis for 'measuring' obligation and benchmarks of capacity. On contractualism, see Eardley (1997).

aside from being paternalistic towards people who are poor, invokes an explicit moral and behavioural discourse. Patricia Harris (2001: 6) provides a rather snappy definition of what she terms the 'moral-behavioural dimension' of welfare rationalities:

> The 'moral-behavioural dimension' revolves around constructs such as responsibility, independence, motive and effort. It embodies governmental evaluations of proper/improper and responsible/ irresponsible behaviours, suggests how people ought to behave, and sets out governmental strategies to achieve the desired ends.

Such disciplinary strategies become glaringly evident in the Press Release for the 1996 Social Security Budget. Minister for Social Security, Jocelyn Newman states:

> The government has maintained the basic structure and level of unemployment payment and savings have been achieved by reducing the scope for abuse, encouraging greater self reliance and reducing complexity…the Budget [tightened] job search requirements for the unemployed… The community has indicated very clearly that it is concerned people meet all their obligations when receiving taxpayer-funded income support because they are unemployed… The Government is taking action to ensure unemployed people seek out and accept work opportunities that provide a greater level of self-support, including part time and casual work opportunities (Newman, 1996).

Statements such as these represent a shift towards focusing on the poor themselves and away from broader structural inequalities by placing the onus on the beneficiary, thus 'blaming the victim'. Both sides of politics (Labor and Liberal coalition [conservative]) draw up the rhetoric of 'reciprocal obligation' (in the case of Labor) and 'mutual obligation' as rationalities for governing.

Lois Bryson argues that the shift to 'targeting' has meant that welfare has become highly regulated affair: "A great deal of organizational effort is now expended to ensure that no one with a questionable entitlement receives assistance" (1996: 37). With this change in 'welfare' ethos, "surveillance has become central and the option to voluntarily quit a job has been curtailed" (37). White's analysis extends the boundaries of surveillance and posits that welfare's purpose is one of social control which often means that contrary to economic monetarist beliefs about minimal state intervention, involve "heavy state intrusion into private affairs …As part of eligibility criteria the welfare recipient tacitly agrees to an unprecedented level of bureaucratic surveillance in their life" (White, 1996: 118). In fact 'welfare' recipients are forced to forfeit 'fundamental' civil rights enshrined in international covenants such as a freedom of movement and the right to privacy in order the receive benefits. This trend in Australia mirrors the experience of the United States (Fraser and Gordon, 1994: 69); the difference is that our Constitution does not afford Australians guaranteed protections of human rights whereas the United States Constitution does through its Bill of Rights[155].

The rhetoric of 'obligation' (Abbott, 2000; Hage, 2000; Harris, 2001; Kinnear, 2001; McClure, 2000; Moss, 2001; Newman, 1999; Saunders, 2002) enables a heightened control of the euphemistically termed 'disadvantaged' and has allowed the state to cast and 're-present' potential beneficiaries of welfare as either 'deserving' or 'undeserving' by focusing on the behaviour of members of the aberrant or minority groupings. Furthermore, Australia is witnessing the re-emergence of concepts of 'moral panics' and 'dangerousness' as ways of portraying recipient behaviours (Cohen, 1972). For instance, unruly individuals are cast as "having a propensity to cause serous physical injury or lasting psychological harm" (Small, 1988: 14) thus making it possible for the State to justify and sanction the use of coercion against a group that is non-compliant. The focus on recipient behaviours suggests that the individual is responsible for their own situation and draws attention away from other mitigating circumstances produced by various networks of power and historical contingencies.

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[155] Expressed rights can be found in sections s51(xxxi), s80, s92 and s116 of the *Australian Constitution.* Recent decisions of the High Court have also identified a number of implied rights in the Constitution. Since 1975 there has been an ongoing debate within Australia about the introduction of a Bill of Rights akin to the Canadian Charter of Rights. (See Alston, 1994; Bailey, 1990; Charlesworth, 2002; O'Neill and Handley, 1994; Williams, 1999).

Indeed the tensions between the necessities to work on the 'unproductive' body in order to make it 'productive' in a recessionist economy grow increasingly evident (McClure, 2000). Western neo-liberalism's 'individual' is an increasingly commodified entity. Like inanimate objects, individuals are constantly being packaged and marketed in terms of 'use value'. This use value becomes a measure of one's worth[156]. A common understanding of liberal rights theory is that in order to have rights there is an implication of reciprocity, which is there are certain duties that must be fulfilled. However as Doyle and Gough (1991: 93) point out a belief in the necessity of performing duties implies *inter alia* the mobilisation of resource to carry out these duties. With resource mobilisation the expectation of a level playing level of duties and obligations becomes an unreachable benchmark for those individuals who do not (and are unable) to fit the majoritarian mould of liberal man.

5. 2 Biomedicalism Meets the Counting of Cripples

> DSM- II, appeared in 1968. Its aim is to produce a nationally standardized classification in mental disorders, not in terms of their causes but in terms of the ability of practitioners from different ideologies to agree on the classifications into which patients fall … if the A.P.A. [American Psychiatric Association] has its way, it will become illegal to go mad except according to the classifications of DSM-III. Then we will be able to count up all the mad people in the world, suitably grouped into categories designed for ease of classification by doctors. (Hacking, 1982: 294).
>
> … biomedical science has emerged entangled with other knowledges and practices which effectively divide bodies around a norm. The healthy are divided from the unhealthy in terms of what is useful and what is 'less amenable to profitable investment'… (Diprose, 1995: 215)
>
> For constitutions … are like principles that claim to be general, to govern, to regulate. Despite the fact that they never did, this is no doubt a sometimes useful fiction. One we will hold onto sometimes, perhaps even much of the time – but also one which we give up here and there in order to interfere and try to make specific differences to the arrangements of specific institutions. (Law, 1999).

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[156] The Howard government's increased emphasis in social security reform on 'mutual obligation' is a case in point. C.f. McClure (2000).

In 1997 whilst teaching a course titled 'The Politics of Disablement' for community development students at Victoria University of Technology in Melbourne I would frequently remark that despite the hegemonic influence of the medical model on the understandings and implications of disability – this perspective was waning and to a greater extent had been superseded by other professional 'psy' regimes. Writing in 2003, this observation proved short-lived or at least ill founded. With the increasingly sophisticated use of medical technologies and the rise of the 'new genetics' – medicine, biomedicalism and a kind of administrative functionalism have reasserted themselves through the forging of links and networks of association with technological regimes and administrative apparatuses.

The aim of this section is to revisit the terrain of the biomedical paradigm and the science of 'counting cripples' as part of an exploration of the production(s) and governing of bodily peculiarities called 'disability'. I first introduce the topic of biomedicalism and then move onto an outline of the politics of enumeration. My discussion is expanded by a consideration of the World Health Organization's (WHO) strategy to universalise disability and at the localized level I look at the state of disability in Australia.

5.2.1 The Biomedicalisation of Disability

> Defining disability entails providing a statement and/or set of criteria that essentially describe what is meant by 'disability'. A classification system provides a structure within which information about different aspects of the disability experience can be organized. A classification approach can be used to delineate different disability groups (physical, intellectual, etc.) with disability generally (Wen and Fortune, 1999: xiii).

Somatophobia within Western philosophy and social theory can be traced back to the writings of René Descartes (1596 - 1650) whose formulations about the relationship between the mind and body, known as Cartesian dualism, became dominant. In fact, the bio-medical body discussed in this sub-section is predicated upon a Cartesian style mind/body split (Shildrick, 1997: 13 - 14). A Cartesian understanding of embodiment construes the human constitution as made up of two fundamentally distinct and exclusive substances: 'thought' and its extension 'matter'. In *Meditations on the First Philosophy* (1641), Descartes states:

> By the body I understand all that which can be defined by a certain figure: something which can be confined in a certain place, and which can fill a given space in such a way that every other body will be excluded from it; which can be perceived either by touch, or by sight, or by hearing, or by taste, or by smell: which can be moved in many ways not, in truth, by itself, but by something *foreign to it, by which it is touched* [and from which it receives impressions] … (Descartes, 1968: 279, para 26 ~ emphasis added)

In order to clarify the place of 'self' within Cartesian dualism, Descartes reminds us that

> I *possess*[157] *a body* with which I am very intimately conjoined, … I have a clear and distinct idea of myself inasmuch as I am only a thinking and extended thing, … it is certain that this I that is to say, *my soul by which I am what I am, is entirely and absolutely distinct* from my body, and *can exist without it* …(Descartes, 1968: 285, para 78 ~ emphasis added)

The 'I' refers not to the material embodied person, but rather to a disembodied 'mind', best summed by the Cartesian imperative: *cogito, ergo sum*[158] which privileges the 'mind' qua knowing subject (the mainstay of rationality). Human subjectivity was figured as a kind of transcendental pretence, being "the unwarranted assumption that there is universality and necessity in the fundamental modes of human experience" (Solomon, 1988: 7). The enlightenment 'self' was timeless, universal, inherently rational and governed by reason and it follows then that to know one's self is to know the universal self who will "come to the right conclusions, though perhaps only after considerable education and argument" (Solomon, 1988: 11). Such transcorporeality meant that some bodies became redundant; they did not 'matter', ultimately are reassigned to a liminal position within the human continuum.

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[157] The idea of the entitling self possessing subject came to fruition within enlightenment discourses, wherein the universal 'man', ruled by reason and rationality became self- contained and containing owing little to society. C. B. Macpherson's *The Political Theory of Possessive Individualism*, (1964), provides an in-depth analysis of the "possessive" quality of enlightenment individualism.

[158] I think, therefore I am.

Cartesian dualism shaped the limits of human subjectivity. Women whose bodies lacked self-containment were deemed 'existentially disabled', due to the demands of reproduction being unable to transcend materiality (Grosz, 1994: 203; Shildrick, 1997: 26). Whilst Margrit Shildrick proposes a link between 'disability' and the engendered 'feminine' body, she does not extend her analysis to explore the constituting of disablement itself[159]. It appears that the spectre of biomedicalism haunts her analysis when it comes to matters of disablement - for 'disability' serves as a trope of inessentiality or deficiency.

For Thomas Osborne (1997: 197), the question of body amnesia is irrevocably related to corporeality and 'disability'. The presence of the 'disabled body' means that materiality cannot be forgotten; embodiment is constantly recalled. In a similar way, Grosz (1994: 203) argues that women's bodies are "inscribed as a mode of seepage", a boundedness that penetrates the ordering of subjectivity. This very possibility of contamination, or to use anthropologist Mary Douglas' phrase 'matter out of place', recalls the permeability of bodies and places 'disability' ontologically as fundamentally negative. 'Degenerate' bodies, unable to flee from materialization (for example through the utilization of 'new technologies'), are locked into a vortex that constantly reiterates the "epidermalizing of their world" (Young, 1990: 123).

We can cluster biomedicalism among those relations termed naturalism, a frame of beliefs that holds to a relational distinction between nature/culture. The ontological norm of naturalism suggests that the human entity is biologically and genetically determined and as such has universal and trans-Social attributes. Whilst there have been variations (and 'divide' jumping) in the theorising of proponents of naturalism, the hegemonic

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[159] In a recent article by Shildrick (2000) she explores the relationship between notions contamination and the disabled body.

location of naturalism among institutional formations has meant "our present capacity to experience the body directly, or theorize it indirectly, [has become] extricably medicalized" (Frank, 1990: 136). As one commentator put it, biomedicalism has resulted in the patientisation of the population (Taylor, 1979). Freidson (1970) points out that this state of hegemonic biomedicalisation has meant that doctors have had a sanctioned monopoly to be able to define the continuum of health and illness and approaches to the treatment of illness. In the case of disablement, biomedical epistemologies and the assumption that so-called abnormal conditions are the principle obstacle to disabled people's integration into society have shaped social and technological practices as well as the formation of disabled subjectivities.

The birth of biomedicalism can be traced back to the seventeenth century (Canguilhem, 1978; Foucault, 1975; Stiker, 1999). At that time, the investiture of the 'disabled' body required new configurations of boundaries, administrative and political spaces and technologies that separated and changed physical relationships. A new therapeutic space emerged based on enclosure; partition and functional sites 'constituted a real table of juxtaposed and carefully distinct singularities' in which 'deviation' could be studied (Foucault, 1977a: 144). The emergence of 'medical space' rendered the 'disabled' body docile, its 'darkness' was dissipated through its opening up to colonisation[160] in the form of modification, improvement and disciplinary assimilation. As Thomson (1997c: 12) summarizes during that period: "statistics quantified the body; evolution provided a new

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[160] The links between eugenics, empire and the racializing/sexing of bodies are well documented. Mc Clintock (1995) provides a comprehensive study in *Imperial Leather: Race, Gender and Sexuality in the Colonial Context*. Bryan Turner's expansion of the notion of 'colonisation' is useful here: "colonialism represents a geographical anatomy of the exterior world analogous to the pathological anatomy which sought to expose the structure of the inner world of bodies". (1987: 29).

heritage; eugenics and teratology[161] policed its boundaries; prosthetics normalized it; and asylums cordoned off deviance".

This kind of 'capturing' of the 'aberrant' body is best represented in what is commonly referred to as the 'medical model', a system of 'truth', based on the assumption that there is an:

> … objective reality of observed symptoms and the facticity of a disabling condition that exists in the individual. It assumes the disability exists, *regardless of whether it has been diagnosed*, and that it has been caused by factors that can be identified and studied, such as genetic flaws, disease processes, or trauma (Mercer, 1992: 20 ~ emphasis added).

On the basis this definition, disability is assumed to have an existence that is *factual, significant* and *objective*, altogether autonomous from any social context. Medical practices, organised around the medical model, presume that the doctor's task is to diagnose diseases, to discover their causes and symptoms and design treatments. Any knowledge standpoint of the patient is sloughed off. In this sense biomedicalism has encroached on the psychic life of the disabled individual because it asserts that disability is internal, inaugurating a crisis within the person's bodily or cerebral self, and as such is a state that warrants medical interventions and/or curative treatment wherever possible. The treatments are aimed at eliminating or minimising the symptoms of the disease/impairment, or the cause of the disease, or the disease/impairment itself.

Biomedical realism is sometimes referred to as a 'model of disease', but as Bickenbach rightly points out:

> strictly speaking it is a model of scientifically adequate theories about diseases, since it purports to lay out the essential components and ground rules of disease explanations. The model analyses a disease into three sequentially arranged components: the antecedent causal history or aetiology of the condition; the somatic changes, or pathology that result; and the manifestations of those changes in subjective symptoms or signs (Bickenbach, 1993: 65).

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[161] The 'scientific' study of 'monsters' invented by Zoologist Isidore Geoffroy Saint-Hilaire in 1832.

The model is made up of causal chains, of primary, secondary, and tertiary causes. The primary cause is often seen as the original cause. It is often depicted as a 'problem' at the biological level. For example, germs cause the common cold, brain injury resulting from motor vehicle accidents or strokes cause communication impairments. The symptoms of diseases are often cast in psychological terms. Acquired brain injury can cause difficulties in understanding and producing language. A final link in the causal chain is usually seen as a social one - a language impairment causes a person to withdraw from social situations or be excluded from them by others – the person is thus rendered 'handicapped' or 'disabled'. A model that characterises illness or assumed disablement in terms of an organic pathology means that

> …neither non-organic complaints nor the social context of patients' lives fit comfortably. The medical problem to be solved is located in the individual's body – organs malfunction in the mechanistic style. Diagnosis identifies the specific aetiology –the specific pathological disturbance – and treatment optimally returns the systems to its normal state of balance. Normalcy, here, is physiological, essentially unambiguous and universal. (Fisher, 1991: 158).

Based on this formulation, biomedical realism purports to be transcultural and asocial. In the rather florid words of Daniel Albert, Ronald Munson, and Michael Resnick " … diseases are items that form the furniture of the world … [they] have a real existence, and that existence is as historically, socially, and culturally invariant as is the existence of the Victoria Falls [in Canada]" (quoted in Bickenbach, 1993: 65). This kind of rhetoric becomes dangerous when a medicalised 'disability' formulation is adopted, for 'defectiveness' within this paradigm does not merely imply difference. Rather, 'disability' embodies a moral discourse[162] as if malignancy were inherent in the individual.

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[162] The root word for malady is the Latin '*malus'* which means 'evil'.

Briefly the key characteristics of the biomedical persuasion include *inter alia*: (1) the establishment of a definitive discourse of medical expertise with disabled people almost always acting as 'receivers' of 'care' due to their perceived organic vulnerability; (2) 'Disability' is normally located in the mind/body of the 'patient'. The 'aberrant', 'disabled', 'in-valid' body is usually represented in terms of 'patient', 'sufferer', or a person with a (medical) 'problem', with 'special needs' requiring sympathy, pity and charity. Whilst medicine has a role in providing assistance with the management of the effects of some impairments, biomedical approaches easily slide into paternalism reinforcing ontological dependency and deficiencies in the person.

The explanatory power of biomedicalism is only possible because medical epistemologies appear not only to be 'common sense' (rational), but also gain credibility from the prestige of being connected to scientific-techno-medical apparatuses and corresponding notions of scientific objectivity. Whilst the neo-positivist tendencies of biomedicalism have been subject to countless critiques, from the perspective of the government of disability, biomedical models appear quite attractive especially in negotiating the 'needs' of partitioning and administering (non-productive) elements of the population. Biomedicalism's strengthen lies in its capability to engage in processes and investigations of *accounting* (of social and disease patterns), *explaining/predicting* and *advising* (about the impacts of predictions for policy) (Scambler, 2002). Jerome Bickenbach's (1993: 90) exegesis of the strengths of the model provides a good summary of chief elements:

> The theoretical strengths of the model – the firmly grounded standards of deviance and normality it offers and the powerful explanatory theory of impairments it employs – make it inevitable that the goal of accommodation [inclusion/integration/assimilation] will be interpreted medically, and so will focus on ways the individual can be changed. The model's capacity to identity, and quality, the needs of people with disabilities ensures that accommodation will assume a position of priority in matters of policy.

Medical assessment and classificatory systems fit with the administration of disability by meeting statistical needs and presenting clear demarcations between government departments based of epidemiological target groupings. In other words, producing the 'truth' about 'legitimate disability', questions of causation (and culpability) and the 'genuine disabled citizen' has been made possible through the nexus between law and medicine.[163] It is at this point of coupling that the transgressive body, according to Foucault '… snares the law, provoking effects, triggering mechanisms, calling in prejudicial and marginally medical institutions' to assist in the mastery of flesh (Foucault, 1997a: 52). The so-called 'objectivity' of the bio-medical paradigm in measuring the self-evidence of 'disability' reaches its zenith in the utilization of tables of maims, for an assessment of percentiles of 'loss' and rarely discloses the basis of 'normative judgments'.[164] The hegemony of biomedical realism has spilled over into the arena of social policy creating practices that divide the 'eligible' from the 'ineligible'[165].

One the weaknesses of the medical model of disability is that it fixes upon the 'problem' of the individual (impairment inheres in the person) and ignores those aspects of impairment that are socially or biographically produced (Mishler 1984; Todd, 1989). This focus has the effect of *redirecting* social policy toward medicalised and corrective services. Often what is ignored or forgotten is that barriers seemingly due to impairment may not be caused by the impairment *qua* impairment, but rather the way *an impairment*

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[163] I am using 'medicine' here in its broad sense, so as to include the health sciences, psychiatry and psychology.

[164] Victorian *Workcover* claims are based on the American Medical Association's *Guides to the Evaluation of Permanent Impairment*, 2nd Edition, (McPhee, 1997: 598). An example of the way the disabled body is (hetero) sexed has been documented in a study by Ellen Smith Prior. Prior reports that in the "assessment standards: lack of sensation in the penis is assessed as a 5 to 10 per cent whole-person impairment whereas lack of sensation in the vulva or vagina constitutes no impairment at all, since sexual intercourse is 'possible'." (Prior, quoted in Bickenbach, 1993: 87).

[165] In Australia, to receive a Disability Support Pension the applicant is required to show that they meet a minimum level of medical impairment based on an assessment under the DSP Impairment tables administrated by a doctor. See the Australian *Social Security Act 1991*, Schedule 1B: *Tables for the Assessment of Work-Related Impairment for Disability Support Pension*.

is mediated within social structures such as social planning and the design of space creating 'geographies of disability' (Gleeson, 1999). Many of the factors contributing to the marginality of disabled people in society are related to economic disadvantages and discriminatory practices.

Classificatory systems by definition involve an evaluative ranking both at physiological and ontological levels. The interesting aspect of classificatory frameworks especially those related to fixing disability is that they remain relatively unstable, shifting in response to others' forces and contestations. Medical and administrative regimes however like to give the impressive that such systems are not only scientifically objective but also definitionally consensual and stabilized. The delimitation of disablement then, I argue, when predicated on the 'logic' of biomedicalism is another form of biological essentialism (Colligan ,1999).

The compulsion to turn the disorder and unintelligibility of the aberrant body called 'disability' into processes of order can be seen in the attempt to universalise, systematize (and thus make coherent) the constitutional atom interpolated into and known as, the 'disabled person' via the development of national[166] and international[167] definitional benchmarks. This process of constitutional demarcation between the 'healthy body and the (re)creation of its constitutive opposite, would not be possible without the convergence of techno-medical and statistical apparatuses.

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[166] The project of the Australian Institute of Health and Welfare. C.f. Madden (1996; 1995)

[167] The recently revived WHO *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) introduces four 'new' dimensions for the mapping of disability – Impairment, Activity, Participation and Context.

5.2.2 The Social Model of Disability

Increasingly disability rights activists and disability scholars grew frustrated not only by the explanatory power of biomedicalism and its impact on the lives and kinds of services available to disabled people, but also with the foundational premises of biomedicalism and its dissonance with the experiences of disabled people. In order to contextualise this chapter's discussion on the governmentality of disablement, this section provides a brief discussion of a 'first wave' response by disability scholars to modernist discourses of medicalism now referred to as the *social model of disability*[168]. I will outline the key features of the *social model* within the literature and then move onto explore shortcomings of the model.

The *social model of disability* emerged within the context of political and academic developments in the United Kingdom. Today the *social model* acts as litmus test for progressive disability politics and disability studies research both within the United Kingdom, Australia and New Zealand. For now it is useful, to keep in mind the test, devised by Michael Oliver to assess the rigour of social theories and decide whether the *social model* indeed fulfils such criteria. Oliver argues that:

> … all social theory must be judged on three inter-related elements: its adequacy in describing experience; its ability to explain experience; and finally, its potential to transform experience. (Oliver 1995: 1)

The *social model of disability* emerged within the context of political and academic developments in the United Kingdom, especially emerging critiques of capitalist modernism such as socialism. The model makes a theoretical distinction between disability and impairment in the same way that early feminist writing distinguished between gender and sex (Gatens, 1991; Rubin, 1975). Finkelstein (1995) points to the origins of the model in the

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[168] The shift to a post-modern or postructuralist analysis of disablement can be characterized as the 'second wave'.

‘experience’ of people with disabilities and their struggle against/over residential institutional control. This politicisation of people with disabilities as well as a debate over the relationship of theorisations of disablement to the basis of political strategy, led to the production by the *Union of Physically Impaired Against Segregation* (UPIAS) of a document known as the *Fundamental Principles of Disability* (1976). For the first time a view about disablement was espoused that severed ‘disability’s’ connection to the body:

> Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. … To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called “disability”, of people with such impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression. (UPAIS, quoted in Oliver 1995: 16 - 17)

The *Fundamental Principles of Disability* document understood disability to be socially produced or as a wrapping around and over impairment. Changes in the conceptualisation and delimitation of disability are consequences of changes in the economy and social organization of society. The *social model* does not wish to deny the existence of impairments and physiological differences - far from it; rather the model addresses them without attaching value judgments such as ‘normality’ and shifts the emphasis towards those aspects of our world (and economic infrastructure) that can be changed. The term ‘*social model,*’ was coined by Michael Oliver (1983) in *Social Work with Disabled People*, in reference to the UPAIS document.

The emphasis on the production of social theory by and for people with disabilities as the grounding of its ‘authenticity’ is a recurring theme in the literature (Oliver 1990; Oliver 1996; Barnes 1998). Leaving aside the vexed question of ‘experience’, the majority of the model’s proponents have been white, male sociologists (with disabilities) holding tenured positions within the academy; strongly influenced by Marxist theory and class analysis (Oliver 1995: 1; Pfeiffer 1996: 158; Shakespeare and Watson 1997: 293; Abberley 1998: 82; Priestley 1998: 80).

Paul Abberley's paper, *The Concept of Oppression and the Development of a Social Theory of Disability* (1987), has become a landmark text in the social exposition of disability. It is still referred to a decade later in the literature. Abberley, a sociologist formerly at the University of Bristol, established a new methodological framework in which to configure disability. Located within a Marxist perspective, the strength of the text lies in its call for conceptual clarity regarding the concept 'oppression' and approach to theorization that is comfortable with multiple subject positions. As Abberley articulates:

> To argue that we need to analyse the position of disabled people as a form of oppression is not to make the claim that we can arrive at a monolithic theory of oppression into which we can fit women, black people, disabled people or gay people … A crucial feature of oppression and the way it operates is its specificity, of form, content and location … (Abberley 1987: 7)

Furthermore, the text signals key themes that will become sources of contestation for the next decade (and beyond), such as the relationship between impairment and disability. Informed by feminist works, Abberley recognises the significance of the disabled body arguing, "the body is the site of oppression, both in form, and in what is done to it" (Abberley 1987: 14). Indeed, the reach of a "theory of disability as oppression" must extend to "a social theory of impairment" (Abberley 1987: 9). In one of the few texts to confront the 'ambivalence of disability', Abberley argues that this position on disability must condemn the "social production of impairment", yet at the same time adopt a position that affirms the disabled body (9, 17). The ideas developed by early disability theorists/activists were subsequently refined into what is broadly termed the *Social Model of Disability* I have represented in diagrammatic form in Figure 6:

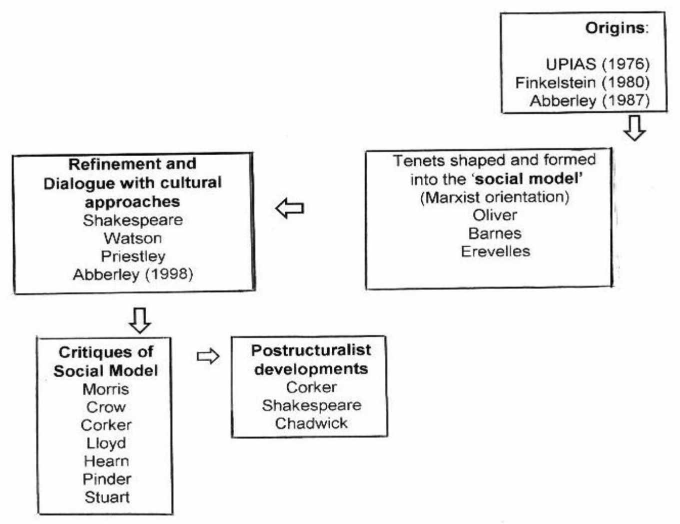

Figure 6: Evolution of the Social Model in the United Kingdom

The *social model* has been subject to elaboration and modification since its inception. Strictly speaking, it is more accurate to make reference to social *models* of disability. According to Mark Priestley what sets this model apart from individualised materialist and idealist perspectives is the assertion that:

> …disability has some *real collective existence* in the social world *beyond* the existence or experience of individual disabled people. … this claim is premised upon the existence of some form of *objectively identifiable* commonality amongst disabled people. (Priestley 1998: 83 ~ emphasis added)

Priestley's remarks provide a clear and absolutist statement of the universalising tendencies of the *social model*. More concerning is the adoption of a *new* kind of disability *essentialism* situated in the 'social'; having an abstracted existence independent of any ontology of the corpo-*real*. There is a ring of positivist rationality in Priestley's comments, wherein mastery over the contingency of disability is achieve by way of collapsing a multiplicity of identities constituted by the disabled body into an objective substratum to fit materialist narratives of disablement.

So how is disability constituted according to the *social model*? There appears to be a degree of fluidity and difference in emphasis amongst writers. For instance, Colin Barnes in 1991 suggested “the term “disability” represents a complex system of social restrictions imposed on people with impairments by a highly discriminatory society” (Barnes, quoted in Abberley 1998: 79). This understanding I would suggest is as broad and non-specific as to be bordering on vacuous. Whereas, Nirmala Erevelles (1996: 519) engages a classic Marxist formulation arguing that “disability can be re-understood as an ideological condition … structured by the … exploitative material conditions of capitalism”. Likewise, Priestley, in keeping with a materialist conception, creates ‘space’ for the transposability of the *social model* within a range of historical and cultural settings:

> From a socio-materialist position disability can be regarded as the material relations of power arising from the development of political economy and/or patriarchy within a specific historical context. The unit of analysis are disabling barriers (mostly physical, structural or institutional). (Priestley 1998: 80)

Equally significant, is the work of Michael Oliver who has as I have already mentioned, played a central role in the development of a materialist *social model*. An analysis of the discursive shifts in his figuring of disability from a period of 1989 - 1996 reveals a terrain grounded in ambiguities, uncertainties and contradictions. An early work written by Oliver in 1989, republished in 1993 *Disability and Dependency: A Creation of Industrial societies?*, provides an insight into his understanding of the disabled body. Influenced by the work of American political scientist Halan Hahn, Oliver (1989: 49) states that “the category disability, is itself produced in part by the policy responses to it”, adding that this very process naturalises embedded ideologies that create dependency. For Oliver, work becomes a central mechanism of exclusion for this activity “creates a particular form of social relations” (51).

In 1990 Oliver went onto publish *The Politics of Disablement*, a text that became highly influential in the development of a particular discursive formation of the *social model* throughout the United Kingdom, Australasia and to a lesser extent America. What is interesting here is the manner that disability has been reckoned. On one hand, Oliver (1990, 58) is emphatic that "the disabled individual is an ideological construction related to the ideology of individualism", and yet in contradiction, earlier in the same work, he claims that "disability is an essential part of self … it is nonsensical to talk about the person and the disability separately" (1990, xiii), and later refers to the "personal responses of individuals to their disabilities" (60). Aiden Chadwick (1995: 43) in a critique of Oliver's construction of disability, argues that "he occasionally slips into the medical vernacular … It is only rarely that he uses the verb *disable* to describe the actions of others upon people with impairments".

As a response to such concerns and in contrast with previous formulations, Oliver in *Understanding Disability* (1996) insists that "disability is wholly and *exclusively* social … disablement is nothing to do with the body. It is a consequence of social oppression" (1996: 35 ~ emphasis added). Tom Shakespeare's voice has been used by Oliver to add weight to his argument:

> The achievement of the disability rights 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. (Shakespeare, quoted in Oliver 1996: 39)

The development of a materialist conception of disability hinges around two allied concepts: 'ideology' and 'hegemony', supported empirically by reference to the nonrandomness of disability within anthropological studies and history. The centrepiece of Oliver's theory, 'ideology' is defined as being "a set of values or beliefs underpinning social practices" (1990: 43). However, Oliver is not referring to a plurality of values or the diffusion of power; rather the notion of ideology is appended to Gramsci's concept of 'hegemony',[169] in order to designate the *core* (organic) *ideology* of individualism. Oliver then moves to situate discourses of the body, specifically the "construction of "able-bodied" and "able-minded" individuals" (45), in what he terms *peripheral* (arbitrary) *ideologies*. My reading of the text suggests that Oliver has created a hierarchal dualism – with the "mind" at the apex and the 'body' relegated as Other. In fact, Oliver fails to make a connection between the rational knowing subject and Enlightenment conceptions of the 'essential' perfectible body (Oliver 1990: 45).

Let us pause for a moment to consider, as Slee (1997: 408) puts it: "to what ends are theories manufactured and deployed?" The deeming of 'disability' as an ideological construction presents significant epistemological and ontological challenges. In a post-capitalist society what is left of 'disability'? … impairment? A romanticist turn of the *social model* becomes evident when we look at what is meant by the 'self'. Oliver is in agreement with Finkelstein's belief in the unity of the subject, constituted by an "essential human nature" (Oliver 1990: 125). People with disabilities are conceived of as victims who while now engulfed by the ideology of ableism, when released from their/our subjugation will have our "essential human nature automatically revealed" (Chadwick 1995: 47).

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[169] Hegemonic dominance is achieved through the successful projection of a particular way of seeing the world, the formulation of a prism of understanding concerning human and social relationships - the delineation of "naturalness" and "common sense" as non-problematic. See Gramsci (1971).

Both Erevelles (1996) and Abberley (1998) point to a Marxist conception of human nature that is inherently incompatible with the notion of 'disability'. In a moment of reflexivity, Abberley (1998: 82) remarks: "I have come to see profound problems in utilizing a Marxist model of human beings for the liberation of disabled people". This is an extraordinary admission from a man whose work in 1987 provided the catalyst for development of a *Social Model.* Within Marxism people with 'disabilities' are the residual by-products of an 'evil' capital system and act as a kind of 'symbolic capital', having "propaganda value as one of the things socialism will abolish …The analysis is not then one of disablement but of impairment, and rates of impairment" (Abberley 1998: 83).

The *use value* of disability is located in its ability to act as a signifier of the 'irrationality' and 'inhumanity' of capitalism. The absence of utility renders the disabled body invalid, for in a Marxist utopia there is no 'home'. To be an entitled subject, with full citizenship is dependent upon the body's capacity to labour usefully (Erevelles 1996: 522; Abberley 1998: 87). As Abberley puts it:

> Marxism … can never be other than a project of the Enlightenment. It shares with other such enterprises a rationalist adherence to aspirations of "perfection", and can identify non-workers only with historically redundant bourgeoisie, one aspect of whose alienation is their failure to participate in social production. (Abberley 1998)

Shortcomings of the Social Model of Disability:

During the mid 1990's a proliferation of dissenting and critical voices surfaced concerning the *social model* of disability. It is important to note that whilst many theorists have concerns about the model they *do not* reject its central propositions outright. Rather, critics believe that it is possible to reformulate or extend the model. Recently Shakespeare (2002) has argued that the *social model* cannot be reformed rather the British conceptualisation of the *social model* has outlived its utility. One common criticism is that by focusing on the social creation of disablement, the *social model* has by default diminished the importance of experiencing impairment in the lives of disabled people. Attempts have been made by some social theorist to 'bring the body/mind back in from the cold'. As Morris argues (1991: 10):

> There is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created… to suggest that this is all there is to it is to deny the personal experience of physical or restrictions, of illness, of the fear of dying.

Many of these theorists believe that it is important to undertake narratological research into the 'lived' or 'experiencing' body where disabled peoples' voices are at the speaking centre of the discourse. One of the aims of undertaking this approach is that it will be possible to further theorise phemonologically, disabled peoples' experience across the continuum of hope, joy and despair. Phenomenological research can also provide insights into other ways of experiencing humanness beyond a simplistic tragedy approach to disablement. Liz Crow (1996) has argued that the model has failure to encapsulated disabled peoples experiences of pain and limitation that can be attributed to impairment. A criticism of a different kind focuses on the fact that the *social model* of disablement is based on a false dichotomy between impairment (which inheres in the body/mind) and disability (which inheres in the social). This schema presents this division as clear cut but as Thomas (1999, 124) notes impairment is not a pre-social form rather impairment "refers to those body related variations which …have become markers of socially, or more precisely medically, defined 'significant deviations from the normal type' or abnormalities".

Another emerging voice critical of the social model come from race and gender scholars who argue that because all bodies are sexed and raced they are experienced differently social, political and economically (Atkin & Hussain, 2003; Hill, 1994; Morris, 1996;

Stuart 1993, 1994; Vernon, 1998). The *social model* according to these critics, ignores differences according to gender, class, age, sexuality, ethnicity etc for example, a woman with quadriplegia will experience her body and sexuality differently from a male with a similar impairment. Many people of colour already experience subordination and disadvantage due to systemic racism, coupled with impairment two marginalised identities intersect.

Despite the limitations of materialist approaches to the theorisation of disablement, I argue that the s*ocial model of disability* has made an important contribution to social theory concerning disablement. Certainly, the emergence and utilisation of this model has resulted in a paradigm shift away from bio-medical discourses towards a focus on discourses about political technologies in the 'social'. Whilst the *social model of disability* has gain 'credibility' in the social theory 'stakes', the biomedical approach to disablement remains very attractive in the government of disability, particular in its capacity to enumerative the lives of people deemed 'disabled'. The next section examines the marriage between the forces of administration and medicalization through a discussion of the 'science' of counting cripples.

5.2.3 Knowing the Population: The Science of Counting Cripples

Contemporary social organization within a liberal polity depends upon the creation and collection of 'facts and 'figures' (statistics) in order to 'know' and therefore govern the population. Indeed the science of turning actors (both artefacts and sentient beings) into numbers and classifications have enacted, in the words of Michel Foucault, not only 'great bipolar technologies' but have also produced the form and character of social facts mediated by regulatory and juridical regimes. The works of Ian Hacking (1982; 1991;

1999) and Theodore Porter (1986; 1995) points to the debate as the whether social laws act from 'above' shaping individuals, i.e. probabilistic laws, or are epiphenomenon, which are derived from the actions of individuals (mere descriptions of reality). Nowhere is this debate more obvious when it is acted out in the production, delineation and subjectification of the 'disabled citizen'. Transposing the articulations of Actor- Network Theory, we can say that the 'disabled subject' is created and constituted by a cluster of relations.

The demands of technologies of enumeration suggest that statistics of disability involve a mere mapping of pre-existent and self-evident populations that divert from an assumed and objective norm of species typical functioning. Such is the importance of calculation for administrative purposes that the turn to enumerative fetishisation not only perpetually scales bodies from birth until death[170], it also provokes such circulatory obsessive questions as 'who is the genuine disabled person?' 'How many of them are there?' 'How do we survey for the fraudster or impostor?' Enumeration's compulsion is aptly explained by Hacking (1982: 280): "Enumeration demands kinds of things or people to count. Counting is hungry for categories. Many of those categories we now use to describe people are by-products of the need for enumeration". Furthermore, Bowker and Star (2001) point out that the art of government requires that the good and perfect citizen is one that can be well counted, on demand and mapped and divided along a multitude of dimensions. They conclude Americans (and by extension the west) exist under a regime of countability within " … a particular spirit of quantification …[wherein the] uncountables in America are our version of the untouchables in India." (2001: 423). The concept of 'disability' and a 'disabled person' are examples of such categories. Regimes

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[170] Within five minutes of a child's birth, the Apgar score is administered. The baby is ranked according the five criteria on a scale from 1 – 10 (Kaminsky and Oberklaid, 1996: 67). Ian Hacking points out that the WHO nosology of death makes it illegal to die of 'natural causes', that is, old age. (Hacking, 1991)

of countability and enumeration place upon the “disabled subject” a mandatory requirement of classificatory essentialism. To put it more simply, the disabled subject needs a label, diagnosis, and ascription - an *enumerative passport* so to speak, to negotiate, access and manoeuvre networks of social organisation and regimes of disability governance (see Figure 7).

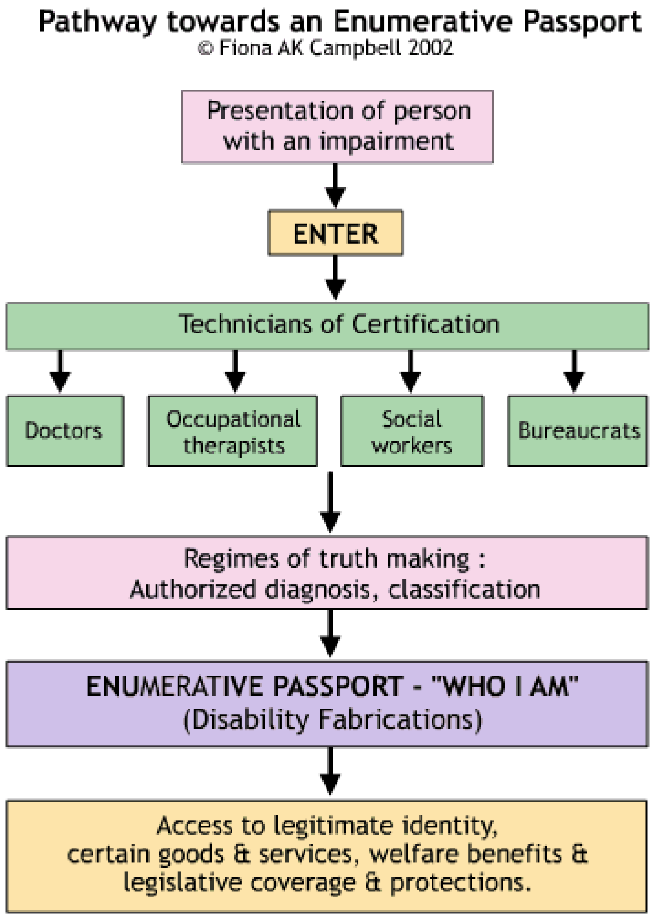

Figure 7: An Enumerative Passport.
Source: The Author

Without a [diagnostic] passport – the disabled subject is not real, they become an illusion: persona non-gratia – untouchable, indeed seemingly going nowhere; treading water[171]. Furthermore disabled people have become experts in negotiating and usurping the governing of disability by engaging in a process of *De-cripping*™ and *Re-cripping*™ oneself to 'fit' our bodies to the prescriptive guidelines[172]. Within the inherent statistical functionalism of classificatory discourses lies a sub-text of classificatory moralism. The push to create new orderings of people not only invoke new formulations of what it means to be human but also in turn delimit humanity's constitutive outside – the deficient aberrant Other.

I want to now return to matters of theory and consider Michel Foucault's theorising around the 'species body' and his working concept of a biopolitics of the population. By using Foucault's schema I believe we can link the statistical imperative and other networks of association such as theories of biomedicalism and the apparatuses of administrative regimes, law and bioethics and technological industries that create an understanding of disability as not only pathological but ontological intolerable. In *The History of Sexuality, Volume 1* Foucault formulates a notion of power that fosters and orders forces, a kind of life-administering power. Such a power can promote life or disallow [erase] it and is "situated and exercised at the level of life, the species, the race, and the large-scale phenomena of population" (Foucault, 1976: 137). Governing the population through a focus on the species body, the basis of enframing and ordering

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[171] The strategic essentialism of label usage becomes important in stances where an impairment is not recognized thus denying the individual access to medical treatment, legal protections and so on. C.f the ambivalent status of chronic fatigue syndrome.

[172] The process of *De-cripping*™ and *Re-cripping*™ occurs when an individual mitigates the effects of their disability so as not to 'look' too disabled in order to qualify for a program or alternately to re-crip™ – to magnify their impairment to meet the 'level' of impairment' requirements. I have rather cheekily trademarked these concepts to highlight the increasing commercialisation/commodification of disabled people's experiences, including those strategies of resistance.

things via regulatory controls, is what Foucault terms of a 'biopolitics of the population':

> the body [is] imbued with the mechanisms of life and serving as the basis of the biological processes: propagation, births and mortality, the level of health, life expectancy and longevity, with all the conditions that cause these to vary (Foucault, 1976: 139).

The importance of systems of calculations and ordering make it possible for a number of relations to shape and bring into being spectrums of human constitutionality. As such the field of biopolitics stimulates various conceptions of (human) ontology by surveying and mapping out constitutional arrangements dependent upon corporeal differences. The cartography of population inaugurates a framework that assigns utility and value[173] to being, but also the "tak[ing] charge of life needs continuous regulatory and corrective mechanisms … [which have] … a power to quality, measure, appraise, and hierarchicalize…" (Foucault, 1976: 144). Foucault's analysis of the processes of biopolitics moves onto the matter of the operation of norms, in particular the law as a pre-eminent norm that filters into a range of biomedical and administrative apparatuses.

In Foucault's later work his analysis of biopolitics and bodies is articulated further. Foucault overturned the Cartesian legacy by disputing the existence of a pre-discursive body, some unmediated pure corporeal state, wherein the 'I' precedes the process of the formation of subjectivities constituted by race, sex and disability. In *Nietzsche, Genealogy, History* (1984) Foucault explores the use of the genealogical method to "listen" to bodies inscribed by history, to unpack the domain of the *herkunft* wherein bodies are infused by anamnesis that recalls the past, present and future[174]. Our very

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[173] This assignation induces the debate within bioethics and tort law about which 'lives are not worth living'.

[174] *Herkunft* refers to the ordering of bodily difference based on stock and descent (Foucault, 1984c: 81 - 83).

soul, that sweeps us into life "is the effect and instrument of a political anatomy … [a] prison of the body" (Foucault, 1977a: 30).

Bodies are regulated through the use of disciplinary power that produces subjected 'docile' bodies that become elements that may be moved, used, transformed, improved and articulated with others. Grosz points out that these processes transmogrify the very biological constitution and knowability of the subject

> biological and physical processes can be induced in subjects through the inculcation into certain beliefs about the body and its place in social and religious life … Our ideas and attitudes seep into the functioning of the body itself, making up the realm of its possibilities and impossibilities (Grosz, 1994: 190).

The clinical 'gaze' is interiorised by the patient subject who, in acting as her own overseer, casts the 'gaze' over her own bodily self (Nettleton, 1995: 113; Shildrick, 1997: 49). In many ways the body consumes its own inscription, which in turn maps the very boundaries of subjectivity. Techniques of 'self-production' Grosz (1994) remarks are not imposed, but sought. Shildrick provides an example of this phenomenon in the context of the production of 'disability'. The trend towards self assessment (certification) in human services necessitates that the applicant must "fit" institutional definitions of 'disability' in order to receive services. To benefit she must take responsibility for surveyal of her body and undertake a corporeal mapping so

> no area of bodily functioning escapes the requirement of total visibility, and further, the ever more detailed subdivision of bodily behaviors into a set of discontinuous functions speaks to a fetishistic fragmentation of the embodied person. (Shildrick, 1997: 53).

In this way disciplinary practices produce "objects and rituals of truth" (Foucault, 1977a: 194). Not just in each singular moment, but the ritualistic performance is constantly citational and reiterated so that the subject under the process of normalization constructs her own concept of selfhood as 'disabled' (Butler, 1993: 2; Shildrick, 1997: 54).

Classificatory systems by definition involve an evaluative ranking both at physiological and ontological levels. The interesting aspect of classificatory frameworks especially those related to fixing disability is that they remain relatively unstable, shifting in response to others' forces and contestations. Medical and administrative regimes however like to give the impressive that such systems are not only scientifically objective but also definitionally consensual and stabilized. As Mildred Blaxter (1987: 6) points out as part of her socio-historical research, definitional delimitations do not emerge in a vacuum, rather "… the definitions made of 'the disabled' [sic] are affected by, and in turn affect, the definitions of other groups such as 'the unemployed' or 'the poor'. When it comes to a discussion of the difference between impairment and disability, advocates of the *Social Model* resort to biologism by arguing that whilst impairments are fixed and stable phenomena, disability as a concept (a wrapping over impairment) is profoundly unstable subject to the whims of cultural and situational factors. This rather neat binarism is inherently flawed because of its failure to recognize and factor in dynamics of relationality that enframe the constitutionality of impairment and later disability. Marks (1999: 114) whose work agrees with me on this point also succumbs to a denial of the catachrestic nature of impairment by arguing, "impairments are universal …".

It is only after deconstructing the impairment construct that its predictive power diminishes and its vacuous and fabricative nature is exposed. The reality is that all we can say is that corporeal difference and constructed bodily aberrations are universal. Impairment on the other hand is a different matter, for in arguing that 'impairment' is a problematical and highly fallacious concept means that it becomes difficult to speak in terms of a self-evident universalism. The leaky constitution of 'impairment' suggests that any attempt at universalism breaks up and break down.

Therefore, we come to an example of grand narratives (universalised attempts at) systems of ordering appended to the juridical apparatus of the World Health Organization (WHO). The grand narratives of the WHO announce to the world and tell stories about what it is to be healthy, the nature of death and disease and finally the dimensions of disability. This statistical and classificatory chatter is significant to the production of the 'normal and the pathological' as John Law reminds us such narratives:

> … narrate more or less plausible relations and distinctions. They make possibilities acceptable by telling listeners, speakers, how it is, out there, in the world. … We also need to say that stories also help to make more or less plausible relations and distinctions" (Law, 1999).

It is not surprising then to learn that government's in advanced liberal welfare states are seeking to delimit further and remedicalise (and redefine) administrative and legal categories of disability in order to reduce the increase in numbers of classified disabled persons and potential welfare recipients. For instance in the United Kingdom, the Office of Population, Census and Surveys reports the incidence of disabled people almost doubled between the years 1979 and 1988[175]. As Tom Shakespeare rightly suggests that the explanation for this increase may be due to a change in the criteria for being rendered a disabled person (Shakespeare, 1999: 28). In Australia, the statistical picture is similar. Conservative Liberal Party Minister for Family and Community Services, Jocelyn Newman in a discussion paper titled "The Challenge of Welfare Dependency in the 21st Century" when arguing for a large-scale welfare system review notes

> Ten years ago, the number of people on disability income support was around 300, 000. Today, almost 600, 000 people receive Disability Support Pension [sic]. Estimates are that numbers will reach over three-quarters of a million by 2006 (Newman, 1999).

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[175] Michael Oliver (1990: 6-9) provides an extensive critique of the questionnaire design and medicalized methodologies of this survey and juxtaposes this modelling with the kinds of question provoked by a social constructionist approach to disability.

Such comments give rise to significant epistemological questions related to the problematical nature of certain conceptual frameworks of disability and what Hacking (1982) calls the 'subversive unintended effects' of classificatory practices and clusters of relations and the explanatory power of certain epistemological engagements. Of significance, here are the kinds of explanations and causes that can be attributed to an increase in the incidence of DSP pensioners[176]. Later in another section of this chapter I discuss in detail battles over the legal definition of disability in the United States Supreme Court, including attempts by big business and Wall Street financiers to further delimit the meaning of 'disability' under the *Americans with Disabilities Act 1990*. The explanatory power of a universal biopolitics of classification is strengthened almost to the point of infallibility by its conjunction with medical – therapeutic epistemologies and practices.

5.2.4 A Grand Fabrication: The Universalising and Essentialising of Disability

> The purpose of the disability category is to keep everyone in the work-based distributive system except for the very neediest people, those who have legitimate reason for receiving social aid. Like any other mechanical device, it had to be deliberately designed to accomplish its purpose. (Stone, 1985: 118)
>
> … when you can measure what you are speaking about, you know something about it; when you cannot measure it … your knowledge is of a meager and unsatisfactory kind. (William Thomson Lord Kelvin (1899), quoted in Hacking, 1991: 186)

The centrality of a diagnostic fetishism is invoked by the law through its insistence on certification under the 'gaze' of experts with power to render corporeal anomaly significant or not. A classic example of this, is the continued use of intelligence tests

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[176] One argument suggests that the criteria for acceptance onto the DSP is too flexible resulted in an increase of pension recipients. Another view suggests that there are problems with flow through arrangement to non-pension vocational options. Yet in a graph in Newman (1999), the Senator reports that just under one-third of DSP recipients have muscular- skeletal injuries.

within the World Health Organization 'WHO' classificatory system[177] and disability legislation[178], despite serious concerns about their validity[179].

In respect to making broader categorical distinctions, the universal definition(s) of the 'disabled body', were introduced and systematised in 1980 by the 'WHO' in what has become a canonical document: the *International Classification of Impairments, Disabilities and Handicaps*. The 1980 ICIDH contains three elements that make up dimensions of 'disability':

> "Impairment is defined as any loss or abnormality or psychological, physiological or anatomical structure or function. Disability is defined 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. A Handicap is defined as a disadvantage resulting from an impairment or a disability that limits or prevents the fulfillment of a role that is normal (depending upon age, sex and social and cultural factors) for that individual". (World Health Organization, 1980).

The epistemological framework of the 1980 ICIDH has been adopted by the national government and has shaped the domestic scene in terms of definitions and assessment instruments contained in legislation, social policy and the very semantics of disability (what is sayable and unsayable). Whilst allowing for the realization of social contexts,

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[177] For example, intelligence quotients are divided into Mild (52 -67); Moderate (36 - 51); Severe (20 - 35); Profound (under 20) (Hayes and Craddock, 1992: 7).

[178] s.8(1)(b) of *Intellectually Disabled Persons' Services Act 1986* (Vic) states that an assessment of eligibility be performed by use of "one or more standardized measurements of intelligence". The most frequently used battery of tests are those originally developed by David Wechsler in 1939 - the Wechsler Adult Intelligence Scale (WAIS-R, for ages 16-74 years) and the Wechsler Intelligence Scale for Children (WISC-III, for ages 6-16 years). These scales have a mean score intelligence quotient of 100 and are divided into Average (90-109); Low Average (80-89); Borderline (70-79); Mild (60-69); Moderate (50-59); and Severe (49 or less). (Sattler, 1992; Wodrich, 1997).

[179] Scheerenberger points to the difficulties of IQ tests in distinguishing between "mild degrees of mental retardation [sic] and normality". (1983: 180). The shifting of mental age goal posts has resulted in 50% of the white population in the United States being rendered as "intellectually disabled". He goes on to say that "even the most ardent advocates of mental tests did not want the percentage of mentally retarded persons to deviate significantly from approximately 2 or 3 percent of the population". Other critics have focused on the assumption of staticity of IQ. Mercer, (1994: 519), is critical of the DSM-III-R category of 'mental retardation', arguing that such "an overriding explanation has led to a neglect of any search for more specific explanations for particular behaviours".

this model is still infused within a biomedical discourse, for as Oliver (1990: 4) observes, the model still:

> conserves the notion of impairment as abnormality in function, disability as not being able to perform an activity considered normal for a human being and handicap as the inability to perform a normal social role.

Leaving aside the problematic concept of normalcy, such an understanding of disablement is not surprising, for the classification is grounded to have definitional congruence with the *International Classification of Disease* (ICD-10)[180].

In January 2001 after several draft revisions, the 54th World Health Assembly adopted the *International Classification of Functioning, Disability and Health* (ICFDH)[181] (Executive Board WHO, 2001). The new system inaugurates four dimensions related to disability, namely, impairment, activity, participation and context. The instrument's authors argue that the aim of the ICFDH to develop a common language for speaking of 'health' and by default 'disability' (World Health Organization, 1992-1994: 1- 4). Moreover, the new ICFDH provides the basis and tool for implementing various United Nations instruments by member states and enacting coherent national legislation.

Reforms aside, the WHO (re)writing of disability is still based on the premise that disability can be objectively and universally known, mapped and treated[182]. The framework still places 'disability' as ontologically negative with solace being available via the liberatory scaffold of liberal rights discourses and protections[183]. Furthermore, the

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[180] Refers to the tenth revision: (World Health Organization, 1992-1994).

[181] Previously known as the *International Classification of impairments, disabilities and Handicaps* (second edition) – ICIDH-2.

[182] See Fujiura & Rutkowski-Kmitta (2001) who critique the viability and utility of a universally applicable and singular definition of disability.

[183] A defence of the universality of the ICDH-2 can be found in Üstün (2001). Further reading on the ICDH system can be found in Fougeyrollas (1993). A good summary of international classificatory frameworks of disability can be found in Altman (2001)

new ICFDH formulation whilst being cognizant of the ‘participatory’ and ‘contextual’ dimensions of ‘disability’, continues to be constitutionally aligned with and thus becomes a sub-directory of the ICD-10. In the event of any contestations over the weighting of various elements, this prismic framing within a disease paradigm will most likely ensure that etiological factors remain pre-eminent.

5.2.5 An Australian Disabled State, or the State of Disability in Australia

> When we accept a person into the category ‘disabled’ we may be entitling them to certain benefits or subjecting them to an oppressive label. When new legislation and new benefits are introduced, then official definitions of disability change. New groups of people ‘become’ disabled. This is not to imply that such people are frauds, but rather to show the extent to which disability is an administrative concept (Marks, 1999: 119).

In Australia, the science of counting cripples has mainly been a State affair. The Federal government only really became a player in the late 1940’s with the establishment of the Commonwealth Rehabilitation Service (CRS) in 1948[184]. Historically there has been little uniformity across the Commonwealth and States in the statutory defining of disability (Australian Law Reform Commission, 1996: 91). The formation of disability policy by governments has been narrowly construed and can be thematised into three prongs, namely

- Social security/ benefits apparatus;
- Service provider business (funding and administration) and
- Legislative protections.

with the bulk of activity occurring in the first two areas. In reality, a history of disability policy is really a history of service provision and welfare administration. It is only since the 1990’s that legislative protections have become part of the governmental agenda at a federal level. Along side this administrative system; the Australian Bureau of Statistics

(ABS) also manages the enumeration of disability. Whilst there are informal linkages between the two sites of managing disability, particularly in the areas of research and planning, the classificatory criteria utilized for the producing (defining) disability remains separate and independent. In this sub-section I will outline briefly the ABS system and move onto a more nuanced analysis of policy formation at the Commonwealth level focusing on the role of statistics in defining disability and producing tensions over disability's meaning.

The Australian Bureau of Statistics (ABS) has conducted *Disability, Ageing and Carer* surveys in the years 1988, 1993 and 1998[185]. During this period the ABS has adjusted its criteria for defining disability, from twelve limitations, restrictions or impairments in 1988 to seventeen criteria in the 1998 survey (Australian Bureau of Statistics, 2000)[186]. The 1998 survey found that there were 3.6 million people with a disability, approximately 19% of the Australian population. An interesting feature of this data is that physical impairment (including musculoskeletal impairment) accounted for 85% of disability identification (Australian Bureau of Statistics, 1999). However, as the Australian Institute of Health and Welfare (a subsidiary of the Commonwealth) points out it is possible to shift either in an expansive or restrictive way the prevalence of disability groupings (Madden et al., 2001):

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[184] Section 51 of the *Australian Constitution* defines 'health' as a State issue. The Commonwealth did introduce a limited means tested, non-contributory invalid and aged pension in 1908. Prior to World War Two, government emphasis was on providing places of asylum and protection.

[185] The ABS has adopted the ICD for coding 'disabling conditions'.

[186] See Appendix 2.

TABLE 4: Broad/Restrictive Definition of Disability

Broad definition includes all people who report relevant impairment or disabling condition. Restricted estimate includes people who always or sometimes needed personal assistance or supervision with activities of daily living.

		Broad	Restricted
I	Intellectual	1.9%	0.9%
II	Physical	11.9%	3.8%
III	Acquired brain injury	1.9%	0.9%

Even though there have been changes to criteria along with modifications to terminology and language, the 1998 ABS survey methodology is still primary attached to functional areas of restriction in activities of daily living (self-care, mobility and communication) and in essentially diagnostic and functionalist in orientation appearing unable to break out of a biomedical mould. This kind of classificatory containment is significant at both an operational and ontological level in the production of disabled subjectification. As the Australian Institute of Health and Welfare somewhat uncritically points out, the ABS checklist of ‘restriction, limitation or impairment’ (negativised ontologically at the outset) implicitly creates a definition of disability (Australian Institute of Health and Welfare, 1999: 215).

The ABS emphasis highlights the ongoing contestations over the life domain approach to disability measurement and services development and the more conservative diagnostic approach. In the mid 1980’s at the Commonwealth level there was a short-lived departure from diagnostic functionalism towards a needs based (service types) thematic approach to mapping and funding the disability sector[187]. As part of the conservative liberal

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[187] Service types under the *Disability Services Act 1986* (Cwth)

government's review of its welfare framework, administrative systems have returned to a diagnostic funding approach, adopting a classificatory framework of 'disability' based on impairment type rather than broader groupings based on ethnicity, sex, or regional location[188]. The shift (or return) to defining 'disability' in terms of 'disability groups' not only constitutionally separates and distinguishes individuals from each other, the regime of division in effect inscribes a similarity and essentialism in the way individuals mediate disability relations amongst other activity of lived associations. Put another way, the move towards disability groupings implies a coherency in 'activity restriction' and therefore output in terms of 'needs.' These disability groupings (or what I prefer to call disability fabrications) are given life (credibility) through their incorporation into administrative and legislative frameworks that define (and delimit) what 'is' and 'isn't' 'disability'[189]. As Margaret Sargent (1994: 150) in another context argues

> The medical perspective is reinforced by the positivist notion that people with disabilities can be identified and counted by means of censuses and surveys. Surveys of the incidence (i.e. occurrence) of impairment are of dubious value, for there is no necessary connection between impairment and the loss of capacity in any area of life. However, while the interpretation of the survey results maybe unclear, statistics have political uses, and that is where their real value lies.

The ABS orientation toward disability groupings has contributed towards to development of a targeted approach to disability service development by both federal and state governments[190]. Despite governments' commitment to the principles of

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[188] One umbrella organisation that faces an uncertain future in terms of funding because of this shift is the organization Women with Disabilities Australia.

[189] For a recent discussion of the workings of this framework, consult Australian Institute of Health and Welfare (1999), chapter 7 Disability Services.

[190] Here I refer to the DSA 1986 with its emphasis on regulated target groups and service types and similar state legislation, namely *Disability Services Act* 1992 (QLD); *Disability Services Act* 1993 (WA); *Disability Services Act* 1993 (SA); *Disability Services Act* 1991 (VIC); *Disability Services Act* 1992 (TAS); *Disability Services Act* 1991 (ACT) *Disability Services Act* 1993 (NT) and the *Disability Services Act* 1993 (NSW).

individualization[191], the blatant focus and obsession with service delivery concerns meant that the disabled person as a distinct constitutional atom has mainly been erased (and hidden) from the explicit formulations of territorial definitions, that is until the enactment of the Commonwealth *Disability Discrimination Act 1992* (DDA)[192]. Section 4 of the DDA provides a broad and expansive definition of disability that has come to be seen as a national benchmark. The section states that

> disability, in relation to a person, means:
>
> (a) total or partial loss of the person's bodily or mental functions; or
>
> (b) total or partial loss of a part of the body; or
>
> (c) the presence in the body of organisms causing disease or illness; or
>
> (d) the presence in the body of organisms capable of causing disease or illness; or
>
> (e) the malfunction, malformation or disfigurement of a part of the person's body; or
>
> (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
>
> (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;
>
> and includes a disability that:
>
> (h) presently exists; or
>
> (i) previously existed but no longer exists; or
>
> (j) may exist in the future; or
>
> (k) is imputed to a person.

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[191] The DSA was one of the first pieces of legislation to use a human rights framework to develop cogent principles and objectives (Commonwealth of Australia, 1987) and extrapolate these into what was know as Prescribed Services Outcomes (Disability Service Program, 1990) In retrospect, the DSA represented landmark legislation inauguration a program of massive cultural change in the disability sectors at both governmental and community based levels. The implementation of the Act involved an attempt by government (civil servants) to break up and re-structure 'whole of life' services and shift away from a diagnostic emphasis to a needs focus. At this time also a human services ideology known as Social Role Valorization Theory (normalization) became vogue.

[192] For more on the mapping of commonwealth disability policy changes Conway (1992) and Parliamentary Library Service (1996) are worth consulting.

This section of the DDA is interesting on a number of accounts. Whilst sub-sections (a) to (g) incorporate and continue to reinforce an etiological and functionalist tradition, sub-sections (h) to (k) not only invoke the fluid and temporal aspects of embodiment; they recognize the constructed and relational dynamics of disability as a signifier. What is missing from section 4, is a depth of analysis that moves away from the notion of disability as having an objective reality and towards understanding disability as being enacted in relation to other forces, for example, other scaled human bodies; the use or non-use of technologies, or coverage under various administrative regimes.

With the securing of the *Commonwealth State Agreement* of 1991 and the assent of the DDA 1992, all States have enacted concurrent legislation[193] resembling the Commonwealth *Disability Services Act* 1986 (DSA) thus creating an (illusionary) state of uniformity and coherency. Since the late 1990's and into the new millennium, the state of disability has become sharply unsettled and become a battleground for delimitation. Various technological practices are now starting to confound (confuse, confront) the being of disability especially in relation to questions of mitigation. Enhancement technologies are rewriting the boundaries of the divide between the 'normal' and the 'pathological', let alone relations between 'human' and 'non-human' actors. The fixity of 'objective' disability is starting to fragment and protest with difference emerging between 'legal' disability and those with 'referential disability' of the 'outlaw' kind.

Whilst there are emerging critiques of disability, essentially those proposed within biomedical conceptualisations, disabled people ourselves have recognized the need to hold onto some form of strategic essentialism in order to make any 'gains' within the

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[193] DSA 1992 (QLD):

rights and welfare framework of liberalism. The next section is concerned specifically with an examination of Social Role Valorisation Theory (SRV), which has been adopted as a significant philosophical framework for guiding the development of human services, especially the disability sector.

5.3 Operationalising Disability: Social Role Valorisation Theory as Discourse: Bio-medical Transgression or Recuperation?

> I wish to congratulate you for your courage in publishing Michael Bleasdale's critique of [SRV]. For too long Wolf Wolfensberger's messianic treatise on 'normalization', and more recently 'SRV', has gone unchallenged in the Australian scene.(Parmenter, 1994: 5)

> One of the central contradictions of normalization [SRV] is that while it purports to re-value people with disabilities, it is rooted in a hostility to and denial of 'differentness'.(Szivos, 1992:126)

> … having given such a negative meaning to abnormality - the non-disabled world assumes that we wish to be normal, or to be treated as if we were. From this follows the view that it is progressive and liberating to ignore our differences because these differences have such negative meanings for non-disabled people. (Morris, 1991: 17)

The arrival of Social Role Valorisation Theory (hereafter referred to as SRV) into the Australian 'disability' body politic in the early 1980's represented, at least at a public level, a new paradigm of 'disability' talk. To use Foucauldian language, SRV is best described as a disciplinary technique, a form of 'biopower' concerned with the regulation, manipulation and transformation of the unruly bodies of people with disabilities. The SRV apparatus is a maze of complex mechanisms concerned with guiding principles of human service delivery, both at operational and 'client' based levels. It is also engaged as an evaluation tool. As such the introduction of SRV has not only been instrumental in the development of new methods for the 'management' of disability, the very discourse of SRV has effected the constitution of the disability – talk and conceptualisations within social policy and legislative reforms. Contrasted with the unenlightened era of the ‘old’ bio-medical paradigm, SRV is presented as a new ‘liberating’ paradigm offering new hope and valued lives for the ‘suffering’ individual. In my home state of Queensland, allegiance to SRV has become the lynchpin for access to employment in State government initiated services.

In this section, I will put forward three propositions about SRV. Firstly, I will show that it is questionable whether SRV represents a departure from the bio-medical discourse of ‘disability’ (as suggested by its exponents). Instead, I will argue SRV can be understood as a recuperative strategy that extends the tentacles of bio-medical disciplinary practices, appearing at the very moment medical dominance has waned and undergone contestation. Secondly, it is my argument that SRV is a technique that coerces a particular form of human self - the sovereign individual of liberalism who is rampantly autonomous, competent and rational. Finally, I argue that SRV can be seen as an incitement to hetero-normativity (and an erasure of peripheral sexualities).

This section is divided into four parts. First, I analyse the history, diversity and application of SRV. Next, I expose SRV’s heteronormative compulsion. Then, I turn to a critical reading of SRV. This includes an exposé of SRV’s Parsonian structural-functionalist roots as well as its fundamentalist, ‘New Right’ standpoint. Finally, I explore, albeit briefly, the legislative impacts of the hegemony of SRV. Unfortunately, it is beyond the scope of this chapter to explore in detail the way ‘disability’ is put into law and understandings of the welfare state.

5.3.1 History and Diversity

The precursor to Social Role Valorisation Theory in the disability field was known as the Normalisation Principle[194]. Developed by Neils Bank-Mikkelsen (1980) of Denmark and Bengt Nirje of Sweden in 1969, normalisation was essentially a tool and mechanism to examine the lives of people prescribed as having an 'intellectual disability'. Nirje in 1969 defined normalisation as

> making available to all mentally retarded people [sic] patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society (Perrin and Nirje, 1985: 69).

Implicit within this definition is the presupposition that the 'social' should be inclusive and 'integrate' people with disabilities. This formulation is utterly consistent with liberal rights theory. Writing fourteen years later, Nirje is explicit about the tradition within which the normalization principle stands[195]. Trained in philosophy and law, Nirje wished to extend the purview of the *Universal Declaration on Human Rights* promulgated by the United Nations in 1945, by enshrining notions of equality and humans rights into an 'ethical values' theory that would compliment the law in bringing about change (Nirje, 1985).

The implementation of normalization theory takes 'culture' as its starting point. Nirje's ideas about 'culture' were influenced by American anthropologist Ruth Fulton Benedict (1887 - 1948), especially her influential 1934 work, *Patterns of Culture* . In that work, Benedict underscored the power of custom and learning as an argument against biological determinism and (almost as a precursor to the developmental model of

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[194] For the purposes of clarity and to minimise confusion between Wolfensberger's and Nirje's concept of '*normalization*', the term *Social Role Valorization Theory (SRV)* will be used to denote the 'theory' and practice of the Wolfensbergerian school. Normalization emerged from the experiences of the intellectual disability field in Scandinavian countries.

[195] For a review of some of the long term issues on evaluating normalization in Norway (see Jenssen, 1995).

learning) maintained that human beings had an infinite capacity to change. Benedict argued that each individual could effectively alter the conditions of their life and in so doing profoundly change culture. So, for Nirje (1985: 66) normalization meant following the "normal rhythm of the day, week, year" and the "normal development of the life cycle" making up the 'normal' conditions of life. The ability of an individual to engage in the 'normal' conditions of life, Nirje contends, is determined by the type and severity of disability experienced by the individual.

Whilst examples of 'normal rhythms' are defined in Nirje's work, 'culture' is presented as an organic and axiomatic unity (Chappell, 1992: 41), and as such remained unproblematised and universalised. It would appear that the concept of 'normal rhythms' is based on what might be called 'benchmark' assumptions concerning the life of an elusive 'normal' member of the community (Nirje, 1980). Such a citizen expresses the virtues of masculinity, rationality, autonomy, activity and detachment.

Unlike Wolfensberger's understanding of normalization that will be discussed later in the chapter; for Nirje 'integration' is predicated on a fundamental equality and integrity of person, "meaning to be yourself among others - to be able and be allowed to be yourself among others" (Nirje, 1985: 67)[196]. Indeed, the normalization principle is not meant to be prescriptive, yet Nirje's own work appears to be profoundly culturally - bound and hetero-sexed[197]. In *The Normalization Principle* (1976), section titled "Living in a Heterosexual World", Nirje states:

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[196] Despite over two decades of literature about the differences between SRV and normalization many staff remain confused about the distinctions.(See Wilson and Bartak, 1997).

[197] I am well aware of the socio-historical context in which Nirje made his claims and the dominance of non-consensual single sexed environments. However, this state of affairs does not excuse Nirje solving the 'problem' by moving from one prescriptive environment to another that is dubiously posited as universal and natural.

> Normalization also means living in a heterosexual world … handicapped [sic] people sometimes suffer a senseless loneliness and it may be *better for them* to be married like anyone else. (Nirje, 1980: 43 ~ emphasis added)

It could be said that Nirje's observations were a step on the way to recognizing the hetero-sexed nature of the 'disabled' body, but let us not be too generous! Aside from the paternalistic nature of his remarks, Nirje was thoroughly hegemonised about matters of relationality, let alone the changing and problematic concept of 'family'. In fairness to Nirje, the normalization principle does advocate the right to make choices and the right to self-determination. Writing nine years later, in the midst of contestation around the 'real meaning' of normalization, Nirje errs on the side of 'choice' and diversity, when he says:

> Just as (within certain limits which vary from society to society) a 'normal' individual may engage in popular non-conformist or even 'deviant' behaviors, the normalization principle implies that the same right also should apply to … handicapped [sic] people. (Perrin and Nirje, 1985: 71)

This position, we shall see in the following section, is in sharp conflict with the views of Wolfensberger who has become the dominant 'voice' in the debate. In 1972 United States based Dr. Wolf Wolfensberger developed his own version of the normalisation principle "into a guiding principle for the design and conduct of virtually any kind of service" (Wolfensberger and Thomas, 1983: 23). The theoretical congruence between Nirje's and Bank-Mikkelson's concept of normalization and the Wolfensberger approach is questionable. Though influenced by Scandinavian developments, Wolfensberger argues that he "elaborated, universalised, refined and systematized" (1980: 74; Wolfensberger and Thomas, 1983: 23) the principle as originally conceived by Nirje. Yet a significant, though subtle, epistemological and methodological shift has occurred. Nirje's liberal rights-based 'values theory', normalization became transmogrified into Social Role Valorisation Theory (SRV) and has, according to Wolfensberger, become a universalised, higher order, 'scientific' meta-theory of devaluation (Wolfensberger, 1995: 367).

Wolfensberger defined SRV as encompassing "as much as possible, the use of culturally valued means in order to enable, establish and/or maintain valued social roles for people" (Wolfensberger and Thomas, 1983: 23). SRV relies on two strategies to facilitate the movement of 'devalued' people into becoming 'valued' members of 'society'. The first strategy is to reduce stigmata; and the second, is to change perceptions of community members through the re-valuing of 'devalued' people. The methods utilized to activate such strategies are incorporated into service provision goals focused upon the enhancement of a 'devalued' person's social image and competencies. Stanley Cohen (1985: 183 - 191) in the context of criminology, but equally applicable here, described the 'cognitive passion' for testing (judging normalization) by 'professionals' and bureaucrats.

The obsession in SRV to produce 'competency enhancements' that conform with a fictitious "… typical citizen [who] … has a culturally normative degree of personal autonomy and choice" (Wolfensberger and Thomas, 1983: 28) masks the masculinist basis of the liberal subject of western modernity, erasing alternative ways of living human subjectivity[198]. The normalizing gaze of 'experts' is extended to the testing and ranking of 'human service' agencies. With Susan Thomas, Wolfensberger developed PASSING (Program Analysis of Service Systems' Implementation of Normalization Goals), a service provision evaluation tool which is "a device for the objective quantification of the quality of a wide range of human service programs … and even

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[198] In recent times there have been attempts by some practitioners to 'modify' SRV by de-emphasising the 'role' aspects and refocusing on concepts of valorization (See Elks, 1994). The 'success' of such an approach is debatable as 'roleness' is an inherent aspect of SRV.

entire service systems" (Wolfensberger and Thomas, 1980: 28). Each service provider engages in a process of self - production - surveillance; a ritual of 'truth – making' in order to map - construct - conform to SRV's imperative[199]. The Seven Core Themes[200] of SRV constitutes the framework of SRV-in-action and an outline follows:

- The role and importance of (un)consciousness in human services;
- The relevance of role expectancy and role circularity to deviancy-making and deviancy-unmaking;
- The conservatism corollary of normalization;
- The developmental model, inclusive of competency enhancement;
- The power of imitation;
- The dynamics and relevance of social imagery; and
- The importance of personal social integration and valued social participation; (Wolfensberger and Thomas, 1983: 23 - 29)

A brief perusal of the seven themes suggests the centrality of values and cultural valuation in the effective implementation of SRV. Although recognizing that subordination, or in Wolfensberger's language 'devaluation', is culturally relative, Wolfensberger (1995: 366) insists that SRV's object is twofold, namely, to "capitali[ze] upon cultural values and the need to change at least some of them". The question of 'who' decides, in the event of a value conflict, which values prevail, is not particularly addressed. It is assumed that the human 'community' is a social system structured

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[199] This process has at times been coercive with many Commonwealth funded services being threatened with de-funding should they not conform with the Principles & Objectives of the *Disability Services Act 1986 (Cth),* based on *SRV.*

[200] It is my understanding that the new *SRV* Theory workshop now has 10 themes. As of November 1997, the Australian *SRV* Group is yet to critically evaluate the additional 10 theme course.

around a homogenous or shared (or at least consensual) value base. The 'social' is a biological organism, its capillaries made up of norms and values.

SRV appears to uncritically reinforce such a construction of social ordering by its emphasis on the reduction of 'devaluation' via the prevention of 'differentness' or stigmata that may result in 'devaluation' or marginalisation from the mainstream. The following examples support this conclusion:

> Since deviancy is, by definition, in the eyes of the beholder, it is *only realistic* to attend not only to the limitations in a person's repertoire of potential behavior but attend as much as or even more to those characteristics and behaviors which *mark a person as deviant in the sight of others*. For instance, wearing a hearing aid may be a *greater obstacle* to finding and keeping a job than being hard of hearing. (Wolfensberger, 1972: 28 ~ emphasis added)

The 'shame' of 'disability' is further highlighted by the need to avoid body sculpturing that as Wolfensberger & Thomas (1983: 37) put it "unnecessarily draws attention to devalued physical characteristics, such as a close-cropped brush haircut on a man whose head and ears are malformed…". Such strategies, I argue do violence to the integrity and corporeality of the person with a 'disability' and sends mixed messages about the repugnance - unthinkability - intolerability of 'disabled' bodies. This view finds support in a recent piece by Culham and Nind (2003) who argue, *inter alia*, that for any strategy of inclusion be enduring there is a necessity to engage in a deconstruction of the conceptualisation of SRV and normalization.

The rest of this section will concentrate on the 'conservatism corollary', one of the 'seven core themes'. According to Wolfensberger, the 'conservatism corollary' posits that:

> the greater the number, severity, and/or variety of deviances or stigmata of an individual person, or the greater number of deviant/stigmatized persons there are in a group, the more impactful it is to: (a) reduce one or few of the individual stigmata within the group, (b) reduce the proportion or number of deviant people in the group, or (c] balance (compensate for) the stigmata or deviancies by the presence, or addition, of positively valued manifestations. (Wolfensberger and Thomas, 1983: 26)

Wolfensberger clarified the meaning of promoting positively-valued manifestations within the 'conservatism corollary' by arguing that it was preferable to choose the more positive (or conservative) option. In other words, the corollary requires that human service workers overcompensate to reduce or minimize any 'devaluing characteristics'.

The reality of the corollary is that it does nothing to interrogate and challenge hegemonic ideas that exclude, separate and subordinate people with disabilities. Instead, the tenets of the corollary actively promote separation between and within groups of so-called 'stigmatised' peoples[201].

> When a significant proportion of people within a distinct or compact group have one or more such *oddities*, then the whole group including non-stigmatized members, is apt to be negatively stereotyped. (Wolfensberger and Thomas, 1983: 26 ~ emphasis added)

Such so-called 'oddities' include 'retardation', a 'speech impediment', an 'odd' hairstyle, and the wearing of 'odd' clothing. The 'normalized' body in contrast is one that presents as "clean, neat, fashionable, and flattering grooming and dress" (Wolfensberger and Thomas, 1983: 37). The tenets of the 'conservatism corollary' are in sharp conflict with Nirje's understanding of the normalization principle that advocates the right to make 'choices', even if those 'choices' are, as he puts it, unpopular. Nevertheless, where does the Enlightenment notion of the individual as a free and knowing subject fit? According to John Armstrong, a senior 'SRV' trainer, "freedoms are bought at the price of compliance, cooperation with the 'rules' of society". He believes that the consequences

> will not be changed by thrusting vulnerable people into circumstances where it *is they, and not us*, who receive the onslaught of societies [sic] retribution when they innocently and unintentionally act upon our advice - or its lack - and unwittingly violate some societal principle. (Armstrong, 1997 ~ emphasis added)

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[201] The separation is increased when the concept of 'deviancy image juxtaposition' is engaged. According to *SRV,* in situations where marginalised (read: negatively valued) people, things and symbols are likely to be transferred onto 'devalued' entities or symbols they should be avoided. Negative image transfer is reduced through association with valued social images.

Armstrong's interpretation of 'freedom' at the hands of SRV erases the agency and capacity for subordinated peoples to negotiate their/our own subjectivities. The epistemic and physical violence of SRV is best illustrated in Wolfensberger's advice for dealing with 'aberrant' and unruly flesh:

> Cosmetic surgery can often eliminate or reduce a stigmata, and can be as effective in enhancing a person's acceptability as teaching adaptive skills, changing his [sic] conduct or working on his feelings. (Wolfensberger, 1972: 104)

We are denied a deliberative capacity to adopt a resistive positionality. Such a statement reveals the ableist hegemonic standpoint of Armstrong as well as the 'benchmark' speaking position of SRV.

5.3.2 Compulsory Hetero-Normativity or, We may be 'Disabled' but We Can Still be 'Real' Men and Women!

The normalizing gaze of SRV comes into force in the operation of the 'conservatism corollary', a corrective technique that simultaneously marks out boundaries of permissibility for bodies inscribed as 'woman', 'man', 'queer', 'respectable' and so forth. The policing of sexed boundaries are revealed in a reading of the PASSING Manual's narrative on the 'Promotion of Client Socio-Sexual Identity', rating 225 (Wolfensberger and Thomas, 1983). A pursuit of 'valued sex roles' translates into a disciplinary technique that figures hetero-normativity as self-evidently preferable and 'natural': "Adults may choose either marriage and parenthood, or singlehood" raters are advised. Staff in facilities act as mentors for 'appropriate' sex role development (1983: 461 – 463).

In order to proffer a reduction in stigmata and overcompensate for 'devaluation', the corollary requires that the 'disabled subject' adopt ableist and heteronormative postures. The body marked for 'transformation' and 'taming', is required to suspend its life-flow and our/its very expressiveness, by engaging disciplinary 'tactics'. For in the end, "where clients are devalued, they should be supported in more conservative socio-sexual role developments" (1983: 463).

To ensure that the borders of sexed bodies remain fixed, Wolfensberger recuperates the naturalized body in order to ensure that there is no 'matter out of place' (Douglas, 1984), rendering the unruly 'disabled' body bounded and potentially knowable:

> … rather than those [bodies] which may be avant-garde or common, but only marginally valued at best … A delicate balance [must be struck] between acknowledging culturally normative and prevalent sex role stereotypes on the one hand, whilst simultaneously try to avoid sexism … raters are advised to be somewhat conservative if an *aggressive anti-sexist measure* would result in the projection of a deviancy image upon the client. (Wolfensberger and Thomas, 1983: 468 ~ emphasis added)

In other words, such bodily abjection, necessitates that:

> … the issue of sex role stereotypes … becomes especially troublesome when societally devalued people are at stake …the image of already devalued people should not be further endangered by associating such persons with images and activities which are marginal in the larger culture (Wolfensberger and Thomas, 1983: 462).

The dissolving of permissible boundaries may subvert and indeed contaminate the 'correct' ordering of 'nature' that is already under siege. Adherence to a heteronormative conception of reproduction within the context of marriage would reduce the moral complexities characteristic of late modernity (Wolfensberger, 1994: 406). SRV then posits certainty of sexed roles:

> …it would probably be harmful to the image of a mentally retarded [sic] man for him to spend his work day at tasks which have historically been thought of as 'women's work', or to be encouraged to occasionally wear a skirt because women often wear slacks. [In other words], … devalued people should not be at the vanguard of breaking down sex role barriers. (462)

Through a combination of sarcasm and snide remarks, Wolfensberger has discursively re-packaged the equal opportunity (gender neutrality) goals of liberal feminism in a way that makes these aspirations only available to the elite 'valued' few and unrealistic, if not counterproductive to ‘integration’ of ‘devalued’ people. The ‘sexed troubles’[202] of Wolfensberger permeate SRV and it is for this reason that feminists and others ‘Othered’ need to continue to foreground its violence, dangerousness and intolerance.

5.3.3 An ‘Agenda’?

The SRV Internet web site[203] represents SRV as a strong, vibrant and coordinated international movement spanning at least seven countries. Indeed, much of the language and rhetoric used by Dr. Wolfensberger and his followers closely resembles the style typical of ‘far right’ and fundamentalist religious cults. Individuals who transgress the SRV holy writ are subjected to the full force of SRV zeal and shunning. Indeed Hilary Brown & Helen Smith (1992a: xvii) supports this observation and note that “the commitment and fervour which it [SRV] can engender in individuals has led to it being likened to an evangelical movement, with associated doctrinal squabbles and schisms”.

Until recently, critical attention has focused upon SRV’s methodological flaws, either as a ‘deviancy’ theory (Bleasdale, 1994a; Bleasdale, 1996; Brown and Smith, 1992a; Campbell, 1984; Graycar et al., 1986) and more recently, its construction of ‘disability’ (Branson and Miller, 1992; Oliver, 1995; Rapley and Baldwin, 1995). Aside from Lindley and Wainwright (1992), few references have been made to the socio-religious context of SRV. This is surprising given the reference that Dr. Wolfensberger has made

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[202] My reading of the PASSING Manual’s heterosexed narrative is supported, somewhat ironically by Wolfensberger’s work that is more recent. In that work, Wolfensberger argues that civilisation is collapsing. It’s ‘glue’, in an advanced collapsed state include: “traditional family and home life, competent reproduction and child rearing. … Many traditional legal and cultural norms regarding human life, sexuality, morality …” (1994: 398).

[203] http://www.21century.com.au/jarm/*SRV*/address/address.html

to Christian influences upon his own work[204]. I believe that these religious foundations are critical to understanding the stance and direction of SRV.

Since the late 1980's the language of moral coherency has crept into the work of Wolfensberger and the Training Institute of Human Service Planning, Leadership and Change Agentry, whose mission is to read "… the sign of the times" and interpret their meaning for human services" (Wolfensberger, 1990)[205]. According to Lindley and Wainwright (1992: 31), SRV trainees are asked to "examine the negative dynamics of a society which opposes rational and moral goals and to explore the difficulties which await those who pursue such goals". Much of the language of the Institute has a doomsday flavour[206] and is obsessed with the destruction of civility, and with 'evil' and 'deathmaking'. 'Deathmaking', a central concept in Wolfensberger's thought, is defined as "any action or pattern of actions that brings about or hastens the death of any person or group" (Wolfensberger, quoted in Lindley and Wainwright, 1992: 31)[207]. The outline of a four-day workshop states that the curriculum will cover issues that require urgent attention[208]:

> This event is intended for people who (a) perceive there is gathering momentum in the world that works towards 'deathmaking'; (b) are uncomfortable with a pick-&-choose approach that endorses some 'deathmakings' in the world but objects to others; and [c) would like to work towards a more coherent position on the sanctity of life (Social Role Valorisation Page, 1998).

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[204] In 1979 Wolfensberger published an article on a theology of 'disability' . The following year, after claiming that his formulation of normalization squares with the central tenants of Christian theology, he refers to another work *Judeo-Christian Perspectives on Human Services* (1980: 89).

[205] Such a phrase has a distinctly theological 'ring' about it. On the 11th April 1963, His Holiness, Pope John XXIII, in *Pacem in Terris* (Peace on Earth), called upon Roman Catholics and Christians in general, to discern "… the 'distinctive characteristics' of our age, a concept and approach which in Vatican II became discerning 'the sign of the times'… " (Gremillion, 1976: 12).

[206] Indeed Bleasdale (1996: 8) suggests that Wolfensberger has an 'apocalyptic vision for the world'.

[207] An extensive nine-point definition can be found in Wolfensberger (1994: 395-396)

[208] Workshop title: "*Crafting a Coherent Moral Stance on the Sanctity of All Human Life, especially in the Light of Contemporary Society's Legitimization & Practice of All Sorts of 'Deathmaking' of Unwanted & Devaluated People."*

It is not surprising then, to discover an increasing convergence between the millenarianist concerns of the Christian far right in the US and the mission of the Institute, headed by Dr. Wolfensberger[209]. The Grace Baptist Church, who describe themselves as "a fundamental, independent … Church", in their Cutting Edge, a weekly radio show, cry out that "our society is deteriorating, and Bible believing Christians are ill-prepared to face that deterioration". (Cutting Edge Ministries, 1996). Wolfensberger, somewhat conjointly, is also concerned. He says

> we are witnessing the collapse of civilization … a rejection of the Greco-Judeo-Christian morality that has been the basis of Western culture, morality and polity for up to about 1600 years". (Wolfensberger, 1994: 396- 397).

The Cutting Edge radio transcript (1996) goes on to announce that the views of Dr. Wolfensberger who, introduced to listeners as " … a Jewish Holocaust survivor and born-again Christian", denounces the ushering of a 'new world order' and decries *inter alia t*he intentional killing of 200,000 people per year in the United States:

> We are killing far more handicapped people per year, than the Nazis did between 1939 - 1945 … deathmaking is normally so repugnant that, when you see one public instance of it, you can rest assured that as much as 100-fold has occurred *secretly that no one will ever see it …* Remember that the *New World Order has a goal* of forced reduction of the world's population by two-thirds by the year 2,000. (Cutting Edge Ministries, 1996 ~ emphasis added)

Could the Grace Baptist Church's use of Dr. Wolfensberger's material constitute a mere appropriation of his views to support the agenda of the Christian right, in ways not intended by Wolfensberger? Whilst there is a paucity of evidence at this point in time to support a direct connection between SRV, Wolfensberger and the New Christian Right, the sentiments expressed in Dr. Wolfensberger's recent works appear to support such a claim. Practitioners of SRV and Moral Coherency workshops are called upon to take a

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[209] Dispensationalism or premillenialism, is a particular strand of Christian evangelical fundamentalism which chiefly focuses of the eschatological aspects of Christianity, in particular the 'second coming' of Christ at the end of a millennium. According to Mc Grath (1994: 472), this movement has developed a strong influence with Christian subcultures in the United States of America.

"coherent stance against deathmaking" (Wolfensberger, 1994: 412) by becoming zealous advocates of SRV[210].

Let us re-cap after what may appear as a digression. Part of the task of my analysis is to expose and lay bare that which appears self-evident, as inherently problematic. Like with other new 'technologies', Australia was quick to pick up and respond to the SRV fervour originating from the United States. SRV's adoption into the Australian polity has occurred in the absence of much critical comment[211]. The remaining two sections of this chapter, then, will firstly survey these critical voices and secondly, indicate the influences that SRV has had in developments in the law and social policy.

5.3.4 A Genealogy of Critical Voices

Fear is a great silencer and as such speaking can involve risk. It was not long ago that critics of SRV risked 'silencing', reprisals and threats of dismissal by employers and de-funding of service provision[212] (Graycar et al., 1986: 27; Parmenter, 1994: 5). This section maps out critical responses to Social Role Valorization Theory from a broad spectrum of commentators. This document is not the first to foreground concerns about SRV. However, to my knowledge this presentation is unique in bringing together a synthesis of critiques in one text so that the reader can grasp key focal concerns[213].

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[210] For an additional discussion about issues arising out of the religious connection, (see Greiner, 1994).

[211] Earlier critiques were undertaken at great personal & professional risk, so whilst there was some critical *SRV* 'talk', few of these ruminations were put down on paper. For examples of early work see (Campbell, 1984; Graycar et al., 1986; Meekosha, 1986; Ministerial Review Committee of Educational Services for the Disabled, 1984; Perrin and Nirje, 1985).

[212] Should the reader be in any doubt about the currency of this threat assessment, they should note that as of 2003 the State public service in Queensland Australia responsible for disability service planning and funding, Disability Services Queensland (DSQ) requires prospective employees to sign a statement of allegiance to SRV. It is my understanding that a refusal to do so would result in non-consideration of employment, irrespective of meeting other aspects of hiring selection criteria.

[213] The literature used has been collected over a ten-year period from sources not readily accessible to people in the 'disability' field in Australia. The best collection on *SRV Normalisation: A Reader for the Nineties* (Brown and Smith, 1992b) contains a mix of essays favourable and critical of *SRV* from a British perspective. This text had to be ordered in from the UK.

Whilst there are differences in emphasis, the critical literature lends support to the view that SRV privileges ableist normativity and maintains the racializing and sexing of the 'disabled' body through disciplinary practices that assimilate and invoke separation between people with disabilities. In presenting my argument, I will commence with an outline of Nirje's response to Wolfensberger's 'reformulation' of normalization. Next, I will identify three clusters of concern: the methodology, practices and effects of SRV.

Burt Perrin and Bengt Nirje (1985) contend that SRV is predicated on a substantially different epistemological base from the principle of normalization as conceived by Nirje and therefore cannot be considered as "a reformulation, refinement, or operationalisation" of that principle (Perrin and Nirje, 1985: 71). The shift in the epistemological grounds of normalization from an 'ethical values theory', based on human rights, to that of the 'positivist scientism' of SRV, produces profoundly different effects on the way 'disability' is mediated. In this respect, SRV can be understood as a discursive manoeuvre. Nirje argues that SRV with its emphasis on conformity and the acquisition of culturally valued roles, sharply contrasts with normalization which (a) emphasizes the integrity of the person (Parmenter, 1994: 5; Rapley and Baldwin, 1995: 145) to make her/his choices (Brown and Smith, 1992a: 160); (b) promotes her/his self-determination (Perrin and Nirje, 1985: 71); and (c) considers important "an individual's subjective experience of self" (Szivos, 1992: 114).

SRV promotes the pursuit of culturally valued forms of self-determination for the person with a 'disability', but, if a 'preference' is in conflict with what is defined as 'appropriate' or more valued, then the latter must take priority. Perrin and Nirje's response to such a process is damning: "this authoritarian approach, however benevolent in its intentions, represents an unwarranted abuse of the powers of the therapeutic state"

(1985: 71). In summary, Perrin and Nirje argue that SRV is essentially an ideology that promotes ‘passing’ in society and the ensuing minimization of ‘deviancy’. The kinds of ‘deviancy’ I believe SRV has in mind, are deviations from hetero-normative corporeality and the autonomous disembodied ‘self’ of liberalism.

The founder of structural - functionalism, Talcott Parsons developed a universal theory of society which, “did not so much justify capitalism (although it often did) as offer an explanation and understanding of its difficulties without condemning it” (Craib, 1995: 379). Parsons’ ‘systems theory’, as it became known, emphasized a system “built up around norms and values”, in which a “system of ‘status roles’ developed … to which expectations of behaviour (and rewards and sanctions for fulfilling or not fulfilling those expectations) are attached” (382). Wolfensberger’s transmogrification of SRV into a ‘values theory’ resulted in a closer alignment with Parsonian functionalism (Bleasdale, 1996: 6), though this is not made explicit. In fact, a more accurate rendering would put SRV as a combination of societal reaction theory and functionalism (Burton, 1983: 54, 55; Chappell, 1992: 39). Even so, Rapley and Baldwin (1995: 151) argue “SRV has not drawn widely upon the theoretical extensivity of its supposed theoretical underpinnings”. A number of writers argue that functionalist role theory is outdated and inadequate to explain the marginality of people with disabilities (Bleasdale, 1994a: 17; Szivos, 1992: 116). Especially because of a focus upon ‘social problems’ at the individual and/or sub-cultural level, little “thought is given to the possibility that the source of the problem lies not within the system but is the system itself” (Mullaly, 1997: 124).

The positive reception and dominance of SRV within disability discourse in the United States, Australia and the United Kingdom, has been due to the appearance of a ‘scientific’ style of reasoning, an ‘empiricist persuasiveness’ (Szivos, 1992: 115).

Historically well timed, the development of SRV "fortuitously coincided with the zenith of the cultural hegemony of 'science' as an infallible weltanschauung" (Rapley and Baldwin, 1995: 145). Even though, Wolfensberger argues that SRV is self-evidently valid, using positivist-empiricist criteria, SRV's tautological reasoning fails for it is not amenable to refutation.

The sharpest criticisms have been reserved for the jargon of SRV, which according to Bleasdale and Graycar is "convoluted and elusive … designed to convey a mystique that [is] out of proportion to its meaning and context" (Graycar et al., 1986: 26). Not only does this language remove the 'theory' further away "from the consumers themselves" (Bleasdale, 1994a: 18-19), but I argue that SRV does violence to the experience of people with disabilities and reifies the power of 'experts'[214]. Furthermore, language is important as it plays a role in the discursive production of subjectivity itself. In this case, the discourse of SRV, whilst purporting to be a cutting edge paradigm of 'disability', in fact acts as a recuperative strategy involving a 'repackaging' of the binarism of 'normality'/'abnormality'[215]. The violence and subordination experienced by many people with 'disabilities' is referred to as 'wounds' in SRV training, which Bleasdale (1994a: 18 - 19) argues obscures instances of systemic exclusion and shifts the emphasis away from a 'rights' focus towards a therapeutic model under the power of the expert's 'gaze'.

The notion of 'devaluation' is a pivotal concept in SRV. Brown and Smith (1992a: 150) point out that 'devaluation' involves the exercise of power and thus should not be viewed in a passive way. The important question of agency is left unaddressed and absent, if not

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[214] See Butler (1997), on injurious speech.

[215] *SRV* masquerades as a 'new behaviourism' where "the same groups of experts are doing much of the same business as usual. The basic rituals incorporated in the move to the mind … are still being enacted. (Cohen, 1985: 152)

erased from the discourse of SRV. Wolfensberger's framework delineates that the performance of certain sexed and cultural roles leads to 'devaluation'. However, 'devaluation' in this sense, I argue, is misrepresented, as Wolfensberger does not discuss the way particular attributes or forms of embodiment are related to roles. In any case, in order to have 'valued cultural roles', Gillian Dalley (1992: 101-102) points out that "there must be a fundamental re-evaluation of those categories of persons *qua* persons".

I would take this analysis a step further and argue that we need to explode the whole concept of 'disability' and interrogate the constitution of the 'disabled' body (Campbell, 1999). Meanwhile, it must be stated that it is the values in 'society' which serve the hegemonic interests of 'benchmark' men, that also deny people with 'disabilities' "the opportunity to develop in the way which is best [sic] for them" (Bayley, 1991: 88).

In looking closely at Wolfensberger's theorizing it is evident that there is an irreconcilable tension and incompatibility between the desire to value humans qua humans and "working to develop socially valued roles for them" (Bayley, 1991: 89). Wolfensberger is clear on this point when he says, that to "value the person regardless of the person's identity and characteristics … is almost totally ineffective in bringing about the desired goal [of change]" (Wolfensberger, 1983, quoted in Bayley, 1991: 89). This raises yet again the shortcomings of a Functionalist based role theory. The 'validity' of SRV is highly dependent on an individual who is deemed 'different' and perceived as 'deviant', taking on the ascribed 'devalued' role and then incorporating that role into their subjectivity (Rapley and Baldwin, 1995). This idea appears remarkably similar to Althusser's much-contested notion of interpellation. It is the power of the 'expert' and the 'severely able-bodied' individual who, according to Judith Butler

> … initiate[s] the call or address by which a subject becomes socially constructed. [Interpellation can] compel fear at the same time that it offers recognition at an expense. In the reprimand the subject not only receives recognition, but attains as well a certain order of social existence …(Butler, 1993: 121).

It is difficult to assess the relationship between the characterization of an individual and the 'roles' they perform (Rapley and Baldwin, 1995: 157). Techniques of self-production however are multiple and complex; the individual is in a constant state of negotiating competing subjectivities that may be imposed or sought. Critics of SRV argue that the theory presents an assimilationist and mono-culturalist perspective of social ordering (Bleasdale, 1994a: 21; Branson and Miller, 1992: 17; Campbell, 1984: 96). Assimilation, has an insidious quality about it, for such a process involves an acceptance into the rosters of relative privilege, [and] requires that members of formerly excluded groups adopt professional postures and suppress the expressiveness of their bodies. Thus emerges for all who have not lost the impulses of life and expression of a new kind of distinction between public and private, in bodily behaviour. (Young, 1990: 140)

SRV may have the opposite effect of integration/assimilation, that is, it may produce the "exclusion of people with 'disabilities' from the political process" (Bleasdale, 1994a: 21) unless we/they can be subsumed into a particular human self - the sovereign autonomous individual figured in liberal rights theory. The 'independence' imperative is not only unattainable for many people with 'severe disabilities', it is also a cruel fabrication which simultaneously holds out the 'promise land' whilst continuing to inscribe 'disabled bodies' as 'Other' (Campbell, 1984: 96). In summation Branson and Miller remark:

> … the arbitrary disciplinary process of normalization [SRV] has robbed us all of our difference, our society of its sensitivity to diversity and thus of true tolerance, and our culture of its potential richness, all to serve ultimately the interests of a privileged minority. (Branson and Miller, 1992: 18)

The absence of any structural or socio-economic analysis of disablement and power in SRV is well documented elsewhere (Bleasdale, 1996; Brown and Walmsley, 1997; Burton, 1983; Chappell, 1992; Gleeson, 1995; Oliver, 1995). It is clear that SRV does not 'come up with the goods' to explain why in spite of significant progress in the toleration of disability, poverty and marked subordination remain. SRV advocates an explicit strategy of separation from other people with 'disabilities'. As Szivos puts it: the 'official' view, from the normalization [SRV] perspective, is that integration with non-disabled people is a more important goal than integration with disabled people [sic] (Szivos, 1992: 123). A strategy of dispersal of people with disabilities is predicated on the belief that we will not 'stand out', and our value and self-esteem will increase (Szivos, 1992: 121) via 'mixing'. Such a policy mitigates against people with 'disabilities' developing a sense of 'meaningful association' and solidarity drawing upon shared experiences and peer support (Brown and Smith, 1992a: 167; Brown and Walmsley, 1997: 232) to develop a resistive stance. The question of whether it is possible or indeed desirable for people with 'disabilities' to adopt a kind of oppositional sovereignty, similar to movements of people of colour, needs further consideration. In Chapter Four I have documented clear connections between disability disavowal and the production of not only internalised ableism and the endurance of ableism itself as epistemology of oppression in the lives of disabled (and abled) peoples.

After seventeen[216] years of SRV within Australian disability services, there is a strong argument to be made that, in spite of the process of deinstitutionalisation, the net of social control has widened. Centralized institutional surveillance has been replaced by a 'carceral archipelago' of 'community-based' services (Cohen, 1985: 42), which appear "open and small - sized", yet could be "restrictive and regimented internally" (Cohen,

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[216] My starting point is the Commonwealth *Disability Services Act 1986.*

1985: 291). Oliver argues that it is no coincidence that normalization was embraced at a time when a philosophical rationalization was needed to buffer up the policy of economic monetarism (Graycar et al., 1986; Oliver, 1995: 14). Much has changed for the 'lot' of disabled people since the introduction of the Commonwealth *Disability Services Act* 1986. However the "cosmology remains essentially unaltered" (Branson and Miller, 1992: 19), for

> … despite our lip service to consumer choice and the involvement of families in the planning processes, [we] continue to suffer from the 'cult of professionalism' where the trained professional, be he/she a physician, psychologist, social worker, therapist or teacher, knows what is "best" for the disabled person …(Parmenter, 1991: 3)

Indeed, it has been argued that SRV needs to be exposed as a new disciplinary practice, which provides guidelines about how people with 'disabilities' should understand, regulate and experience their bodies (Lupton, 1997: 99). Within these practices, the docility of the disabled body is produced by the power of the 'experts gaze'. We are taught to manage and understand our own subjectivities, through "classifying and measuring the psyche, in predicting its vicissitudes, in diagnosing the cause of its troubles and prescribing remedies" (Rose, 1991: 3). SRV, instead of investigating the hegemony of 'experts', has enabled the adaptation of 'experts' to 'community-based' and 'user-friendly' options (Chappell, 1992: 40; Ministerial Review Committee of Educational Services for the Disabled, 1984: 7). The spectre of 'institutionalisation' has been transmogrified into a 'softer' type of confinement - buildings being replaced by the extended control net of the 'helping profession'.

At the end of the day, little has changed; the tacit knowledges of people with 'disabilities' have been subjugated through nullification. The question needs to be asked - whose interests are being served by SRV? It would seem that the greater proportion of

SRV's supporters are professionals employed in the disability industry. Academics, at least in the United Kingdom, actively promoted SRV (Chappell, 1992: 37)[217]. In the Australian context, key players in disability policy formation are zealous advocates of SRV. They have the power to shape and construct disability discourse as well as expand their teaching repertoire by opening up new areas of inquiry. The hegemony of SRV is no more apparent than in its consummation in key Federal and State legislation. Meanwhile, because SRV "connects with their [those adopting a severely ableist mentality] common sense" (Oliver, 1995: 17), the 'objects' of SRV namely, people with a 'disability', are framed out of the debate.

5.3.5 Incursions into Law

The influence of SRV on the development of social policy and the day-to-day operations of service agencies cannot be under estimated. I am however interested in sketching (albeit briefly) the incursions of SRV legislative reforms and the theoretical groundings of disability imposed by the rhetoric of SRV.

Writing in the context of gay and lesbian law reform, Wayne Morgan has berated those activists who campaign for human rights protections within the framework of anti-discrimination law. These 'assimilationists' "cling to rights of privacy and equality, magnanimously granted by the State, and they argue that legal strategies should be directed to achieving those rights" (Morgan, 1996: 119). The power of legal discourse lies in its ability to 'trade in symbols' and generate categories of legal persons and legitimate knowledge/competencies[218]. The very rendering of 'disability' within a legal

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[217] For a recent discussion of the role of academics in the UK mediating conceptualizations of SRV (see Race, 1999).

[218] See following discussion in Chapter 5.4.

framework marks out the boundaries of permissible inquiry into the production and performance of disability subjectivities; concealing the discursive formations that entrench ableist normativity, not just within law but broader in citizenship discourse. So how useful then, is law as a mechanism for securing progressive social change?[219] Alternatively, is the law an instrument that entrenches ableist normatively in the form of SRV? Can the law indeed be 'escaped'? For as Margaret Thornton (1997b: 3) reminds us the

> Law can be imagined as a transparency that is placed over prevailing dominant interests so that it absorbs and reflects those interests. The movement at the edges of the transparency provides some scope for change in the configuration of dominant interests, but not very much.

Such ambivalence is reflected in an article by Melinda Jones and Leanne Marks who first argue that the Commonwealth *Disability Discrimination Act* 1992 (DDA), still reinforces a biomedical definition of 'disability'. Such an interpretation

> will teach the wrong lesson about disability to the wider community by failing to recognize that disability and outsider status are not inherent attributes of impairment but are social constructions. (Jones and Basser Marks, 1998: 65)

After concluding that the Act is of 'limited utility', Jones and Marks then proceed to outline critical theorist's concerns about the 'law': "the idea of 'normalcy' and the concept of 'ability' is achieved through the silencing of others, and in what is left unsaid as in what is stated" (83). Just at the moment when an interrogation of 'disability' seems possible Jones and Marks go on to dismiss this opportunity, and recuperate the law by arguing that individuals who adopt this view "expect too much [and are] … naive" (83). Moving from a stance of 'limited utility' on p.65, they conclude that: the DDA has a role

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[219] A good overview of contestations over the meaning of equality in law can be found in Marcia Rioux's essay *"Towards a Concept of Equality of Well-being: Overcoming the Social and Legal Construction of Inequality"* (1994). An excellent synopsis of the dilemmas of 'disability' legislation in Australia can be found in Margaret Thornton's article *"Domesticating Disability Discrimination"* (1997a) Section 5.5 discusses the use of law and the 'benefits' of liberal rights theory.

to play in the discursive formation of new structures of behaviour, including the regulation of subjective integrity, attitudinal shifts and cultures (Jones and Basser Marks, 1998: 82). How is this possible when the very rendering of 'disability' within a legal framework "limits the permissible inquiry into the nature of the construct; [concealing the discursive formations] … that have helped to create - and then re-create - ['disability']" (Hayman, 1960: 1248)?

The DDA was in many ways a response to the shortcomings of the *Disability Services Act* 1986 that is chiefly focused on the regulation of service delivery arrangements and funding to the 'disability industry'. New legislation was also a response to campaigns for civil rights protections by people with 'disabilities'. The Australian Labor Party's policy machine, influenced significantly by SRV, enacted the *Disability Services Act* 1986 (DSA). The legislation emphasized de-institutionalisation by enshrining SRV principles into its Objects (s.3) and the Act's *Principles & Objectives*[220]. At the same time, the government met its social justice objectives and reduced the mounting budgetary deficit (Graycar et al., 1986; Lindsay, 1996). Services were 're-profiled', 'down-sized', funded and occasionally de-funded according to whether they met a prescribed services outcome guidelines[221], based on material contained in PASSING training.

Similarly at a State level the Victorian government, with a policy framework based on SRV since 1977[222], enacted the *Intellectually Disabled Person's Services Act* 1986

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[220] These were drawn up separately and appear in the *Commonwealth Gazette*, No. S118, Tuesday 9th June 1987.

[221] As a Departmental Officer of the Cth Department of Community Services, at the time, I was made very aware of the necessity to ideologically adhere to such prescriptions (Disability Service Program, 1990)

[222] This is made quite explicit in the Victorian State Plan (Disability Services Division, 1996: 22).

(IDPS), enshrining the ideology of SRV in s. 5 - Statement of Principles. A lone dissenting voice within the Victorian policy apparatus was the *Ministerial Review Committee in Educational Services for the Disabled* [sic], who in its report to the Minister for Education specifically rejected SRV. Their reasoning: the philosophy gave power to professionals and the committee recommended instead an approach to 'disability' akin to the social model (Ministerial Review Committee of Educational Services for the Disabled, 1984: 6 - 12). In spite of these concerns more recently introduced legislation at the State level continues to incorporate statutory provisions that are aligned with SRV philosophically (see the *Disability Services Act* 1992 QLD).

Unfortunately, the power of legal liberalism still reigns strong. The former Federal Disability Discrimination Commissioner, the late Elizabeth Hastings (1996: 4) suggested that 'society' still places faith in the law to deliver change, arguing "the law has gone a long way towards recognising the real community which includes people with a disability rather than just the imaginary community". The DDA, she goes onto conclude "recogniz[es] the real composition of the real community". Does it really? It is debatable whether popular understandings of citizenship can readily embrace people who are designated as corporeally Other. Meekosha for instance, cites the exclusionary clauses in the Federal *Migration Act* 1958 wherein entry can be denied to persons with 'disabilities' because they may be a significant drain on the public purse: The meaning of 'significant' is contentious, leaving assessment of the person and their capacities open to subjective interpretation. Most community resources are in short supply … making exclusion a fait accompli in most cases (Meekosha and Dowse, 1997: 64).

Until the nexus between 'disability' and hybrid bio-medical discourse such as SRV is broken, the law will continue to reflect and legitimate the dominance of ableist normativity. The emphasis of change will be on restoring the individual with impairment to so-called valued roles[223] rather than redeploying the direction and emphasis of social policy towards those structures and processes that support and maintain the conditions of ableism (and by default disablement) in the first instance. Our task then is to continue to interrogate the law by "mapping the subversive voice, by telling the story of law from our points of view" (Morgan, 1996: 136) and thus allowing alternative epistemologies of impairment not based on negative ontologies of disability to emerge.

In this section, I have attempted to loosen the grip of SRV within the dominant discourse on disability within the Australian context by providing an alternative reading of SRV. The task of those of us with disabilities and our allies is to speak otherwise, in order to rescue 'disabled' bodies from the vertiginous dread of the tragic. This project of writing/speaking in oppositional/transgressive ways about knowing 'disability' by necessity engages courage, reflexivity and a reassessment of theoretical approaches to disablement, for the very teleological future of 'disability' is at stake. The next section examines recent trends in the government of disability beyond the human service confines of SRV into contesting about the delimitation of 'disability' under US Federal law.

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[223] For a rather unconvincing piece by Wolfensberger on the relationship between SRV and empowerment (see Wolfensberger, 2002).

5.4 Legislating Disability: Negative Ontologies and the Government of Disability

Sociological inquiry and legal investigation into disability[224] must at some point implicitly return to, and negotiate, matters of 'disability' at an ontological level[225]. I use the term 'implicitly', because the predominant forms of socio-therapeutic analysis of disability adopt a reductionist approach, which situate 'the problem' of disability at the level of attitudes or bias that lead to devaluation. Seldom is the matter of ontology (in particular, negative ontology) regarded as a paramount focal concern in unpacking disability subjectification. In what follows, I seek to redress this imbalance. In order to do so, I foreground the ontology question. In particular, I discuss disability-negative ontologies and the ways in which these ontologies are inflected in the practices and effects of law.

Activists with disabilities have placed great trust in the legal system to deliver freedoms in the form of equality rights and protections against discrimination. While these sorts of equalization initiatives have provided remedies in the lives of some individuals with disabilities, their sub-text of disability as negative ontology has remained substantially unchallenged. It is crucial, however, that we persistently and continually return to the matter of disability as negative ontology. Elsewhere in this work I have already made reference to Michael Oliver's (1996) 'personal tragedy theory of disability'. This conception of disability underpins most of the claims of disability discrimination, which

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[224] 'Disability' as a signifier maybe understood in terms of *catachresis*. That is, there is no literal referent for this concept. As soon as we discursively interrogate 'disability', its meaning loses fixity, generality and ultimately collapses. From this perspective I argue that the citation 'disability' invokes a reading of corporeal differences, particularities and unintelligibilities within the context of culturally delineated normative and ableist (benchmark) bodies.

[225] I am using ontology not in an essentialist sense, but rather to denote ways of being that are inscribed, fabricated and shifting. C.f. Butler (1997b: 3-4).

are juridically sanctioned within the welfare state and is imbricated in compensatory initiatives and the compulsion towards therapeutic interventions. Insofar as this conception of disability is assumed, the presence of disability upsets the modernist craving for ontological security.

The terror of falling into impairment can and does produce instances of disability hate-crimes[226], disability vilification, and disability panic[227]. The manifestations of these terrors rarely enter judicial domains, but they rather are excluded from law's permissible inquiry and codification. In short, this erasure and disavowal forecloses the possibility of pursuing legal remedies through the refusal of law's power to name and countenance oppositional disability discourses. Disability 'harms' and 'injuries' are only deemed bona-fide within a framework of scaled-down disability definitions [read: fictions] elevated to indisputable truth-claims and rendered viable in law. Law's collusion with bio-medical discourse informs us not only about modes of disability subjectification; in addition, and more importantly, that collusion informs us about what it means to be 'human' under the rein/reign of ableism.

Thus far, I have discussed matters of an ontological character in order to introduce the notion of the ontological terror as a significant actor in the promulgation of ableism with law in liberal society. In the following section, I turn to consider practices of freedom as they are actualised within this ableist regime of law.

5.4.1 Social Injury – A Transgressive or Recuperative Tool?

> Freedom is neither a philosophical absolute nor a tangible entity but a relational and contextual practice that takes shape in opposition to whatever is locally and ideologically conceived as unfreedom. (Brown, 1995: 6).

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[226] For follow up consult (Disability Rights Advocates, 1999; Gallagher, 1995; Sherry, 2000; Waxman, 1991).

[227] Colker (1999) documents the kind of disability panic that has provoked media backlash against the *American with Disabilities Act* 1990.

Feminist legal scholars have attempted to re-work and engage with liberalism, that is, to move away from a focus on procedural rights that do not effect substantive change. One feminist strategy, which has gained currency, is mobilization of the concept of 'social injury', a theoretical device that translates once privatised injuries into collectivist raced, sexed, and disabled domains from which to make claims to social and legal remedies from the courts or government.[228] (Brown, 1995; Howe, 1990; Howe, 1997; Thornton, 2000). In this section of my chapter, I consider the arguments that Wendy Brown and Margaret Thornton have advanced with respect to these oppositional strategies of legal engagement. In order to motivate their arguments in this context, Brown and Thornton variously draw upon Nietzsche's concept of ressentiment[229].

In the opening pages of *States of Injury: Power and Freedom in Late Modernity*, Brown asks: "What kinds of domination are enacted by practices of freedom?" (Brown, 1995: 6). With respect to the social injury project adopted by some feminists, we can ask: what kinds of domination does the social injury project (as a practice of freedom) enact? The evolution of anti-discrimination law has in fact led to the codification of injury, victim-hood, and dependency within an overall context of docile subject-positions. An analysis of social injury involves the development of a righteous critique of power from the perspective of the injured. Such an analysis delimits a specific site of blame by constituting certain sovereign subjects (and events) as responsible for the 'injury' of social subordination that other subject's experience (Brown, 1995: 27). As Brown notes, the 'social injury' project establishes certain harms as "morally heinous in the law." Exactly which 'harms' does the social injury project recognize? That is, what kinds of 'harm' have legitimacy before the law? I would argue that with respect to disability, an

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[228] The danger with this approach is that it solidifies the notion of a fixed bounded group identity and does not handle the intersection of various subordinated subject positions.

[229] (Nietzsche, 1956 Orig. 1887: 20, 36)

uncritical approach to social injury has (at best) established certain authenticated sites and specific instances of 'disability discrimination' as harm[230]. The discovery of these 'harms' has not, however, been extended to the identification of 'ableism' as their very font[231]. In short, disability discrimination is an outcome of the practices of ableism, not their cause.

The conditions of engagement within the emancipatory project require that 'the injured' relinquish their investment in a harmed politicised identity in order to be free. But does it work that way? What kinds of ontologies of disability does the social injury project require disabled people to trade-in, renegotiate, and maintain? I would argue that the use of legal mechanisms to structure political demands is an act of self-subversion that enforces an internalised ableism. The political identity of disability (i.e., 'the disabled citizen') within law not only contributes to an essentialised and exteriorised ontology; in addition, it normalizes and delimits 'disability' in order to make it regulative. Following Brown, we can say that the language of (disability) recognition in law "becomes the language of unfreedom," that is, "a vehicle of subordination through individualization, normalization, and regulation, even as it strives to produce visibility and acceptance" (Brown, 1995: 66). In other words, the inscription of certain figurations of legal disability requires that disabled people's 'experiences' be regulated within the confines of juridical formations, which ultimately foreclose any alternative perspectives. Furthermore, this form of procedural justice conveys the message that in order to be free

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[230] These findings should not be easily dismissed and are useful for various activist campaigns.

[231] For instance there has been a hesitance amongst policy makers and law reform advocates recognizing the legitimacy of disability vilification and hate crimes.

within neo-liberal societies, disabled people must submit to the strictures of ableist renderings of disability in law, that is, renderings of disability as a personal tragedy[232].

In *Neo-liberalism, Discrimination and the Politics of Ressentiment* (2000), Thornton offers an optimistic reading of a politics of ressentiment. Although the picture of a politics of ressentiment that Thornton paints might at first appear attractive in its treatment of disability subjectification, Thornton fails to adequately consider the impact of negative ontologies of disability upon the formations of disability subjectivities in law. In a critical review of Australia's *Disability Discrimination Act* 1992 Cth ("DDA"), Thornton concludes that neo-liberalism and its shift from equal opportunities to equal responsibilities provides evidence that disabled people can only be assimilated (accommodated) if they replicate their benchmark confrères and do not make too many economic demands on the system. As Thornton puts it: "Neo-liberalism is discomforted by prophylactic measures that are perceived as impediments to the freedom to pursue profits" (2000: 19). Indeed, the tensions that arise due to the necessity to work on the 'unproductive' disabled body in order to make it 'productive' in a recessionist economy grow increasingly evident (McClure, 2000).

Despite this rather disastrous situation, Thornton maintains that not all is lost because a politics of ressentiment allows people with disabilities to 'come out' about disability discrimination and thereby enact positive images of disability. Thornton claims that the focus of ressentiment produces a groundswell of dissatisfaction on the part of people with disabilities, where such sentiment can be deployed as a positive force. Thornton

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[232] The consequences of such a theory is given recognition in the definition of 'disability' in s 4 of Australia's *Disability Discrimination Act* 1992 which incorporates imputed as well as temporal aspects of impairment. I would further suggest that to resist such negative imputations and 'celebrate' the ontological and phenomenological manifestations of 'impairment' runs the risk of erasure and re-inscription through the pathologisation of such desires.

recognizes that ressentiment can produce other emotions (such as passivity and fear) aside from righteous anger; however, she suggests that such emotions can be attributed to, and are a consequence of, the vulnerability of a person who speaks from an institutionalised context (Thornton, 2000: 20).

I am not convinced by this argument. Disabled people who are confined by an institutional location are not the only ones to display emotions of antipathy, ambivalence, and fear. I would argue that all people with disabilities confront the daily challenges of internalised ableism when negotiating daily existence in a world that erases our value, though these challenges always vary in their degree and form[233]. Contra Thornton, I am inclined to propose that neo-liberalism's engagement with minority identities provokes a politics of ressentiment on behalf of the 'majority'. We need only remind ourselves of the cries of 'special rights'[234], legislative rollbacks, and reactive campaigns, both in Australia and the United States. We might find that there are limits to securing equalization protections within the law and social policy, especially in a political climate where the mantras of self-reliance and mutual obligation are increasingly invoked, and complaints about 'compassion exhaustion' are often articulated. Although well intentioned, the promotion of social injury strategies may easily result in unintended consequences, such as an increase in disability resentment and hate-crimes.

The growing number of appeals made to disability-related anti-discrimination legislation might, as Thornton suggests, contribute to the emergence of a new way to think about

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[233] Mullaly (1997) points out that assimilationist incitement not only mean internalized devaluation, but the very act of participation means individuals accept an identity other than their own and are reminded by others and by oneself of one's (real) masked identity.

[234] In Australia, there are debates motivated by the political Right according to which targeted programs and 'land rights' protections for indigenous communities constitute 'special rights' and thus are discriminatory towards the majority (read: white, Anglo-Australian) of the population. Similarly, when gay men and lesbians in various jurisdiction have lobbied for legislative protections in employment or property law, the Right argues that 'special rights' are being claimed (Consider, for example, *Ballot Measure 9*, Oregon, U.S.A.).

citizenship, a new way in which disabled people have ‘the tenacity and conviction’ to believe that they are justified in complaining about discrimination (Thornton, 2000: 22). Yet, disabled people’s complaints must be funnelled into the denunciatory processes of reductionist and single-cause classifications, which are interpreted both within and outside law through a paradigm of ableism. To be sure, possibilities for resistance to this bureaucratic machinery always exist; however, there is also the threat that a positive politics of ressentiment will be chipped away and unravelled by legal prescriptions of disability and foregoing remedies, which foreclose oppositional renderings of disability and play into (provoke) the internalised ableism of the complainant.

Is the concept of ‘social injury’ (allegedly a device of social change) actually recuperative of the structures of liberalism? Or does that concept transgress those structures? As a tool of opposition, the ‘social injury’ approach appears to offer a way out of the loop of discriminatory practices. One ought, however, to be suspicious of a practice that contributes to the elasticity and inclusiveness of the liberal polis. The enduring strength of liberalism lies in its capacity to re-write and repair the edge of its domain and recuperate any flaws that may expose its fundamentalist and ableist basis/bias.

Thus far, I have attempted to problematise the uncritical insertion of ‘disability’ into the neo-liberalist project of freedom-claims prior to an examination of the benchmark legal-subject and the relationship of that subject to disability as negative ontology. In addition, I have considered the strategy of advancing complaints based on claims to ‘social injury’, as well as the limitations of that approach given the overwhelming deployment of internalised ableism. The fact remains that disability is not regarded as a neutral category. To the contrary, it is value-laden and underpinned by a theory of tragedy that makes possibilities of 'pride' difficult (if not impossible) to generate.

5.4.2 'Disability' as Inherently Negative?

> Deafness is increasingly an outlaw ontology, a hunted existence, an experience or way of being that, by definition, evades the biopolitics of the new eugenics. Some believe that deafness has always been an outlaw ontology, but whose fugitive status was generally ignored. How long this fugitive will keep evading capture is increasingly in question. (Wrigley, 1996: 95).

In *A Fragment on Government* (1776), utilitarian philosopher Jeremy Bentham coined the term 'legal fiction' to refer to the fables and wilful falsehoods committed for the purpose of "stealing legislative power, by and for hands, which could not, or durst not, openly claim it, - and, but for the delusion thus produced, could not exercise it" (Bentham, 1990, orig 1776: 118). For Bentham, in other words, the effects of these 'legal fictions' are illusions, which produce a sense of debility in the very subjection of individuals, as well as the sense of trust, and faith that they put in law to deliver 'justice'. Thus, Bentham concludes:

> [F]or the more prostrate that debility, the more flagrant the ulterior degree of depredation and oppression, to which they might thus be brought to submit. Of the degree of debility produced, no better measure need be given, than the fact of men's being in this way made to regard falsehood, as an instrument, not only serviceable but necessary to justice (18).

With respect to disability, it would seem that such 'legal fictions' give rise to a false or distorted ontology, which is formulated on the basis of bio-medical realism, and in whose terms disability is construed as a lack or negative valence. The 'fiction' in this case is the suggestion that a negative ontology of disability coupled with a bio-medical orientation towards disability prescriptions and evaluative rankings is necessary (i.e., a prerequisite) for the efficient administrative management and legal delimitation of 'disability'. A poignant example of the continuing recitation of this kind of legal fiction of disability can be found in the introduction to a special journal issue guest-edited by Melinda Jones and Lee Ann Basser-Marks (Jones and Marks, 2000: 3). According to these authors,

> *Most* people with disabilities would share the view *that being disabled is not a desirable state to be in*, and even agree that disability should, where possible, be prevented. However, the suggestion that this carries negative implications about the entitlement to rights, or the values, respect and dignity of people with disabilities, should be resisted. While it may seem paradoxical, it is essential to meet the challenge of truly valuing those who are disabled at the same time as *taking action to prevent or limit disability* (emphasis added).

The pursuit of legal liberal rights discourse, which Jones and Basser-Marks encourage, is deployed within the context of a negative ontological framework of disability and an assumed permissibility to performatively enact injurious speech. Insofar as Jones and Basser-Marks ground their arguments in this context on an a priori assumption that disability is not to be countenanced, they bear testimony to the pervasive and normalizing effects of such negative formulations as key to the maintenance of ableist rationalities; in addition, these authors reveal the recuperative and totalising tendencies and tensions in the flawed logic of ableist liberalism (Foucault, 1980b: 98). This logic allows the rhetoric of rights to 'have it both ways', that is, to simultaneously hold out the promises of equalization and to reinscribe negative ontologies of disability that continually produce and effect subordination.

The very inclusiveness of the neo-liberal conception of 'citizenship' hinges upon governing disability according to an ethics of normalization and minimization. The individual of Western neo-liberalism is an increasingly commodified entity. Within neo-liberal societies, individuals (like inanimate objects) are increasingly packaged and marketed in terms of their respective 'use-values', which become a measure of their respective worth[235]. Recent technological 'advancements' hold out the possibilities of

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[235] The Howard government's increased emphasis in social security reform on 'mutual obligation' is a case in point. C.f. McClure (2000).

'elevating' the bodies (and minds) of individuals designated as disabled to the level of 'nearly able'. Thus, we could argue that 'enhancing' and 'perfecting' technologies are really means with which to assimilate by way of morphing[236] ableism. A technological dynamic of morphing creates the illusion (that is, an appearance) that the 'disabled' body transmogrifies into the 'normal' body, effecting a corporeal re-composition and re-formation of subjectivity. Though this sort of phantasmic re-imaging occurs at an ontological level, the violence of some technological applications is profoundly direct and immediate. Carver (1990) writes:

> Footbinding was a method to attract a good husband and secure a happier life. At the speech and hearing clinic, I was trained to bind the mind of my daughter. Like the twisting of feet into lotus hooks, I was encouraged to force her deaf mind into a hearing shape. I must withhold recognition of her most eloquent gestures until she makes a sound, any sound. I must force her to wear hearing aids no matter how she struggles against them. The shape of a hearing mind is so much more attractive.

In fact, an inducement to co-operate with treatments, surgery, and fittings may not be necessary due to the enduring hegemonic compulsion towards ableist normativity. Individuals with disabilities (and, in many cases, their families) develop a sense of responsibilisation, a sense of correct ethical conduct, that is, a "regime of truth" about what it is to be a 'proper' citizen[237]. These judgments about the 'correct' way in which to conduct oneself are often shaped by (or, despite) one's awareness of the ontological, epistemological, and political effects of resistance or transgression against such

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[236] The dynamic of morphing creates an illusion (appearance) of the 'disabled' body transmogrifying into the 'normal' resulting in a bodily re-composition and re-formation of subjectivity. This usually occurs through the engagement of technological practices that mimic what is understood to be 'able-bodied' or 'normalcy'. The morphing aspect refers to those elements of technological practice or application that give the appearance of bodily wholeness. For instance, amputee = lack: returned to able-bodied status = normal by way of hand transplant or prosthesis.

[237] For a further explanation of the neo-Foucaultian concept of technologies of responsibilisation, see Rose (1999: esp. pp 69 – 78).

prescriptions (c.f. Foucault, 1988a [Orig. 1981]; Foucault, 1997b)[238]. In this regard, let us briefly consider a juridical move made within the U.S. context, but which could easily be replicated in the Australian context in which I am writing, namely, the introduction of the legal category of voluntary/elective/chosen disability.

5.4.3 To 'Elect Disability' or not to 'Elect'? – That is The Question

Proponents of the legal concept of elective disability argue that legislatures should distinguish between two categories of 'disability' when they make assessments for coverage (protection) under anti-discrimination legislation, namely, the categories of immutable and elective (or, voluntary) disability. As these legal theorists explain it, the category of 'immutable disability' should apply to situations in which it is not possible (at least, not at present) to eliminate the disability (where this term usually means 'impairment'). Under these circumstances, a plaintiff should be deemed innocent and, therefore, deserving. Proponents of this bifurcation of disability argue, furthermore, that the category of 'voluntary' ('elective') disability should, on the other hand, be used in situations where disabilities were caused, continue to exist, or have been worsened by individual 'voluntary' conduct (Key, 1996).

Lisa Key argues, for instance, that someone who chooses not to mitigate a 'condition' voluntarily chooses to be disabled, that is, makes an informed, conscious decision to live with that impairment. Key allows that this is the individual's prerogative. Key maintains, however, that 'society' should not be obligated to bear the cost of that choice (Key, 1996: 84). Thus, Key proposes that coverage under the *Americans with Disabilities Act* 1990 (ADA) be limited by the introduction of a notion of 'reasonable

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[238] The media/medical treatment of Clint Hallam, recipient of the world's first hand – forearm transplant and his request to have the transplant amputated is an apt example.

accommodation' according to which 'unreasonableness' encompasses the choice — refusal — by a given individual to eliminate a disability (Key, 1996: 96).

Bonnie Tucker (1998) makes this sort of argument against 'deaf culturalists' (to use her term) and others who oppose the correction of deafness. Speaking in the context of the U.S., Tucker claims that the state provides welfare and equal opportunity provision on the basis of a moral obligation. With the advent of remedial technologies, Tucker contends, deaf people (and, by extension, people with disabilities) are morally obligated to submit themselves to such technologies in order to reduce the state's mounting financial burden. As Tucker sees it, people who are deaf should support research endeavours whose goal is to ameliorate or eliminate deafness, rather than protest against that research. Tucker argues, furthermore, that deaf people who choose not to have their deafness (or their children's deafness) 'corrected' lack (that is, forego) the moral right to demand that other members of society pay for the costly accommodations required to compensate for their lack of hearing (or that of their children) (Tucker, 1998: 10).

The claims which Key and Tucker make are dangerous. They incite a reconfiguration of disability that effectively casts corporeally anomalous bodies out into the wilderness where they must fend for themselves. The alternatives from which people are, in some instances, forced to choose can be grim: either submit oneself to technological procedures whose long-term consequences may be unknown[239], or exist with little or no legal protection. In such instances, the very notion of 'choice' in such instances seems more like wishful thinking. As Owen Wrigley (1996) notes in the opening epigram to

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[239] The case of Clint Hallam who recently underwent a radical limb transplant highlights the violence of the quest for normalcy. According to one commentator, "Hallam was previously a well man [with amputation] and now, under the influence of immuno suppressive drugs [which are needed to keep the "new" limb viable] is a sick man." (Ferrari, 1998: 17-18). Equally, the installation of a cochlear implant is invasive, requiring regular adjustment, often obliterating any residual hearing the recipient might have through permanent ear damage. See Wrigley (1996).

this section, any positive ontology of disability is an oppositional or outlaw ontology. What space, if any, can be made for this fugitive and dissident body? I would argue that in the world according to Key and Tucker there is no space or place for subaltern or previously unarticulated experiences of impairment/disability that diverge from the predominant biomedically-defined interpretations of it.

5.4.4 The U.S. Experience: Ableism and the ADA?

The juridical power of law and its capacity to name or erase different ways of framing disability were put to the test in a series of decisions that the U.S. Supreme Court handed down in 1999[240]. The cases which were heard related to coverage under the *Americans with Disabilities Act* 1990 (ADA); in particular, the cases concerned how the definition of 'disability' ought to be delimited under the Act. Under section 12102(2) of the ADA, a 'lawful disability' is defined in this way:

> With respect to an individual, the term 'disability' means
>
> (a) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;
>
> (b) a record of such an impairment; or
>
> (c) being regarded as having such an impairment.

The decision rendered in *Bragdon v Abbott*[241] clarified the meaning of 'major life activity' insofar as it held that the phrase 'life activity' should not be restricted to activities that take place in the public sphere. Furthermore, the ruling in this case extended the definition of 'life activity' to include reproduction. At the time, observers believed that Bragdon signalled a broadening of the scope of the ADA and the range of

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[240] Whilst Australian federal legislation such as the *DDA* (Cth) differs markedly from the *ADA*, the history of developments in US disability policy suggests that disability debates have had a *persuasive influence*. in the shaping of Australian policy and law reform both at governmental and activist levels. Current debates over the 'meaning' of 'disability' in US law provide a rich environment for the examination and analysis of ontological concerns due to the significant transparency of the ontological dimensions of 'impairment' within legal discourse.

[241] *Bragdon v Abbott* 524 US 624, (1998); 118 SCt 2196; 141 LEd. 2d 540.

people who could claim coverage under it. This optimism was short-lived. Against a backdrop of backlash against the ADA by employer organizations and sections of the financial media, it was no surprise that a series of ADA-related judgments handed down at the end of the 1998-1999 Supreme Court term redefined and re-evaluated disability in the context of mitigating[242] circumstances.

Known as the 'mitigation trilogy'[243], there were three cases that altered the definition of disability under Title 1 (Employment) of the *ADA*. The central question in the trio of cases was whether disability should be measured in its 'untreated' state, or in light of any corrective measures that would give the appearance of normal functioning. In the context of my discussion in this chapter, what is interesting about these cases is not only the contestability of setting parameters of disability under law; these cases are in addition interesting because they illustrate some of the ways that technological applications mediate various discourses about the ontology of disability in law. Let us turn to consider the lead case of *Sutton v United Airlines Inc*[244].

The plaintiffs in Sutton were twin sisters, trained as commercial pilots, who applied for positions as pilots with United Airlines in the U.S. Both sisters have myopic eye impairment, with uncorrected vision less than 20/200. When these women wore 'corrective' lenses, however, each of them had vision of 20/20 (or better) and was able to

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[242] Space precludes me from teasing out the notion of 'mitigation'. However I am struck by its relational and comparative quality. The dictionary definition points to an aspect of the word that denotes "make milder in manner or attitude, make less hostile or mollify." *The New Shorter Oxford English Dictionary*, 5th Ed. 1993: 1797.

[243] Known as the 'mitigation of disability cases' the parameters of defining 'disability' under the *ADA* have been realigned, in respect to 'corrective measures' to mitigate 'disabling conditions': *Sutton v United Airlines Inc*, 527 US 471 (1999); 119 SCt 2139; *Murphy v United Parcel Service*, 527 US 516 (1999); 119 SCt 2133; *Albertson's Inc v Kirkingburg*, 527 US 555 (1999); 119 SCt 2162. I would argue in addition that the 'disability' concept is already occluded – as prong of the definition is tied to the notion of substantially limiting a major life activity'. s3 (2)(a) of the *ADA*.

[244] *Sutton v United Airlines, Inc.*, 527 US 471 (1999); 119 SCt. 2139 (1999). The other two cases ostensibly followed the reasoning in *Sutton*.

function similarly to individuals without a visual disability. United Airlines terminated the women's selection interviews by arguing that the women did not meet the company's vision requirements, which stipulate that flight personnel must have uncorrected visual acuity of 20/100 (or better). The sisters, who took legal action under the ADA, alleged that they had been denied employment based on disability. Interestingly, the defendants (United Airlines) argued that the plaintiffs were not disabled: the women's impairments were corrected though the use of technological aids; therefore, those impairments could not be said to interfere with any major life activity. Here, then, is an example of how technological engagements can destabilize the meaning of 'disability'.

In its examination of the meaning of the term 'disability' in the context of the ADA, the U.S. Supreme Court held that the terms could not be read to support the proposition that determinations of whether a person is 'disabled' or not should be made by evaluating an impairment in its unmitigated state" (*Sutton* 2146-2147, per O'Connor). To the contrary, the Majority judgment of Justice Sandra Day O'Connor held that:

> if a person is taking measures to correct for, or mitigate, a physical or mental impairment, the effects of those measures — both positive and negative — must be taken into account when judging whether that person is 'substantially limited' in a major life activity and thus 'disabled' under the Act (2146, per O'Connor).

What is interesting about the majority judgment is that it was based, in part, on a particular reading of the legislative history about the number of people who are covered under the Act[245]. This is not the place to introduce an extended discussion of that aspect of legal reasoning. While the Court acknowledged a biomedical definition of disability, it actually erred in favour of what Jerome Bickenbach (1993) has called 'an economic

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[245] The science of counting 'cripples' brings to the forefront contestants over the delineation of 'disability' in an environment where people are firstly turned into objects and then numbers. For administrative purposes, it is imperative that the (real) disabled person is made visible through the processes of calculation and therefore can be made governable. The obsession with 'disability fraud' induces such questions as 'who is a genuine disabled person and how many of them are there?'

model of disability'. On the terms of economic models, disability is a socially constructed category which is made necessary by inescapable features of collective action and which is founded upon an individual's incapacity to participate as a worker in the distribution mechanism (Bickenbach, 1993: 93). Because the court assumed an economic model of disability, it concluded that the intention of the legislators who designed the ADA was to restrict coverage under it to individuals whose impairments are not mitigated by corrective measures (Sutton, at 2149). This checkerboard approach to the figuring of 'disability' by the court exposes the tenuous nature of legal reasoning, as well as the capacity of technological artefacts to confound and usurp seemingly self-evident formulations of 'disability'.

Instead of clarifying (that is, securing) the meaning of disability and that meaning's relationship to the question of mitigation, the trilogy of cases (Sutton, Murphy, and Albertson's) has provoked a series of new questions with respect to the technological morphing of normalcy. At stake, is the rendering of the species-typical body. The Court in all three cases concluded that individuals who 'mitigate' their impairments must have this factor considered when evaluation is made with respect to their coverage under the lawful 'disability' definitions of the ADA. However, none of those cases addressed the question of whether (as Key and Tucker contend) individuals have a duty to mitigate impairment; that is, if individuals 'choose' not to engage technologies (aids, prescriptions drugs, and so on) that seem to mitigate their impairments, should they still be considered disabled? For example, should a woman without arms be required to wear a prosthesis or have a hand transplant in order to be considered 'disabled' under the ADA? We might extend these questions further in order to ask this question: will current (and future) morphing technologies contribute to the framing of a benchmark mitigated disabled body[246] which is used to assess definitional conformity irrespective of the matter of usage or 'choice'? Will today's 'normal' body be superseded, that is, become tomorrow's 'abnormal' body?

The ableist leanings of the law (in this instance, exemplified in rulings by the U.S. Supreme Court) are exposed in its attempts to re-frame disability subjectification. Yet, such attempts at reinscription potentially enact two rather strange paradoxes: proponents of the concept of 'elective disability' would prevent individuals who have rejected the normative path from accessing welfare and social security programmes; yet, people who are considered (under *Sutton*) to have 'mitigated' their disability may not be covered under the ADA. In other words, we are left with a rather ambiguous possibility: namely, technologies that hold out the promise to eradicate or compensate disabled bodies may, by default, create new sites of ontological and corporeal confusion. Nevertheless, the underlying sub-text of law, which figures disability as anathema, remains unchallenged. One ought to wonder, therefore, how far the courts will proceed in deploying the concept of 'mitigation'. In particular, how much compliance will the courts expect in cases where the 'cure' could be more detrimental (riskier, more expensive, and so on) than the effects of the impairment? To take one example, how cognizant will legal reasoning be of the high financial costs often associated with normalizing treatments such as immuno-suppressant drugs? Obviously, the answers to these questions lie in the realm of the future; however, I suggest that it is critical to watch the reasoning used in the lower courts post Sutton. My guess is that the definition of 'disability' in the ADA, rather than becoming more certain and strictly interpreted will, at the lower court level, the level of

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[246] One of the problems of operating within the duality of 'abled' and 'disabled' is that the boundaries between these two signifiers interpenetrate. The rise of new perfecting technologies not only re-inscribes 'disability'; in addition, the ascendancy of these technologies re-inscribes 'normalcy' (construed as that which is species-typical).

State and regional practices, produce incongruous, discordant and fluid readings of disability[247].

Postscript:

The Supreme Court decision of January 8, 2002 in *Toyota Motor Manufacturing Inc. v Williams*[248] appears to signal a narrowing of the definition of 'disability' under the ADA. While there is no room here for a thoroughgoing analysis of the case, I want to highlight some initial observations relevant to the argument presented in this chapter section. One of the key debates in *Toyota* was the relationship between impairment and disability, that is, what elements need to be present for an impairment to be constituted as disability.

The strict medicalisation of disability, where medicalisation equals disability would seem to have been rejected by the Court — linking the designation of disability status with the effect that the impairment has on the daily life of an individual. Mention was also made in the judgment of the need to assess disability status on a case-by-case basis. The Court held that in order to be included within the ambit of the ADA, "...an individual must have an impairment that prevents or severely restricts the individual from doing activities that are of central importance to most people's daily lives. The impairment's impact must also be permanent or long-term" (*Toyota* III, paragraph 5, per O'Connor). According to this definition, disability is no longer governed according to a separation of domains (i.e., the public (work) and private spheres); rather the chief elements of the

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[247] In one recent *ADA* case, the Arizona District Court upheld a claim of 'disability' (and therefore coverage under anti-discrimination legislation) irrespective of the use of compensating/mitigating measures such as prostheses. In *Finical v Collection Unlimited* 65 FSupp 2d 1032 (1999); 16 NDLR 107 (1999); US DistLEXIS 13080, the plaintiff who was hearing impaired decided against using a hearing aid on the basis that such a device picked up background noise and therefore was annoying. The defendants argued that hearing aids should be included as a mitigating measure. The court however held that an employee with a hearing impairment was disabled irrespective of their use of 'hearing' devices.

[248] No. 00-1089 U.S. Supreme Court (January 8, 2002).

definition cross-domains and focus on those activities that are significant in most people's daily affairs. What this means for niche activities not practiced or seen to be important by a majority of the population will remain to be seen.

Ontological themes also feature strongly in *Toyota*. Not only do these themes relate to the scaling and delineation of disability (from mild-moderate-severe), but also to that carefully guarded constitutional divide between 'able-bodiedness' and 'disability'. The question for legal interpretation that arose from the case was how should respondent Ella Williams' carpal tunnel syndrome be inscribed under the ADA? , we return to that age-old problem of shifting the goal-posts vis-à-vis the normative body. For to limit 'disability' under the ADA to significant or severe impairment ensures that these populations stand out, and are delineated from the general American population — i.e., people with disabilities as a minority group. On the other hand, by including so-called 'minor' impairments, the danger is that disability becomes a normative and not unusual experience for the general population. I believe that ableist norms of legal reasoning cannot allow for this possibility, this ontological crisis about the 'normal' and 'pathological' to unravel. To extricate itself from such an awkward moment, the Court in the Opinion of Justice Sandra Day O'Connor (*Toyota* III, paragraph 4, per O'Connor) returned to the intentions that Congress held when it framed the ADA, arguing that if Congress intended for everyone with a physical impairment that precluded the performance of all sorts of manual tasks to be considered disabled, then, the number of projected disabled Americans would have been estimated at a higher level! In *Toyota*, there is a marriage between regimes of countability and calculation and the activity of governing disability by fixing discrete ontological categories of disability in law.

Putting Ontological Matters on the Agenda

In this section, I have attempted to focus on the relationships between ontology, disability, and ableism by highlighting the role that law plays in reasserting an ableist dynamic. I have pointed out how under technologies of responsibilisation, in tandem with the 'gentle hand' of the ableist body of the law, the 'problem' of disability resurface in ways that could potentially 'roll-back' the civil rights gains of the 1980's and 1990's, especially in the arena of legislative reform. I believe that an increased emphasis on coercive strategies to normalize, which are facilitated through the use of legal regimes of penalty that aim to eliminate or morph 'disability', provides persuasive evidence that neo-liberal societies are sliding into a 'positive', laissez-faire form of eugenics, albeit under the guise of the liberal promise of 'choice' and 'freedom'. Indeed, the very inscribing of 'legal' disability may well become the new battleground of a future disability politics. Legal fictions of 'disability' act as an incited citation of the logic/neutrality of 'ableness' within the practices of neo-liberalist freedom and simultaneously promote the illusion of inclusion.

Engagements with law reform that are based on the notion of disability as inherently negative will continue to produce fabricated equality rights and responses of ressentiment. As long as the figuring of disability as negative ontology lurks as an undercurrent of legal and welfare-economics debates — framed as part of a 'cold' (ontological) war, that is, the unthought of being fully human — we have much about which to be concerned.

5.4.5 Drawing Together the Threads in the Government of Disability

Chapter Five set out to chart the techniques and processes used to govern disability at the level of epistemological formulations and through various regimes of governmentality, especially law. In the early stages of the analysis, the work focused on the formation of the sovereign subject of liberalism that structures optimal subjectivities and impacts on notions of worth, use value, autonomy and freedom. What I have shown in my analysis is that the sovereign subject is firmly bound up with constructions of ableism. This is especially the case when pursuing the virtue of freedom, an ethos thoroughly saturated with ablest compulsions. The desire to gain a sense of autonomy by disabled people, sometime results in disabled people being cheated and 're-injured' by the system – and being granted provisional social, political and economic status.

The road to freedom means that disabled people are required to engage in and perform classifying practices that inaugurate containable prescriptive bodies. A section of the chapter considered the ways 'remainder' populations are governed through the ideology of mutual obligation and how that ideology impacts on concepts of societal belonging. A significant discussion of the chapter considered the epistemology of biomedicalism and how this knowledge formation has been deployed as a technique for governing the lives of disabled people by administrative apparatuses of the State. Biomedicalism has reduced the 'problem' of disability to the organic sphere wherein deficiency and abnormalcy inheres in the individual. Biomedicalism has been harnessed to enact the practices of counting 'cripples' through the crafting of enumerative passports. Regimes of countability make it possible to make visible disablement and therein 'know' the population. Enumerative passports become the technology from which disabled people are able to manoeuvre, access and negotiate the welfare system and disability industries.

Enumerative passports have become invested in the formation of subjectivities and as such can be considered a key mechanism of technologies of self.

As part of this chapter's analysis of technologies that open up the disabled population to knowing and surveillance, my analysis explored the use of diagnostic fetishism to bolster up the view that disability, can universalised and essentialised. The discussion specifically problematised the varied basis for measuring, mapping and defining disablement within the Australian context, especially at the Commonwealth level. The operation of regulatory norms in the governance of disabled people at the grassroots level has been explored through the interrogation of Social Role Valorisation Theory. This chapter concluded, that in order the govern disability, the usage of negative ontologies of disability are paramount.

A specific focus of the inquiry has been on laws participation in ontology wars over the delimitation of disability and the ways notions of harm are understand in order to secure legal remedies and entitlements. My aim has been to draw connections between the notion of disability as unthinkable and a logic of supplementarity which shores up a place for an autonomous, 'perfectible', transcendent self and the necessity of preserving that constitutional divide between 'ableness' (positive ontologies) and 'disability' (aberrancy/negative ontologies). Finally, I suggested that the law's continual reiteration of 'defective corporeality', through the designation of the legal categories 'disability' and 'disabled person', disallows the 'disabled' subject any escape from the normalizing practices of compensation and mitigation. This reiteration continues to negate possibilities of imagining the desiring 'disabled subject' in ways that are alternatives to the hegemonic ableist figuring of the disabled body.

The next chapter shifts the inquiry away from law to another site where there are contestations over the meaning of ableness and disablement, namely technological productions and practices. Specifically Chapter Six studies the function and deployment of epistemologies of ableism and the way the ableist ethos is translated within the quest for technological enhancement, ableist morphing and the rhetoric of curative solutions.

Chapter 6 - 'Disablised Bodies' in Process – The Nemesis of Technologies?

6.1 Parameters and Possibilities – Philosophical Excursions into Technology

The new technologies developed during the 1990's are really quite am-azing. And although people with 'disabilities' more so than other kinds of humans have had an erotic consubstantial liaison[249] with technologies it can be argued that more recent developments in the world of techno-science materially and ontologically usher in a kind of somatic fusion between the corporeally anomalous body and the artefact[250]. More than ever, I argue along with many other pre-eminent scholars, we are witnessing a new kind of human subjectivity – an intersubjectivity if you like – technological humans – hybrids, cyborgs[251], or monsters[252]. However, before we become too carried away, there is a need to 'step back' from this moment (to exteriorise) and contextualise as well as position these developments by exploring the contested terrain of philosophy and technology (and its disciplinary hybrid – science studies).

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[249] Despite this, I am in agreement with Johnson & Moxon (1998) who point to the paucity of critical analysis regarding technologies positioned from the perspectives of disabled people.

[250] I am following Bruno Latour's (1993) delineation 'artefact' to refer to those objects/subjects of the non-human, transhuman kind.

[251] C.f. Donna Haraway's work: (1990; 1991a; 1995).

[252] Again this signifier can present both epistemological and ontological confusions. Here I am using 'monsters' as a neologism for the 'boundary – crossing' techno-human. This terminology is a particular feature of the writings of John Law (1991; 1992; 1994b; 1999; 2000; 2001). We need to hold this rendering in distinction from the ascribing of the corporeally anomalous/noxious body as 'monstrous' or grotesque. Here 'monstrosity' as Foucault (1997a: 51) argues 'combines the impossible and the forbidden' and as such not only disturbs juridical regularities but conjures up mystery, sublime, prodigy, awe as well as repulsion. There is an element of hybridity to this intonation – not of the technological kind, as we would know it – rather in the vein of so-called *interspecism*. Seventeenth century 'hybridity theory' posited that such entities were the offspring of bestial activity, therefore called "monsters". Martin Luther believed such beings to be "a mass of flesh with no soul, because they were possessed by the devil" (Weir, 1984: 28). However a broader rendering found in the Monster Theory of Cultural Studies would consider 'monsters' as any (body) human or otherwise, that induces unease/dis-ease in the cultural body. For a good introduction to this approach see: (Cohen, 1996; McClintock, 1995; Terry and Urla, 1995; Thomson, 1997c).

This section sets the scene and introduces debates about the nature of technology, its relationship to science, matters of 'progress' and actors in a network of association. Rather than holding to a simplistic view that technologies are inherently dangerous[253] or implicitly beneficial, this work will attend to ways technology is engaged, its disjunctures and constructed boundaries. I begin this undertaking firstly with a discussion of the Appropriate Technology movement influenced by eco-philosophy and the work of Schumacher (1973) and Greeley (1977). Then I move back in time to revisit the later work of Martin Heidegger, arguing that aspects of Heideggerian thought can be appropriated as useful 'tools' from which to assess technological formations. French historian - philosopher Michel Foucault's own work has been influenced by Heidegger's ruminations about technology, techne, essence and ontology. So I continue this philosophical excursion by foregrounding what Foucault has to say about techniques of self - production and technologies of normalisation. Finally, we move into an exploration of contemporary developments in science studies – from the point of view of trends within 'Actor-Network Theory'[254] (ANT) *a la* Bruno Latour (1988; 1993; 1996) and feminist science studies, a la Donna Haraway in order to ascertain the usefulness of these works as methodological frameworks from which to foreground the production of 'disabled', 'enhanced' and 'human' bodies.

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[253] Hickman (1998: 59) argues that technological determinism has been a central feature with philosophical and sociological discourse related to technology.

[254] The separation of ANT from feminist science studies in some respects is quite arbitrary, yet I do get a sense when reading some works of a kind of 'divide' between Latourian and Haraway adherents. For Latourian-ANT approaches: (Callon et al., 1986; Latour, 1988; Latour, 1993; Latour, 1996; Law, 1991; Law, 1994b; Law and Hassard, 1999). In terms of feminist science studies: (Balsamo, 1996; Haraway, 1990; Haraway, 1991a; Haraway, 1995; Haraway, 1997b; Haraway, 1988; Haraway, 1989; Haraway and Goodeve, 2000; Hopkins, 1998; McKenzie, 1999; Rapp, 1997; Rapp, 1998; Star, 1991; Star and Griesmer, 1989; Waldby, 1999) In opposition to this perception a number of scholars engage with both spectrums of the science studies terrain: (Fujimura, 1992; Fujimura, 1996; Hayles, 1999; Sassower, 1995).

6.1.1 'Appropriate Technology' Movements – [Appropriate to 'Whom' for 'What']

> **Appropriate** 1. attached or belonging to as an attribute, quality or right; peculiar (to); inherent, characteristic; specifically suitable (for, to); proper, fitting. 2. Annexed or attached (to) as a possession, appropriated; *The New Shorter Oxford English Dictionary* (NSOED), Oxford: Clarendon Press, 1993: 103.
>
> **Technology** [Gk *teckhnologia* systematic treatment, f. *tekhnē* art, craft] 1.a The branch of knowledge that deals with the mechanical arts or applied sciences; a discourse or treatise on (one of) these subjects. *The New Shorter Oxford English Dictionary* (NSOED), Oxford: Clarendon Press, 1993: 3235.
>
> By and large, our present problem is one of attitudes and implements. We are remodeling the Alhambra with a steam-shovel, and are proud of our yardage. We shall hardly relinquish the shovel, which after all has many good points, but we are in need of gentler and more objective criteria for its successful use. (Aldo Leopold *A Sand County Almanac*, Cited in Schumacher, 1973: 7).

O'Brien and Marchand (1982) identify three approaches towards technology and its relationship to 'politics' (their terminology and not mine). The first approach, aptly termed the 'technicist projection' figures 'technology' as autonomous, monolithic and determinist, the polis being beholden to its ebb and flow[255]. The interesting aspect of this 'projection' lies in the convergences of both the pessimistic viewpoint of domination and the utopian dream of a 'technological fix'[256]. Using Alan Drengson's typology[257], I would go so far as to suggest that the technophilic and techno phobic stance perform as the inside/out of technological practices/representations. The rein of technocracy induces a pursuit of technology as love object – "humans are technologized by their own love of the technical and of techniques. Life has become mere mechanism" (Drengson, 1990: 30).

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[255] Already we have emergent themes of the eroticisation of technologies – which according to Marcuse (1964) American's are seduced by technocracy tyrannical edge.

[256] Carlisle (1999) provides an excellent piece of augmentation of the relationship between persuasion and technological determinism.

[257] Drengson outlines four philosophies of technology: Technological Anarchy, Technophilia, Technophobia and Appropriate Technology (Drengson, 1990).

O'Brien and Marchand point to another variation of technological determinism expounded by Emmanuel Mesthene who argues that technological innovation can simultaneously create opportunities in culture as well as generate new problems. However, even then, the essence of technology is 'value neutrality', whereas the problems produced by technologies are solely 'political'. Mesthene, a true soldier of liberalism (and probably utilitarianism) suggests all will be well, technology is essential *laisse faire* and self correcting – "In the end … the problems that technology poses (and the opportunities it offers) will be resolved (and realized) in the political arena." (Mesthene cited in O'Brien and Marchand, 1982: 4).

The third approach identified by O'Brien and Marchand is designated as a dynamic interdependent model between politics and technological innovation (pluralist or 'systems' stance). In such a relationship a symbiotic dialectic (not oppositional) is generated between the development and diffusion of technologies and technological impacts on governmental institutions and processes giving birth to a regulatory regime coined 'technology assessment'[258]. Technology Assessment (TA) is geared towards systematically appraising the effects of technological introduction and its consequences – intended, unintended or delayed[259]. As O'Brien and Marchant remind us, TA is more than a 1970's fly-by-night reform movement, rather its utilization signals the philosophical adoption of a pluralist consensus orientated approach to governance (O'Brien and Marchand, 1982: 12)[260]. However the implementation of TA regimes in turn problematises other issues which I argue continue to be relevant to contemporary

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[258] This idea was developed by US congressman Emilio Daddario – who proposed a body that would monitor technological development reporting on the potential for hazards and negative impacts.

[259] Recently there have been attempts to re-jigger TA and called for a new TA: real time technology assessment underpinned by a reflective R & D enterprise (Guston and Sarewitz, 2002: esp 100 - 106).

[260] Hans Mohr (1999) provides of six point statement of agreement among TA practitioners:

debates especially related to the management of disablement and the morphisation of ableness:

1) The notion that governmental apparatus' can act as a neutral arbiter between the 'public interest' and economic and R & D stakeholders – veiling its own stakeholder interest;
2) The communication and utilization of TA reports and their function in Latourian terms, in technological translation, stabilization and foreclosure.

In fact, the very cognate 'assessment' as an objective mechanism of evaluation provokes consideration and acknowledgement of a number of fundamental theoretical concerns, namely that all TA epistemologies are situated and constrained/produced by power relations engaged to varying degrees in Commodity Fetishism[261]. TA has developed into two approaches: one that is *instrumental* relying heavily on the speculations of 'experts' and the other of a *discursive* nature where the public engages in educative and consultation processes. In either approach, Guston and Sarewitz (2002) point out TA practices have become wedged in advisory governmental apparatuses. The technological laboratory itself is a site or acts as a hub of power, a centre of calculation constantly self-assessing and responding to a range of levels/sources of mobilization of support [read: pressure lobbying]. We may wish to ask that within this vacuum of activity–assessment, various networks of association, what position and degree of leverage consumers of disability-orientated technologies have. Johnson and Moxon (1998) suggest very little. Technologies when conceptualised as a form of 'care', become susceptible to administering to the biomedical/functional/normalizing needs of disabled bodies as commonly defined by service providers, designers, retailers and rehabilitative experts –

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[261] I am calling upon the notion of *commodity fetishism* embraced by Donna Haraway (1997b: 135, 143, 147) to denote that kind of exhilarating erotico-economic zeal for reshaping/recreating/translating the boundaries between nature/culture, what Latour (1993: 99 - 100) calls the 'first great internal divide'.

bearing minimal resemblance and thus potentially subverting the coupling requirements of persons with disabilities. As Hasler puts it:

> The [disability] movement does not reject the idea of gadgets. One of the basic requirements for independent living is appropriate technological equipment. But even here, appropriate can be defined differently by a non-disabled person and a disabled one (Hasler, 1993: 15).

Having alerted your attention to some of the complexities of conducting technological assessments qua assessment, I now turn albeit briefly, to a consideration of the Appropriate Technology (AT) movement.

The AT movement sprang to life in an era buoyant with technological growth coupled with a degree of critical reflexivity (at least within the purview of political and social sciences). Schumacher almost in a Heideggerian fashion, suggested that the development, pursuit and implementation of technologies be conceived of in terms of a metaphysical practice (Schumacher, 1973)[262]. Whilst being created out of the human hand, Schumacher suggests technological devices take on a 'life' or agency of their own engaging in forms of enrolment that are not self-limiting. Rather paradoxically, instead of relieving the burden of so-called human limitation, the non-human artefact simultaneously fabricates a reduction in 'burden', whilst inducing new, pervasive and unpredictable other kinds of 'burden'[263], Consider the growth of the ergonomics industry as a consequences of computerized changes in the workplace. The solution to this conundrum is to ask of technologies – 'what does it do?', and 'what should it do?' Indeed, is it possible for technologies to reveal a 'human face'? (Schumacher, 1973: 123)[264] Schumacher's early ruminations in *Small is Beautiful* have influenced *inter alia*

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[262] Interestingly this metaphysical analogy has been used by computer techs to describe certain glitches in systems, suggesting certain problems occur for no obvious reason.

[263] For a well-argued appraisal of this perspective and the 'revenge effect' of technologies, see (Tenner, 1996; Winner, 1977; Zerzan and Carnes, 1991).

[264] I am not really sure what qualities are imbued in the 'human face' – rather than being essentialised we return again the question of subjectivity and the rejection of a universalised human condition.

the eco-philosophical approach to technology appraisal. Here appropriate technology starts from the assumption that the artefact is 'neutral' and formulations of 'appropriateness' are governed largely by situational indictors. Restraint as such should not be deemed to imply hostility to technologies.

The work of Alan Drengson (1990; 1983; 1995) is pertinent here. Envisaged as a conglomeration of practices, the technological apparatus/realm extends to four dimensions, namely cultural, organizational, technical and environmental. The task of the appropriate technology movement is to develop holistic approaches to design formats, to critique the underlying philosophical assumptions of technological development and articulate an alternative vision of being human 'free of anthropocentrism' (Drengson, 1995: 45).

Whilst the appropriate technology perspective may initially seem somewhat seductive, as a potential analytical framework for studying relationalities of disability and technologies it lacks the rigors to negotiate not only complexities of the debate in terms of power and networks of association, but appears (despite its denials) to be entrapped in an antagonistic relationship with systematic, large-scale technologies, preferring the 'small' localized artefact. In addition, the weakness of both TA and AT is that both approaches succumb to the restrictions of instrumentalist and anthropological orientations. Such an idealistic orientation lends itself to lapses into romanticism – not the kind that begets domination over 'nature' by 'culture', rather a vision that sees the utopic dream in terms of restoration to holism – this perspective may indeed imbricate ableism to new heights, reinforcing the notion of disability as brokenness.

6.1.2 Technology as Characterological and Fabricative: The McGinn Approach.

I have taken the liberty to single out the work of Robert E McGinn (1990; 1991) simply because McGinn's approach to philosophising about technology provides a refreshing alternative to dominant romanticism and determinist tendencies of much of the literature. McGinn's 'spin' on technologies I argue, not only dismantles this deadlock, but also offers a re-visioning of explanatory frameworks around disability and technologies. Whilst there is little agreement as to the definition of technology, McGinn does offer a framework in an attempt to systematize technology. He suggests that technology be viewed as material, fabricative, purposive, resource-base expending, knowledge, method, enabling/informing activity, including the practitioners own [mind] mental set (McGinn, 1990). I am interested here in McGinn's departure from the usual understanding of technology in definitional terms, towards a description of technologies as characterological (e.g. having a character, behaviour and personality) and as a form of human activity that can lead one to the conclusion that there is no 'inside or outside' of technology.

It is the fabricative dimension that is also worthy of further investigation. According to McGinn the processes by which technics (material outputs of technological production) are produced are ontologically fabricative:

> … some of the significant features of the technic are due primarily to the technologist working of his or her will on the constituent ingredients or parts, rather than their all being primarily the result of the operation of chemical … laws. … In sum, the fabricative character of technology pertains to the nature of the processes in which its issue is brought into being. (my emphasis) (McGinn, 1990: 12).

McGinn's formulation unifies and merges the relationship between the object and the creator. Leaving aside the birthing imagery, the practices of technology incarnate and embody aspects of the comported 'will'. In other words, drawing upon McGinn's notion of the fabricative, we can say that such practice draw in, interface and are prefaced by, an ontological process of subjectification, that is, techniques of self coitally unifying with the art of techné. As McGinn suggests:

> … technologies maybe individuated or related by characterising the substantial differences or similarities in technics, specific purposes, methods, bodies of knowledge, resource bases, contexts and practitioners mental sets associated with the different incarnations or embodiments of the activity- form. Technology is the practice of the technologies under consideration (McGinn, 1990: 23).

On this basis, an analytics of technologies can act as a rich font for the extrapolation of techniques of boundary policing between artefact – human – mis-confirmed beings[265]. Indeed McGinn's approach helps us to keep in mind that technology is not just mere mechanism, but always has as its subject ontological concerns.

6.1.3 Back to Heidegger – *Lebenstechnik* and Onwards to Foucault – Technologies of Governing Self.

So far our philosophical excursus has surveyed broadly speaking, instrumentalist and anthropological approaches to thinking about technologies with McGinn's approach representing an attempt to transcend the strictures of such frameworks. I turn now to a consideration of the work of Martin Heidegger, echoes of who can be found in McGinn's formulations and are later systematized by Michel Foucault. But back to Heidegger for the moment. The strength of Martin Heidegger's work concerning technology lies in his refusal to essentialise the existence of technology and thus lapse into mitigation projects seeking to arrest technological determinism[266]. Instead, Heidegger attempts to refigure,

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[265] This is a kind of conglomerate of categories which includes all sorts of corporeal misfits assigned to the edges of human subjectivity – changelings, abominations, sub-humans, freaks, post-human, cyborgs.

[266] In fact Heidegger adamantly rejects both instrumentalist and anthological definitions of technology (Heidegger, 1977 (Orig.1953)). These approaches seem quite futile, being locked into a permanent vortex/tussle over domination and subordination concerns. Heidegger does recognise the 'dangers' counter posed by the 'promise' of technologies.

reframe our orientation to technological concerns by moving discourse out of the realm of the mechanistic to the philosophical. Very early in the lecture *The Question Concerning Technology* (1977, Orig.1953), Heidegger makes is quite clear that it is not possible to just 'opt out' of the technological matrix – just like power, technology cannot be escaped, like a möbius strip – there is not inside and outside to technology and human subjectification:

> …thus we shall never experience our relationship to the essence of technology so long as we merely conceive and usher forward the technological, put up with it, or evade it. Everywhere we remain unfree and chained to technology, whether we passionately affirm or deny it. (Heidegger, 1977, Orig.1953: 287).

Now it would be easy to assume from this statement a kind of technological nihilism. On the contrary, our consubstantiality with technology presents new openings to rethinking technological relationality, thus breaking away from the rigid circular thinking that dominates much of the debate about disabilities and technology. Heidegger's new episteme can open up the conversation about the connectedness of ontology, corporeality and artefact. Heidegger proposes a new discipline, a metaphysics, a new way of figuring the essence of technology that precedes the development of 19th century mechanised forms – indeed he returns us to Greek philosophy. After revisiting the philosophical question of causality, Heidegger exacts the Aristotelian understanding of 'cause' as 'effecting'. Using the example of the creation of a Communion Chalice, Heidegger introduces the notion of an artefact coming into being – not just as a mere object, but its 'chaliceness' (or essence). Such a bringing forth 'poeisis' results in a kind of enlightened aletheia, an 'unveiling' or 'revealing' of a concealed essence of technology:

> …technology is therefore no mere means. Technology is a way of revealing. If we give heed to this, then another whole realm for the essence of technology will open itself up to us (Heidegger, 1977 (Orig.1953): 294) (emphasis added).

In conjunction with this understanding, Heidegger returns to the etymological source of 'technology' – stemming from technikon, meaning that which belongs to *techné* (294). Imbued within this definition is not only the skilled craft, but also a poetic bringing forth – a kind of desirous knowing that discloses 'technologies essence constitut[ing] the meaning of being in our age" (Dahlstrom, 1988: 150). In contrast, modern technology's mode of revealing itself to the world is one of 'challenging forth' (*herausforden*), where there is an obsession with techniques of extraction, exploitation and exhaustion enframed[267] within a 'resource' paradigm (Heidegger, 1977 (Orig.1953): 296). The hegemony[268] of challenging forth revealing most often results in ontological transformation of living beings and artefacts. Heidegger uses the example of the Rhine River to support his argument (Heidegger, 1977 (Orig.1953), 297). The Rhine is transmogrified from a source of philosophical, aesthetic and cultural inspiration to mere energy source/resources when coupled with a hydroelectric dam.

In terms of the perfectible human body, we can see a similar patterning and re-ontologising. For instance, the demands of labour and operationalisation of mechanics may re-invent the productive, resourceful human body (under the sign of ableism), one that is permanently 'standing in reserve'[269], one not of value for itself, but only of use for something – a 'human resource'. It is a body that can be surveyed and cartographically inscribed in terms of species-typical functioning. We can argue then that this dominant

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[267] Space does not allow for a extensive discussion of 'enframing' as developed by Heidegger, suffice to say *enframing* (*gestell*) denotes a mode thinking, an armature or framework that seeks to systematise, compartmentalise and classify the world (animate & inanimate) in order to maximum order and control. C. f. *Concerning Technology*, p. 301 – 305.

[268] I am using *hegemony* in the Gramscian sense, to denote that sense of constructed reality through the prism of naturalisation and common sense thinking categories.

[269] The 'notion of standing in reserve' – something has value only so far as it is good for something. Human ontology becomes transformed to that of 'human resources'.

process of technological enframing and revealing that ontologically converts the productive body also creates its constitutive outside – the useless body.

It is important however not to become stuck here, for Heidegger suggests it is possible to have a renewed orientation, revealing of technology as enframing occurs as the point of its interaction with the world. So there is always a possibility of play, of resistance, of ‘saving power’ by employing a poiesistic orientation – a taking part in the processes of coming to being. Heidegger’s conclusions provide a firm basis for developing an analytics of disability and technological intersections. By employing a strategy of techne, mindfulness towards ‘things’ it is possible to move with technologies. As Daniel Dahlstrom summarises:

> … Such composure demands that thinking and not mere reckoning, be brought into play as, a measure of things. In other words, maintaining this equanimity towards things requires seeing them for what they are, a kind of thinking that does not pre-emptively subordinate things to special interests or to a particular scheme of organization. Heidegger was in dead earnest about the necessity of searching for a way out of the danger presented by modern technology, but the search can only begin with this composure toward things and the kind of thinking that sees the technological world for what it is, a world of danger and promise (Dahlstrom, 1988: 153).

We can summarise Heidegger’s ideas about technology by arguing that the very essence of technology not only constitutes the meaning of contemporary being – but that human life, geist and action (poiesis) are technologies that are in a constant state of disclosing and unfolding. It is this denial or mis-recognition of such ‘truth’ that prompts a separation between being and doing – and incites a suspicion of not only technologies but a mis-negotiation of necessary equipmentality and the prosthetic imagination.

In his 1982 lecture *Technologies of Self* (1997d, orig 1982), Michel Foucault made reference to four kinds of technologies that govern how human beings come to a knowledge about themselves, namely technologies of production, of sign systems, of power and of self. Technologies of self, refer to instances/practices that

> … permit individuals to effect by their own Means, or with the help of others, a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality (Foucault, 1997d (orig 1982): 225) .

Such assemblages of technologies both interact and overlap and extend to the material, productive and attitudinal. There is no doubt that Foucault's work takes up and has been significantly influenced by the challenges of the Heideggerian ethos (Kendall and Michael, 2000; Schwartz, 1998). Like Heidegger, Foucault turns his attention to the ancient Greek understanding of techné and the way in which technai are played out in the daily routine of '*souci de soi*' (care of self). In this sense, Foucault extends the notion of technology, using it in the wider sense to explore problems of self to work on the question of "how have certain interdictions required the price of certain kinds of knowledge about oneself? What must one know about oneself in order to be willing to renounce anything?" (Foucault, 1997d (orig 1982): 224).

Whilst Foucault's insertion of the self within the technological is significant, he does not go as far as Heidegger (and later Latour[270]) to extend technological being to flora, fauna, inert nature and artificial artefacts (McHoul, N.D.). Nonetheless, a Foucauldian analytics of technologies or a technique of self offers us a device from which to investigate the formation of subjectivities of disability through the lens of technological mechanisms, apparatus' and corporeal prosthesis. This linking of episteme and praxis provides a

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[270] For an extended discussion of this theme, vis a vis Latour see: Kendall (2000).

framework to examine local understanding of the productive and docile bodies relationship to 'normalization', 'enhancement' and so-called 'restorative' technologies[271].

6.1.4 Taking up the Lineage ~ ANT and Feminist Science Studies

The newly emergent field of science studies, particularly the work of John Law (1991; 1994b; 1999; 2000; 1999; 2001) provides useful tools that can be deployed to critically interrogate the relationship of technologies to ontological understandings of 'disability' (Berg and Mol, 1998; Clarke and Fujimura, 1992a; Clarke and Fujimura, 1992b; Fujimura, 1992; Fujimura, 1996; Latour, 1993; Pickering, 1992; Pinch and Bijker, 1987; Star and Griesmer, 1989). Science studies methods such as Actor Network Theory (ANT) and feminist technoscience[272] enables an exploration of networks of association that link laboratory/biotechnological practices to other domains, whilst at the same time attending to the engagements, disjuncture, and constructed boundaries that disrupt what might otherwise appear to be a seamless web of unassociated linkages. As John Law explains:

> ANT is a semiotics. That is, a method (or better, a sensibility) that has to do with and explore relations, relationality. …This means in ANT entities, things, people, are not fixed. Nothing that enters into the relations has fixed significance or attributes in and of itself. Instead, the attribute of any particular network, are entirely defined in relation to other elements in the system, to other nodes in the network (Law, 2000).

We can see from this perspective that space is opened up for an in-depth analysis of the nature of being humaned, the hybridity and mixtures produced by technological liaisons and coupling in an enduring performance. It is possible to speak in terms of human

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[271] As Foucault rightly points out, the fashioning of self is not a private-orientated venture, rather the subject in formation draws upon, inserts tropes of self "…he finds in his culture and are proposed, suggested, imposed upon him by his culture, his society, and his social group" (Foucault, 1988a (Orig. 1981): 291).

[272] Whilst feminist technoscience approaches vary considerably, like ANT there is a general assumption that existing social and material practices generate new practices about the created and material world. The differences between the two, broadly relate to the way such practices are inflected by raced and sexed concerns.

subjectivity as an assemblage; wherein technologies are networks folding into our-selves morphed into punctualised and fixed actants[273]. In exploring the production of disability we can say that what is inscribed as a 'disabled body' is an effect generated by performance of bodies and bodies in a heterogeneous network of association. As Kendall & Michael (2000) remind us there is no such thing as a pure human – we are always combined with nonhumans wherein the environment is mediated through a layer of technologies (wrappers). This corporeal expansion/elasticity is exemplified in the surprise of Roseanne Allucquère Stone (1996: 4 -5) when she attended a lecture by physicist Stephen Hawking:

> And there is Hawking. Sitting, as he always does, in his wheelchair, utterly motionless, except for his fingers on the 'joystick of the laptop; and on the floor to one side of him is the PA system microphone, nuzzling into the Votrax's tiny loudspeaker. And a thing happens in my head. Exactly where, I say to myself, is Hawking? Am I any closer to him now than I was outside? Who is it doing the talking up there on stage? In an important sense, Hawking doesn't stop being Hawking at the edge of his visible body. There is the obvious physical Hawking, vividly outlined by the way our social conditioning teaches us to see a person as a person. But a serious part of Hawking extends into the box in his lap. In mirror image, a serious part of that silicon and plastic assemblage in his lap extends into him as well ... not to mention the 'invisible ways, displaced in time and space, in which discourses of medical technology and their physical accretions already permeate him and us. No box, no discourse; in the absence of the prosthetic, Hawking's intellect becomes a tree falling in the forest with nobody around to hear it. On the other hand, with the box his voice is auditory and simultaneously electric, in a radically different way from that of a person speaking into a microphone. Where does he stop? Where are his edges?

The ANT method lends itself to the unpacking of such disabled-hybrid-assemblages through its explication of the generative processes (in Latourian language) of translation and purification. In *We Have Never Been Modern* (1993), Bruno Latour formulates two distinct dichotomies of the 'modern condition' that need to be demarcated in order to be 'effective'. Translation involves those time-honoured practices of creating blends/fusions " between entirely new types of beings, hybrids of nature and culture" (10). Elsewhere I have pointed to such ontological wrestlings in the ancient world, typified by the question

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[273] To follow up this theme consult Law (1992) and Rose (1996: Chapter 8 *Assembling Ourselves*).

‘what is it?’ (Campbell, 1999: see also Chapter 3). It is Latour’s ascription of practices of purification[274], the creation and boundary policing of two distinct, apartheid zone of the ‘human’ and ‘non-human’ that lends itself to review the boundaries of normalcy (the real human) and disability (the non-human, cyborg, changeling)[275].

In the context of our present discussion about philosophical excursions into technology, what is interesting are feminist techno science’s and ANT’s approaches to technical practices, especially elements that meld and mobilize heterogeneous, networks, practices and indeed semiotics. This is especially important with regard to discussions of the role of technological stakeholders, the failure/success process of artefact development and questions of compliance and consensus. I have already mentioned earlier in this chapter, the unfortunate fact of the low involvement of disability - referential persons and organisations in technological research and development[276]. ANT may be a vehicle to foreground the kinds of ontological understandings and projections technological stakeholders bring into, incorporate and justify in research practices in order to enact strategies of resistance. Methodological concepts such as ‘boundary objects’ and ‘standardized packages’ are also useful to such an analysis.

Susan Leigh Star and James Griesmer (1989) developed the concept of boundary objects (BO’s), which are produced when financiers, theorists, rehabilitationists and retailers collaborate to produce representations of disability, wellness and cure. The boundary nature of these objects are reflected by the fact that they are simultaneously concrete and

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[274] Space does not allow for a full presentation of this concept. To deploy this modern critical stance this separation is necessary. See Latour (1993: particular chapters One, Two & Four). Chapter four of this thesis provides a further explanation.

[275] For further comments see Chapter Four.

[276] Refer to section on Technology Assessment. See also Johnson & Moxon (1998) and Hasler (1993).

abstract, specific and general, conventionalised and adaptive. In their research Star & Griesmer (1989: 408 – 411) identified different kinds of BO's, namely

> (1) **Repositories.** These are ordered 'piles' of objects that are indexed in a standardized fashion. People from different worlds can use or borrow from the 'pile' for their own purposes without having directly to negotiate differences in purpose.
>
> (2) **Ideal types**. Serves as a means of communicating and undertaking a joint venture - a working 'blue print' for all parties. An example of an ideal type is the species-typical function (benchmark perfectible) human body that clearly delineates the 'normal' from the 'pathological'.
>
> (3) **Coincident boundaries**. Are the result is that work in different sites operating within radically different disciplinary schemas can be conducted autonomously while collaborating parties share a mutual referent. The advantage is the resolution of different goals; and finally
>
> (4) **Standardized forms**. These are boundary objects devised as methods of common communication and ordering across dispersed work groups, what Bruno Latour (1988) calls 'immutable mobiles'.

Joan Fujimura (1992; 1996) builds on both Latour's and Star & Griesmer's works to examine practices of consensus building and the phenomena of 'bandwagons'. Her concept of 'standardized packages' enables the analysis of the achievement of agreement across various (often conflicting) social worlds in order to 'get the job done':

> [‘Standardized packages’] … consists of a scientific theory and a standardized set of technologies which is adopted by many members of multiple social worlds to construct new and at least temporary stable definitions (Fujimura, 1992: 169).

‘Standardized packages’ are used by researchers to define a conceptual and technical workspace through the development of scientific/genetic theories and standardized sets of research/methodological techniques and the construction of new and appearingly stable definitions. e.g. the definitional categories of ‘disability’, a ‘gene’, ‘gene defect’ and even so-called common sense concepts such as ‘hearing’[277] and ‘deafness’.[278]

Our discussion about philosophies of technology would be bereft without at least briefly commenting on feminist science studies. The contribution of feminist technoscience lies in its capacity to negotiate and bring the concept of marginality into the debate. The technological enterprise operates with a domain, a network of power relations, what Donna Haraway refers to as an ‘informatics of domination’. This is not the place to rehash and rehearse Haraway’s early writings on cyborgs; we can however hone in on those aspects of her work that are relevant to our focal concerns. Haraway deploys a feminist critical analytic of technological practices the figuring of scientific expertise.

In *Simians, Cyborgs and Women*, Haraway provides several elaborations of her understanding of ‘cyborg’:

> A cyborg is a cybernetic organism, a hybrid machine and organism, a creature of social reality as well as a creature of fiction. Social reality is lived social relations, our most important political construction, a world changing fiction (Haraway, 1991a: 149).

Later she states this coupling and coded device is: “… text, machine, body, and metaphor – all theorized and engaged in practice in terms of communications” (212). Indeed it is

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[277] See Mirzoeff (1995) and Wrigley (1996) on the relationship of constructions of ‘hearingness’ to ‘deafness’ and the debates over definitional closure and delimitation.

[278] See also Haraway (1997b, 133 - 149).

this symbiotic coupling that most disturbs, for the cyborg refers to more than mere additions or extensions to the body, but rather to humans and machines in interaction, a kind of refiguring, blurring (and weakening) of border relations between humans, other living beings and machines ultimately challenging the coherence of the human form as self contained, delimited and organic unity.

In later work Haraway (1997b: 211) argues that heterogeneous technoscience practices act as ‘wormholes’ wherein “the laboratory continues to suck us into uncharted regions of technical, cultural, and political space” and as such are a form of life that move in and out of the domains of collective life. All objects whether animate or otherwise can be absorbed into the ‘wormholes’ reappearing as transmogrified, refigured entities. For instance, Haraway uses the example of field mice being transformed into “finely tailored laboratory rodents” or “model systems” (1997b: 211). Based on Haraway’s proposition, in context of impairment, it follows that the individual who is short statured (or a ‘dwarf’, to use the old fashion term) when propelled through the laboratory ‘worm hole’ has an existence that is reduced (transmogrified) into a ‘gene defect’. More specifically in the example of pseudoachondroplasia to an ‘abnormal gene’ located on chromosome 19 called the cartilage oligomeric matrix protein (COMP) for short.

Despite Haraway’s interest in forms of ‘hybrid’ and the pleasure of such boundary confusion and fruitful coupling, she has little to say about the relationship between the discursive production of ‘disabled’ and cyborg bodies. It is difficult to reckon with this silence[279] and the lack of connection Haraway makes between techno science’s redefinition of the ‘disabled body’ as an object for technological reconstruction (the

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[279] I should mention that Haraway is not alone here. In fact the vast majority of literature concerning corporealities and/or technoscience is silent about ‘disability’ despite its discussion of monstrosity, mutilated body and surgical reconstruction. Like ‘race concerns’, until recently feminist scholarship has failed to taken on board ‘disability’ as another axis of subordination.

morphing of ableism) and the creation of cyborgs. Some possibilities for exploration are raised, but have not been fully developed. Haraway argues that with the increased interconnectedness between machines and humans

> …it is not always clear who makes and who is made. Biological organisms have become biotic systems, communications devices like others. There is no fundamental, ontological separation in our formal knowledge of machine and organism, of technical and organic. … One consequence is that our sense of connection to our tools is heightened … Perhaps paraplegics and severely handicapped [sic] people can (and sometimes do) have the most intense experiences of complex hybridization with other communication devices (Haraway, 1991a: 178).

And later

> Why should our bodies end at the skin, or include at best other beings encapsulated by skin? … For us, in imagination and in other practice, machines can be prosthetic devices, intimate components, friendly selves. We don't need organic holism to give impermeable wholeness, the total woman and her feminist variants (mutants) (Haraway, 1991a: 178).

The problem here is that Haraway presents an uncritical and overly optimistic perspective on prosthetic relationality, almost ignoring cultural practices that generate and fuel the prosthetic imagination. Where is Heidegger's sense of technological 'dangerousness' now? Can we read into Haraway's work an understanding of cyborg prosthesis that assumes supplementation, supplying/cancelling 'deficiency'? As Mark Seltzer (1992: 157) remarks prosthetic/cyborg imbues a 'double logic' as self-extension, self-mutilation or even self-cancelling making visible the fragility and fragmentation of such concepts as atomistic agency and an essentialized human ontology.

Just as the knowing self is always partial, in a process of unfolding " … never finished, whole, simply there and original, … always constructed and stitched together imperfectly" (Seltzer, 1992: 193), so is knowledge situated and technological perspectives partial. In Haraway's early work (1991b) she develops the concept of situated knowledges[280], to alert us to the embodied and positioned nature of scientific objectivity that grounds the imagination of scientific vision.

In recent work concerning reproductive technologies and genetic engineering, *Modest_Witness@Second_Millennium. FemaleMan _ Meets _OncoMouse*, Haraway examines those practices that count as knowledge. She calls upon the 'Modest Witness', one who has epistemic authority to testify, to act and reveal their presence in the sociotechnical order. In describing the practice of witnessing, Haraway recalls

> … witnessing is seeing, attesting; standing publicly accountable for, and psychically vulnerable to, one's visions and representations. Witnessing is a collective, limited practice that depends on the constructed and never finished credibility of those who do it, of whom are mortal, fallible, and fraught with the consequences of unconscious and disowned desires and fears (Haraway, 1997b: 267).

For the prospects of witnessing to be transgressive, technological practice needs to be cognizant of knowledges from subjugated standpoints. Feminist techno-science yearns for knowledge practices to be coupled with freedom projects.

Summing up:

In this section I have attempted to explore some of the conversations concerning technologies, including technology's character, the processes of creation and importantly the relationship of technologies (organic and inorganic) to the formation of species 'human'. In addition, it is clear for a number of the discussions surveyed that the historical and situational contexts of emerging technologies are intrinsic to the development of technoscience practices and the artefact itself. In the next section I turn to a discussion of instances of ways technology mediates understandings of disability/normalcy and argue that whilst many liaisons with technologies can contribute to a 'quality of life' for individuals with impairment(s) the impetus and compulsion

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[280] See Chapter Two on the approach the research methodologies in this dissertation.

towards technological 'solutions' often reinscribes negative ontologies of human aberration/disability.

6.2 'Disability' Meets Utopianism and the Romanticist Turn, Or A Return to the Monstrous?

Despite the high level of engagement that people with 'disabilities' have with a multitude of technologies few writings can be found that subject this engagement to critical analysis, beyond mere questions of functionality and economics (Pell et al., 1999; Roulstone, 1998)[281]. If we exempt the literature relating to euthanasia, writings interested in new biomedical technologies dominate (Asch, 1989; Franklin and Ragoné, 1998; Hughes, 1996; Johnson and Moxon, 1998; Lippman, 1993; Lupton and Seymour, 2000; Newell, 1999; Rowland, 1998; Silvers, 1998a; Spiewak and Wild Yard, 1999 (Dec); Wolbring, ND; Zimmerman, 1991). However, if we delve further and restrict our search of the literature to critiques of technological applications, in particular 'perfecting' technologies, the flow of works reduces to a trickle (Crouch, 1997; Henk and Have, 1995; Law, 1991; Law, 1999; Lysack, 1997; Parens, 1998b; Tenner, 1996; Thornton, 1993; Wrigley, 1996). Yet the convergence of technological practices and ontologies of disability make interesting bedfellows. In this section, we will explore the kinds of dynamics and impulses that are generated when productions of disability are coupled with the technological apparatus.

Before we can fully appreciate this critical juxtaposition between technology's engagements with disability, it is necessary to digress momentarily and consider one dominant representation of disability – the 'personal tragedy' perspective.

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[281] The 'will to technologise' has been particularly subject to challenge predominantly in the field of Deaf studies.

6.2.1 Personal Tragedies and Curative Solutions.

> As with discrimination more generally, with prenatal diagnosis, a single trait stands in for the whole, the trait obliterates the whole. With both discrimination and prenatal diagnosis, nobody finds out about the rest. The tests send the message that there's no need to find out about the rest. (Asch, 1989: 81)

> [We must] … embark on a disease defense build-up similar to that undertaken in the 1980s to respond to the perceived military threat of the Soviet Union. We must reorder our nation's budget priorities from programs that destroy life to those that will preserve and enhance life. It is ironic that we can defend our country from a foreign foe but we cannot defend our people from disease. And what if our next foreign foe comes in the form of the Ebola virus, with no known cure? I will continue to challenge those who believe that our national defense lies solely in our military arsenals. They are missing the point--if we cannot protect our citizens from disease and disability, the true enemy lies within our borders (Hatfield, 1995: 1077).

In Chapters Four and Five I canvassed and argued for the proposition that disability or impairment is conceived as inherently negative and that the outcome of this belief system in everyday discourses is the 'personal tragedy' theory of disability. This framework has become the barometer and rationale for most of the impetus in developing assistive technologies and the pursuit of cures or indeed modes of elimination. In this sub-section, I wish to return to the theme of 'tragedy' if but only for a short moment. I have a desire to do so because of two controversial narratives concerning technological mediations of disability within the public media.

The first concerns American Football's event of the year, the SuperBowl. At the XXXIV SuperBowl (January 30th 2000) Slayers Public Relations produced an extraordinary video advertisement for Nuveen Investments featuring actor Christopher Reeves (aka Superman) with quadriplegia – rise out of his chair, and walk with the help of computers in order to present awards (Figure 8).

Figure 8: Christopher Walks…

Nuveen Investments Corporation Advertisement,
Superbowl XXXIV, 2000

Source:
http://abcnews.go.com/onair/goodmorningamerica/transcripts/gma000131_reeves_transcript.html

The advertisement was about making money and doing something with it that matters, like funding medical research. – it was a vision of the forbidden, the impossible, a dream of the future. The prime-time advertisement was disturbing as its key message played into discourses of miraculous cures via the enrolment of ‘make believe’ super-technologies. Reeves who had previous argued in public for money to be redirected away from ‘care’ to ‘cure’ communicates the impression that life is unbearable with an impairment.

The other media event was in two separate, but linked pieces in The *Courier Mail* (Brisbane, Australia), dated Saturday April 6th 2002 concerning the case of a Deaf lesbian couple using reproductive technology to conceive a Deaf child. One piece was headlined "*Lesbians admit plan to create deaf child*" (Griffith, 2002b), the other had a highly charged moral headline "*Hearing the Evil*" (Griffith, 2002a). What was offensive to the author of both articles and the people she interviewed (incidentally not Deaf people) was that two people (possibility also considered deviant because of their sexuality) desired and carried out their plans to have a deaf baby at the same time the scientific community is taking active steps to eliminate disability. In particular the actions of these women (in the US) were considered a threat to the research plans and investment portfolio of the Australian company Cochlear Ltd, manufacturers of the cochlear implant as if prospective buyers would put off their implant purchase because some people felt Deafness (and by extension, other impairments) as positive and valuable attributes!

In Section 6.4, I discuss in detail the processes of marketing the cochlear implant to Deaf people and the rest of the community. Here, however I wish to use this piece to demonstrate the way such a perception of disability as inherently negative provokes such a threatened response when Deaf people wish to use technologies in ways that produce an oppositional discourse of affirming disability. According to Dr Bill Glasson, Queensland President of the Australian Medical Association (AMA), to "*deliberately* … create a disabled child was criminal and would have not support among the general community or the medical community" [emphasis added]. In unveiling the bias of technological research, Glasson further remarks, "Here we are talking about stem cells and curing all sorts of ailments, now we are talking about producing kids with disabilities" (Griffith, 2002b).

The rhetoric of technological promises holds out the possibilities of enhancement and perfectibility – where prospective parents are dangled the 'carrot' of trait selection. Yet such selections become highly selective when the subject of disability/impairment enters the discursive arena. Ken Connor, President of the US based Family Research Council commenting on in this case concludes:

> We've seen many parents try to ensure they create children possessing a certain trait, however this couple has sought to create a child so that he does not possess a certain trait – in this case the ability to hear. One can only hope that this practice of intentionally manufacturing disabled children to fit the lifestyles of the parents will not progress any further. The places this slippery slope could lead are frightening. (Griffith, 2002a).

No mention is made by Connor of the common desire of parents to produce a baby like themselves, whether that be on the basis of skin colour, intelligence, red hair, height and so on. So why the moral discourse of wrongness (and indeed criminality) when Deaf/ Disabled people wish to have children like themselves? It is difficult to disagree with the assertion of John Radford (1994) who describes 'disability' as the Enlightenment's 'recidivist element', representing an ontology of failure, hopelessness requiring surveillance, repair and management.

It seems that the ableist world goes into an ontological shock so to speak, when the gaze of ableism is inverted and 'disablement' assumes the norm, becomes the speaking center. The following three statements from the 1990's demonstrate this point:

> A married couple's hypothetical conversation about the discovery of 'deaf genes':
>
> Husband: Have you read this article?
>
> Wife: Yes, it is groundbreaking.
>
> Husband: Now, we can (have) babies without worrying.
>
> Wife: That's right. With a little bit more progress of science and technology, we can avoid having hearing babies.
>
> (D-ko, cited in Nagase, 1995).

> I mourn for that 'disablised' corpo-reality that I have 'lost' and for the disabled-person I have become as a consequence. A 'post-quadriplegic' woman, cited in (Campbell, 1998).
>
> When one hearing parent said ' … I have a right to want surgery for my child which will make him more like me, a hearing person', Gary Malkowski, then legislator in Ontario, Canada, replied 'then presumably you have no objection to deaf parents requesting surgery to make their child deaf'. (Lane, 1992a)

It is only when there is a reversal of a narrative of 'ableness' that we can fully appreciate the ramifications of a system of ableist normativity that postulates a belief in the 'objective' preferability of 'ableism' and/or 'hearing'. So inconceivable is the desire of 'disability', the ableist mindset becomes affronted by any suggestion that the neologism 'disability' is epistemologically 'neutral'.

Consider the vigorous debate contained in the Hastings Centre Report *The Disability Rights Critique of Prenatal Testing* (Parens & Asch, 1999) over the 'status' of 'disabling traits' by members of the working group. A majority of the working group came down on the side of a negative ontology of 'disability' believing that

> … disabling traits [sic] are disvaluable insofar as they constrain or limit some opportunities", at the same time acknowledge their surprise that "conjoined twins would report feeling about their lives pretty much like people with "normal" bodies report feeling about theirs (Parens and Asch, 1999: S16)[282].

Such expressions, unconscious or otherwise, of anxiety and dis-ease about impairment/ disability become consequent when negative ontologies are transposed into the arena of technological applications and legal constructions of 'disability'[283].

The drive to eliminate 'anomaly', enhance and perfect bodies through the utilization of technologies in effect results in solidifying our definition of human life to what

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[282] See also Parens & Asch (2000). Conjoined twins seem to elicit this kind of startled shock. Kenneth Miller after interviewing Abby and Britty Hensel describes the twins existence as mind boggling and adds that the greater paradox is that the girls ' … were happy, outgoing, well-adjusted kids'. (Miller, 1998a).

[283] Lupton & Seymour (2000) are in agreement here also acknowledging the link between ontological phenomenologies and human/machine interactivity,

technology is able to sustain. In other words, human subjectivity and asceticisation increasingly are framed as geneticised (Cherney, 1999; Shakespeare, 1998). Shifting levels of articulation and enhancement may create new understandings of a species-typical benchmark body[284], overturning and reconfiguring our very concept of 'normative' functioning. Indeed, we may wish to consider the extent of 'difference' necessary to be classified as 'pathological' or 'abnormal'. In other words, the quest for 'morphologically free'[285] persons, in turn reproduces others forms of alterity, a revived monstrosity on the move. As McGuire and McGee put it – '…today's normal might be seen as subnormal, leading to the medicalisation of another area of life' (Maguire and McGee, 1999: 11). We may ask whether 'therapy' is a transmogrified form of 'enhancement', in the sense that it is predicated on a refutation of 'disability' and can be reconfigured as an enhancement to 'normalcy'?

6.2.2 Promises – Should we Beware of Those Who Bring 'Gifts'?

> From a millenarian perspective, things are always getting worse. Evidence of decay is exhilarating and mobilizing. Oddly, belief in advancing disaster is actually part of a trust in salvation, whether deliverance is expected by sacred or profane revelations, through revolution, dramatic scientific breakthroughs, or religious rapture. For example, for radical science activists like me, the capitalist commodification of the dance of life is always advancing ominously; there is always evidence of nastier and nastier technoscience dominations. An emergency is always at hand, calling for the need for transformative politics. For my twins, the true believers in the church of science, a cure for the trouble at hand is always promised. That promise justifies the sacred status of scientists, even, or especially, outside their domains of practical expertise. Indeed, the promise of technoscience is, arguably, its principal social weight (Haraway, 1997b: 41).
>
> A prophet wandered the land (Britain) and he had a vision; that all those who had a spinal injury would one day be able to walk again. Not only that, but this could be achieved within five years if certain things were done. These included a range of behaviours and rituals and necessitated forming an organisation to support them.

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[284] Typicality does not refer to statistical occurrence but rather an assumed/implied conceptual formulation concerning the 'natural' design of a particular organism, in this case 'human'.

[285] Chislenko (1997: 14) suggests that "a truly morphologically free' person may change all his [sic] parts and their configuration, and preserve only the general goals. Though goals will drift too. Even our current inflexible designs, our fundamental goals and interests change several times during our lives. In advanced entities such processes would speed up. The outside observer with some stretch of the imagination could still call such a sequences of goals, or teleological thread", an identity, but entities themselves may feel different about it".

> He wandered the land and spoke to people of both high and low status, those afflicted and those not and convinced some that his vision was true. So the [philanthropic charity] organisation was formed (Oliver, 1996: 101).

The unification of disabilities and technologies contains two seemingly conflicting themes. One of purification, in the Latourian sense of ensuring clear demarcated and unpolluted lineages between the ‘ably-well-pure’ and the ‘disably-monstrous’ subject/being. Yet at the same time, contained within this theme of separation, of ontological apartheid, is another theme of conflation – a desire to fabricate a morphing of an uncritical ableism (See Chapter Four).

Two other ways of representing technology are worth noting in an assessment of technology’s promises’, namely that of technology as a form of ‘care’ and technology as ‘prosthesis’. Let’s tackle the former aspect first. My initial meditation concerning this concept provoked usual associations – technological apparatus such as hoists, cochlear implants and telematics could be deemed assistive devices or independent living aids and thus in tandem with the emancipatory project. Yet a second look at the concept of ‘care’, in particular the word’s etymology reveals another more shadowy perspective.

> **1. Care** [n] Anglo-Saxon. cearu, caru, sorrow, anxiety. Old High German - kara, chara, a lament. 2. Care [vb] Anglo Saxon. Cearian. To be anxious from, cearin, anxiety, sorrow (McKechnie, 1959: 274).

Within neo-liberal regimes, what does it mean to speak of ‘care’? As a profoundly relational concept what kind of ontological images are prescribed to those in need of ‘care’. Equality what is being stated about those ‘caring’ technologies – human, object or hybrid – indeed, what is the nature of technological ‘becoming’ when those artefacts are relationality coupled with those in need of ‘care’. This line of enquiry certainly provokes many challenging questions. Our starting point is to examine the sovereign subject of liberalism whom it is assumed does not require ‘care’. It is simply assumed that he [and later 'she'] is an independent center of self-consciousness, fully autonomous and self-sufficient.

In turning the mirror back on the disability-referent subject, it becomes clear that such bodies are unable to meet such criteria of expectation. Furthermore, the processes of thinking and practicing technologies engage relations of exchange that are often asymmetrical[286]. The very prosthetic motif reveals, not the metaphor of extension, rather a transfiguration of 'identity' that is deficient, defective, insufficient and creates in Derrida's words, 'logic of supplementation', a gap or viscous space/zone to be filled and contained within a circular mode of dependency (Derrida, 1974: 144 - 152).

The increasing use of technologies have recuperated the waning influence of biomedicalism to the extent that the promises of technologies can be summarized in a twofold manner:

- The promise of eradication, transmogrified as 'cure'; and
- The promise of 'equalization' via the disciplinary practices of 'normalization' and technologies of self.

The actualisation of both promises requires a convergence of technologies of production and technologies of the self. Indeed, in a different context from what I am discussing, Foucault remarks:

> The care of the self isn't another kind of pedagogy; it has to become a permanent medical care. Permanent medical care is one of the central features of the care of self. One must become a doctor of oneself (Foucault, 1997d (orig 1982): 235).

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[286] Two recent British studies are in support of my argument. (See Johnson and Moxon, 1998; Thornton, 1993).

Such promises and pleasures of the ableist technological imperative are revealed in the typology of Chris Hables Gray et al in their paper *Cyborgology* (1995):

TABLE 5: Four Cyborg Typologies (adapted from Hables Gray (1995: 3))

Typology	Function/Goal	Concrete Example
Restorative	**Restore lost functions and replace lost organs and limbs**	**Cornea transplant.**
Normalizing	**Restore some creature to indistinguishable normality**	**Cochlear implant, Behavior modification.**
Reconfiguring	**(Ambiguously) creating posthuman creatures equal but different from humans**	**Robots with human organs.**
Enhancing	**Cyborg envy/cyborgphillia fantasize. C.f. Extropy and transhumanism**	**Brain/memory uploading devices, smart pills. Gene selection.**

All four typologies, I would argue, to a variable extent are underpinned by a vision of perfection[287], a teleological mastery over nature, which begets a utopic ontology of becoming, fear of risk and unproblematic autonomy. Richard Hindmarsh captures this biotechnological dreaming well:

> Civilization, finally, will be able to control its biological destiny. By escaping from their genetic straightjackets and the constraints of nature, people will find a new kind of freedom – a freedom to overcome disease and hunger, to have an improved standard of health and, of course, to live longer (Hindmarsh et al., 1998: 5).

Discourses of technological utopia are infused with the quest for transcendence, either in the quasi-religious sense, or its secular cousin, Nietzsche's *Übermensch*, what Haraway (1997a: 212) refers to as the erotic impulse/transgression to plumb all those 'secrets'. Such impulses to pursue 'perfection', 'restoration' and 'cure' are evidence of a

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[287] Such 'perfections' maybe longitudinally offer great 'potential'; 'potentiality' mitigated by ongoing technological developments.

millenarian subtext in technoscience, rather than a mere response to objective scientific epistemologies[288].

Two pertinent examples, influenced by different schemas and interests, are provided by Haraway and Oliver. Haraway's (1997a; 1997b) interrogation of the Du Pont OncoMouse™, that creature violated to produce a tumour-producing gene, takes on the cloak of Christian realism, becoming a scapegoat, a suffering servant and bearer of salvation – "a cure for cancer" (Haraway, 1997a: 222) .

In contrast Oliver, undertakes an analysis of what will call 'compulsory walking' epitomized in the slogan adopted by the Hart Walker program (St George Foundation) 'May every child walk with pride for it is their right'. In critiquing Bryan Turner's description of walking as a mere biological /functional act, Oliver suggests that 'walking' acts as symbolic capital associated with (real) life (Oliver, 1996: 97) [289]. A whole vast apparatus is deployed to make non-walkers nearly-walkers and nearly-walkers walk. As one father exclaimed when seeing his child use the Hart Walker (see Figure 9): "Here was my son – who can't walk, can't talk, can't even roll over if you put him on the floor – in this walking frame. Even if he never gets out of it, he is walking, and that's the best therapy he could have" (St George Foundation (NSW), 1999). The privileging of walking over other modes of mobility has resulted in large numbers of people submitting themselves to regimes of medical torture – to be surgically modified and re-sculptured.

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[288] Michael Oliver (1996: 94 - 104) also comes to this conclusion regarding *compulsory walking* – the promise of bodily transmogrification via miraculous means. This theme also links back to my analysis of 'disability as fallen' in Chapter Three. See also my conclusion in Chapter Five, section 5.3 on Social Role Valorisation Theory (SRV).

[289] See also Oliver (1993).

This figure is not available online. Please consult the hardcopy thesis available from the QUT Library

Figure 9: The Hart Walker

Source: (St George Foundation (NSW), 1999)

The elevation and compulsion towards ‘walking’ brings together those modes of domination under the power of techniques of normalization and biopower. As Oliver puts it, in the rehabilitative apparatus

> … walking is rule-following behaviour; not walking is rule ignoring, rule-flouting or even rule- threatening behaviour. Not-walking can be tolerated when individuals are prepared to undergo rehabilitation in order to nearly walk or come to terms with their non-walking. Not-walking or rejecting nearly-walking as a personal choice is something different however; it threatens the power of professionals, it exposes the ideology of normality and challenges the whole rehabilitation enterprise (Oliver, 1996: 104).

Princeton ethicist Lee Silver, prophesised that humankind would separate into two new species – the genrich (those who could afford genetic engineering) and the natural class (those unable to access genetic enhancements): ‘… the genrich class will be supremely talented intellectually and athletically, free of physical and mental illness, and possibly immortal’ (Silver, quoted in Horgan, 1999: 161). A new vision of human self would ensue based on extropian[290] principles of boundless improvement, self-transformation, self-ownership, dynamic optimism, intelligent technology and spontaneous order. How the notion of 'perfection' is distilled down to the level of the treatment of 'disabled' bodies is not all clear, at best the implications are confusing and the effects disparate. At the other end of this spectrum, the practice of 'perfecting technologies' is more insidious through the use of so-called 'therapeutic' and 'enhancement' technologies.

These 'dividing practices' of technologies are somewhat dubious and illusionary and are really configured on the basis on a dialectical exchange between the 'social' and 'material' body. The reality is that it is only possible to develop a differentiating typology such as Hables Gray because of an assumed *a priori* species-typical functioning baseline for the 'essential' normative body. A number of writers have refuted the notion of a fixed and stable 'physical', inherently human body that is trans-cultural and historical (Grosz, 1994; Halberstam, 1995; Lingis, 1994; Sobchack, 2000). Such a fabricated and undeconstructed concept of a species-typicality in turn produces the figuring of 'disease', 'disability' and 'deviation'.

So far I have briefly introduced the context of 'promises' of new technologies and the way in which that context intersects with an ontological understanding of 'disability'. In the next section I will critically analyse the mechanisms for governing 'disability' as played out through the practices of 'eugenics of normalcy'[291]. Firstly, I will briefly discuss matters related to pre-natal testing, by problematising the principle of 'choice'. Secondly, I consider technologies of normalization as part of a eugenicist paradigm.

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[290] *Extropianism* is described as a transhuman philosophy, which seeks to challenge our ideas about human limits, and desires to improve the future. For a good introduction see: More (1995). For a less 'offbeat' mainstreamed stance, based on Utilitarianism refer to the work of Peter Singer (1995b).

[291] An expression coined by Keller (1992).

6.2.3 Whither 'Disability': New Reproductive Technologies (NRT's), Human Genome Project (HGP's) as a New Eugenics?

> With every tool man [sic] is perfecting his own organs, whether motor or sensory, or is removing the limits to their functioning … Man has, as it were, become a prosthetic god. When he puts on all his auxiliary organs he is truly magnificent: but those organs have not grown on him and they still give him much trouble at times (Freud, 1962 (1932): 42).

This section explores ways desire and dis-ease of 'disability' intersect when located within the terrain of certain eugenicist technological discourses– it is as such about matters ontological. I argue that far from being an anachronism, the eugenicist imperative in late modernity has been transmogrified into a variety of practices which seek to 'eliminate' the birthing of bodies marked as 'disabled' or, in the event of our/their post-natal 'existence' to engage 'perfecting' technologies that morph ableism and enshrine a particular understanding of ableist normativity and (real) human subjectivity.

The metaphor of 'the hunt', the forming a posse to root out 'disability' underpins the narrative drama of the eugenicist drive to rein/reign in 'disability' through the continual reiteration of technologies as salvific signifiers promising 'able-bodiedness'. The persistent figuring of 'disability' in terms of negative ontology involves the constant rewriting of 'disability' within social policy and the ableist body of the law. I begin by locating and establishing the eugenicist compulsion. Next I move onto an interrogation of ontologies of 'disability'. For the eugenics/disability debate foregrounds the ontology wars about lives worth living. Then after summarizing the 'promises' of technology, I shift my attention to the modern practices of eugenics firstly by briefly focusing on pre-natal testing and then centring on post-natal 'perfecting' technologies and their legal consequences.

How deep is your hatred? - Eugenics Old to New

The notion of killing and disposing of corporally anomalous bodies, in particular persons with 'disabilities', throughout history is not particularly new or startling[292]. In the twentieth century in the West, we have witnessed the systematic and programmatic destruction of segments of the population by way of the practices of forced sterilizations, euthanasia, torture and murder, countenanced or sponsored by a centralised State apparatus. Despite difficulties in securing agreement about the definition/purview of 'eugenics', eugenistic presuppositions invoke ' … largely unexamined and unspoken preconceptions about who should and should not inherit the world' (Hubbard, 1997: 199). For this reason I argue that matters of eugenics are inherently ontological, positioned within the realm (and borders) of human subjectivity.

We can characterise the pre – 1945 eugenics as being of a 'negative'[293] type, State controlled and initiated by way of transparent, coercive practices. The Nazi Aktion T4 programme (1939 – 1941) where approximately 275,000 people with disabilities were murdered is a case in point[294]. I wish to draw attention to two characteristics of that programme whose significance re-emerges later on in the chapter. Firstly, the Nazi euthanasia programme was driven by a particular understanding of the (real) citizen informed by a contributory/performance ethic, and secondly, the 'logic' of the strategy was primarily economic. As Robert Proctor (1995: 171) summarizes: 'euthanasia was defended as a means of cost cutting, or ridding society of 'useless eaters' …'

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[292] For a concise 'history' refer to the Disability Social History Project http://www.disabilityhistory.org

[293] 'Negative' in the sense of preventing the reproduction of categories of persons deemed 'unfit' or 'undesirable'.

[294] C.f. Proctor (1988), 'Handicap', U.S. Holocaust Memorial Museum http://www.holocaust-trc.org/hndcp.htm

By contrast, modern eugenics practices are more insidious and covert. Today the State plays a less direct and de-centred role in the governing of 'disability'. Under the mantle of political liberalism boldly proclaiming rampant individualism and freedom of choice, the individual acts as her own overseer, wherein techniques of self-production are not imposed but actively sought. Such technologies of responsibilisation ensure the shaping of conduct (relations of self to self and to others), is mobilised in a desired direction[295]. Under the guise of a 'laissez-faire eugenics'[296], the onus is on personal decision making within an overarching framework of 'risk-assessment'[297] and 'positive eugenics'[298]. The mechanisms of 'laissez-faire eugenics' engage the practices of pre-natal screening, 'disability' dispersal policies and the compulsion towards 'perfecting' and 'morphing' technologies of normalization.

Consider the deployment of such negative ontologies in the reasoning of Justice de Jersey, Queensland Supreme Court in *Veivers v Connolly*[299] in allowing for the lawfulness of a 'selective abortion' based on taking into account the characteristics of the foetus and the impact of those characteristics of the mother's mental health. Speaking with a privileged Ableist voice, de Jersey speaks of the young woman with a 'disability' (the defective offspring) and the support she requires in terms '[a] burdensome task, … with terrible lifelong deficiencies …[whose existence causes anguish of an] … immense [and] almost passing comprehension'[300]. Similarly in *McKay v Essex Area Heath*

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[295] It is beyond the parameters of this paper to discussion the concept of 'freedom' in any detail. I refer readers to Nikolas Rose's work (1999).

[296] A term coined by Black (1996) to describe the role of 'market forces' in shaping predictable outcomes under the guise of consumerism and choice.

[297] I will however argue later that the elements that inform that risk assessment are profoundly coercive – where any transgressions from the imperatives of ableist normativity incur a (legal & financial) penalty.

[298] A compulsion towards favoured human characteristics, what I term *ableist normativity*. This concept is quite fluid, with increasing emphasis on *enhancing* characteristics.

[299] (1994) Aust Torts Reports ¶ 81 – 309.

[300] The quotations are extracted from Fitzgerald (1995).

Authority[301], the precedent setting Anglo-Australian anti - 'wrongful life' case, Lord Justice Stephenson exhorts the right to be born (which we should all assume) of a child to be born whole and perfect or not at all (1181).

On the Hunt for 'Disability' – Before Birth

> The prevalent belief in American [and Australian] society is that the quality of life for a person with a disability is seriously compromised, and therefore disabilities should be avoided or ameliorated. Prenatal diagnosis and carrier screening of healthy adults are tools used to reach this goal (Kenan, 1999: 3).

Projects such as the 'Holy Grail' of biology, the International Human Genome Sequencing Consortium, have constructed a map of the whole genome that will be used to diagnose, 'treat', and prevent 'dis-orders' (Human Genome Management Information System, 1999 Kevles, 1992; The International Human Genome Mapping Consortium, 2001). It is here within the confines of a therapeutic space (genetic screening and counselling) under the rhetoric of 'procreative rights', that women are assisted by disciplinary actors 'to make decisions about whether or not they should bear children - and increasingly which *kind* of child they should bear' (Rowland, 1998: 88- her emphasis). Such decision-making processes induce an abstracted 'autonomy' wherein women are positioned in a role of moral philosophers, shifting through so-called 'choices'. The *tentative-mother-to-be* is constrained in reality by narrow, clinical and medicalised classifications which foreground genetic difference above other factors and a social context that narrow 'free' choices (Hubbard, 1997; Kenan, 1999; Parens and Asch, 1999; Rapp, 1998). The illusion of 'choice' can be figured as an attempt to mask (erase) the eugenic spectre and blur some of the issues under consideration, such deciding whether to continue to be pregnant in contrast with 'deciding which foetus to be pregnant with' (Shakespeare, 2000) .

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[301] (1982) 1 QB 1166.

To add to the chaos, the authorizing power of law has cast the rights of the foetus (the 'defective' child/human) and the rights of parents (the mother as woman) in an oppositional and adversarial relationship[302]. Such conflicting juxtapositions, highlight the limitations of liberal rights discourses when the 'rhetorical flagships' of the right to 'choose', to be 'born healthy', to 'life' and to have protection from discrimination based on 'difference' are pitched over and against each other.

In an era where the possibilities of gene therapy and the creation of 'normalized' bodies exists, it becomes more difficult for the woman - mother to resist the compulsion towards rejecting a 'defective' foetus in conformity with the imperatives of ableist normativity. Her decision may become a persuasive question about the responsibility to 'support' such 'choices' by the State[303]. Rowland suggests

> ... less and less assistance will go to those who make the 'mistake' of having an imperfect child. ... in the age of the perfect bioengineering and homogenized product, difference - named 'defect' or 'abnormality' - will become increasingly less acceptable' (Rowland, 1998: 83).

Alternatively, some indirect coercion might suffice through the practice of 'biocolonialism' where genetic testing is compulsory and/or in order to receive coverage under health insurance[304] such testing becomes a pre-requisite. Put more strongly, a

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[302] This makes social and legal research in this area both interesting as well as a terrain that requires careful navigation skills in engaging in dialogue between feminist and disability rights discourses.

[303] Already there have been calls for protection against loss of medical, insurance and legal benefits on the basis of a decision to carry a 'defective' foetus to term (National Down Syndrome Congress, 1994). The mother may face the possibility by proxy, of having her child classified with a 'voluntary'/ 'elective' disability – in the sense that she knowingly did not 'mitigate' the possibility of 'disability' before birth.

[304] In the American context, the 1998 Supreme Court judgment in *Bragdon v. Abbott*, 524 US 118 S.Ct.2196 (1998) suggested that the *Americans with Disabilities Act* 1990 (ADA) would protect individuals from discrimination on the basis of future 'disease'/'disability' (Helmuth, 1999). For a more in-depth discussion about the relationship between insurance, genetic testing, prognosis and confidentiality refer to the paper by The American Society of Human Genetics (1995) and an online bibliography on genetic testing and insurance.

woman who resists the 'desirability' of prenatal testing or the compulsion towards selective termination[305] becomes a pariah, a carrier of a criminalized (negligent) womb[306]. Consider the argument of legal ethicist George Smith who recommends that children with 'disabilities' have a right to sue their parents for being born, as the decision to knowingly continue a 'defective' pregnancy can be characterized as a form of 'negligent foetal abuse' (Smith, 1981: 38).

6.2.4 'After the Fact' - Morphing Ableism: Technological Applications Enforcing Normalcy

Increasingly economic rationales are playing a role in the emergence of selective population control strategies. Echoing the pre-1945 eugenics situation, the coercion towards a compulsory utilization of technological fixes is justified by arguing that such strategies make 'disability' acceptable by way of an increase in commodity/use value to the ableist world. A 'strong eugenics'[307] approach rejects any claims by the state to support economically and morally, unproductive (and non-participative) 'citizens'. Indeed the very inclusiveness of liberalism's understanding of 'citizenship' hinges upon governing 'disability' according to an ethics of normalization. Such 'conduct of conduct' upon oneself functions

> … as an instrument that secures the ends of democratic political morality. For on the view that being a well-functioning individual is critical to performing the social responsibilities of citizens, normalizing is seem as qualifying functionally defective

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[305] Shakespeare (2000), points out that some women may selectively terminate because of the social implications of raising a child with a 'disability', rather than eugenicist hostility towards 'disability' per se.

[306] However the effects on criminalization are different – depending upon the ways the ableist, sexed and raced bodies of the pregnant woman and her foetus intersect. For example selective abortion on the basis of so-called 'disability' characteristics is less contentious than on the basis of sex and race. Furthermore the nature of 'foetal selfhood' takes on vastly different representation when we are dealing with a foetus figured as 'abled' in need of protection, especially from 'victimization'. Such 'care and concern' is not often shown for the 'defective' foetus that suffers entry into a disabled life. See for a brilliant discussion of the dynamics of women and their foetus in terms of race and sex (Karpin, 1994; Maher, 1991).

[307] Tom Shakespeare makes this distinction to delineate more coercive eugenist practices. He argues that (at least in the UK) the shift to an increasingly cost-benefit analysis in genetic screening may signal a move to a 'strong eugenics' approach. (Shakespeare, 1998).

> individuals for citizenship by repairing them so they can execute the usual social interactions and sustain common social responsibilities … For whoever cannot perform competently as a cooperating and contributing and, therefore, an equal, social partner is fully neither citizen nor person (Silvers, 1998a: 100).

In Chapter Five, section 5.4 I signalled the gradual shift towards seeing (legal) disability in terms of mitigation, forcing not only a reliance on technological applications but a coercive relationship to the context within which these technological practices occur. For example, the take up of technologies may be linked with access to systems of welfare and benefits as well as the identity recognition (an enumerative passport – see Figure 7) needed for negotiating the system and additionally protections under anti-discrimination legislation. Another pressure, if you like, placed upon people with impairments is the compulsion towards forced participation in work (on the terms of expectation usually presented to people without impairments). In section 5.1.3 I mentioned the trend by government's to institute regimes of mutual obligation or mutual reciprocity in order to be regarded as a contributory citizen (or in some cases a 'real' citizen at all).

The equalizing tendencies of Western liberalism means that for people with disabilities, entry into the polis, into full citizenship increasingly occurs by 'crossing-over' into the breached boundaries of 'cyborghood' through the merging of 'perfecting' technologies. For many of us with 'disabled bodies' the cyborg is a merged intimacy with technologies, usually non-organic but not necessarily so. This quality of intimacy is difficult to grasp/contain – it is almost perichoretic – a dis-possessive giving and receiving, an unbounded merging and compression. Haraway describes this 'coupling': "the cyborg is a kind of disassembled and reassembled, post-modern collective and personal self" (Haraway, 1991a: 163). In this sense, technologies can be understood as prostheses – signifying simultaneously a discursive framework for the figuration of subjectivity as well as a material actant.

In the following two sections two case studies will be exploring in-depth whether cyborgian vision of a new 'humankind' rings true, and whether the bells toll joyfully for people with disabilities. The first study tells the story of Clint Hallam, recipient of the world's first forearm transplant. Whilst the second study focuses more specifically a machine, an artefact that allegedly produces 'sound'; the cochlear implant. This study is not interested in the development of the device but attempts to trade in ontological symbols of 'disability' (deafness) and 'hearing' in order to selling the product. The final section of the chapter builds on the two case studies and extends our exploration of simulating or morphing ableism by considering the post or transhuman movements and literature.

6.3 The Case of Clint Hallam's Wayward Hand

The Clint Hallam international surgical soap-opera played out in the electronic and print media during 1998-2000 is an apt example of the ways contemporary technological practices interface with both popular and technical formations of what it means to be 'dis-abled' and 'nearly-abled'. Hallam's saga is also a study of the way in which networks of ableism can be recuperated and thus remain reinforced and unchallenged. This case study follows the travails of Clint Hallam and the (re) writing of Clint's 'hand' in media discourses. It analyses the convergence of the personal tragedy approach to 'disability' with the criminalized 'hand' (body). I conclude that far from considering new technologies as neutral isolated objects, the practices, coupling and effects of technologies reassert a new and vigorous bio-medicalisation of species-typical functioning and ultimately protect domains of ableism from critical review.

The Story

In September 1998 a radical hand transplant involving 13.5 hours surgery was performed at the Edouard Herriot Hospital, Lyon France by an international team[308] of surgeons on the body of then forty-eight year old New Zealander, Clint Hallam. As a patient-subject, the body of Clint Hallam is marked by two features that become significant in media reportage about Hallam's surgical saga and its underlying moral discourse. First, Clint Hallam had a criminal past, which becomes transmogrified over time into an all-embracing 'criminal mind' in opposition to the notion of the 'responsible citizen'. Second, Clint prior to the surgery lived for fourteen years as a person with a physical impairment[309]. It is this translation or mixing of the 'criminal' and the 'disabled' that not only infuse the style of media reporting but in many ways set the terms of the debate and the ways in which ableist-medical experts responded to criticisms over their technological practices.

According to media reports Clint Hallam lost his right hand in a circular saw accident in 1984 while serving a two-year prison sentence for fraud in New Zealand. The UK newspaper *The Observer* notes a rather quirky aspect to this saga – hand transplant aside – Hallam "is now the first person to have his right hand amputated three times" (McKie and Paton Walsh, 2001)[310]. It was after the failed re-attachment that according to one report, Clint developed his dream or obsession of "a replacement human hand in full working order", as Clint states: " I chose an artificial hand, believing that it would almost become humanoid … but I also thought that if they [the doctors] could do hearts and

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[308] The team of was led by Jean-Michel Dubernard of Lyon and Earl Owen of Sydney and included Nadey Hakim (UK), Marco Lanzetta (Italy) Hari Kapila (Australia), Guillaume Herzberg, Marwan Dawahra, Xavier Martin (France).

[309] Media reports do not indicate whether Clint identified as a 'disabled person'. Certainly, as an amputee his 'disabled' status would be recognised by some government and non-government organizations.

[310] The initial amputated hand was restitched and then re-amputated after loss of sensation.

livers, one day they would be able to do limbs too" (Whittell, 2000: 5). Hallam pursued this quest and after meeting up with Sydney micro-surgeon Dr Earl Owen set in place a chain of events that led to the world's first forearm-hand transplant.

A Few words on Approach

Australian researchers Gerard Goggin and Christopher Newell recently pointed to a paucity of literature within media studies examining representations of disability (Goggin and Newell, 2000). Ross (2001) takes this criticism further and contends that mass media researchers have totally ignored disability as a thematic of interest, arguing that limited research has been content driven or positioned from the perspective of non-disabled people. There are however some notable exceptions examining such diverse aspects as newspaper disability terminology (Ann-Lewis, 1988; Auslander & Gold, 1999; Barnes, 1992), general media portrayals (Pointon & Davies, 1997, Meekosha & Dowse, 1997), fundraising imagery (Corbett & Ralph, 1994; Phillips, 2001) and radio (Ross, 1997, 2001).

Whilst this case study redresses this paucity by drawing upon the methodological insights of content analysis and grounded theory (narrative analysis), this case study's underlying argument is that existing cultural and media studies approaches to disability can be fruitfully extended by sociology of science and technology studies approaches situated within a poststructuralist disability studies framework. The study examined a sample of articles on Clint Hallam's transplant published in Australian and overseas newspapers (including internet versions). In utilizing *content* and *narrative analysis*, I focused on those aspects of media reportage related to *appearance* (headlines, definitions), *intensity* (claims, argument style and evidence), *agendas* (presuppositions) and *status* (competence, credentials of the speaker) (Berelson, 1952; Holsti, 1969; Kellehear 1993; May 2000; Lee & Pointon, 1998).

Pinch and Bijker's (1987) work on *artefact stabilization* and technological closures were deployed to enhance the discussion and analysis. *Artefact stabilization* refers not only to the choice of technological apparatus (in this case a hand transplant donated by a deceased man) but also the dominant 'meaning(s)' given to that artefact. The mechanisms of closure can be grouped into two kinds, namely *rhetorical closure* and *closure by re-definition of the problem*. Rhetorical closure in our case study draws attention to the existence of contestable meanings over the nature and purpose of a 'transplant' and any corresponding ethical dilemmas. For instance, is a transplant 'restorative' or merely a prosthetic enhancement'? *Rhetorical closure* involves a cessation of controversy, with the dominant actors (here, the medical community and media) instituting a fixed meaning and 'disappearing' any problems. This process involves mobilizing allies across networks of association to assist with inducing a particular thematic spin. As Pinch and Bijker remark, " … in technology, advertising [and media] can play an important role in shaping the meaning which a social group gives to an artefact" (1987: 427).

The second strategy of *closure by re-definition of the problem* is particularly pertinent in the story of Clint Hallam. In this instance, on the occasion of the first hand-forearm transplant, there were serious concerns about technological practices and artefacts. Instead of responding to perceived 'problems', the meaning of either the artefact (the limb) or its application were translated by the medical established mediated by media commentaries, to constitute a solution to *another* problem. The methodological approaches adopted for the case study assisted in foregrounding the way in which the body, psyche and voice of Clint Hallam has been put into speech. Additionally I document the formation of the *criminalized disabled* subject as a justificatory identity for the failure of the transplant.

6.3.1 Viability or Freakish Novelty – Contestations over Transplant Plans

> To the doctors who performed the pioneering hand transplant surgery, it was a work of art that would cement their place in medical history. But for the man who has to live with the hand and forearm of a dead motorcyclist, it is a grotesque and useless appendage that has left him physically and socially damaged (Middap, 2000).

From the start, Earl Owen's plans to conduct a hand transplant were shrouded in controversy. The early media reports bear testimony to this context. It is only later (post-surgery and pre-re-amputation), that the contentious nature of the surgical experiment is erased and evaporates in media reports to be replaced by the underlying theme of the marvels of medical discovery, 'gift-giving' and Clint's ungrateful 'deviant' response.

Owen initially made approaches to the British St. Mary's Hospital in Paddington. However according to *The Weekend Australian* (Whittell, 2000), " … British authorities baulked at letting the operation go ahead". It is not clear why baulking was the response as no reason is given for this insinuation of hostility. An earlier piece in the *New Scientist* magazine headlined "*Hands today, faces tomorrow*," raises the spectre of creating a Frankensteinian monstrous body[311]. Noting that the hand transplant was controversial, writer David Concar suggests in his opening sentence that the operation " … raises the prospect of something even more macabre – a human face transplant" (Concar, 1998 ~ emphasis added). Aside from this rather glib and emotive statement, little analysis is provided to substantiate his concern. As if almost to allay any 'floodgate' type fears, a Dr. John Williams, Vice President of the Royal College of Surgeons is quoted as saying

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[311] For an interesting exposition of the monstrous body in relation to rights discourse see: MacNeil (1999).

that the low incidence of severe injuries would call into question the 'worthwhile ness' of such surgery. Within Concar's report the voice of Clint Hallam is silent.

Justine Ferrari's piece under the banner of "*Hands-on Experience*"[312], in an October 1998 edition of *The Weekend Australian* remains one of the few articles that attempts any critical analysis of the Lyon corporeal-surgical intervention/corporeal violence[313] (Ferrari, 1998). While still being written from the perspective of a biomedical paradigm with its emphasis on immuno-suppressant drugs, Ferrari does give Hallam a mediated[314] voice. Using the metaphor of bodily recycling as well as a resurrection motif she suggests that Clint Hallam might not be an ideal choice as a transplant patient: "…irrespective of his criminal charges … counting against the success of the operation is the length of time since Hallam lost his arm". Ferrari is not referring to the possibility of conflict and turmoil that Clint may experience when renegotiating changes in subjectivity, that is from an 'amputee' to a 'transplant recipient'. Rather in an isolated frame, she is referring to the more mechanistic physical aspects of regeneration (coupling)[315]. It is Ferrari's exposition of the politics of immuno-suppressant drugs that raises significant questions about the ethics of normalising and perfecting technological practices. The problem of this technology, for Ferrari, is rhetorically closed off by limiting the discussion to the level of biological compatibility, rather than matters related to living with impairment at an ontological level.

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[312] I am not sure whether this banner is a play on words, however I initially mis-read it thinking the slogan said 'Hands-on experiment'.

[313] I would argue that such normalizing surgery – the cutting and re-attaching, can be represented as a form of legalised violence against the disabled body.

[314] It is often the case that the 'voice' of the subject is never direct but mediated by the 'voice' of so-called knowable others such as doctors, journalists and other social commentators.

[315] The psychic aspects of this couple re-emerge later. The significance of such surgery lies in its crossing over into a form of hybridity – a mixture of two different beings.

The challenge of the surgery is that the impaired body has to be 'tricked' into accepting the colonizing transplant. As many HIV/AIDS activists point out, life-long immuno-suppressant drugs have many significant and detrimental side effects (Paton, 1990). Most media reports are silent about this aspect of the transplant. There is an implicit assumption that a transplant is morally *preferable at all costs*. Later in this section I shall discuss what happens when an individual refuses to conform to and challenges this hegemonic ideal. But for now an important point should be made. Elsewhere I have written about 'disability'/'impairment' being posited as ontologically intolerable, in other words, as inherently negative (Campbell, 2001a; Campbell, 2001b). The logical conclusion of this belief results in a bizarre and cruel bodily transmogrification, as Ferrari concludes "…Hallam was previously a well man [with amputation] and now, under the influence of immuno- suppressive drugs, is a sick man" (Ferrari, 1998). The irony of Ferrari's conclusions is left hanging. This state of affairs is only possible through the existence of a rampant ableism and the ways this ethos is mediated by and in technological practices. As I argue in another context:

> We can argue that 'enhancing' and 'perfecting' technologies are really a form of assimilation by way of morphing[316] ableism. A technological dynamic of morphing creates an illusion (appearance) of the 'disabled' body transmogrifying into the 'normal' resulting in a corporeal re-composition and re-formation of subjectivity (Campbell, 2001b: 53).

In Ferrari's closing paragraph she points uncritically to the psychic dilemma of "living with a stranger's hand". Apart from the 'yuk effect', no real discussion takes place concerning the psychic or ethical implications of transplant practices. In a discursive manoeuvre that contrasts a face transplant, Ferrari rather glibly remarks, "… looking in

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[316] "The dynamic of morphing creates an illusion (appearance) of the 'disabled' body transmogrifying into the 'normal' resulting in a bodily re-composition and re-formation of subjectivity. This usually occurs through the engagement of technological practices that mimic what is understood to be 'able-bodied' or 'normalcy'. The morphing aspect refers to those elements of technological practice or application that give the appearance of bodily wholeness. For instance, amputee = lack: returned to able-bodied status = normal by way of hand transplant or prosthesis". (Campbell, 2000c: 15)

the mirror and seeing a completely different person seems beyond the realm. But then, imagine living without a face" (Ferrari, 1998).

Before moving on, Justine Ferrari's "*Hands-on Experience*" makes two additional points that are useful to keep in mind when examining the matter of techno-closure. The problem of the effects of immuno-suppressant drugs is discursively side-stepped by re-negotiating normative rules of clinical practice, what Joan Fujimura calls a 'grey box', of 'doable problems' in order to get the job done (Fujimura, 1992: 176). So as Ferrari reports "… doctors who say they would not perform a hand transplant because of the side effects of the immuno-suppressant drugs are demonstrating a paternalistic attitude that is now outdated" (Ferrari, 1998). The 'problem' then, is not one of technological practices; rather it has been discursively re-routed to a 'problem' of the individualized (backward) attitudes of certain (deviant) doctors. The second point Ferrari makes relates to the trans-temporal media hype about the forthcoming hand transplant. She reports the 'event' was reported in a self-congratulatory manner weeks *before* the transplant even took place. Whilst Ferrari's piece provides some useful insights, in the end it skirts across issues of disability/normalcy by its lack of sustained attention to psychic matters of subjectivity and technologies of normalization. Her piece ultimately lapses into a Cartesian dualism that privileges biologism over social organisation.

I conclude this section by considering two examples of more 'upbeat' media reportage about the proposed transplant. In particular, I focus on the way science and media practices converge in order to convey a sense of 'consensus' and closure in the 'hand' transplantation debate[317]. The work of Joan Fujimura around the politics of cancer research is instructive for our survey of the handling of rhetorical closure in the proposed

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[317] See also Hindmarsh (1998).

transplant operation (Fujimura, 1992; Fujimura, 1996). Outsiders to science often believe that scientific procedures obtain agreement and objective verification before commencement. However Fujimura shows us that procedural knowledge is constructed. Her work examines practices of consensus building and the phenomena of 'bandwagons'.

Fujimura's concept of 'standardized packages' enables the analysis of the achievement of agreement across various (often conflicting) social worlds in order to 'get the job done'. This is achieved through the narrowing of 'work space' and the range of possible practices. Such strategies create a standardized set of technologies that make it possible not only to enrol large numbers of players from multiple social worlds (e.g. media, financiers, government, and the 'public') but also to construct new and stable definitions. e.g. 'disability', a 'transplant', 'cure', 'health' and 'disease'. The electronic and print media in its hype over the 'futurist- robotic man' is a significant player (actor). The two media pieces examined are a 1998 *Resoftlinks News* piece under the banner of "*the first hand transplant in Lyon*" and a later, retrospective piece (2001) by McKie and Paton Walsh in *The Observer* headlined "*Trickster has transplant hand cut off*".

The 1998 anonymously authored piece in *Resoftlinks News* (1998) opens with the statement that surgeons are optimistic about the recently performed hand transplant. Optimistic that is, about Clint Hallam's body resisting rejection of the foreign parts. This spin is followed by that now familiar motif of salvific hope, an instituting of a 'bio-utopia'[318]: Team member Dr Jean-Michel Dubernard is reported as saying: "The surgical breakthrough gives hope to millions of victims of workplace and domestic accidents, survivors of war or land mines and individuals born with hereditary deformities" (Resoftlinks News, 1998). The reader is not provided with any substantiation of the

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[318] Although related to gene technology Hindmarsh's (1998) piece is useful here.

‘logic’ of this view of ‘hope’. It is assumed (and probably rightly so) that the majority of readers hold to a deficit and tragic view of disability as something that requires correction. Instead of providing a critical reportage of the transplant event, this journalistic piece becomes an instrumental ally not only in the reinforcement of medical hegemony, but also of an uncritical ableism that posits the dis-ease of disability as intolerable and sickly.

A 2001 retrospective piece by Robin McKie and Nick Paton Walsh “*Trickster has transplant hand cut off*”, in *The Observer* again takes up this theme of optimism and ‘doctor as gift giver’. However it contains traces of confusion and discontinuity related to the reading of the ‘transplant event’. We are told that the operation was “deemed a complete success”, although no criteria or further explanation is provided to support this conclusion. Hallam’s own ‘voice’ is allowed provisional entry. He says he woke up expecting ‘to find life had returned to normal’, yet Hallam’s reaction to the immuno-suppressant drugs resulted in him feeling ‘more handicapped than before’. This moment of profound irony is just left hanging by the reporters – no comment is made about such an awkward juxtaposition. Instead the tried-and-tested strategy of ‘blaming the victim’ is deployed in order to draw attention away from the contestability of technological transplant practices. Concepts of normalcy and disability as pathology remain unexplored.

Such *closure by re-definition of the problem* focuses on Hallam’s deviancy and disruption of the gift giving. The reader is told that the problem is not the drugs but all “… the fault of Hallam, [who] … went without drugs for weeks”. Yet in a rather an apologetic fashion, McKie and Walsh comment that the “perennially cash-strapped Hallam … could not afford his £10,000-a-year drug bill”. Again, another insightful moment is missed: an opportunity to make critical connections between technologies, cost and matters of equity. Instead, the 'money problem' is recuperated in a rather perverse manner via the voice of surgical team member Dr Nadey Hakim:

> The longer the hand stayed on him, the longer it cost him money… He just said 'thank you' to me after the operation, and I felt he was being genuine. He is free of the burden of the last few years. That hand was something that he could no longer afford to possess (McKie and Paton Walsh, 2001).

Aside from the rather unfortunate monetarist imagery, Dr Hakim is given the last word in re-interpreting the potentially subversive 'voice' of Clint Hallam. Hallam is positioned as the rather ungrateful, untrustworthy and suspect actor/recipient of the surgical experiment. Just as the 'new hand' would be soon separated by way of amputation from Hallam's body, so too it is rendered ontologically separated/isolated in Hakim's speech. Indeed the 'hand' is allowed limited agency to be an actor, albeit a controlled one. 'The hand' has become a commodified object capable of being possessed and no doubt dispossessed and repossessed. This possession is contingent upon Clint Hallam's impaired body taking control of it, mastering its renegade forces. The catch is that such limbly possession is conditional upon acquiescence to the ethos and sacrifices of ableism; conditional upon the forces of economic monetarism capturing the uppity limb (the hybrid actant) that refuses re-unification.

6.3.2 Who's Tricking Whom? – The Criminalized Body of Clint Hallam

> I mean this in the nicest way, but he [Clint Hallam] is a liar of extraordinary talent. He's an absolutely charming chap. He's clever enough to have fooled a great many people in his many careers. (Dr. Earl Owen. Cited in, Middap, 2000).
>
> Beyond admission, there must be confession, self-examination, explanation of oneself, revelation of what one is. … 'can one condemn to death a person one does not know?' (Foucault, 1978: 76).

Before the rather public 'outing' of Clint Hallam's difficulties with his new transplanted hand, typical commentary on the world's first hand transplant incorporated Clint's criminal escapades as a young man into the 'story'. This fascination is inserted to add some sizzling excitement to what might appear as another boring science story. It is only later when Clint strays from being the perfect docile patient, becoming an unco-operative body, that the criminality of Clint Hallam provides fodder for discounting/sabotaging his subversive speech and subjugated knowledge[319]. Criminality, i.e. deviancy, becomes the explanatory narrative for the un-cooperative patient.

New Zealand Herald reporter Bruce Butler (1998), under the banner of "*Hand Gained, Home Likely Lost*", plays with the theme of 'gain and loss'. The piece contains a series of one-liners about the career and travel circuit of 'convicted fraudster' Clint Hallam. Butler reports that the Western Australian police were considering refusal of entry into Australia because of his criminal record. The piece closes with a nationalistic angle, reporting that New Zealander's can be refused entry into Australia if they have a criminal record.

A more alarming piece, reported two months later in the same newspaper, headlined "*Hand at Risk as Hallam bails out*" (The New Zealand Herald, 1999) draws upon the jail-bird iconography and contains a greater level of hysteria and judgmental overtones. Building upon the criminal sensibilities of the headline, this reportage readily connects Clint Hallam's alleged lack of 'co-operation' with the medical establishment with his criminalized body. The context is that Hallam has broken contact with the transplant surgical team. Dr Jean-Michel Dubernard initially provided a psychological explanation for the actions of his defiant patient, suggesting he might be sick of doctors (!) and then

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[319] As a member of the 'public' I am no more informed about Hallam's criminal history than any other citizen. I am not attempting here to make any statements of the authenticity of any 'criminal claims', Rather I am more interested in how notions of Clint's criminality feed into discourse concerning the failure of the transplant. As such I argue that Clint's crimes really perform as a 'red herring' in any informed critical debate about technological practices.

shifts gears in his suggestion that Hallam's problem may be related more to his problems in Australia with "a marketing investment scam allegedly worth $NZ1.16 million". It is not the surgery that is the problem, rather Clint's inescapable criminality.

Ellen Connolly's (2000) piece in the *Sydney Morning Herald*, 'Transplant man '*fled to avoid arrest*', is an interesting attempt to weave the Hallam's criminal pursuits into an explanation of his actions in resisting hospital treatment. Although uncertain about Hallam's intentions, the headline infers to the reader that Hallam's disappearance is dubious – he fled to avoid arrest. Furthermore, he is now referred to as a hybrid being, the 'transplant man'. Although this journalistic piece reads like a 'rap sheet', it is reported that NSW police are uncertain as to whether Hallam's United States trip is to avoid arrest or seek new treatment to 'save' his hand.

The piece by McKie and Paton Walsh (2001) that I have already briefly discussed in the previous section, headlined "*Trickster has transplant hand cut off*" was written after a very vigorous (if not one-sided) debate concerning the increasing rejection of the transplant by Clint Hallam's body and its eventual amputation. In terms of *intensity* this report adopts a moral tone of the normative voice of ableist reason, chastising a renegade, uncooperative and disruptive child (the impaired person). The voices of authority, the technicians of expertise, are doctors from the transplant team and the naughty patient is the criminal Clint Hallam. Hallam's criminal story is not just an adjunct to his life story, here in this report it is infused in his very psyche; becoming a core object of Hallam's being. Clint Hallam's body is criminalized – he is a 'trickster', a 'fraudster' and an opportunist not to be trusted. And as such the very legitimacy of Hallam's Voice is not only totally discounted in this piece but is refused the 'right of reply'.

The space given to the doctor's 'gaze', his capacity to make powerful exhortations, as 'truth' are insightful. French philosopher Michel Foucault suggests that the 'gaze' of the medical expertise is not confined to that of merely looking or observing, but rather the 'gaze' is calculating making possible the assessment of risk and chance (Foucault, 1975: 89). Dr Nadey Hakim can say without risk of criticism, that his technological performance of amputation is conditional not only on the utter docility and compliance of Hallam, but on the basis of a panoptical surveillance of his criminalized soul. The 'space' given by the media reports to the oppressive speech acts of the medical 'gaze' already condemns to 'death' a man named Clint Hallam whose re-constructed 'story' it *thinks* it knows. The ethically unsayable becomes legitimate in the 'voice' of the knowing expert:

> Hakim revealed he had carried out the amputation on the condition that his patient – *a convicted fraudster- agreed not to speak* to the press to earn money from his story. 'I asked for the telephone to be removed from his hospital room,' said Hakim (emphasis added) (McKie and Paton Walsh, 2001).

This statement is framed by the reporter's unsubstantiated comments that Hallam stopped taking the immuno-suppressant drugs and being an unruly fellow, 'demanded' amputation. After Hakim's conditions, almost in order to reinforce the criminalized body, the piece continues its foray into the alleged criminal activities, both past and present of Hallam. Although acknowledging that the "cosmetic miracle … had all the attraction of a Frankenstein reject", McKie and Paton Walsh still lay blame for the 'failure' of the transplant at the feet of Hallam himself. The last word is given to the transplant surgeons who argue, "… this unpleasant status was the fault of Hallam himself …". The reporters agree, pointing out that another six transplants have taken place and "… all are *performing* perfectly (emphasis added)".

Before closing this section I want to make some comments about the use of the metaphor 'trick' or 'trickster' that appears either in covert or overt form in the print media coverage. Earlier in this case study I referred to the fact that the ‘amputee body’ has to be ‘tricked’ into accepting the colonizing transplant; which is where immuno suppressant drugs take on the role of actors in this network of association. As part of the task of deconstructing the nexus between media reports, technological practices and biomedicine, I want to pause and look at this metaphor of the ‘trick’ more closely, albeit briefly. If the concept of ‘informed choice’ is critical, then it seems reasonable that critical discourse should not just focus on the ‘miracle’ of the transplant, but also on the other parts of the compulsory package – such as the anti-rejection drugs. Print media discussion should have focused on issues such as the side effects and management of life-long drug taking as well as matters of cost and the investment of the pharmaceutical industry as a dominant actor in this saga. Furthermore, within this dialogue, technologies of transplant should not necessarily be seen as *inherently good*.

We could say that it was *Clint Hallam* and not ‘the public’, the doctors or the media who was ‘tricked’. Discourses that adopt the optimism of technology say little about the meaning/reality of ‘cure’, ‘perfection’ and ‘restoration’. What is absent from discussion is a critical perspective about the ‘good life’ of being disabled, in distinction from being ‘sick’ and the preferability of ableism (or at least a morphed ableism). We could say that Hallam and others who submit to experimental and potentially dangerous, so-called ‘restorative surgeries’, have been ‘tricked’ by the power of ableism. The media reportage in alliance with the medical surgical team, suggest that it was Clint Hallam who acted in ‘bad faith’ – who became a ‘trickster’. I would suggest otherwise, maybe we need to ask ‘who’s tricking whom’? Certainly the press has not provided the public with a balanced perspective on the ethics of technologies and their convergence with technologies of normalization.

'Biting the hand that feeds you" – Clint rejects his 'gift'

> It is longer than his other hand; a 30cm section sawn from a French motorcyclist that does not fit where it meets Hallam's arm. It is wider, attached to its host by a broad flange of scar tissue. The flesh is pink, whereas Hallam's is tanned. The outer layer of skin is flaking off; whereas Hallam's is hairy and healthy … There are leathery light-brown patches where there should be fingernails and ominous red dots where the hand is being rejected. (Whittell, 2000: 4).

This section will examine the price of Clint Hallam's non-compliance with the techno-practices of 'new' transplant technologies and the way Hallam's refusal is mediated within media discourses through the usages of concepts such as 'harm' and blame'. The tenets of *biomedical realism*[320] ensure that when assessing for morally heinous 'harms', the kinds of 'harms' be spoken of are restricted to the purview of the biological and ensuing *medicalisation* of life. As such, surgical ventures and technological practices are geared towards 'fixing' the so-called 'biological problem', whilst ignoring the socio-environmental dimensions and potentially disastrous consequences of the 'fabricated' fix.

Two media articles report that Clint Hallam was forced to keep his 'new' hand covered at all times in a glove to avoid the stare of strangers and the terror and screams of children (Middap, 2000: 31; Whittell, 2000: 4). This reaction of repulsion towards Clint's hybridity it not restricted to strangers but also extends to his friends[321]. As a consequence, Clint speaks of becoming steadily 'mentally detached' and feeling "more handicapped than before" (BBC News, 2001). Dominant media discourse did not take up the opportunity to consider the kinds of *ontological harm* that could occur, and in fact did occur, in the instance of Clint's hand transplant. The ontological harms if stated within various report are more or less contained and de-legitimised. The *BBC News* provides

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[320] I am using the definition taken from Jerome Bickenbach: "… the view that the entities described in a biomedical explanation have a real, substantial, and objective existence wholly independent of any social environment" (1993: 65).

[321] In a BBC documentary Clint talks of his best friend refusing to shake his hand. 'Superhuman', Episode 2, 2000.

testimony that Hallam's feelings were totally erased and overridden: "… [Hallam's] request [for an amputation] was turned down by the French doctor who led the team on the grounds that the body was inviolable under French law".

What then of other 'harms'? Media commentary has given some space to what I term Hallam's *functional 'harms'*. The compulsory anti-rejection medication according to two surveyed media reports caused Clint Hallam significant physical and emotional injury: "…The drugs have side effects that include diabetes, chronic diarrhoea and a weakened immune system" (BBC News, 2001), and not putting too fine a point on it, Hallam says " … [the] diarrhoea … can make him shed 2kg a day" (Middap, 2000). In terms of activities of daily living, Clint Hallam experienced burning pain and limited movement, making tasks typically performed by the hand difficult, if not impossible (Whittell, 2000).

Harms of an ontological or functional nature play second fiddle to the 'harm' experienced by the transplant team of surgeons. Two headlines capture this alleged harm well: "*Clint hands gift back to doctors*" (Melbourne *Herald Sun*) and "*Hand Transplant surgeon says he was used*" (AAP/Ninemsn, 2001; Smith, 2001). Hallam's troubles, many reports suggest, were due to Hallam's disregard of the proper treatment and not " … behav[ing] the way we [the surgical team] were hoping he would behave" (BBC News, 2001). French surgeon Dr Jean-Michel Dubernard was more harsh in his criticism "we were all used, the surgeons and psychiatrists … he (Hallam) played on our emotions" (AAP/Ninemsn, 2001). Giles Whittell (2000: 5) is the lone voice in suggesting that maybe the panic about the amputation was less about 'harm' to the doctors and more about "…preserv[ing] their entry in the annals of surgical history". What I have been attempting to do in this section is to foreground the enduring hegemony of experts, in this case the medical apparatus and show the way media reportage has been mobilized to ensure the buoyancy of the medical – technocratic ableist dream. In the process of such one-sided reporting the experience and insights of Clint Hallam himself were not generally addressed and were consistently erased.

6.3.3 'Wasted Days and Wasted Nights'[322] - Is a Hand Handy to Have?

This section is an attempt to document and understand the processes by which the saga of the world's first hand-forearm transplant has been represented by the medical apparatus and mediated uncritically within print media discourses. I have discussed the ways that contestations over plans for a 'hand' transplant have (not) been handled. In addition, this piece has tried to make connections between the criminalisation of Clint Hallam's body in accounts of the 'failure' of the transplant and the problematic concept of 'harm'. The text also points to ways *artefact stabilisation* occurs when various actors are mobilized to enact forms of closure and recuperation of techno-medical practices. The final portion of this section examines outstanding issues, in other words, what has been left unsaid.

The Clint Hallam saga presented the media with a clear opportunity to deconstruct not only the knowledge-power relations of the medicalisation of life, but also the practices and ethics of transplants *per se*. Nowhere is there any discussion of the meaning of a 'transplant' strategy. Surely there is room to elicit a vigorous debate from a variety of actors in the community, including social science academics, transplant recipients, ethicists and disabled people in general. In an age of increasing geneticisation of human life and various enhancement technologies, the emerging 'transplant culture' already has

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[322] This is the title of a proposed book by Clint Hallam.

a sacrosanct status. Any critique of this culture is usually consigned to the 'backward thinking' of religious conscientious objectors[323].

There needs to be serious ethical debates about the increased commodification of body parts. I was interested as part of my research, to observe the way the 'donor hand' was put into speech. The hand was often talked about as an isolated object, with no agency or linkage, in any real sense with the donor as an expired human being. This conundrum meant that the question of who 'owned/possessed' the hand was left unresolved and bitterly contested.

At the level of formations about human subjectivity, a silent sub-text never really addressed, except by Clint on the odd occasion, is the interface between technological practices and the production of 'nearly abled' persons. It became obvious in the various speech acts of the doctors and Clint that there is considerable ontological confusion about what Clint Hallam (and other recipients) have (ontologically) become post-transplant. Are these people expected to have a 'self' that adopts a normative subject position (able-bodied) or are they seen as not-quite-there-yet, 'nearly-abled' or a hybrid being – the 'transplant man' (or woman)? What does all this confusion suggest about the politics of 'ableism', and by default 'disability'? Is 'disability' such a personal tragedy that impaired people are morally obliged to adopt an uncertain morphing technological practice, because the 'normalized' body is seen as the *most preferable option*? These kinds of questions are many and complex, the type that could be the substance of investigative reporting. At the end of the day Clint may well ponder the question 'is a hand handy to have'?. We can be less certain of his answer. In any case, as Giles Whittell points out "Hallam's life does not depend on his hand, and even without it he water-skied and rode

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[323] I am referring here to Jehovah's Witnesses and people of Jewish faith who do not believe in transplants.

a motorbike… [Hallam warns] … of the dangers of pinning one's hopes on other people's limbs" (Whittell, 2000, 5). The saga of Clint Hallam's wayward hand begs the question as to how 'experimental', medically 'birthed' technologies (devices) are sold (marketed) to a target group, i.e. people with disabilities. The next section is a case study about the development and rhetorical investments made necessary to sell the cochlear implant to government, the public and lastly, deaf people.

6.4 Selling the Cochlear Implant

> Medical technology has become the measure of all things; a kind of *ars mensura*. It has become the *technê matriké* of the modern age, the measure of what is good and bad, what is to be treated and not, and hence, what is diseased and what is not. This can be entitled the *technological invention of disease*. (Hofmann, 2001: 17-18).

> A great deal of medicine's general "technological dynamic" … can be understood in terms of the articulation of [a] common interest between medical and surgical specialties on the one hand and their industrial suppliers on the other … patients are typically not seen as competent interlocutors in the innovation process. (Blume, 1997: 32).

> Cochlear implants remind me, more than anything else, of sex-change surgery. Are transsexuals really members of their chosen sex? Well, they look like that other sex, take on the roles of that other sex and so on, but they do not have all those internal workings of the other sex, and cannot create children in the organic fashion of members of the chosen sex. Cochlear implants do not allow you to hear, but rather to do something that looks like hearing. They give you a process that is (sometimes) rich in information and (usually) free of music. They make the hearing world easier, but they do not give you hearing. What they give you has value, so long as you know in advance what that is. (Solomon, 1994: 14).

The three epigrams selected to open this section act as markers, key stopping and discernment points into a highly polarized techno-social debate about the crafting and using of a particular artefact. But before picking up our travel packs for the journey, for the *conversation,* it is useful to take pause and draw out the 'gems' contained in the quotations that become threads woven into the following narrative. Biotechnologies enact, to use Hofmann's (2001) language, a *technê matriké* inaugurating a constitutional binary of 'this' and 'that', 'what is' and 'what isn't'. From another angle, such versions of constitutionality shape and ultimately seek to enforce certain *moral landscapes* of reading difference and cultural ordering. Another gem worth taking on board is that whilst the theme of this section may well be described in terms of ontological contestations, my analysis also points to sites of *converging interests* between apparatuses of medicine, law and commerce. Concomitantly Solomon (1994) provides the reader with some sizzling metaphors, more importantly he reminds us that the tale of the cochlear implant is primarily about *ontological transitions* and tussles over the locus of power.

This section is a story, a story about the incubation and birth of an artefact that its designers argue creates or mimics 'sound'. The device is known as a *cochlear implant* (hereafter referred to as CI). It is also a story about persuasion, the transmogrification of an experimental and rather novel 'hearing device' into a *bona -fide* curative solution to the 'problem' of profound 'deafness'. It is also a story of culture (wars) and therefore ostensibly about ontologies – those privileged and those outlawed and the ways competing being-ness and rhetorical positioning are fashioned through either *etic* and *emic* lens[324] (Clifton, 1968; Freire, 1970). As part of the storytelling I am interested in examining the *conditions* of the implant's production, the kinds of *commitments* invoked in product development and the processes of *bandwagoning* that led to the creation of a cochlear implant *black box*[325]. I conclude that the 'successful' normalisation of the cochlear implant is due not just to the obtainment of inter-organizational networks of 'relevant' social groups but was made possible through a deferment to, harnessing of negative ontologies of Deafness[326] (and disability). Instead the deployment of the

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[324] In examining constructions of identity, the concepts of *emic* and *etic* are useful. An emic perspective refers to views of the 'insider' group whilst an etic perspective by observers outside of the group being studied. Suffice to say most scholarship about disability is based on an etic positioning.

[325] A *blackbox* can be described as a tool kit of knowledges, devices, plans and rationalisations.

[326] In line with established conventions I refer to Deaf to refer to people who identify with the Deaf community, language and culture, in distinction from *audiological deafness* represented by a lower case 'd'.

inherent preferability of 'hearing' as social capital was invoked. In this way, I argue that technologies of cochlear implantation, by being promoted as a technology of 'treatability' in effect produce agreements and foreclose discussion on understandings of deafness and hearingness, aberrancy and normalcy. My discussion is divided into two parts. The first looks at the development of CI as morphed hearing. Part two moves to a discussion of critical ontological concerns that feature as subtexts in the rhetoric of deafness and cochlear implantation.

6.4.1 Working on a Doable Problem: The Evolution and Acceptance of the Cochlear Implant

CI's are touted by the popular press and the flashy brochures of manufacturers as providing the 'miracle of hearing', as resembling a 'bionic ear'. This is despite the fact that both audiologists and otologists alike regard children with cochlear implants as remaining "severely hearing impaired" [sic] (Boothroyd, 1993; Horn et al., 1991). In the following discussion we will examine how this rhetorical situation came to be, how the CI was transformed from a dubious experimental device to an established, celebrated developing technology. It was Jean-Marc Gaspard Itard (1774 – 1838), a doctor at the Paris Institute for the Deaf who developed in 1808 a medical formulation of deafness after the investigation of a "mute" student named Lefebvre. Nicholas Mirzoeff (1995: 56) provides a pithy summary of Itard's criteria for diagnosis:

> If the patient showed signs of improvement in understanding and intelligence, the disease was simply deafness; if not deafness compounded with idiocy. Diagnosis thus depended upon the results of treatment, not upon the invisible and unmeasurable deficiency of hearing it was supposed to correct.

Now that a definition and diagnosis of 'deafness' was possible all that was needed was a 'cure', Itard had his life's work cut out (no pun intended) for him[327]. The CI can be

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[327] Itard was understood to have used injections, astringents, electricity and hot irons to "unblock" deafness. See Lane (1992a: 212 - 213) for an outline of these "treatments".

understood as a modern descendant of this search for a cure. The first direct stimulation of the auditory nerve was carried out by Lundberg in 1950 and improved by ontologist Charles Eyries and medical physicist Djourno in Paris in 1957 after a desperate request by a deaf man for some hearing (Clark and Tong, 2000; Djourno and Eyries, 1957). Stuart Blume (1997) provides a worthy synopsis of the history of CI development that I do not intend to duplicate herein; rather I will detail key points of technological emergence. The period from the 1960's from the development of the multi-channel CI William House prototype until the late 1970's can be characterized as *experimental,* ambiguous and somewhat controversial (Blume, 1994; Blume, 1997; House, 1995). It was only with the surgical implantation in 1978 by Australian otologist Graeme Clark[328] and throughout the 1980's that CI's were understood as a useful *therapeutic artefact* thereby gaining credibility amongst otological peers (Clark, 1987; Clark and Tong, 2000; Epstein, 1989). Since that period, to the release in 2000 of the *ESPrit 3G*™, a behind the ear processor by Cochlear Limited, the development of what I term 'morphed hearing' transplants has been *multidirectional* alternating between single and multiple electrodes, invasive and non-invasive prototypes (see Figure 10).

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[328] Like Alexander Bell, Graeme Clark's 'motivation' to develop a 'solution' to deafness was due in part to his experiences with a deaf father. Both Bell and Clarke conceptualised deafness as a world of silence and horrendous isolation (Bruce, 1974; Clark, 2000; Mackay, 1997).

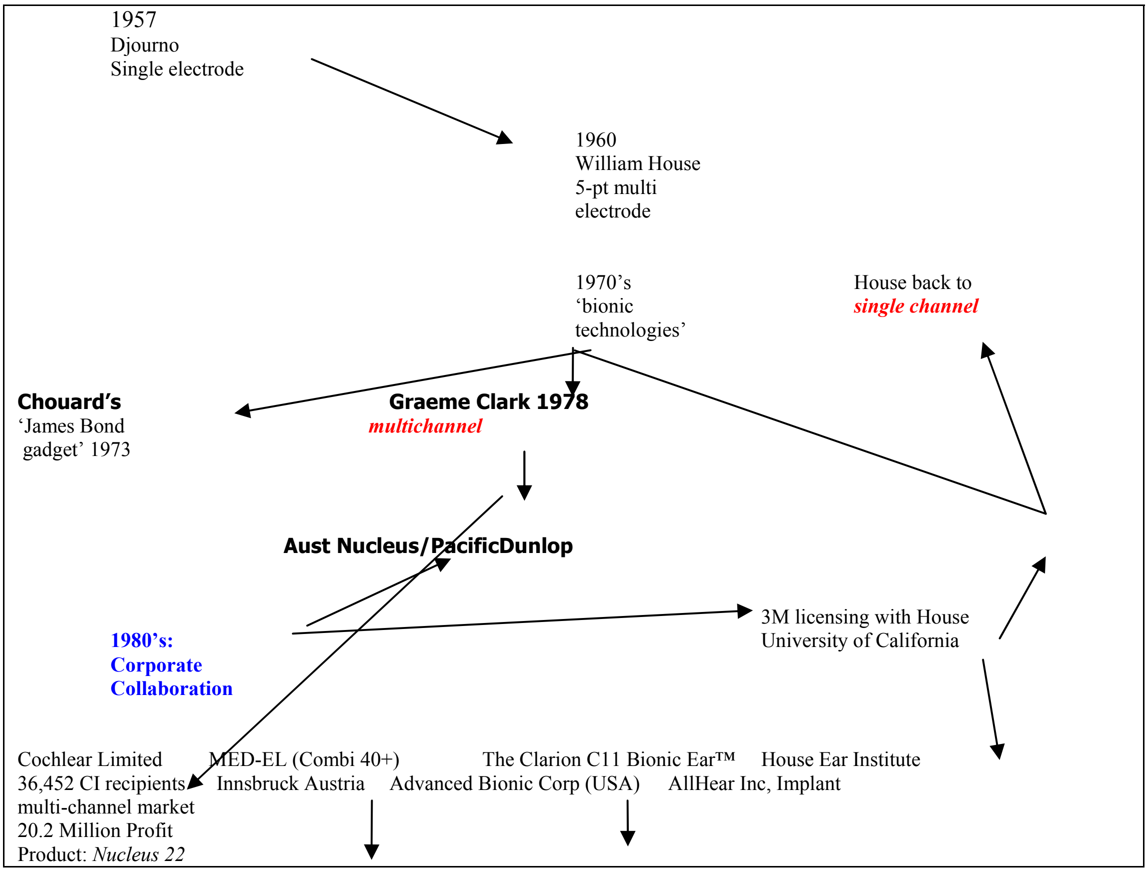

Figure 10: Multidirectional View of the Development of Morphed Hearing Implants

I now turn to the work of Clarke and Fujimura (1992a), for assistance in identifying what needs to be studied to create a "roadmap" for our inquiry. Their schema for studying scientific work of CI is instructive:

> *Everything in the situation*, broadly conceived: who is doing it and how is the work organized; what is constructed as necessary to do the work; who cares about the work (in the pragmatist and philosophical sense); sources of sponsorship and support both locally and elsewhere; what are the intended products, and for which consumers or users; what happens to the products after they are sent out of the door into the user workplaces; and last … what interpretations do participating actors construct over the course of the work. (Clarke and Fujimura, 1992a: 5)

Pinch and Bijker (1987) provide a slightly different, but complimentary process. Using modelling based on a Social Construction of Technology (SCOT) methodology, they formulate a *multidirectional approach* to technological development by mapping four key areas, namely, artefact, social group, problem and solution. Combining these two approaches not only provides a rich source of information but also will help in the mapping of broad networks of association across many social worlds.

One of the most striking features of the multidirectional development of CI's is the lack of artefact stabilization, i.e. the switching from single to multi-channel electrodes and back, the regional diversification of key stakeholders, and the non-linearity of product development. Nonetheless the project of building a 'hearing device' was viewed by scientists and technicians as doable from the start. According to Joan Fujimura "the construction of a doable problem is the process of solving a problem from the beginning to the end. … Doable problems are sociotechnical achievements" (1996: 10). Yet the doability inscribed to the scientific work, occurs *ex post facto*, after the 'solution' to describe and mask developmental problems.

Arguing from a different perspective, Hesslow (1993) suggests that technological treatability (in this case the CI) constitutes the 'disease' i.e. formulations of deafness and hearingness. He concludes: " it is not really the presence of a disease that is crucial, but the fact that some medical intervention may be beneficial and that it is within the physician's power to help the patient" (Hesslow, 1993: 7). In other words, technologies of 'treatability' engage in a circular logic with the agency of the artefact folding back onto the potential recipient who is then figured as diseased or deficient. i.e. the possibility of 'curing' deafness means that Deafness needs and must be 'cured'.

Description of the C.I. as a product

Around 1,000 Australian adults and children use a cochlear implant and this estimate according to the *Cooperative Research Centre for Cochlear Implant and Hearing Aid Innovation* (CRC, for short) represents only 5% of potential users (Cooperative Research Centre for Cochlear Implant and Hearing Aid Innovation, 2001)[329]. A cochlear implant is a form of instrumentation that directly stimulates the cochlea and purports to "elicit patterns of nerve activity that mimic those of a *normal* [sic] ear for a wide range of sounds …today's devices enable about *10 percent* of those implanted to communicate without lip reading and the vast majority to communicate fluently when sound is combined with lip reading" (Eddington and Pierschalla, 1994 – my emphasis) (See Figure 11).

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Figure 11: Interior View of Implant. Source: (Eddington and Pierschalla, 1994)

The device is made up of five components: The electrode array (which is inserted into the inner ear); a receiver; a speech processor that is usually worn by the user and a transmitter coil and microphone that are worn behind the ear (Figure 12).

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[329] This figure represents to 'tip of the iceberg' is terms of potential users. The annual reports of CI producers reiterate to stockholders that the market reach has been barely exhausted arguing significantly larger market exists that is yet to be captured.

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Figure 12: The Internal Component of the Cochlear Implant
Source: http:www.medoto.unimelb.edu.au/cic/implant1.htm

Lane provides a precise description of the three to four hours surgery required to insert the implant:

> …The surgeon cuts the skin behind the ear, raises the flap, and drills a hole in the bone. Then a wire carrying electrodes is pushed some 25 mm into the coiled inner ear. The tiny endings of the auditory nerve are destroyed and electrical fields from the wire stimulate the auditory nerve directly. A small receiver coil connected to the wire is sutured to the skill and the skin is sewn over it. [See Figure 13]. A small microphone worn on an ear piece picks up sound and sends signals to a processor worn on a belt … The processor sends electrical signals back to the implanted receiver via a transmitter mounted behind the ear, and those signals stimulate the auditory nerve (Lane et al., 1996: 388).

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Figure 13: A) The Receiver-Stimulator Device in Place. B) The fascial flaps sutured in place over the implanted receiver-stimulator device

Source: http://www.medoto.unimelb.edu.au/info/history3.htm

What is rarely mentioned in literature produced by exponents of the CI is that creation of 'sound' occurs at the expense of any residual 'hearing' during the surgical implantation of long electrode CI's in the recipient (Bogies et al., 1989; Wrigley, 1996). This kind of destruction represents a point of significant divergence from traditional hearing 'aids'.

The nature of the artefact – "what is it meant to do?"

Representations about the nature of CI have not only shifted since the early prototypes of the 1950's they reveal contestations over the 'purpose' and outputs of such devices and their reception within various socio-medical contexts. CI's have moved from being figured as Experimental – as an Established device – to a Developing Technology. So what professions are engaged in research and development (R & D) and how has the work been organized? The key players have been otologists working in conjunction with biotechnology corporations. In addition, alongside these players are various fundraising/education bodies funded either by the corporations or in an adjunct relationship[330]. As we will see later, a vast inter-organizational network of association has converged around this emergent technology in order to authenticate and entrench CI's future. Whilst the work was originally (especially in the 'experimental' phase) conducted by various universities today it is situated with the context of high technology specialized companies spanning various global networks.

The CI industry is dominated by two major players, the North American corporation, Advanced Bionics[331] (AB) who manufacture the *Clarion* range of implants and the

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[330] Alfred Mann Foundation http://www.aemf.org/; The Bionic Ear Institute, to name a few.

[331] Advanced Bionics was founded in 1993 to manufacture and distribute the CLARION CI.. Advanced Bionics evolved from two other highly successful companies that developed and marketed medical devices, such as pacemakers and micro-infusion systems (miniature drug delivery pumps used in the treatment of diabetes). The Clarion System was based on work of the research laboratory of the University of California at San Francisco conducted by Alfred Mann. Mann entered into a License Agreement with the University in 1988 for the right to make, use and sell the inventions of the University developed over the previous 15 years. Thereafter, a small team of engineers and scientists began to develop the device in the Alfred Mann Foundation for Scientific Research, as well as MiniMed Technologies, Limited, the predecessor of Advanced Bionics.

Australian multinational Cochlear Limited (COH) who produce and market the *Nucleus* implantation system[332]. Minor players include AllHear Inc which manufacturers a single electrode CI in the tradition of the work of William House[333] and an Innsbruck (Austria) based company MED-EL which manufactures a 'thin' high speech multi-channel CI known as the *COMBI 40* system.

Whilst most of the manufacturers of CI's appear to have adopted a relatively cautious approach to terminology describing the outputs of CI hardware, the rhetorical and fundraising arms of such ventures aren't so restrained – they represent CI's as "miracles of hearing" or machines that enable an adult or child "to hear because of a bionic ear"[334]. Another variation to this theme is the expression that CI's produce "useful hearing sensations" (Cochlear Implant Clinic, 2000). Concomitantly, corporation logos provide interesting examples of imaging and iconic representation. The Cochlear Limited web page opens with the following logo:

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Home Logo of Cochlear Limited Web Page.
Source: http://www.cochlear.com.au

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[332] There are currently two CI systems made by Cochlear Limited: the Nucleus® 22 system uses the CI22M implant and the Spectra 22 speech processor. This system has been available worldwide since 1984. In 1997, the Nucleus® 24 was released and offers the choice of a body level (the SPrint^{TM}) and an ear level (the ESPrit^{TM}) speech processor with its CI24M implant.

[333] AllHear Inc is a company that designs, manufactures and sells cochlear implants. The company was founded by Dr. William F. House who produced the first practical cochlear implant in 1984 in conjunction with the House Ear Institute and the 3M Corporation. The CI of AllHear, Inc. is unique among the current crop of implants because it uses a short, single electrode which apparently does not destroy natural or residual hearing. AllHear's cochlear implants are not yet approved by the FDA for general sale in the United States. See House (1995).

[334] See the claims of the Bionic Ear Institute.

An earlier edition (April 2002) of the Advanced Bionics web page advertised in graphic form the following jingo: “More Sound Better Hearing. Imagine the Possibilities”.

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Advanced Bionics: About Us
Source: http://www.bionicear.com/aboutus/aboutus.html (accessed 29/4/02)

The October 2002 edition of the page no longer includes this representation. Are these shifts and changes merely a sign of regional and contextual variations or is something more rhetorically significant happening here? I am in agreement with Blume who observes that there is a wide gulf between “the extravagant claims by media [or marketing flyers and] the rather more modest claims made in professional periodicals” (1997: 44.) Our analysis needs to take Blume’s observation’s one step further and examine the kinds of constructions of CI’s that are being used in order to justify, legitimate and carry out scientific research, product development and sales of CI. Whilst COH still speak of “bring[ing] the gift of hearing to every child and adult who can benefit”, in the same breath when referring to the device terms of functionality; the representation is discursively manoeuvred to become a “stimulation is designed to allow individuals with severe to profound hearing loss to perceive sound” (Cochlear Limited, 2002).

The subtext of this manoeuvre provides fertile ground for bigger philosophical battle over the nature and representation of ‘sound’, ‘hearing’ and by default ‘deafness’. If ‘hearing’ became an explosive term – how is ‘that’ which is produced by the CI to be framed? – but as ‘sound’ of course is the rejoinder, the discernment and perception of complex sounds (Cochlear Limited, 2000: 2; Wrigley, 1996: 208). We may well ask whether ‘sound’ and ‘hearing’ is one and the same thing? According to House (1995) they are:

> Implants provide access to sound, do they not? To say no is to engage in a semantic dispute which begins in words and ends in words, and which has no pragmatic consequence. Come, let us admit the matter until we have some useful reason to deny it: implants provide access to sound …For those who would quibble, the phrase might be more accurately rendered as "implants provide a stimulus which is interpreted as sound," but my point is that a functionally significant difference has never been proven (House, 1995).

A more nuanced interpretation is provided by Timothy Reagan (2002: 55) who suggests that “implants do not restore hearing; rather they create the perception of sound”. This perspective is supported by a group of CI users who articulate the outcome of CI in the following terms: “[CI’s] do not provide normal hearing – they provide an improvement in the use of sound” (Cochlear Implant Association Inc, 1997). Nevertheless, what is meant by ‘sound’ and what are the conditions of its interpretation? Is what is being referred to a matter of degree (and quality) of audiological inputs, i.e. a strictly medical delineation or does ‘sound’ denote and elicit a more cultural nuance, a qualitative aspect of subjectivity that interfaces and mediates a world obsessed with oralist interactivity[335]. Does such a concept of ‘cultural sound’ provide space for a Deaf person to ‘see a voice’[336]. Certainly biomedical perspectives have shaped and dominated this debate (actually there has not really been a “debate”) to the exclusion of issues raised by the Deaf community (culturalists) and have made it ‘safe’ (at least within academic cohorts) to acknowledge the provisional dimension of CI ‘sound’. As Arthur Boothroyd suggests

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[335] In 1880 the International Congress of Educators of the Deaf in held in Milan marked the turning point in framing sound and its relationship to communication in narrow terms. At this meeting the use of sign language in schools was officially banned.

[336] Two books in fact convey this very sentiment in their titles. See Ree (1999) and Sacks (1989).

> the immediate purpose of hearing aids, tactile aids, cochlear implants, and visual aids is to enhance sensory evidence. This point cannot be emphasized strongly enough. Prosthetic assistance does not directly change the perceiver's knowledge or skills. It may do so eventually, in combination with training, maturation, and experience, but its immediate effect is at the sensory level (1991).

Similarly, Thomas Balkany acknowledges that such "hear[ing] does not approximate that of normal subjects" (cited in Cherney, 1999: 29). Overall, many questions remain unanswered about the benefits and efficacy of CI's suffice to say that evaluations overall report poor performance and little understanding of 'sound' variability across patients. Dr Robert Shannon of the House Ear Institute in Los Angeles has the last word on this matter:

> I think we are at the stage in cochlear implants at present which is analogous to getting a pair of glasses, except that, in the cochlear implants, we give everybody the same set of glasses. Although that works pretty well for some people; for others, those glasses aren't well suited for this kind of vision problem…(Shannon, 1999).

For the public the representation of the 'success' of CI's is less provisional. CI's are touted as a technology of possibilities (… made real).

Networks of Interest

For the CI to become viable in terms of market reach and credibility the product developers (otologists and corporations) needed and continue to need to enrol many allies to support their project. These networks of interest in their connectivity perform and configure ontologies of deafness and hearingness. The achievement of consensus about the merits and efficacy of CI's is necessary to make the project continually doable (especially as the target group for the device grows broader). Consensus is required amongst otologists about the reliability and design of the technology and further consensus is required about product justification, which is the necessity in the first place to 'cure' deafness thereby making the enterprise a form of ethically valid work.

CI's networks of interest have moved beyond the containment of the audiological industry and developers have actively solicited the interests of a broader cross-section of society who they have deemed may 'care' about the work. I argue that this elastic and broad enrolment is the key to the rise of the hegemonic status of CI as a 'cure' for deafness. Other allies to 'care' are obvious: educationalists, speech therapists and the 'cure' industry in general, whilst some actors such as multinational companies and governments emerged by necessity. In the case of companies, CI's are big business (more on that point later); whilst governments have been enrolled to potentially defuse concerns about cost containment and funding (Blume, 1997).

Increasingly as competition beefs up amongst the two largest CI producers, the rhetoric underpinning these networks of interest is taking on a nationalistic tone. This turn to nationalism reflects the changed context in which the discourses of science and technology are produced in a fluid market economy. As Cohen et al (2001: 146) points out there is a view that

> … sees the purpose of scientific endeavour as the generation of national prosperity and the improvement of quality of life … publicly funded research should take its lead from industry … to ensure that its work addresses real problems, thus benefiting industry and (by extension) the country as a whole.

Two recent news stories come to mind to support this assertion. The first relates to a report in March 2002 about a Deaf same-sex couple in the United States[337] who used assisted conception to conceive a Deaf child. The Australian press could not report this story without reference to the impact this choice [of donor] had on the shares of Cochlear Limited should Deaf Australians dare consider this option (Griffith, 2002a; Griffith, 2002b)! CI's have become it seems integral to Australia's GNP! The other story also

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[337] For a further discussion of this story see: (Anstey, 2002; Hays, 2002; Levy, 2002; McLellan, 2002; Spriggs, 2002; Young, 2002).

from America (July 2002) concerned the link between the use of CI's and the risks of contracting meningitis. COH went to great lengths to distance themselves from the US story suggesting that consumers should buy the superior Australian product[338]. Professor Graeme Clarke in one story was reported as saying "I am concerned that what has been a wonderful thing for so many deaf people [has been] tarnished by a company that has actually designed something incorrectly" (Infolink, 2002). Many Deaf people report a hesitancy to criticize CI's because to do so would be to criticize the work of Professor Graeme Clarke and bear the allegation of being pronounced un-Australian.

"Would the real deaf stand up?": Battles over target groups

It would not be possible given concerns about the efficacy of CI for this device to be trumped as a technological miracle had not the carriage of the CI been accompanied by trading in negative symbols of disability and deafness in particular. An *etic* framework of deafness assumes a life of tragedy and silence. As Robert Crouch (1997: 14 - 15) puts it

> According to many among the hearing, the life of a deaf person is a priori an unfortunate and pitiful life, and is considered by some to be a full scale tragedy. The hearing parents of the deaf child, themselves members of hearing society …will naturally turn to the medical community in the hope that their child's disability will be 'fixed'.

In other words, the aim of CI's is to simulate (fabricate) 'hearing' in order to facilitate the assimilation of deaf individuals into the dominant hearing world and thereby ensuring the deafened become productive citizens. The original target population for CI's was post lingually deafened adults aged eighteen and over[339]. However, the uptake from this group was slow. One explanation for this was that Deaf communities were not involved

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[338] Cochlear limited shares plummeted 7.5% ($27) when to story broke only to surge five days later (to $33.40) when its' rival, Advanced Bionics, withdrew their product.

[339] The U.S; Food and Drug Administration (FDA) approved the first 3M/House device for adults in October 1984.

or consulted in the processes of product development. ‘Hearing’ designers simply assumed that Deaf adults would have nothing to contribute to the CI prototype or understanding of deafness and would willingly accept such technological gifts with open arms (Blume, 1994; 1997; Reagan, 2002).

Despite vehement opposition from a large number of otologists and neurophysiologists to implantation of pre lingually deaf children over the decade of the 1980’s CI’s steadily became normalized and thus accepted (Bertling, 1994; Blume, 1994; Carver, 1990; Crouch, 1997; Horn et al., 1991; Lane and Grodin, 1997). This broadening acceptance and increased target group purview does not however mean that CI candidacy is an ‘open affair’. Candidacy is for reasons that will become clear, strictly policed.

Although the dominant rhetoric invoked by manufacturer focuses on the scientific and outstanding capacities of CI’s as a therapeutic artefact, when it come to the actual usage of CI’s this rhetoric ‘thins out’ and transmogrifies into an emphasis on the burden of ‘success’ of the technology falling squarely on the recipient. In the case study on Clint Hallam in section 6.3 we have became aware that this shift of the burden of responsibility to the patient when using *tentative technologies* becomes useful should the technology ‘fail’ in any way. Acceptance into a programme requires the candidate (and their families) to be motivated, productive and compliant with the therapeutic regime installed as part of the implantation package. As Wrigley (1996: 211) argues the promises of the CI are based on a process of continual deferment where the candidate “need[s] to sacrifice immediate needs for the possibilities held out for the greater good”. Crouch points to the ‘opportunity costs’ of such a process and suggests that the burden of ‘failure’ extends beyond the CI process itself. He argues that

> the child whose life is centred upon disability and the attempt to overcome it grows up in a context that continually reinforces this disability, despite his or her own best efforts to hear and to speak and despite the diligent work of the educators …These children are therefore always aware that they are outsiders, outsiders attempt to be on the inside (Crouch, 1997: 18).

It is not surprising then that the CI recipient's relationship with the implant can be aptly spoken in terms of a *marital merge* – not just with the artefact[340] but with the corporation. In fact manufacturers to instil a sense of brand loyalty amongst their customers have used this 'lifetime therapy' with the corporation as a marketing tool. The branding and badging of implants has resulted in 'brand wars' amongst recipients posting flames in defence of their brand in various Internet listservs. I will now move into Part two of our discussion and consider critical ontological concerns that feature as subtexts in the rhetoric of deafness and cochlear implantation.

6.4.2 Ontology Wars: Hearing vs. Deafness

The 'hearing world' in general thinks-deafness in the audiological and displays a limited awareness of Deaf culturalist paradigms. For some people a Deaf worldview is so foreign, so subaltern that the following statement by Karen Lloyd from the Australian Association of the Deaf may appear (feel) shocking. Lloyd states:

> to us [Deaf identified people], deafness is a natural part of life, it is something that has always been there and is an integral part of who we are. It is not something we have lost or that needs to be 'cured'. The Deaf community has a rich cultural heritage that revolves around its language, Auslan, and Deaf people who belong to this community enjoy a fulfilling and active social and cultural life (Lloyd, 2001).

This sub-section explores the silencing of Deaf sensibility and the subject of hearingness and the productive citizen.

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[340] Katherine Hayles (1995) remarks that this kind of union constitutes a cyborg in the technical sense.

The silencing of Deaf Sensibility

Like other forms of different bodies considered impaired, the life of deaf people (because of deafness) has been considered one that is *inherently* negative - silent and pitiful. In this view deaf people are not just different but are evaluatively ranked and are considered "at least in a physiological sense, inferior to hearing people" (Reagan, 2002, 45). It is easy then to appreciate that for many hearing parents with a deaf child that they would unquestionably assume that hearing is *objectively preferable* to being deaf. Whilst internationally there have been flourishing Deaf subcultures for centuries, it is only recently that the Deaf community has euphemistically 'come out of the closet'. Dolnick in *The Atlantic* remarks:

> Lately … the deaf community has begun to speak for itself. To the surprise and bewilderment of outsiders, its message is utterly contrary to the wisdom of centuries: deaf people, far from groaning under a heavy yoke, are not handicapped [sic] at all. Deafness is not a disability. Instead, many deaf people now proclaim, they are a subculture like any other. They are simply a linguistic minority [speaking sign language] and are no more in need of a cure than are Haitians or Hispanics (Dolnick, 1993, 302).

Earlier I pointed to the highly developed networks of interest that have converged to legitimate CI's. The Deaf community's entrance into this terrain has been very late and therefore I would proffer that they have been on the 'back foot' in challenging dominant perspectives. As Blume (1997: 51) has pointed out that unlike other marginalized groups, Deaf people have been required to harness allies with legitimated and privileged voices due their own lack of cultural and social capital (credibility). The adoption of counter rhetoric about the cochlear implant has been through engaging articulate academics[341] to put forward alternate viewpoints and well as the use of television documentaries[342].

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[341] (Blume, 1994; 1997; Crouch, 1997; Lane, 1992a; 1997; 1996; Reagan, 1995; 2002; Wrigley, 1996) come to mind.

[342] For example the US Oscar nominated documentary *Sound and Fury* (Weisberg et al.,) and the Australian production *Sound Decisions*. (Kneebone, 2000).

Broader attempts have been made to showcase Deaf culture in the public domain by way of Deaf Festivals of the arts.

Overall, the response by Deaf culturalists has been to view the CI as another emergent technology that represents a cultural invasion where the dominant hearing world seeks to impose their values on a smaller minority culture. In other words whilst CI maybe the newest gadget – as a technology its construction is in keeping with historical genealogies of Deaf subjugation. Deaf activist Paddy Ladd described the implants in terms of "Oralism's Final Solution!" (Ladd, quoted in Blume, 1997: 48). Equally, strong language has been used to describe and deconstruct the technicians engaged in CI production. Invasive medical procedures have been described as a form of child abuse that has robbed the Deaf child of their priceless gift of deafness. George Montgomery (cited in, Cherney, 1999: 28) accused the implants of being "cheerful headchoppers in the Sir Lancelot mould, hell bent on curing deafness an thus committing casual genocide[343] on the deaf community and its language". Wrigley (1996), in rather an understated fashion (quite uncharacteristic of him I must say), summarizes the tension as a clash in *ways of being*, the exclusion of an alternative way of knowing and the meaning given to different kinds of personhood.

Telling about Hearing

As with many forms of asymmetrical relations much of the orientation of the CI/deafness debate has centred on the delimitation of deafness rather than on the deconstruction and problematization of hearing, hearingness and hearingism. Elsewhere in this dissertation

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[343] It is beyond the confines of this work to explore competing discursive interpretations of the concept of genocide. There seems to be an orthodox view of 'genocide' as defined in various United Nations conventions and broader views as articulated by various indigenous and minority cultures. The assertion that CI's represent a genocidal action against the Deaf community is frequently made and has currency within the Deaf community. Indeed earlier in this Chapter (6.2.3) I have argued that some new reproductive technologies could be seen as a form of new eugenics bent at eliminating the existence of disablement.

(Chapter Four) I have made mention of the imbalance and eschewed scholarship in the field of disability research where the epistemological foundations have placed an ableist disposition at the speaking center of discourse. My pedagogical strategy was to propose that we invert this traditional, seemingly 'common sense' gaze and ask what these wars over Deafness tell us about hearingness. My own comments here are provisional as I argue that there is much work to be done in thinking through the various elements – enough to be another dissertation!

Mirzoeff (1995) in his work on the Deaf in sixteenth century Turkey introduces the concept of the 'silent screen' to denote the processes of interactivity between hearing and deaf persons that configures ontologies. In the interaction between 'hearing' people looking at deafness Mirzoeff proposes that Deaf people respond to such voyeurism by subverting[344] or confirming the image produced. This screen/visualization becomes a fabrication, a simulation that does not necessarily bear any resemblances to Deaf subjectivity or hearing subjectivities of deaf people. The conclusion reached by Mirzoeff it that the 'silent screen' is a shifting construction that requires two people to see deafness. Whilst I agree, Mirzoeff neglects to mention is that this 'silent screen' also produces the *seeing of hearing* especially for the hearing subject who can make 'sense' of their sensorial difference. The literature supports this conclusion asserting that the delimitation of deafness could only be achieved within the context of the development of technologies that could visualize/see hearing/sound (Hogan, 1997; Mirzoeff, 1995; Ree, 1999; Sacks, 1989; Sterne, 2001).

I wish to conclude this section with a discussion about the productive citizen. This theme and its significance has already been addressed in Chapter Five in relation to attempts to introduce the concept of ‘elective or voluntary disability’ into law and the semantics of social policy. In its documentation Cochlear Limited continually stress that CI’s will reduce the economic cost of supporting a deaf child as “ benefits may translate into reduced educational costs and increased earnings” (Cochlear Limited, 2000: 12) and even though there has been a paucity of research undertaking a cost benefit analysis of competing options (Newell, 2000). The underlying assumption of this view is that Deaf people are somehow deficient and as adults they do not contribute to civil society and are economically unproductive. This is not the case. What is more worrying about this approach is that there is an implication that a proper citizen is a productive one, that the use value of personhood is conflated with restrictive notions of ‘productivity’.

An etical view of deafness cannot be other than assimilationist geared towards “breeding the deaf out …” or at the minimum pursuing the goal of making deafness acceptable (palatable). Making deafness acceptable through the use of morphing or simulative technologies enables deafness to bear some commodity/use value to hearing society (Crouch, 1997; Wrigley, 1996). The CI performs this role. One of the unintended consequences of that move (to use CI’s) is I argue the creation of hybrids, who are destined to exist in the twilight zone[345] of the hearing and Deaf worlds. This possibility is further explored in the next section of the post human.

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[344] Mirzoeff (1995: 62 - 64) notes that in resisting appropriation of their culture Deaf people have engaged in acts of mimicry – lampoon imagery and conceptualizations.

[345] This phrase was the description used by CI users on a Yahoo group electronic discussion list.

6.5 Whither Impairment? Disabled Bodies Metamorphosed into the Transhuman

> You can increasingly tell the background of a young person by his or her looks and intelligence; if someone doesn't live up to social expectations, he tends to blame bad genetic choices by his parents rather then himself. … Scientists have not dared to produce a full-scale chimera, half human and half ape, though they could; but young people begin to suspect that classmates who do much less well than they do are in fact genetically not fully human. Because, in fact, they aren't … (Fukuyama, 2002: 9)
>
> … there are certain large constraints on being human and we have certain emotions that tell us when we are pressing against those constraints in a dangerous way. This is part of the job that disgust, horror and the sense of the uncanny do; they tell us when we are leaving the human for something else; either downward toward the material, mechanical and bestial, or upward toward the realm of spirit or the world of pure hokum…. (Miller, 1998b: 87).

Consider this possibility: people with disabilities, in the West at least, are living on the cusp of a wide reaching transmogrification - of entering a new plane of embodiment where new technological practices may ‘cure’ their impairment, or at best enable us to morph or simulate ableism (normalcy) and in the not so distant future, leave our bodies via teleportation or cyborghood. The field of post humanism and transhumanism has been alive with activity since the late 1990's. These fields raise a number of concerns in relation to the status and parameters of human impairment and by extension that which is defined as 'disability'.

Concisely, two lines of inquiry will be explored further in this section. Namely, is the evolution of the post human figure/entity a 'way out' of impairment? Indeed, does the adoption of particular kinds of posthumanism by disabled people elevate their status to being suprahuman - a shift from 'deficiency' to being 'hyperendowed'? In other words, what kinds of beingness or to use Heidegger's (1977, Orig, 1953) term of phrase 'enframing', are being produced and how are these figurations accorded value? What transformed notions of productivity and uselessness are being formed? In contrast to these first set of questions exists the second inquiry relates to those matters concerning the 'hiddenness' or unintended consequences of post human technological practices.

Transhumanists argue that their agenda is to 'move on and out of bodies' into another spectrum of beingness, a Promethean animal who is contingently embodied and thus on a negentropic journey. This eschatological vision of enhancement may present dangers to people with impairments, and really be a 'wolf in sheep's clothing', not just in terms of a fabrication of ableness but rather as a *re-encryption* of the binary opposition of the normal and pathological (the deficient, mediocre and mundane). In these strands nothing has really changed, the conceptual schemas and mind maps of ableism remain intact - and the pool of the remnant, the 'have not's' and 'not quite's' grows larger and more diverse.

With all these jumbled questions laid out, this section will explore posthumanism and the production of (dis)ableism. I start with an outline of a selection of technological developments related to 'enhancement' and move into a discussion about the rationality and conceptualisation of posthumanism. The section closes with a consideration of contemporary impacts related to the treatment of impairment and future scenarios.

Simon Cooper (2002), in an essay reviewing Francis Fukuyama's (2002) recent book *Our PostHuman Future*, correctly poses the central ontological, political and conceptual dilemma that has arisen when grappling with the cultural context and impacts of contemporary developments in techno-sciences, namely "how many times can we resolve problems through the technological simulation of embodied processes and still remain human?" (Cooper, 2002, 35). Indeed this quandary represents not a mere philosophical abstraction or a voyage into the world of SC-FI fantasy; rather the matter of representing the ambiguous technocratic 'body' has already arrived. In fact to be precise this body arrived in graphic visual form in the February 1989 issue of *Life* magazine containing an image titled "*Replaceable You*" - a catalogue of replacement body parts (Figure 15).

James Hughes (1995) showcases an up loadable brain chip developed by the INTER Consortium (see Figure 14). Such a chip is made up of matrices into which nerves can grow, and may permit two-way communication between neurons and computers (Agnew and McCreery, 1990; Compston, 1994; Hughes, 1995; Seabrook, 1994).

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Figure 14: The Neural-Computer Chip Interface.
Source: (Hughes, 1995: 8).

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Figure 15: The Replaceable You, *Life* Magazine February 1989

Source: Reproduced in (Balsamo, 1996: 7)

This small sample[346] of techno-scientific developments raises a myriad of questions and challenges the foundations not only of the Judeo-Christian legacy of personhood as having a distinct and inviolable essence but also the Enlightenment concept of atomistic man whose self is transcendental: timeless and universal (Kyle, 1993; Mainzer, 1996; McGrath, 1994; Rae et al., 1994; Solomon, 1988; Strong, 1992). An exemplar of this orientation can be found in the writing of J.S. Mill who in *On Liberty* suggests:

> …among the works of man [sic], which human life is rightly employed in perfecting and beautifying, the first in importance is man himself … Human nature is not a machine to be built after a model, and set to do exactly the work prescribed for it, but a tree, which requires to grow and develop itself on all sides, according to the tendency of the inward forces which make it a living thing (Mill, 1975 (orig.1859): 73).

Although this transcendental belief fosters growth, the 'self' is essentially conceived as intact, in a state of finishedness, having a "universality and necessity in the fundamental modes of human experience" (Solomon, 1988: 7). The reader justifiably might ask about what *degree* of implants or new body parts would constitute a changeover into a 'new' person or another form of species or quasi human? For instance, is the figure represented in *Life* magazine to be considered 'human' and what difference, if any, does it make if the 'foreign body' is machine or organic (human or animal origin)? Fukuyama whilst acknowledging the fluidity and variability of human behaviour concludes that "it is not infinitely so; at a certain point deeply rooted *natural instincts* and patterns of behaviour reassert themselves" (Fukuyama, 2002: 14 - emphasis added).

6.5.1 *Űbermensche* City! Worlds of Transhumanism and Posthumanism

The phenomena referred to today as 'posthumanism' has been developing since the early 1940's but one can identify its antecedents in the world of fiction (Mary's Shelley's

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[346] And there are many others. See the popular press *Scientific American* Special Issue Your Bionic Future Vol 10(3) 1999, *New Scientist* 15 January 2000, *New Scientist* 12 June 1999, N02190.

(1818) *Frankenstein)*, and film (Fritz Lang's (1927) *Metropolis*). Katherine Hayles (1999: 7) provides a three-point trajectory of cybernetic development in the post human. The first period in the 1940's until the 1960's centred on the operational concept of *homeostasis and control* where artefacts performed as servants or protectors of human beings (i.e. robot in the sit-com *Lost in Space*). The second stage throughout the 1960's until the 1980's represent a period of *reflexivity* wherein freedom beyond human control was contemplated and the quest for 'life-like' temptations emerged. The third stage, in the contemporary moment concentrates on *virtuality* and the breaking of the divide between human and machine.

Hayles (1999) notes that the significant point of departure from the other two phases lies in the emergent character of artificial 'life' (A.L) into a realm and beingness that supersedes the control and anticipations of the designer/creator, taking on an identity (or consciousness) of its own. This ontological eruption is brought into sharp relief by Hayles (1999: 11) who indicates that some researchers believe that A.L's. are not "merely models of life but are themselves life". Hayles goes on to argue that this conclusion is philosophically sustainable if one views sentiency in terms of *informationalcy*. On this basis, A.L's "… are life forms because they have the form of life, that is, an informational code. As a result the theoretical bases used to categorize all life undergoes a significant shift" (11). This assertion is supported by Kurzweil (1999b: 60) who uses the hypothetical situation of scanning a person's brain and reconstituting the 'mind file' into a computer medium. Kurzweil asks whether we implicate 'consciousness' in such an entity and in distinction from an actant that simulates consciousness.

Bruno Latour (1999) identifies two versions of the cyborgian/transhuman quest - that which is technophilic, disembodied and masculinist and the alternative incarnational (often feminist) version concerned with embodiment and its zones, shiftings and make up (*à la* Haraway (1990) and Shildrick (1997; 1998). The distance between the two versions creates a map, a front line for a 'war zone' which induces such questions as "what it is to have a democratic body? … what sort of bodies do we wish to have? What sort of bodies is it worth having?" (Latour, 1999: 2) and how do we delimit sentiency?

Fukuyama (2002) additionally identifies three key areas of developments within technoscience that are likely to produce that which is called ‘post human’, namely neuropharmacology, cloning and genetic engineering. Whilst these developments are dispersed amongst scientists and researchers[347] acting in a seemingly disconnected way from other developers of prototypes there is also a growing movement of networks of association amongst philosophers, transhuman apologists, hi-tech cybernetic research companies and individuals willing to 'live out'[348] (experiment with) transhuman transitions. In the following section, I aim to provide a brief sketch of developments as they apply to our broader exploration of sifting through the consequences of transhumanism for the production of disability.

A search on the World Wide Web using the keyword 'post human' uncovers a large array of frontier organizations which could be regarded, if only cursorily considered, as fringe groups celebrating the virtues of posthumanism and transhumanism (both words are often used interchangeably). Whilst purporting a global membership most organizations

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[347] Examples include John Wyatt's computerized eye implant (Associated Press, 1995), Peter Meijer The vOICe™ seeing ear machine (Meijer, 2002) or brain chipping (Maguire and McGee, 1999).

[348] The case professor Kevin Warwick from the cybernetics department of Reading University (UK) who self-implanted a computer chip into the nervous system of himself and his wife Irena comes to mind (Hanlon, 2002). See also the National Library of Medicine (USA) awarded a contract to the University of Colorado Health Sciences Centre in 1991 to create the digital cross-sections of a 39-year old convicted murderer (on death row) who had donated his body to science. This research became the *Visible Human Project*® a creation of complete, anatomically detailed, three-dimensional representations of male and female human bodies. http://www.nlm.nih.gov/research/visible/visible_human.html.

originate in the United States. The oldest is the *Extropy Institute* (Marina del Rey, California) founded by Dr Max More in 1988. A number of prominent technologists such as Dr Marvin Minsky (1988) (Toshiba Professor of Media Arts & Sciences MIT and Ray Kurzweil (1990; 1999a; 1999b) have been engaged as its advisors. The Institute produces a journal '*Extropy*', discussion papers and publishes the *Extropian Principles 3.0, A Transhumanism Declaration* (More, 1999). According to this document extropianism is:

> … a transhumanist philosophy. The Extropian Principles define a specific version or "brand" of transhumanist thinking. Like humanists, transhumanists favour reason, progress, and values centred on our well being rather than on an external religious authority. Transhumanists take humanism further by challenging human limits by means of science and technology combined with critical and creative thinking. We challenge the inevitability of aging and death, and we seek continuing enhancements to our intellectual abilities, our physical capacities, and our emotional development. We see humanity as a transitory stage in the evolutionary development of intelligence. We advocate using science to accelerate our move from human to a transhuman or post human condition. As physicist Freeman Dyson has said: "Humanity looks to me like a magnificent beginning but not the final word." These Principles are not presented as absolute truths or universal values. The Principles codify and express those attitudes and approaches affirmed by those who describe themselves as "Extropian". Extropian thinking offers a basic framework for thinking about the human condition. (More, 1999).

The *Extropy Institute* adopts a seven-prong principle philosophy: Boundless Expansion. Self-Transformation, Dynamic Optimism, Intelligent Technology, Open Society, Self-Direction and Rational Thinking. Another similar (competing?) body is the *World Transhumanism Organisation* (WTA) who aim to promote "discussion of the possibilities for radical improvement of human capacities using genetic, cybernetic and nano-technologies" (World Transhumanism Organisation, 2002). The WTA was established 1998 by Yale University philosopher Nick Bostrom (2002) to initially produce an international document: *The Transhumanist Declaration* (see Appendix 4) . This declaration whilst purporting to be at the cutting edge of transforming the world – is in reality firmly entrenched within an arcane liberal humanist framework – definitely a philosophy of ‘this’ world! Reading like a tract on humanism the WTA declaration argues from a base of possessive individualism (i.e. classic liberalism) to support the notion that the individual has a moral right to use 'enhancement' technologies[349]. The declaration is silent about the potential changes to the (currently asymmetrical) relationship between human and machines and between categories of humans.

There is a raft of other fringe organisations such as David Pearce's *Hedonistic Imperative* web and the California based *Foresight Institute* (*aka* Eric Drexler & Glen Reynolds) established to prepare (an assumed given) for nanotechnology. Whilst there are differences in the emphasis taken by these groups, one striking feature uniting them all is an uncritical belief in a *teleological views* of progress (e.g. Principle 1: Perpetual Progress . *Extropian Institute principles 3.0*) and a Darwinian orientation (Bendle, 2002; Kurzweil, 1999a; Kurzweil, 1999b). Whilst transhumanism purports to be a post-modern move, it is argued that in reality it is firmly embedded within an enlightenment, liberalist tradition. Indeed biophysicist and director of the Medicine, Technology and Society program (School of Medicine) at the University of California, Dr Gregory Stock (2002) asserts that it is the duty of all citizens to pursue biological enhancement. No doubt there would be even more pressure on those 'disabled bodies' to make the grade. Transhumanism as boundless optimism is summed up well in a paper written by Stock for a BBC program audience debating 'designer babies':

> The human species is moving out of its childhood. It is time to acknowledge our growing powers and begin to take responsibility for them. We have no choice in this, for we have begun to play god in so many intimate realms of life that we could not turn back if we tried. Some, of course, believe we should stop our audacious incursions into the very fabric of human biology - at least until we can summon up more wisdom. But the way to find wisdom about our newfound capabilities is not by trying to deny them (and thereby relegating their exploration to outlaw nations and scientific renegades), but by using them judiciously, by carefully feeling our way forward, and yes, by making mistakes and learning from them (Stock, 2000).

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[349] Extropian Max More (1997) has also written a paper titled "self-ownership A core Transhuman Value", where he indicates independent thinking, individual freedom and personal direction as key aspects.

Our review of transhuman activity would not be complete without making mention of an extraordinary project to design and eventually create a new post human physique. A team of physicists, roboticists, visual artists and mathematicians have been engaged in creating a prototype named **Primo 3m+** (Figures. 16a and 16b) The *Primo* is designed to be upgradeable, reliable and changeable and the purchaser can pick and choose specific characteristics such as size, colour, contour and body length. As the designers' promo states:

> **Primo's RADICAL body design** is more powerful, better suspended and more flexible—its body offering extended performance and modern style. The expansive interior provides advanced metabrain and enhanced senses. Our nano-engineered spinal communication system runs under the guidance of networked AI with a wide range of optional features. (Vita-More, 2002)

Primo 3M+ is not some laughable fleshful fantasy rather its development has the backing of an interdisciplinary scientific team and research house money. Who knows what the finished 'product' or upgrade will look like?

This figure is not available online.
Please consult the hardcopy thesis
available from the QUT Library

Figure 16a: Primo 3M+, Source: (Vita-More, 2002)

This figure is not available online.
Please consult the hardcopy thesis
available from the QUT Library

Figure 16b: Primo 3M+ “More comfort, better performance …”

Source: (Vita-More, 2002)

6.5.2 A Meditation on Transhumanism – What Does it all Mean?

Trans/Post human literature takes an almost naïve approach to matters of social ordering and the further engendering of asymmetrical relations between humans, animals and machines. Indeed the social realm – is kept at arm's length. It is assumed that a cooperative or consensual process will be evolved to work out any conflict or inequalities. Extropian's for instance, indicate there will be a free exchange of ideas where problems can be resolved in an open fashion (More, 1999). What is missing from much of the literature is a rigorous and sustained discussion of the contextualisation of developments towards transhumanism and the relationship of these developments to broader themes such as globalisation and the growth of asymmetrical relations between first and third worlds[350]. Transhumanism as an aspirational ethos matrixed to high technologies is very much a Western, first nation phenomenon. Other missing components of the debate relate to the very culturality of the transhuman entity and its linkage (if any) to certain kinds of racialised bodies.

However, the road to the transhuman has some significant implications – as the degree of change required is of an epochal nature. As Sloterdijk puts it these changes inaugurate a new "era of species-political decisions' (Sloterdijk, in Bendle, 2002: 49). James Hughes (secretary of the WTA) is more explicit about the radical envisioning of the polity by the introduction *inter alia* of cryonics and nanotechnologies arguing that: "sentience and personhood will become the basis of moral concern; regardless of its media … rights will become independent of being a breathing human being" (Hughes, 2001). Hughes correctly identifies that the 'war zone' (to borrow Latour's expression) will be framed by

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[350] The gross inequalities in African and Asians peoples access to life saving HIV/AIDS drugs comes to mind.

two expressive and competing worldviews, namely biofundamentalism and transhumanism. There is little debate that the movement of transhuman technologies fundamentally disrupts deeply embedded notions central to western philosophy (and indeed theology) related to human be-ingness and an essential essence.

The biofundamentalist camp's response to transhumanism has been to return (regress?) to a hard-wired approach to human nature ruled by biology and genetics (C.f. Fukuyama, 2002). A way out of this seeming deadlock would be to propose that the 'essence' of being human lies in our fundamental reliance on appendages, prosthesis and that, which is 'outside' ourselves[351]. New technologies, I propose, in fact brings to the foreground what to many was 'hidden': a *post ontology of impermanence*. Humans become disembodied only to be re-embodied into a sphere of assemblages and aggregates. This kind of way of thinking about human scaffolding is not all that new – not at least within the Eastern Philosophy of Buddhism wherein human be-ingness is constituted through a series of graded aggregates coming together to form a whole. (Jayasuriya, 1988; Mahathera, 1986; Thera, 1998). So what we have in the transhuman are humans that are a series of assemblages – viscous, machine and transboundary (virtual). The return to or re-direction of our attention to bodily attachments is what Latour (1999) nicely refers to as the *politics of incarnation*.

It is the elevation of A.I (artificial intelligence) to the potential status of 'life itself' that pushes the envelope, which pressures the practices of purification by reconstituting

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[351] It is really artificial to talk about outside/inside – the reality is human's function rather like a möbius strip with the outside/inside merging into/out of our selves.

‘established’[352] hierarchies of sentiency. Indeed much of the reasoning in related to this question of the ordering of be-ingness has been influenced by the neo-utilitarian logic of ethicist Peter Singer (1993; 1995a; 1995b; 2000; 2002) who places ‘consciousness’ as the key criteria for the possession of civil rights and use-value. Hughes has formulated a schema based on a Singerian rights framework that incorporates the post human actant. This continuum and scaling of organic entities has major implications for shifting formulations of ableism and specifically the zoning of ‘subhumanness’. It is for this reason that I have reproduced his chart in full:

TABLE 6: The Future Continuum of Consciousness and Rights
(Hughes, 2001: 9)

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[352] I have problematised this point as I am in agreement with Latour (1993: 11) when he says that the modern critical stance is to keep the practices of translation (hybridisation) and purification separate. To attend to both processes we stop being modern and move into a different mode.

What are missing from the Hughes schema are the masses of other players[353], the traditionally regarded non-sentient actant – the machine. In her discussion on machine agency Lucy Suchman (2000) notes that the relationship between humans and machines has been based on *asymmetrical* relations. A.I's are now moving into the matrix of being emergent subjects – in other words, the ontological positioning of artefacts is now "up for grabs", an ontology or agency is produced as an *effect* of the morphology of relations of engagements. In other words, in contradistinction to Hughes (2001), consciousness and ontologies are not fixed (in a caste system) or hierarchical, rather they are network generated and are therefore more nebulous and dependent upon the ways in which other actors in the matrix coincide.

Consciousness then, under Hughes' (2001) framework, becomes confused with sociability, whereas the real crux of the focus should be on unseating the sovereign body. Hughes' proposed new constitution is in reality an old one for it still proclaims, "right in the West is the King's right" (Foucault, 1980b: 94). In Hughes, the conditions for the iteration of selfhood (the mark of humanity) are still based on the qualities of rationality, autonomy, separation and self-mastery[354]. Indeed as I have already noted self-ownership is viewed as a core ethos of transhumanism.

6.5.3 Leaving Home – A New Deal for Impairment?

At this point I am aware that there are many gaps and cracks in this conversation but I am mindful of not getting too carried away as the point of the task at hand is not to write a

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[353] Here again I owe a debt to the clarifications of Latour (1992) and his study of nonhuman actants.

[354] An interesting caveat to this point is the desire of enhancement technologists to master and rein/reign in vulnerability. See Mc Kenny (1998).

tome on the post human, but rather to consider what these developments may mean for the lot of those humans considered 'impaired'. I ask in advance then for any rough edges or unfinished business to be excused! There is little debate about the potential merits of certain enhancement technologies in 'bettering' the lives of those individuals that in today's circumstances we consider 'impaired'. The science of physics would be a poorer discipline without Stephen Hawkins whose consciousness is mediated through a voice synthesizer. Yet, other forms of enhancement technologies – such as the mediated communication of a sign language interpreter are not always considered desirable within an ableist polis[355]. In other words the language of enhancement efficacies, are contextually matrixed and mediated by movements that conform to abstract archetypal norms.

In my discussion on ableism in Chapter Four I have already made mention of the numbers of people with disabilities standing in line to join the queue of the enhanced. Jean Baudrillard, rather discourteously in my opinion, suggests that disabled people would make excellent candidates in the transhuman project:

> Such are the blind, and the handicapped; mutant figures because mutilated and hence close to commutation, closer to this telepathic, telecommunicational universe than we others: humans all-too-human, condemned by our lack of disabilities to conventional forms of work. By the force of circumstance the disabled person is a potential expert in the motor or sensorial domain. And it is not by chance that the social is aligning itself more and more with the handicapped, and their operational advancement they can become wonderful instruments because of their handicap. They may precede us on the path towards mutation and dehumanization. (Baudrillard (1988) cited in Overboe, 1999: 21).

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[355] I should clarify this point. The preferability of hearing would have it that sign language interpretation is but an interim measure – for the goal is to have the Deaf speak and hear.

This romanticisation of suffering bodies (endemic to certain kinds of Christian theology) has been replaced by a new Baudrillardian transhuman romanticism, where disabled people are likened in closer proximity to the twilight zone of mutation. We have to cast our minds beyond the dust of a mere *instrumental* argument about the attraction of post human technologies for disabled people and focus on the discursive shifts in the overall meaning and positioning of abnormality. My interest is in the 'lot' of those able-bodied people – who may become the 'new disabled', the new aberrancy – an oppositional sentiency produced by the transhuman.

My hunch is that whilst the movement towards transhumanism may brings gifts for the contemporary 'needy' the transhuman project because it is founded on an unbridled form of ableism combined with an 'obsessive technological compulsion' – will involve a meagre shuffling of the deckchairs – a rearranging of 'bums in seats'. The rankings remain the same (albeit with new labels that tell us/and others who we are). Transhumanism reasserts systems of ranking bodies; vertical and horizontal rankings creating global raced divides. The schema of Hughes (2001) (Table 6) further diminishes the 'rights' of people with intellectual disability (only having the right to life) and bears with it an inference that enhancement technologies can do 'nothing' for those deemed severely retarded [sic]. Little is said within this new ranking about the creation or broadening of new kinds of 'intellectual' disability because of the emergence of cognitively enhanced post humans and the stripping or delimitation of characteristics deemed to be cognitive[356]. Within this world of the transhuman ableism as an ethos is undisputed.

What do Extropian's and other transhumanists think about human impairment, anomalous bodies regarded as disabled? It is hard to tell – I have been unable to find any explicit discussion about disability concerns in the literature. However my intuition is that disability, as a form of legitimate sensibility would be frowned upon. Stock (2002) for instance appears ambivalent – he notes that deaf people who want deaf children can utilize new reproductive technologies to make that selection. Yet when it comes to any ethical consideration of those choices, Stock's response is that these choices should be left to parents until those choices amount to child abuse or endanger society. Simplicity of the argument aside, Stock demonstrates little awareness of contested notions of child abuse and social endangerment especially when the parents concerned have non-traditional profiles (e.g. gay, lesbian or intellectually disabled). In an earlier online interview with BBC's online Horizon program, an interviewer asked the following question of Stock:

> [Interviewer]: "Technology has positive connotations - people believe in its promise. Do you think that in the future when people can design their own babies, those who refuse it will be accused of not giving their offspring the best possible care?"
>
> [Prof. Gregory Stock]: "I think that when we have the ability to intervene in this realm, there will be a whole new area of law - issues such as wrongful birth, where children sue their parents for not correcting some disease, and others who sue their parents for "improvements" that were made. But my perspective is from the United States, where everyone sues everyone!" (BBC Horizon, 2000)

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[356] The point being that not all cognitive enhancements will be valued. There maybe a division between those enhancement that transcend the or favour disembodied virtues, rather than enhancements geared towards the senses or emotions.

The inference being that whilst the social is usually kept at arms length by transhumanists – choices made by parents and others maybe coerced by the prospect of future or predicted penalties. The *Primo 3m+ Posthuman Body* (Figure 16a) indicates in its advertising a warranty against genetic defects and other pathogens!

Possibilities of posthumanism developed within the context of technologies of ableism may provide a 'new deal' for some – but on closer examination the tentacles of ableism reassert itself through the a dominant trend in the literature and research to propose a virile style of transhumanism that despises vulnerability. Technological determinism, certainly not! Other opportunities and emancipatory styles of transhumanism may emerge. Alternatives rejecting the conflation between use-value and the delimitation of humankind, an oppositional transhumanism that proposes cyborgs whose central qualities are those of relationality and the experience of growing.

In keeping with this section's focus on a new imaginary and the looking forward to a 'new deal' for disabled people, the next chapter (and a new thesis division) makes what some readers might suggest is a significant leap into a potential site of resistance to technologies of ableism, namely desiring disability and the matter of disability devoteeism.

DIVISION THREE: DESIRING BODIES

Chapter Seven - Desiring Disability – Towards an Ethics of Affirmation

> Desire: a kind of madness, an enchantment, exaltation, anguish … perhaps the foundation of a lifetime of happiness. Writing about desire: compulsive, a challenge, self-indulgence, anxiety … above all, a project that defies completion (Belsey, 1994: 3).
>
> Disability is not a brave struggle or 'courage in the face of adversity' … disability is an art, an ingenious way to live (Marcus, 2000).

It should be evident by now that people with impairments considered as disabled have had to live under the enormous weight of negative figurations of disablement. I hope that I have clearly demonstrated that this burden is not just a surface discomfort restricted to the arena of discrimination and prejudice. Rather, regimes of ableism have produced a depth of disability negation that reaches into the caverns of collective subjectivity to the extent that the notion of disability as inherently negative is seen as a 'naturalized' reaction to an aberration. Having said this, it is all the more extraordinary that disabled people have not yielded to this repression but have resisted docility and engaged in transgressive figurations of disability. Certain subjugated desires can, in their unfreedom, cultivate alternate kinds of liberty.

The placement of concepts such as 'desire' and 'disability' within a single context almost appears to be an oxymoron. We may well question whether a concept like desire, which has almost wholly been figured in heterosexual and ableist terms can be harnessed so that it is capable of accommodating the very categories on whose exclusion it has made feasible? This chapter introduces discussion of 'desire' within a framework of some of Michel Foucault's early writings (1976; 1998, Orig 1966). It will explore the relevance or otherwise of Foucaultian 'desire' in its consideration of 'disability' as oppositional ontology and engage in a project of alternative formulations. I open discussions by briefly surveying various philosophical treatments of the desire question in order to assess their usefulness to this undertaking. Next, I signal some of the quandaries that may emerge in applying desire and disability in the same context. The final section moves into an analysis of conflicting practices of *reading* desire and disability, in the form of the pathologization of disability desire.

Our discussion engages the imagination by playing dangerously (yet cautiously) with matters of 'disability' 'desire', 'pride', 'culture' and a transgressive aesthetic. It is a vulnerable conversation, a *speaking otherwise* about 'disability'[357]. By adopting the 'thought of the outside' (as expressed by Foucault, 1998, Orig 1966) and repositioning our gaze it maybe possible to open up 'spaces' for oppositional technologies of self that posit 'disability' as a positive erotic, grounds for subjugated celebratory experiences of 'disability'. As Cheryl Wade puts "what is missing [is] … a true esteeming of the Cripple body" (1994: 35). In this sense, Chapter Seven turns a corner in the dissertation by marking out sites of resistance to technologies of ableism.

7.1 Some Philosophical Treatments of the Desire Question

> This does not mean that I proposed to write a history of the successive conceptions of desire, … but rather to analyse the practices by which individuals were led to focus their attention on themselves, to decipher, recognize, and acknowledge themselves as subjects of desire, bringing into play between themselves and themselves a certain relationship that allows them to discover, in desire the truth of their being, be it natural or fallen (Foucault, 1976: 5).

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[357] It is also a 'new' conversation where there is much discussion at a grassroots level – but little analysis in print.

> Instead of attempting to determine what we should do on the basis of what we essentially are, attempts, by analysing who we have been constituted to be, [we should] … ask what we might become (Rajchman, 1986: 166).

The disabled body is a site of struggle over its signification and corresponding social meaning. As such, the task of discerning the relationship of desire and disability must be concerned with the conditions of the disabled body's referentiality. In other words, we need to keep reflecting on the prevailing conditions that not only make the disabled body intelligible but also enable us to refer to 'disability' in a particular way. Instead of desire being a peripheral preoccupation within Western philosophy, Michel Foucault notes that in reality the desiring subject has performed as a central theme within the tradition, even in those philosophical strands that seemingly disassociate themselves from such concerns (Foucault, 1985: 5).

The treatment of the desiring subject however has not been uniform. Rather discussions of desire have oscillated between two frames of reference, either '*desire as sex*', following Freud; or '*desire as power*', following Hegel (and later Foucault). Indeed as Hugh Silverman remarks, "these two models [still] dominate twentieth century continental philosophy … [and can be] situated in the context of the whole history and text of Western metaphysics" (Silverman, 2000: 2). In this chapter, I am concerned with the latter, *desire as power*. Frederick Hegel's master/slave dialectic formulated in *The Phenomenology of Spirit* (1977) has in many works been allocated a pre-eminent position (Butler, 1987; 1995; Silverman, 2000). For Hegel desire was formulated in terms of lack, a type of longing that remains unsatisfied. This Hegelian desire Grosz explains has a "peculiar object all of its own – its object is always another desire. The desire of the Other is thus the only appropriate object of desire" (1995: 176). We could consider the use of Hegelian desire theory as a means to reconnect desire with disability (as Other) and therefore close the gap between kinds of difference. Such a strategy may have limitations – the catch is that desire is figured on the basis of unsatisfactoriness that is hardly conducive to the development of an ethics of affirmation. Desire, understood in this way, may have the appearance of rupturing and subverting existing constitutional arrangements but in reality, Hegelian desire is predicated on the maintenance of bodily polarizations. Such polarizations may end up re-instilling the notion of disability as deficient.

Contrary to popular perceptions the enactment of desire is not a free-for-all, rather the substance of desire is always played out within a regime of power relations, where so-called perversions are a fixture of the game (Foucault, 1976: 48). The very imaginary of desire is mediated by the productivity of power. *Reading* 'disability' in a positive ontological light requires an *a priori* negotiation with what Foucault refers to as the instrumental effects of the 'implantation of perversions', the consolidation and fortification of tangential desiring:

> The implantation of perversions is an instrument – effect: it is through the isolation, intensification, and consolidation of peripheral sexualities that the relations of power to sex and pleasure branched out and multiplied, measured the body and penetrated modes of conduct (Foucault, 1976: 48).

These peripheral desirings, the will-to-truth do not occur in isolation. Rather they are framed within a 'double bind' of individualization and totalisation. Strategies of dispersal and division – 'dividing practices'[358] result not only in the phenomenon of *internalised*

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[358] Dividing practices are situations where "the subject is either divided inside himself or divided from others" (Foucault, 1983: 208).

ableism but also in an ontological separation of the normal from the pathological[359]. On this basis, Foucault's' hermeneutics of desire suggests that a desire towards emulation of the ableist subject mitigates against the development of desiring disability outside of the realms of the perverse[360]. Indeed the very necessity to mark off 'matter out of place' requires the subjugation of tangential corporeal forms and behaviours. The insurrectionary challenge then, is to take up these 'implantation of perversions' and map out new territories of desire, to develop as Foucault puts it 'the thought of the outside', a thought at the margins of culture:

> A thought that stands outside subjectivity, setting its limits as though from within, articulating its end, making its dispersion shine forth, taking in only its invincible absence; and that, at the same time, stands at the threshold of all positivity, not in order to grasp its foundations or justification but in order to regain the space of its unfolding, the void serving as its site, the distance in which it is constituted and into which its immediate certainties slip the moment they are glimpsed – a thought that, in relation to the interiority of our philosophical reflection and the positivity of our knowledge, constitutes what in a phrase we might call 'the thought of the outside' (1998, Orig 1966: 150).

It is in between these conflictual traces of subjectivity that the perverse inkling of disability desire, an insurrected ontology lurk. For Foucault, 'the thought of the outside' contains a double imperative: (negative) desire reaches into our (disabled) interiority, the emptiness, and the state of be-ing outside: "the fact that one is irremediably outside the outside … infinitely unfold[ing] outside any enclosure" (154). Whilst inaugurating a space for positivity to unfold, Foucault's later work on governmentality (1991; 1997d (orig 1982) extends his analysis of desire towards a conception of 'conduct of conduct'. The concept of government as 'conduct of conduct' provides a useful theoretical

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[359] This seems a particular obsession to the extent that separation of desiring *between* disabled people is obscured. (see section 7.3). On this point also see (Canguilhem, 1978).

[360] Both Brown (1995) and Butler (1997b) speak of the subject being passionately attached to his/her own subordination, a wounded attachment.

mechanism for examining devoteeism especially the techniques that form conduct by working on the devotees and desires and beliefs. Desire shapes how we behave and act on others and ourselves. In terms of our discussion what are we to make of these ideas and are they helpful? The terrain of disability desire is in many respects slippery and elusive depriving the positivist gaze any openings, any colonizing ontological autopsies. Foucault is correct that we can never really 'know' the outside, the liminal margins because its 'essence' remains inherently unknowable and ambiguous.

7.2 Desiring Disability or Disability and Desire?

The influence of the 'personal tragedy theory' of disability, a position that formulates disability as *inherently* negative, cannot but have an impact on our negotiations concerning desire and disability (Campbell, 2001a; Campbell, 2001b; Oliver, 1990). It is difficult, if not impossible in this present moment to *speak of disability as desirous or desirable* given the overwhelming influence of such negative ontologies. As Swain and French (2000) point out one cannot assume that so-called emancipatory models of disability (such as the Social Model) are supportive of an affirmative approach to impairment, or are underpinned by a non-tragedy perspective. Certainly many practitioners and academics who embrace contemporary disability studies theoretical paradigms draw the line to different degrees on the notion of celebrating and indeed enjoying disability. In my own teaching at a university I am constantly mindful of treading carefully in this area because of the possibility of a backlash from students and other colleagues following lectures on themes such as eroticizing disability or even suggesting that impairment may be a good 'thing'. Again Swain and French (2000: 570) are in agreement, arguing that although many non-disabled people support the social model in principle they " … are much more threatened and challenged by the notion that a wheelchair-user could be pleased and proud to be the person he or she is [because of their impairment]"[361].

When it comes to matters of 'desire' (and in a more narrow sense 'sex') the status of disability takes on an act of perversion. We may ask whether it is possible or indeed advisable to break this circuit and envisage disability as a desirous, celebratory possibility. When disability and desire are placed in close proximity, the question of 'what is excited and incited?' needs to be invoked. Additionally the linking of desire and disability confronts the performance of gender by problematising the construction(s) of masculinity and femininity[362].

Two problems or concerns become apparent when tackling these matters. What does it mean to speak in terms of *desiring disability*? The answer seems incumbent on the location of the speaking position of the addressee. For a self-identified disabled person, the matter relates directly to the formation of individual subjectification and ontological positioning. Power not only forms the subject by naming the conditions of its existence but also simultaneously inaugurates specific trajectories of desire. To step outside of the normative trajectories of negativity, not only destabilises the conception of disability, but also confuses and disrupts the processes of subjectification by confronting the 'goodness'

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[361] Even within a range of so-called emancipatory 'disability' writings we continue to be haunted by analysis that invariably casts 'disability' in terms of negative ontology, albeit 'suffering' joyfully. Examples include the work of Hillyer (1993) and Wendell (1996).

[362] More recent writing in masculinity and impairment see Charmaz (1994) and Gerschick (1998).

of disability[363]. Such an act is subversion because to position the impaired body as erotic is perverse – I posture that ontologically the disabled body *qua* body is perverse[364]. Hugh Hefner, editor of *Playboy* magazine describes the erotisation of disabled people as the "dirty underbelly of human sexuality" (Waxman Fiduccia, 1999: 279).

By *desiring disability* the subject adopts an oppositional trajectory of desire, demanding to be represented as one who delights in the state of be- ing disabled and re-cognising disability. If this is the case, what kinds of possibilities become imaginable when 'disability' is re-cast (or inverted) in terms of 'desire'[365]? Is it possible to carnally fantasize about 'disability'?

The matter of desiring disability becomes a different one, when the desirer's standpoint, or speaking position is situated within the purview of being 'able-bodied', that is identifying as a non-disabled person (even if they are bodily impaired – to use that reductionist term!). Their gaze refracts the disabled person as Other (albeit as 'positive' Other). What if our different/missing/deviant bits/oozing fluids/states are the *very sources* of that desire/fetish? As Waxman points out [able-bodied] people who have sex with disabled people are stigmatised and are seen as sexual suspects. What 'crime' have they committed? Waxman proposes that pornographic imagery of men having sex with disabled women is especially viewed as perverted, lewd and contaminated because it is under girded by paedophilic imagery – a belief that the man is attracted to having sex

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[363] I refer the reader back to my discussion in Chapter Four on how ableism inhibits self-desire.

[364] I want to be clear here – I am saying that the impaired body outside of the subsets of sex – desire and pleasure is of itself perverse.

[365] "Inversion refers to the reversal of an expected and pleasing appearance to produce a disturbing image". (Miles, 1989: 159).

with a (perpetual) child. She remarks: " It [sex] blows the lids off one of the last taboos, sex with a cripple, which in both a moral and public policy sense, is analogous to paedophilia and incest" (Waxman Fiduccia, 1999: 280). In 1997 Dr Richard Bruno (1997) proposed the psychological concept of *Factitious Disability Disorder* to explain the desires of people termed 'devotees', 'pretenders' and 'wannabees' i.e. people who desire disabilities or people with disabilities. How reasonable is the assumption that a desire for 'disabled' bodies automatically connotes pathologisation on the part of the admirer? Can 'disability' as a bodily signifier be 'queered'[366]?

The second aspect of concern relates to the broader question of representations of desire and disability. People with disabilities have a long history of association with the carnivalesque and freak shows in particular (Cohen, 1996). One of the first modern portrayals of disability in the erotic can be found in the 1987 July edition of *Playboy* magazine featuring images of quadriplegic Ellen Stohl in a provocative pose on a bed. This tightly choreographed image concealed her paralysed legs. Waxman described the uproar that this early image caused from some feminists with disabilities that the images "reproduced non-disabled values of sexual attractiveness … Stoll [sic] started a controversy which got the fledgling disabled feminists [sic] community talking" (Waxman Fiduccia, 1999: 279). Seven years later the controversy still had not died down – so provocative was the image of sexualised disabled women (Figure 17).

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[366] Jagose (1996: 3) suggests "… queer describes those gestures or analytical models which dramatise incoherencies in the allegedly stable relations between chromosomal sex, gender and sexual desire. Resisting that model of stability-which claims heterosexuality as its origin, when it is more properly its effect - queer focuses on mismatches between sex, gender and desire".

This figure is not available online.
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available from the QUT Library

Figure 17: "Ellen's still not taken seriously as a woman who's sexual"

***New Mobility Magazine* May- June Issue 1994**

Image source: http://ellenstohl.com/images/newmobility_lg.gif

In enacting the erotic, great care is necessary in order to ensure that representations do not end up reinscribing problematic images of abjection and alterity. Fascination with alternate images and the explorations of conversations about the erotic and disablement have come from another of those peripheral sexualities Foucault (1976) spoke of: queer sexualities. Gay fetish and S & M magazine *Drummer* issue 93 featured a photographic exhibition titled “Maimed Beauty” by photographer George Dureau in conjunction with a commentary “Different Bodies” by Max Verga (Dureau and Lucie-Smith, 1995; Verga, 2000)[367].

Unlike the typical images of disabled ‘soft’ porn that rarely deviate from traditional constructions of beauty: e.g. well-endowed, blonde-haired person and blue eyed (i.e. like Stohl); the men with disabilities photographed by Dureau were African American and predominantly from local, poor neighbourhoods of New Orleans. Verga’s descriptions of the works are instructive:

> … ragged edged black and white portraits with a lack of background detail that forces the viewer to focus attention on the subject, often portrayed naked. George presents disability without visual comment or apology. George’s subjects had not been in any war other than the war that rages around poverty. Some of them had been in prison. Others would wind up there. Some were from middle-class backgrounds, with only disabilities thrusting them to the fringes of society.
> (Verga, 2000: 4)

This figure is not available online. Please consult the hardcopy thesis available from the QUT Library

Figure 18: ‘A Noble Man’
Source: (Verga, 2000)

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[367] The article and photo shoot led to the largest positive responses from readers to any magazine feature.

I am reminded by the wisdom Foucault imparted in the epigram that introduces section 7.1 where he calls for a spotlight on those practices that lead us to focus on ourselves, recognizing and acknowledging ourselves as *subjects of desire*. It is not only able-bodied people who experience the 'cringe –effect' when exposed to the sexual desire of disability – but also disabled people themselves also often feel an awkward 'strangeness' when confronted with mirroring imagery (Shakespeare et al., 1996). The erotic photography of George Dureau presents an affirming image of the beauty of disability, not of docility and despair. They speak of desiring disability. Take a look and be drawn in … (Figure 18). I am in complete agreement with Verga's summation:

> It was not hard to be impressed by the beauty of George's photos and the desirability of his subjects … beautiful as they were,, the photographs only hinted at the sexual power they depicted … Unlike the photos of Diane Arbus, which emphasize the grotesque qualities of her subjects … Dureau's photographs suggest nobility through the directness of the images. (Verga, 2000).

More and more groups of disabled people are deciphering desire on their/our terms. A web site, Bent voices (www. bentvoices.org), has been established to share the stories of disabled gay men and in scholarly circles Robert McRuer and Abby Wilkerson (2002) have recently edited a collection simply titled *Desiring Disability: Queer Theory Meets Disability Studies*. In this collaborative exchange, "points of contact" are occurring between queer and disability cultures in developing the 'thought of the outside' (Crutchfield and Epstein, 2000). One source of potentially transgressive discourses on desiring disability has come from the unexpected quarter of disability devotees, pretenders and wannabees. These three quite different groups (who it seems keep being grouped together in psychosocial studies) have in the past few years been developing a kind of sociology of peripheral beingness 'from below'. From what initially started out as a defence of desire in response to criticisms from the disability sector (including some disabled people) has grown, I argue, into a carefully reasoned argument on the positive ascetics of impairment.

7.3 Those Who Do It or Want It! : Pathologising Desire, Disability Devotees and Other Peripheral Sexualities

> As a matter of fact or beside the point, it doesn't matter, it's said as a common proverb in Italy that the person who hasn't slept with the cripple doesn't know Venus in her perfect sweetness. Luck, or some particular accident, put this saying in the mouth of the people long ago; and it's said of males as well as of females. For the Queen of the Amazons replied to the Scythian who invited her for love: "the cripple does it best." In this female republic, in order to get away from male domination, they maimed ("amputated" or "mangled") during childhood, arms, legs, and other members which gave them an advantage over the women, and they used the men only for what we've used women in fact. I would have said that the swaying motion of the cripple might bring some new pleasure to the toil (of love) and some bit of sweetness to those who try it, but I've just learned that even ancient philosophy was decided in that; it says that since the legs and thighs of crippled women, because of their imperfection, don't get the nourishment that is due them, it follows that the genitals, which are right about them, are fuller, more nourished and more vigorous. Or that, this default prohibiting exercise, those who are tainted use less force and come more fully to the games of Venus (Michel De Montaigne (1588). *Essays*, Book III, Chapter XI "Of Cripples").

> … desire is also the location of resistances to the norms, proprieties and taxonomies of the cultural order (Belsey, 1994: 6).

Disability 'devotees', so-called 'pretenders' and 'wannabees' have been engaging in peripheral sexual desires throughout history as attested to by the epigram written by Montaigne in 1588. This population however has only been medically delineated since the late 1880's. This section will explore the world of disability devotees and wannabees within the framework of the chapter's overall focal concern with treatment of desire and disability. What I am interested in exploring is how the *processes* of ableism respond to the phenomena of attraction towards aspects of disability and ways the devotee world has the potential to challenge the self-concept of people with disabilities and the formation of an affirmative ontology. I do not intend to present a psychological study concerned with ‘causation’ questions nor do I wish to propose any explanatory frameworks related to ‘origin’ fixations. Before proceeding any further, working definitions are necessary:

- ***Devotees*** are individuals (usually who identify as able-bodied) who are attracted to, fascinated by, or obsessed with, people with a physical disability and their orthosis and/or prostheses. Attraction to people with an amputation seems to be the most documented form; whereas
- ***Pretenders*** (a dreadful word really) refers to someone who, at times, likes to pretend they have an impairment usually by mimicking mannerisms, gestures, movement (they deem to be ‘impaired’) or using assistive devices like callipers. Individuals identifying with this group do not actually (beyond the fabrication) wish to become bodily ‘impaired’; and finally
- ***Wannabees*** (sometimes known as *body dysphoria*): Someone who has an intense and overpowering desire to have a physical impairment. Individuals experiencing this ‘desire’ argue that they feel ‘abnormal’ in their current bodies and incomplete without a particular body part missing or reshaped. The person needs to be physically impaired to be ‘whole’.

As is the case with any working definition these divisions are not clear-cut, some individuals oscillate between all three classifications. In Chapter Three I proposed that one of the central inquiries that emerged within discursive genealogies of disablement in the nineteenth century was the persistent question, “Who are you?” In the case of people who desire persons with disabilities or the manifestation of impairment, this enduring question makes reappearance together with an obsession with matters of origin and causation, speculating about ‘truth’ in order to seek the resolution of a perceived ‘problem’. This critical inquiry into devotees, pretenders and wannabees (hereafter referred to as D–P–W[368]) hinges around the basis of the pathology and meaning given to D-P-W but also the way pathologisation inscribes and marks out the terrain of disability and desire. It is for this reason that this study will be analysed in terms of the ways disability and the devotee are constituted. For as Butler (1997: 41) reminds us:

> The subject is constituted … in language through a selective process in which the terms of legible and intelligible subjecthood are regulated. The subject is called a name, but 'who' the subject is depends as much on the names that he or she is never called: the possibilities of linguistic life are both inaugurated and foreclosed through the name.

It is useful at this point to indicate the profile of D-P-W. The literature indicates that individuals categorized under this banner are overwhelmingly male, heterosexual and white. Whilst this maybe the case, this description may not be wholly accurate. For instance, in early studies of 'homosexual' behaviour and culture a similar characterization was made. It was only as the canon of gay studies matured that female same-sex desire was acknowledged as just as prevalent, albeit hidden from the gaze of sexologists (Abelove et al., 1993; Greene et al., 1994; Kitzinger, 1989; Magee and Miller, 1997)[369]. I believe that this maybe the case regarding women identifying as D-P-W. On the basis of the D-P-W figured as male, Storrs (1996) indicates their ideal woman to be: " … blue-eyed, blonde, 29 years old, five foot five inches tall, 123 pounds, has one leg amputated above the knee and definitely is not wearing a prosthesis". Surprisingly then a chief study (see Bruno, 1997) of D-P-W uses as its sole case studies the accounts of two women. Due to the unusualness of D-P-W the quest to explain and

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[368] I have deliberately used this style of acronym instead of the more familiar DPW in order to resist the conflation of three different forms of peripheral ways of being. Much of the literature seems to link these desirings together without the necessary methodological justification forwarded to justify grouping them together.

[369] The gendering of social and psychological research is a pertinent issue here.

understand their behaviour can also be understood in terms of a desire by 'experts' to erase ambivalence and ambiguity of D-P-W life and create certainty about human variation. Three possibilities exist, one is to medicalise and pathologise D-P-W desire (the aim therefore is treatment or cure), another is to figure D-P-W desiring as another among the myriad of diversities and thirdly, to study D-P-W outside of a pathological frame (maybe sociological), with the D-P-W 'voice' as the centre of analysis. In spite of these methodological options biomedicalism as a powerful explanatory framework, has been the dominant response in trying to make sense of desiring disability.

A small study by Richard Bruno (1997) *has* taken on canonical status both within the devotee and disability communities, amongst those hostile and affirming of devotees. Bruno was not the first doctor to delineate D-P-W desire but he provides a study that summarizes much of the psychiatric literature on this topic[370]. His review of psychological theories is used to propose *inter alia* the inclusion into the DSM of a new category of mental disorder termed *Factitious Disability Disorder.* Bruno (1997: 249-251) documents four kinds of explanations outlined here without comment on my part[371]:

1. The D-P-W has a preference for the disabled body because it is a less threatening and thus a more attainable 'love object';
2. D-P-W attraction is associated with unresolved disability related stimulus experiences;

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[370] Dr Money of the John Hopkins University described the paraphilia associated with attraction to disabled people and their appliances. Defined as "A paraphilia of the eligibilic/stigmatic type in which sexuoerotic arousal and facilitation or attainment of orgasm are responsive to and contingent on the partner being lame, with a limp, or crippled (from Greek, *abasios* lameness + *-philia*)." (C.f. Money, 1996).

[371] My lack of comment at this point should not be taken to mean that I consider these theories to be unimportant, comintantly; they are critical to the inscribing the D-P-W as deviant. Rather a strategic 'silence' has been adopted to avoid my attention from being subsumed by this debate and away from my focal concerns around ontological representations of disability (and desire).

3. D-P-W attraction falls into the bounds of the sexual ‘perversions’ of homosexuality, sadism and bondage; and finally
4. There is a high incidence of *body dysphoria* amongst D-P-W – i.e. a “disabled person trapped within a nondisabled body”.

The personality characterization painted by Bruno of D-P-W is that of an obsessive predator who is excessively solicitous towards people with disabilities. Whilst there have been reports of unsavoury behaviours (such as stalking) by some D-P-W these actions cannot be seen as behaviour definitive of the group as a whole[372]. On the contrary, Child & King (1992) in the *Manifesto of OverGround* an organization whose constituency are people “attracted to others with disabilities” reminds devotees of their obligation “to give consideration to the rights and dignity of people with disabilities. *OverGround* wants devotees to be aware of the vulnerabilities of people with disabilities …” After participation in an online forum of devotees disability activist and journalist Bob Storrs (1996) refutes Bruno’s characterization slur arguing for the *normalcy* of D-P-W:

> I was surprised to find them neither sick nor psychotic. The participants are computer analysts, doctors, engineers, and college educated professionals. There is much discussion of the guilt caused by their ‘socially unacceptable attraction’ and the fear that others will attack them for their ‘dirty little secret’ many describe a terrible frustration at their inability to find a disabled person to date …

Despite these observations, Bruno advocates deviancy making as the clinical response to D-P-W. Although Bruno points out that after a century of research clinicians have yet to determine the origin of D-P-W attraction he suggests that those with factitious physical disabilities (akin to Munchausen’s syndrome) can be included with D-P-W to create a new diagnostic grouping *Factitious Disability Disorder* (FDD) as the ultimate

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[372] Just as the high rates of rape by male offenders is not definitive of male sexualities.

explanatory model for this kind of ‘implanted perversion’. His delineation is interesting in not only what it says of D-P-W but also what it implies about disabled people: “[The condition] in which disability – real or pretended, one’s own or that of another – provides an opportunity to be loved and attended to where no such opportunity has otherwise existed” (Bruno, 1997: 256). This classification would appear to institute the impossibility of communion between an ‘abled bodied’ person and a person with a disability where the attraction is in part disability orientated[373]. The literature about D-P-W assumes that devotees *et al* are able-bodied. It is profoundly silent about devotees who have disabilities being attracted to other people with impairment (either with the same impairment or different from their own). Given the overarching context of a biomedical explanatory framework and the figuration of disability as inherently negative; I want to shift our attention to the self-perception of D-P-W - how they read their bodies and desires and chart the relations between what is sayable and visible.

The narratives of D-P-W bear an uncanny resemblance to the narrative of the early homophile sub-cultures and identity politics of the gay community (Abelove et al., 1993). I have already mentioned that Foucault’s (1997d) notion of governmentality may be a useful tool for analysis of shifts in devotee subjectivity. By honing in on that aspect of ‘conduct of conduct’, is it possible to see how devotees make sense of ‘who’ they ‘are’ by using prevalent discourses of desire and deviancy as filters of referentiality. Fraught with guilt and shame, devotees initially found a home in the world of psychiatry

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[373] A point of clarity is required here: Many able-bodied people argue that they should not be considered devotees as such because their attraction is to the person in spite of their disability. This distancing/disavowal of the centrality of disability may remind the reader of the rationalisations adopted by some men in same sex relationships – ‘I am not gay I am attracted to a wonderful person who just happens to be male’.

and psy-therapies. What they wanted was an explanation of the dis-ease, a treatment and hopefully a ‘cure’. Over time as individuals gathered, shared stories and engaged in the exchange of tacit knowledges, D-P-W began to resist the clutches of psychiatry and what was sayable about D-P-W and develop their own counter-discourse not just about their desire, but a counter discourse of impairment. In the beginning the subversive response was a rather predictable return to immutability justifications and biological determinism[374]. As Child and King (1992) articulate in the *OverGround Manifesto*: “… devotees and wannabees are not responsible for acquiring their interests. These phenomena are neither sick nor sinful *per se*, but different”. Building upon the biological argument “Paul”, a devotee in an academic styled article *Disability as a Symbol of the Ultimate Other,* posits that men are searching for symbols of femininity and D-P-W (whom he intentionally restricts his arguments to males) are attracted to female amputees (he is silent about other impairment attractions)

> … because the absence of one or several limbs … is a symbol of this essential absence, which, of course, is everything but a void. So being an amputee would be a strong symbol of femininity. Therefore, my opinion is that the devotee is not attracted to the stump(s) in particular, but to the symbol of the absence it represents, reinforcing the difference, that is a women, as a whole, the exact one that he defined as fitted to be his partner ("Paul", 2002).

The difficultly with “Paul’s” argument is that it is predicated not just on the notion of *desire as absence* (or lack) but also on a belief in an Aristotelian notion (see chapter 3) of woman as a mutilated male. The stump reads as a signifier of mutilation, a deficient void in need of filling. Recently some D-P-W's have begun to reject psychiatric interpretations of desire as pathological and have employed discourses of normalization

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[374] Again there is the similarity of the debate of whether homosexuality is innate or a choice (Whisman, 1996).

to defend their position. “Jeff”, a devotee, explains disability desire as an attraction to a specific physical attribute along the lines of other attractions people are permitted to have; attraction towards [e.g. blondes] (“Jeff”, quoted in Aguilera, 2000: 261). Likewise, “J” sums up this normalcy:

> There’s nothing bad about having feelings of attraction towards people with particular impairment. It doesn’t mean you’re sick or wicked. It just means you are attracted to people with particular impairments. Nothing to be ashamed of, nothing to be guilty about ("J", 2002).

It becomes clear that it is not enough to acknowledge that disability devotees exist but that the search for explanatory frameworks is critical for the formation of devotee subjectivity. The matter of ‘managing’ and governing their behaviours ensures that devotees after understanding the ‘nature of problem’ behave ‘properly’. The D-P-W world is now a well-organised global network of interests with a range of social organisations, Internet sites and commercial enterprises (often run by amputee women). This networking has increased contact between other D-P-W and their visibility to the organised disability community. In response to the hostilities from some amputee organisations – D-P-W have been forced to articulate their desire in a more nuanced and refined fashion as part of the dialogical process with disability studies scholars and disability groups.

Re-orientating desire … and disability

The ‘problem’ with D-P-W desire seems not to be with desiring as such, but the object/subject of that desire – that is the disabled body. The disabled body as I have documented in numerous instances throughout this dissertation has been configured as the site of monstrosity and unthinkability … so inherently untenable that it has on occasions been pronounced ritually dead (Turner, 1987). Jeffrey Cohen's (1996) work on reading cultures through the monsters they yield can contribute to our discussion. Cohen develops a hypothesis that fear of the monster (and I add here, the monstrosity of impairment) is really a sort of desire that "makes the monster all the more appealing as a temporary egress from constraints. … We distrust and loathe the monster at the same time we envy its freedom, and perhaps its sublime despair" (1996: 17).

Elsewhere (Campbell, 1999) I have written about a kind of endemic desire in the form of voyeurism that inaugurates confessional discourses accessing the 'truth' of living with impairment. The desire to know, I argued, becomes in effect a source of pleasure. Foucault's description captures this pleasure imperative "[we have] … the fascination of seeing it and telling it, of captivating and capturing others by it, of confiding it in secret, of luring it out in the open …" (Foucault, 1976: 71). In the case of D-P-W they too are voyeuristic and they have crossed a boundary – they have inverted the monster and transmogrified it into a sex goddess! That is the 'crime' – D-P-W's have called into question the ontological positioning of disability.

Alison Kafer (2000) documents the trend within the rehabilitation context to encourage women amputees to cover (read: conceal) their stumps with clothing or cosmetic prosthesis in order to avoid the possibility of being "somewhat unattractive and disturbing". This kind of attitude has resulted in disabled women being embarrassed by their bodily differences and engaging in strategies that draw attention away from those anomalies. Such engagements in acts of concealment are fundamentally based on a belief in the *inherent* negativity of impairment and produce as an effect, disability self-hatred (internalised ableism, see Chapter Four). This can be witnessed in the reasoning adopted by some members of the Amputee Coalition of America (ACA) whose hostility to devotees likens D-P-W desire to paedophilia. The 'troubles' of amputees towards devotees is that they focus on something that is understood by the women as a loss, as a deficiency. As Solvang (2002: 6) puts it " … the last thing they find attractive is a special interest in the very part of the body signifying this sorrow [loss of limb]".

Devotees point out that many disabled people find it hard to believe that their disability can enhance their attractiveness. Recent sociologically orientated literature has documented that once a women with an impairment 'gets her head' around the idea that a man is attracted to her (and her impairment) this realization has contributed to a significant rise in self esteem – pointing to the importance of being desired (Aguilera, 2000; Duncan and Goggins, 2002; Kafer, 2000; Solvang, 2002).

One of the fundamental flaws of the predatorial and pathological argument espoused by Bruno (1997) and other clinicians is that much of the reasoning is premised on the belief that people with disabilities are passive, docile and therefore are in need of care and protection. Whilst this maybe the case in certain instances especially with individuals who are newly injured, such an assertion denies the deliberative agency of disabled people. It is assumed that people with disabilities are incapable of making choice about whom to have sex or form a relationship with. Aguilera's criticism of Bruno' study is along these lines: " … he (Bruno,) pathologises the attraction, and thus demeans disabled community [sic]. Not only are we unattractive, but we also are apparently unable to make our own decisions" (2000: 258). Erasure of agency and the accusation of exploitation are easy to make in sector known for its paternalism, patriarchalism and sex- aversion. Kafer (2000), whose study concerns amputees involved in the devotee community, argues that much of the literature by focusing almost exclusively on D-P-W perpetuates a belief in amputees being mere silent bystanders, victims of men's desire[375].

D-P-W communities whilst existing through the ages are at a point in their development where they are resisting moves to pathologise their desire and are at the same time being required (by pressure from the disability community) to better articulate their position. I posed the question earlier on this section whether D-P-W's have anything to contribute towards the development of a positive ascetic of impairment. It is my conclusion that the D-P-W's have much to contribute – albeit with a caveat. As disabled people are experimenting/exploring a new visualisation, a new experience of the erotic, D-P-W's have the opportunity, together with disabled people to disrupt and subvert notions of wholeness and beauty. This will only happen when both communities challenge traditional gendered notions of the body beautiful and embrace beautiful in all its different forms.

Summing up:

In this chapter, I have attempted to refute the idea that the joining of disability and desire is oxymoric by introducing and exploring attempts by disabled people themselves to journey into the erotica of impairment and play with a positive ascetic. In addition, I have introduced the communities of 'devotees, pretenders and wannabees' into our discussion

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[375] In contrast to the suggestion that disabled women are being exploited by D-P-W. Aguilera (2000) and Kafer (2002) independently note that the vast number of businesses and social organisations are owned or managed by the women themselves.

as oppositional trajectories of desire in order to push the envelope further around affirmations of disability desire. No doubt if we start to put desire back into disability – this invocation might gain a foothold. Butler informs us

> … that language only persists through repeated occasions of that invocations. That language gains its temporal life only in and through the utterances that reinvokes and restructures the conditions of its own possibility (Butler, 1997: 140).

One of the areas underdeveloped in the chapter in need of more research and consideration relates to the phenomena of desiring impairment. It was not long ago that to be a gay man or lesbian was viewed by society as subnormal or at best, deviant. Today the commodification of gay culture has meant that this former abomination is now considered sexy fashion (albeit transitory for some individuals). It is uncertain what the future will hold for the creation of an ethic of affirming disability. By inverting the dominant gaze of disability as negative ontology maybe, we will witness in the future (for better or worse) disability envy, sites where disabled bodies are ‘chic’ and sexy.

CONCLUSION:

> I HATE [it] when people tell me how well I've overcome my disability. To me, it's suggesting that I am separate from my body. But my body is me and I am my body. This includes my disability. It is part of who I am and a part of what makes my body beautiful and a part of what makes me a beautiful person. My disability CANNOT be separated from who I am. I cannot overcome my own body. *Intimate Encounters* Exhibition, Melbourne 2002. (Shain, 2002)

> The power imposed upon one is the power that animates one's emergence, and there appears to be no escaping this ambivalence. Indeed, there appears to be no 'one' without ambivalence. That is to say that the fictive redoubling necessary to become a self rules out the possibility of strict identity. Finally, then, there is no ambivalence without loss as the verdict of sociality, one that leaves the trace of its turn at the scene of one's emergence (Butler, 1997b: 198).

I have resisted the usual writing convention of ending a work with a conclusion that neatly ties up loose ends, and provides summaries of the argument presented forthwith. There are no easy endings to the conversation about ontological configurations of disablement. Clarke and Fujimura's (1992b: 28) use of the metaphor of 'the puzzle' captures the non - linearity and disjuncture of such an inquiry:

> … we are puzzle inventors and puzzle solvers. We construct the pieces that compose the puzzle of doing scientific work and wrestle with the problems of how pieces can be made to fit together in order to proceed. In the process, we construct the puzzle itself, and reconstruct it many times over to account for its (and our own) transformative processes. We find there are multiple solutions.

Nonetheless, there are formal expectations by academic bodies as to the composition of a conclusion in a doctorate that needs to be complied. Having noted the requirements, this chapter revisits the purpose of the doctorate as stated in the *Introduction* and provides a summation of the findings of the research including the matters of originality, limitations and those aspects of the research that may require further distilment and elaboration. First, I revisit the Statement of Purposes. Second, the chapter provides a commentary on some of the epistemological and methodological challenges that have been part of carrying out this research undertaking. Third, I provide a summation of findings and evaluate the originality and significance of the research. Finally, the concluding component of this chapter focuses on future directions for research.

Revisiting 'Statement of Purpose'

In the *Introduction* to this doctorate I argued that the purpose of this research, *The Great Divide*, was to dispute the self-evidence of categories/entities of disability and impairment and open up a dialogue between the neologism 'disability' and its relationship to that other, 'normalized' state of being – 'ableness'. At the same time, the doctoral project was committed to examining the production and practices of epistemologies of ableism. By examining both negative and affirmative sites of discursive production of disability, the research has contributed to exploring the operation of ableism within a range of social, legal, religious and technological contexts.

Epistemological and Methodological Challenges

Borrowing Clarke and Fujimura's (1992b) trope of the 'puzzle' it needs to be reiterated at the 'closure' of the doctorate, that theorizations about the puzzle of ableism are still in their infancy. Due to the newness of this inquiry, in planning the research I was faced with a difficult decision – whether to concentrate on matters of *breadth* or *depth*. Whilst both strategies have merit, given the paucity of research that *explicitly*[376] examines the

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[376] This point is significant because much of the disability studies research 'talks around' notions of ableism without bringing ableism as an explanatory and named construct into the center of theorization. The doctorate because of its express and explicit naming of ableism as a focal concern is already 'original' in its oppositional standpoint and conceptual approach.

practices of ableism, and the corresponding paucity of imagination about its effects (on the part of many scholars and practitioners) I felt that it was critical to cover as much terrain as possible in order to build up a map, to unearth those states of disability ambivalence. Needless to say, the many focal concerns contained in the chapters could have 'easily' been the subject of a doctoral thesis in their own right. As this doctorate comes to a close, I believe that my decision to focus on the breadth of practicing ableism has been a wise one, for I argue that the dissertation in its final form represents a significant contribution to *knowledges* about the practices of ableism and the *way* those practices constitute the ontological subjectivities of 'ableness' and 'disablement'.

This dissertation has 'borrowed' extensively from knowledges outside of the purview of typical disability studies scholarship. Sometimes this has created difficulties in terms of concept transposability, but it has also freed my thinking from the circular insularity that is sometimes evident in the small, albeit growing field of disability studies. Epistemological alliances can be found in strange places – outside of the realm of traditional social sciences – in the worlds of technology, science studies, the arts and autobiographical writings. The argument presented in *The Great Divide* has shown how stories of 'the natural' have made *sameness* thinkable for a particular union of (homosocial) beings. Imagining the boundaries between human and machine, abled and in-valid has been a practice that constitutes particular conditions of visibility and performativity.

Summation of Findings – Originality and Significance of the Research

The epigram by Judith Butler that opens this *Conclusion* provides a fitting place for orientating the discussion concerning the research findings and claims to the originality of the research. Ableism as an epistemology, as an explanatory framework, as an ontological modality frames an individual's subjectivity and thus becomes the power "…that animates ones emergence", complicity and resistance (Butler, 1997b, 198). *The Great Divide,* because of its insistence and perseverance to keep returning to the matter of ableism from which the neologism disability unfolds, can and does, provide an 'original' and certainly different approach to the study of disability. The study is at the same time orthodox and unconventional.

The research is orthodox in the sense that its study of disablement can be located within a growing movement of academic scholarship that examines the emergence of disablement sociologically and historically. Whilst it is important to acknowledge the lineage from which this research descends, the doctoral research breaks with contemporary traditions especially those that are an outgrowth of the Social Model of Disablement (see Oliver, 1990) in the way formations about disability and ableism are explored. Furthermore, the notable features of the work's originality can be found in the unconventional sourcing of methodologies and materials (outside of the conventional wellspring of disability studies) and the way that the research refocuses on ontological concerns, legal constructions and delimitations of disablement, combined with case studies that engage with the field of science studies. The unconventionality of the research is further demonstrated by the focal concerns of Chapter Seven which it is argued 'pushes the envelope' regarding oppositional trajectories of desire and marginality. Overall, *The Great Divide*, it is suggested makes a significant contribution to the study of the ways in which disability is known and can be spoken. In addition, this doctorate's findings point to the production and practices of ableism as being a significant and enduring site of harm, injury and disavowal in the lives of individuals designated as disabled.

In Chapter Two on methodology, I identified a number of questions that I intended to explore and ground the focal concerns of the research. This dissertation has demonstrated in many and varied ways the place disability has occupied in the Western imagination. My analysis moved beyond the usual proposition that disability is the perfected body's alterite Other (perfectibility's constitutive outside) to an appraisal of the *necessity* of corporeal anomaly in maintaining and justifying the practices of ableism. In this respect, the research pointed to the existence or the possibility of developing counter-stories of impairment that resist the ascription of tragedy. In order for ableism to be successful, this dissertation has shown that the creation and *enforcement* of *normate* subjectivity and a *constitutional divide* between 'disablement' and 'ableism' is paramount.

My analysis has built upon and extended the argument of Latour (1993) concerning the practices of *purification* and *translation.* I propose that ableism not only requires that the ontologies of perfectibility and disability remain distinct, fabricated, *purified* (and therefore giving the appearance of being a naturalized, albeit, shifting state of affairs) but that the 'reality' and proximity of *translation* (e.g. hybridity, bodily leakiness and impermanence) remain concealed and unacknowledged[377]. The irony of all this, is at the point in history where there are increasing instances of *translation* due to ageing, hyper and enhancing technologies, yet the constitutional divide demands a denial of the existence of translative practices within its reasoning[378]. This can be seen in the so-called technological achievements in 'overcoming' human deficiency that end up inaugurating new kinds of abnormality and so on. The hiddenness and camouflaging of ableist practices in tandem with the compulsion of all us to become 'productive bodies' has constituted the subject's emergence as either *abled* (but always in deferral) or *disabled* (i.e. permanently deficient- but also in deferral until the day of being re-made whole).

This dissertation has made a significant contribution to theorising about the processes and theoretical delimitations of ableism as a sociological and philosophical construct. My commitment to continually shift the gaze, the questions and the inquiry back to the question of what the study of the formations of disablement tells us about the production, operation and maintenance of ableism is a particular strength. This 'reversal' has been difficult at times to maintain because I, like many other readers and scholars, have been schooled in a tradition that places non-disability at the speaking center of social analysis.

By examining ableism through the prism of disability – new rules are required to be made, as are there new objects of scrutiny to be found. Perhaps one of the limitations of the research is that more attention could have been paid to the processes of ableism by

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[377] Any revelation of such a *translation* provokes offence or a scandal wherein the subject matter is deemed pathological, fetishistic and a consequence of dabbling with the 'natural' order of things.

[378] Whilst it is beyond the confines of this research it would be interesting to examine the role of stabilizing rhetoric such as the return to the arms of romanticism during times of ambiguity – to (re)capture creation as it was before the Fall (in utopic times).

having studied a broader range of ableist objects. One new object of scrutiny that this doctorate explored are the processes of internalised ableism[379] and disability self –hatred. Here I have argued that internalised ableism has produced a desire in the person with impairment to constantly emulate the Other and engage in acts of dis-associative disability disavowal. Ableism has led to disabled people deploying negative ontologies of disability to de-invest in their/our bodies and thus constitute (and fabricate) their subjectivities in spite of embodiment.

Based on such a contribution this section provides a summary of key findings of the research:

In Chapter Three the research identified a number of key genealogical formations figuring disablement within western history/philosophy. These formations were identified as modes of inquiry into ambiguous or aberrant bodies along the lines of "What is it?" (in ancient times), to "Who are you?"(the enlightenment obsession) and the contemporary bio-ethical conundrum of "Do you wish to be?". The chapter also surveyed and provided a critical argument related to some of the problematical aspects of attempts to 'write' the disabled subject back into history in circumstances where disabled people had been made invisible. The second focal concern of the chapter considered theological renderings of disability and assessed whether elements of the Judeo-Christian ethic were able to be salvaged and transformed from within the context of a tradition of abusive theologies of impairment. This chapter was able to present feminist and

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[379] Please note I am not referring to 'low self esteem' as this is not a psycho-social study. By referring to *internalized ableism* I am elevating our discussion beyond the atomistic individual to the level of subjectifying discourses in the realm of the social.

ecological theologies of suffering and relationality that can contribute to an ongoing conversation about practical theology within Christian churches. In addition, the exegetical case study of the call of Moses not only provided an over due example of a biblical character who is imbued with affirming disability characteristics but can also act as a catalyst for the developing a new theological basis of leadership (and mentoring) within religious communities and in the secular sphere.

Chapter Four provides a sustained argument related to the production and performance of ableism. Not only does the chapter draw together recent theorising about this concept; it interrogates those formulations and calls for a re-orientation of disability studies research to shift its gaze from disability to the study of regimes of ableism at the level of ontology, ethics and praxis. Additionally in the study of ableism, the research specifically identifies its keys elements and internal contradictions that persistently position disability as inherently negative and the normate state of being as ontological preferable. In my discussion of the double bind of ableism[380], the research (drawing on the formulations developed by Bruno Latour (1993) on partitioning and constitutionalism), proposed a rigorous and original theorisation of the epistemological creation and maintenance of two distinct ontological and epistemological realms called ‘disablement’ and ‘ableness’.

After the presentation of the workings of ableism, the research utilised the previous discussion to introduce and develops argument about the ways in which ableism operates at the psychic level in the lives of people with disabilities. A significant aspect of that discussion relates to the important question of the relationship of impairment to notions

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[380] i.e. The need to claim inclusion but also the compulsion towards simultaneously restating and enshrine the preferability of itself.

of formations of subjectivity, in other words whether disability (in contrast with impairment) is involuntarily adoptive or immutable. Here the research presents a discussion about the relationship between the materiality of impairment and the subjectivity of internalised ableism and disability disavowal. The study of ableism in Chapter Four concluded with a case study that examined the dangers of 'acting out' negative ontologies of impairment within an ethos of ableism within the theatre of law, specifically the proposal to introduce wrongful life tortuous liability claims within the common law jurisdictions of the United States, United Kingdom and Australia.

Chapter Five took on the rather ambitious task of tracing the way the sovereign subject of liberalism is constructed and the way that construction impacts on notions of participative citizenship for people with disabilities. The research concludes that not only is this subject based on an atomistic view of personhood, an essential aspect of its figuration is based on inherently ableist formulations of being-ness. Coupled with this discussion of subjecthood, the work also looks at the drive toward autonomy as a practice of freedom and the implications (ontologically and procedurally) for those individuals unable to become unfree and therefore risks being deemed 'unproductive'.

Within the context of the governing of the welfare state in general and disabled people in particular, the research documents the tensions between the governmentality need to 'know' and count cripples (enumerative and diagnostic fetishism) and the contrasting rhetorical push towards an anti-essentialist understanding of disablement, away from identity politics. The research in an original way introduces and develops the conceptual motif of the *Enumerative Passport* that denotes the processes of authenticating and certifying impairments as well as the resistive strategies of De-cripping™ and Re-cripping™ disabled bodies to overcome prescriptive guidelines.

As part of the inquiry into the governing of disability, the research presented a review and a systematic critique of the philosophy and practices of Social Role Valorisation Theory (SRV), which has acted as a guiding framework for human services practice in the disability sector. Within the context of the dissertation's *Statement of Purpose*, the analysis of SRV is situated as another, albeit enduring practice of ableist norms. Chapter Five concludes with a study of the governing of disability based on the recapitulation of negative ontologies of disablement through acts of legislating disability, resulting in the notion of 'legal' disability and its constitutive outside, namely 'outlaw' disabilities, euphemistically referred to as 'voluntary or 'elective' disabilities. These conclusions are based on a textual and discursive analysis of a series of cases bought before the United States Supreme Court in 1999.

The subject of Chapter Six relates to questions concerning technology and disability and the way that technological developments can mediate modern understanding of what it means to be 'abled' and 'dis-abled'. The research presents an overview and critical analysis of the technological perspective within a number of philosophical traditions and assesses the usefulness of those insights for the theorisation of ableism. Another strategy of the chapter is the discursive analysis of the 'place' of disablement within the movements towards curative and enhancement technologies in particular those technologies that promise the mimicking or morphing of normalcy. Similar to the previous chapter, the philosophical analysis is drawn together using case studies. In this chapter, the research examines the first forearm transplant received by amputee Clint Hallam. The second case study, based on Actor Network Theory and critical science studies, explored the selling of the Cochlear implant, as a doable technology purported to create ‘hearingness’. In both these case studies the focal concerns are linked back to the broader schema concerning the operation of ableism.

As part of the doctoral project to create sites of resistance including oppositional counter-stories of disability, Chapter Seven ventured into the area of desire and disability, which initially may appear to be an oxymoron. The research provided a review of significant ways of theorising desire within philosophical traditions and makes an assessment as to their usefulness in developing an affirmative approach to disability that rejects the notion of disability as a mark of deficiency. The chapter provides a study of the disability (amputee) devotees and the ways in which devotees negotiate their subjectivities including the proposal to pathologise this kind of desire. A study into the devotee phenomena provided the research with fertile ground from which to consider the possibility of affirmative ways of desire disability outside of the discursive operation of ableism and the ways in which ableism attempts to reinforce its explanatory power through pathologisation of ‘deviant’ desiring.

This research has raised many questions and pointed to the complexities of delineating disablement and ableness. The research has found that to dismantle the ‘great divide’ it is necessary to (a) create scholarly environments and sites of daily practice that *unthink* hegemonic foundations of disablement and ableism; and (b) there is an ongoing requirement to destabilise the constitutional separation of ableness and disablement and instead argue for the existence of 'mixtures' (see Latour, 1993).

Future Directions

This doctorate's focus on the breadth of ableist practices has now made it possible and indeed feasible to explore particular aspects of ableism and technologies of disability production in greater depth. I wish to include in this chapter some brief proposals for future research based on specific chapter enquiries. The doctorate's argument and analysis has been supported by a methodological style of *meta-alternation*, somewhat antithetical to a methodological coherence approach. The approach adopted, was intentional in the belief that one single approach would not be elastic enough to be responsive to the broad terrain of materials, objects and disciplinary focus under study. However, as a future project it would be interesting to explore the research outcomes of the focal concerns of the doctorate using a uniform theoretical framework and the consequent insights that maybe derived.

In Chapter Three, I raised some of the problematisations of writing disability into history. More research is needed to fully develop 'general' (genealogical) histories of disability (and ableness). Such a development will contribute to the teaching of disability studies and for the practice of mentoring affirmative representations of impairment. Similarly religious traditions, despite the emergence of secularism in the West, continue to play a critical role in the modern world. Counter theological Christian discourses are critical not just for believers but for the development of emancipatory charisms of human services agencies and the ongoing destabilization of abusive theologies of disability. An area in need of more research relates to beliefs about ableness and disablement in the Buddhist and Islamic traditions.

My explorations of the politics of ableism and disability (self) hatred in Chapter Four are in many respects preliminary and only uncovered the ‘tip of the iceberg’. Greater theoretical dialogue and discernment are necessary around the identification of ableist processes and practices. The non-essentialising and non-universalising approach (in keeping with poststructuralism) to theorizing ableism is a ‘hard road’ to follow. Research on the particularity and specificity of ableist practices is demanding but necessary, especially in relation to mediating and assessing the ethics of biomedical and technological developments[381].

In Chapter Five I examined the government of disability within a liberal welfare state. In particular, I pointed to a convergence between technologies of biomedicalism and practices of enumeration that enact states of (legal) permissible disability as well as those of the outlaw (voluntary/elective) kind. The role and dynamic of what I have called an *Enumerative Passport* requires expansion, probably through exploration of certain sites of enactment (e.g. localised case studies – social security and notions of ‘permanency’ criterion). Similarly, critical legal studies are well placed to research the ways (ableist) bodies of law translate and purify notions of ableness and disablement within case and statute law.

Relational technologies have always played an important role in the lives of people with disabilities. However, the shape and impetus of those technologies has not been directed

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[381] This point is important to order to guard against glib negative and determinist evaluations of technologies.

by the user but by the imperatives of service agencies and government in the name of making us (more) productive. As long as disability is conceived in terms of deferral (a 'holding bay' mentality), its relationship to technological applications will prove to be problematic. Technologies of possibilities are just that – possibilities. Where there are possibilities there are dangers but there are also moments where the practices of those technologies can have unintended consequences, consequence that may destabilize the practices of ableism. Much will depend upon disabled people developing counter stories about technologies and new ways of imagining our diversities of embodiment.

Chapter Seven of this dissertation presents, I believe, one of the greatest challenges to confounding and disrupting ableism. Research on desiring disability is dangerous - because it is peripheral and because some may find such a study abhorrent. There is much work to do in this journey into the unknown: work that may disturb the 'great divide'. The advice of Foucault (1997d (orig 1982), 236) speaking in another context can provide the future researcher some solace in this quest:

> …listening is linked to the fact that the disciple is not under the control of the master but must listen to *logos*. One keeps silent at the lecture: one thinks about it afterward. This is the art of listening to the voice of the master and the vice reason in the self.

Heeding Foucault's wisdom, the matter of desiring disability needs a process of discernment, a listening with the 'ear of the heart' and pondering connections, implications and ontologies.

Some Final Words …

At the closure of the dissertation, I am left with two strong images of living with impairment. The first is of disabled people as *survivors*. It should be clear by now that people with disabilities labour under the pain and burden of violence - violence that is epistemic, psychic, ontological and physical. This labouring has resulted in lives of *ontological vulnerability*. There is an ethical necessity on the part of scholars to interrogate the violence and speak of its injuries (Gramsci, 1971). By exposing the practices of ableism and unravelling the psychic life of internalised ableism I have attempted to do justice to uncovering the insidious harm beyond the realm of daily discrimination (see esp. Chapter Four). In unearthing various states of injury, (to use Wendy Brown's (1995) expression), I am mindful of the necessity when reiterating the violences and injuries of ableism that I am not as part of that iteration re-performing them[382]. To do so would be to fall victim to a theorizing that reinstitutes the notion of an overwhelming vision of catastrophe, where disabled people are forever sucked into the vortex of being perpetual victims (LaCapra, 1994; Roskies, 1984).

The second image is of disabled people engaged in guerrilla activity – rejecting the promises of liberalism and looking elsewhere, daring to *speak otherwise* about impairment. For too long sociologists have figured places of marginality and liminality as places of exile – where the emarginated are to be 'brought in from the cold' and integrated so that they too can sit beside the 'warm fires' of liberalism (and all will be well). However, as Bell Hooks reminds us, the margin can be "… more than a site of

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[382] There is a tendency within social sciences to aggregate and rank injustice.

deprivation … it is also the site of radical possibility, a space of resistance" (hooks, 1990: 149). Counter-story telling within this dissertation would not have been possible without the 'new' confidence of people with disabilities – due in part to increasing opportunities in the west to access education, read and discern hegemonic knowledges and design counter stories and counter desires.

The Great Divide has engaged in acts of counter-storytelling in order to give credence to this radical possibility Hooks speak of. Spaces of resistance have been enacted within this work for speaking and include: counter-stories of resistance within history and leadership (Chapter 3). The doctorate has considered the use (abuse) of statistics that enact practices of enumeration and pointed to acts of 'recripping™' and 'decripping™' on the part of disabled people to destabilise administrative regimes (Chapter Five). Counter-stories where disabled people subvert the meaning given to their ascribed role as docile patients in the performance of phantasmic technological applications such as cochlear implants and hand transplantation (Chapter Six) and finally counter-stories about the disabled body as desirable (Chapter Seven).

How far the notion of reclaiming difference will take off in the lives of disabled people is open to speculation. Such reclamations of difference will no doubt bring us an insight and greater clarity about the ways ableist power(s) produces assignations of difference as well as the way those assignations enable the government of disability.

APPENDICES

Appendix 1: The Governing of Disability in Australia

Level 1: Genealogies of Knowledge

- religious (?)
- biomedical (hegemonic) – new genetics
- Extropianism and Transhumanism
- professional-administrative
- citizenship-rights
- social model (neo-Marxist)
- post-structuralist (Esp. Foucauldian)

⇩

Level 2: Cultural Arena: Values/political philosophy

- Liberalism (human rights discourse)
- Parsonian functionalism (values theory)
- Normalization theory (Nirje)
- Social Role Valorisation theory SRV ~ (Wolfensberger)

⇩

Level 3: Function, Structure, and Institutions: government arena
Law & social policy

- shift in locus of power: policy of "deinstitutionalisation"
- contestations around the welfare state
- citizenship discourse
- Legal battles over the (legal) delimitation of disability definitions
- shifts in policy discourse: preparation (SRV as derivative)⇨ participation (SRV as evaluative) paradigm:

⇒ Disability Services Act 1986 (Clth)
⇒ Disability Discrimination Act 1992 (Clth)
⇒ Disability Services Act 1992 (QLD)
⇒ Anti-Discrimination Act 1991 (QLD)

⇒ Court decisions

⇩

Level 4: Procedures and techniques of power

- administrative/regulatory rules, including funding guidelines and prescribed service outcomes, general service plans, quality assurance management
- regime of competency development
- behavior modification
- curriculum sequencing and skills assessment (individual programme planning)
- tables of "disablement"
- discourses of "empowerment": from self-determination/control ⇨ "participation"

Appendix 2: Disability, Ageing and Carers: Changes over Time for Disability Surveys (ABS)

COMPARISON OF ABS DISABILITY SURVEYS

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Source: Australian Bureau of Statistics, Online at: http://www.abs.gov.au/websitedbs/c311215.nsf/20564c23f3183fdaca25672100813ef1/5f41d2ecf62f1219ca2569440005e3b1!OpenDocument

Appendix 3: Relevant Case Law in Wrongful Birth/Life Torts

1. United States of America[383]

Cases Recognizing Wrongful Birth

State	Case Name	Citation
Alabama	Keel v. Banach	624 So.2d 1022 (Ala. 1993)
Arizona	Walker ex rel Pizano v. Mart	790 P.2d 735 (Ariz. 1990)
California	Andalon v. Superior Court	208 Cal. Rptr. 899 (Ct. App. 1984)
Colorado	Lininger v. Eisenbaum	764 P.2d 1202 (Colo. 1988)
Delaware	Garrison v. Medical Center of Delaware	571 A.2d 786 (Del. 1989)
District of Columbia	Haymon v. Wilkerson	535 A.2d 880 (D.C. 1987)
Florida	Kush v. Lloyd	616 So. 2d 415 (Fla. 1992)
Illinois	Goldberg v. Ruskin	499 N.E.2d 406 (Ill. 1984)
Indiana	Bader v. Johnson	675 N.E.2d 1119 (Ind. App. 1997)
Kansas	Arche v. United States Dept. of Army	798 P.2d 477 (Kan. 1990)
Louisiana	Pitre v. Opelousas General Hosp.	519 So.2d 105 (La. 1987)
Maryland	Reed v. Campagnolo	630 A.2d 1145 (Md. 1993)
Massachusetts	Viccaro v. Milunsky	551 N.E.2d 8 (Mass. 1990)
Michigan	Proffitt v. Bartolo	412 N.W.2d 232 (Mich.Ct.App. 1987)
Nevada	Greco v. U.S.	111 Nev. 405 (1995)
New Hampshire	Smith v. Cote	513 A.2d 341 (N.H. 1986)
New Jersey	Berman v. Allan	404 A.2d 8 (N.J. 1979)
New York	Becker v. Schwartz	386 N.E.2d 807 (N.Y. 1978)
Ohio	Flanagan v. Williams	87 Ohio App.3d 768 (1993)
Texas	Jacobs v. Theimer	519 S.W.2d 846 (Tex. 1975)
Virginia	Naccash v. Burger	290 S.E.2d 825 (Va. 1982)
Washington	Harbeson v. Parke-Davis, Inc.	656 P.2d 483 (Wash. 1983)
West Virginia	Jennifer S. v. Caserta	332 S.E.2d 872 (W. Va. 1985)
Wisconsin	Dumer v. St. Michael's Hosp.	233 N.W.2d 372 (Wis. 1975)

Cases Rejecting Wrongful Birth

State	Case Name	Citation
Georgia	Atlanta Obstetrics v. Abelson	398 S.E.2d 557 (Ga. 1990)
Missouri	Wilson v. Kuenzi	751 S.W.2d 741 (Mo. 1988)
North Carolina	Azzolino v. Dingfelder	337 S.E.2d 528 (N.C. 1985)

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[383] http://members.tripod.com/~Wrongfulbirth/case.htm

United States Cases continued …

Cases Recognizing Wrongful Life

State	Case Name	Citation
California	Turpin v. Sortini	643 P.2d 954 (Cal. 1982)
New Jersey	Procanik by Procanik v. Cillo	478 A.2d 755 (NJ 1984)
Washington	Harbeson v. Parke-Davis, Inc.	98 Wash.2d 460 (Wash 1983)

Cases Rejecting Wrongful Life

State	Case Name	Citation
Alabama	Elliot v. Brown	361 So. 2d 546 (Ala. 1978)
Arizona	Walker v. Mart	790 P.2d 735 (Ariz. 1990)
Colorado	Lininger v. Eisenbaum	764 P.2d 1202 (Col. 1988)
Delaware	Garrison v. Medical Ctr. of Del., Inc.,	581 A.2d 288 (Del. 1990)
District of Columbia	Haymon v. Wilkerson	535 A.2d 880 (D.C. 1987)
Florida	Kush v. Lloyd	616 So. 2d 415 (Fla. 1992)
Georgia	Atlanta Obstetrics v. Abelson	398 S.E.2d 557 (Ga. 1990)
Illinois	Siemieniec v. Lutheran Gen. Hosp.	512 N.E.2d 691 (Ill. 1987)
Kansas	Bruggeman v. Schimke	718 P.2d 635 (Kan. 1986)
Louisiana	Pitre v. Opelousas Gen. Hosp.	530 So. 2d 1151 (La. 1988)
Massachusetts	Viccaro v. Milunsky	551 N.E.2d 8 (Mass. 1990)
Michigan	Proffit v. Bartolo	412 N.W.2d 232 (Mich App. 1987)
New Hampshire	Smith v. Cote	513 A.2d 341 (N.H. 1986)
New York	Becker v. Schwartz	386 N.E.2d 807 (NY 1978)
Ohio	Flanagan v. Williams	623 N.E.2d 185 (Ohio Ct. App. 1993)
Texas	Nelson v. Krusen	678 S.W.2d 918 (Tex. 1984)
West Virginia	James G. v. Caserta	332 S.E.2d 872 (W. Va. 1985)
Wisconsin	Dumer v. St. Michael's Hosp.	233 N.W.2d 372 (Wis. 1975)
Wyoming	Beardsley v. Weirdsma	650 P.2d 288 (Wyo. 1982)

Cases of relevance in other countries

2. United Kingdom

Case Name	Citation
McKay v. Essex Area Health Authority & ors	[1982] 1QB 1166

3. Europe

Country	**Case Name**	**Citation**
Italy	Valenti v. Castaldini	Tribunal of Verona 1990
France	Exp Perruche c/ Mutualle d'assuance du corps sanitaire francais et al	Cour de Cassation, arret n. 457 P, Juris-Data n. 006884, 17.11.2000

4. Australia

State	**Case Name**	**Citation**
Victoria	Watt v. Rama	[1972] V.R. 353
New South Wales	Bannerman v. Mills	(1991) Aust Tort Reports 81 - 079
Queensland	Veivers v. Connolly	(1994) Aust Tort Reports 81 – 309
New South Wales	CES v Superclinics (Aust) Pty Ltd 1995	(1995) Aust Tort Reports 81 – 360. (CA NSW).

Appendix 4: The Transhumanist Declaration of the World Transhumanist Association

(1) Humanity will be radically changed by technology in the future. We foresee the feasibility of redesigning the human condition, including such parameters as the inevitability of aging, limitations on human and artificial intellects, unchosen psychology, suffering, and our confinement to the planet earth.

(2) Systematic research should be put into understanding these coming developments and their long-term consequences.

(3) Transhumanists think that by being generally open and embracing of new technology we have a better chance of turning it to our advantage than if we try to ban or prohibit it.

(4) Transhumanists advocate the moral right for those who so wish to use technology to extend their mental and physical (including reproductive) capacities and to improve their control over their own lives. We seek personal growth beyond our current biological limitations.

(5) In planning for the future, it is mandatory to take into account the prospect of dramatic progress in technological capabilities. It would be tragic if the potential benefits failed to materialize because of technophobia and unnecessary prohibitions. On the other hand, it would also be tragic if intelligent life went extinct because of some disaster or war involving advanced technologies.

(6) We need to create forums where people can rationally debate what needs to be done and a social order where responsible decisions can be implemented.

(7) Transhumanism advocates the well- being of all sentience (whether in artificial intellects, humans, posthumans, or non- human animals) and encompasses many principles of modern humanism. Transhumanism does not support any particular party, politician or political platform.

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