THE DISABLED BODY:
STYLE, IDENTITY AND LIFE-WRITING

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PREFACE & ACKNOWLEDGEMENTS

The Disabled Body investigates disability life-writing and what it reveals about the experience of disability, disability studies and its attendant identity politics, and the role of embodiment in writing. It combines a comparative analysis of theoretical models with close readings of a range of inter-related primary texts in order to theorise new, literary ways of appreciating disability and embodiment.

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ABSTRACT

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The Disabled Body investigates disability life-writing and what it reveals about the experience of disability, disability studies and its attendant identity politics, and the role of embodiment in writing. It combines a comparative analysis of theoretical models with close readings of a range of inter-related primary texts in order to theorise new, literary ways of appreciating disability and embodiment.

The thesis begins by focusing on the limitations of the dominant social model of disability and their impact upon approaches to disability life-writing within disability studies. Expanding upon Tom Shakespeare's assertion that the social model is a political intervention rather than a robust theoretical model, I argue that the rejection of autobiography by initial literary approaches to disability in the 1990s was based on the criteria of the identity politics informed by the social model, which disregards individual, personal and experiential accounts of disability as embodiment.

A growing number of thinkers, such as Rose Galvin and Jim Swan, have since criticised the social model for such neglect. By combining such positions, I construct a theoretical framework through which to re-examine autobiographical writing with regard to four authors with disabilities presented as a sequence of case studies: Christy Brown, Christopher Nolan, Ruth Sienkiewicz-Mercer and Christopher Reeve.

Following G. Thomas Couser's distinction between writing from 'disability experience' and writing from 'disability culture', I complement analyses of this sequence of autobiographies with an examination of several anthologies of writing by disabled authors, which are implicated in a 'disability culture' based on social model identity politics.

In the course of this thesis I demonstrate how an analysis of the experiential aspect of disability life-writing can bring a new understanding of the way in which the body makes itself known in language, which is of significance not only to literary disability studies and disability studies in general but also to the wider field of literary studies.

CONTENTS

INTRODUCTION

This thesis explores the inter-relationship of disability and life-writing. The issue of what disability *is* rages on, with prominent disability studies scholar Tom Shakespeare insisting as recently as 2006 that the very foundations on which the field is built are flawed. Such claims in turn complicate the matter of just what the 'disability experience' and the 'disability identity' politics that have arisen out of explorations of it are. Life-writing in particular has shaped, and been shaped by, such debates. Lennard J. Davis has warned against 'narrativizing an impairment' because it 'tends to sentimentalize it and link it to the bourgeois sensibility of individualism and the drama of an individual story' (Davis 1995, 4). Similarly, David T. Mitchell and Sharon L. Snyder initially rejected autobiography because of what they saw as its association of disability with a 'lone figure' (Mitchell and Snyder 1997, 9-13). Life-writing has been re-appraised more recently as a putative disability aesthetics has made its mark in reshaping literary convention. Key to the

development of this disability aesthetics has been a renewed interest in *the*

perennially vexed aspect of disability: the body. New appreciations of what

disability is allow for the rehabilitation and reconsideration of older texts which

were shunned by the first wave of arts-based disability studies approaches, such as

Davis' *Enforcing Normalcy* (1995) and Mitchell and Snyder's *The Body and*

Physical Difference (1997), for their apparently more traditional nature, but can

now be seen to offer representations of experience that are not mediated by an

identity politics which now risks being discredited. Simultaneously, an aesthetics of

disability which takes the body into consideration offers exciting new possibilities

both for literary expression, and for understanding literature.

Midway through its fourth decade, the disability movement is arguably

becoming a victim of its own success with regard to literature. Its political

achievements, such as the Americans With Disabilities Act (1990) and the UK

Disability Discrimination Acts (1995, 2005), have undoubtedly been influential in

facilitating the self-awareness and self-expression which has led to a boom in the

writing of, and interest in, work by people with disabilities. However, now that

political claims for recognition have (however superficially) been met, the lack of

political direction and stagnation in the movement as perceived by Tom

Shakespeare has led analytical voices, growing in number and sophistication, to turn

from politics to other aspects of the disability experience, in the process revealing

the shortcomings of current, politically inflected, theories (Shakespeare 2006, 1).

Paul K. Longmore, key historian of the disability movement, perceives such

questioning simply as part of the next stage of the movement: the creation and

consolidation of a 'disability culture' based on existent disability identity politics

(Longmore 2003, 215). Much of the literature and analysis produced as part of this 'culture' sticks firmly to the political orthodoxy of disability rights by insisting that the body ('impairment') is irrelevant to disability, and that accounts of individual experience focusing on it, especially those in traditional narrative forms from dominant discourse such as autobiography, are at best misguided, at worst oppressive. However, other writers, and some disability studies academics, have found such dogma theoretically wanting and have sought ways to explore these forbidden topics. Through their work I aim to reconsider the body's role in the disability experience, and the writing of it, and to rehabilitate maligned forms such as autobiography, dismissed by earlier disability studies approaches to literature, and to demonstrate new possibilities for agency, expression and an appreciation of the aesthetic literary qualities of disability.

I will show that the conventional social model of disability, upon which much disability studies and disability rights work is based, is inadequate in its theorising of the disability experience. Key to this will be the idea that the social model's splitting of disability into social ('disability') and somatic ('impairment') experiences is useful only as a 'political intervention' and is in no way theoretically complex enough to serve as a model for the embodied experience of disability (Shakespeare 2006, 33). Next, I will show that early applications of disability studies to disability life-writing, based on the social model, were shaped too much by the model's political aspect to employ a truly literary approach to disability. Such an approach would include an appreciation of aesthetics, incorporating a linguistic analysis, which would trace the influence of the author's disability experience on the shaping of the text's style and content and of their disability on

the production of the text. Thus, such an approach would need a far more robust theory of embodiment, embodied identity (as the social focus of identity politics is tainted by its social model origins), and the relationship between language and the body than the social model can offer. To compile an appropriate methodology it is necessary to combine a variety of approaches not just from disability studies and literary disability studies, but other fields such as medical anthropology and psychotherapeutics. I will show that this new, literary approach to writing by people with disabilities will in fact serve to highlight the agency that the individual can have over literary convention, and that the disabled body can be a resource in this agency. Ironically, therefore, this literary approach identifies more potential for freedom and self-expression than the supposedly liberational orthodox disability studies approach, which has in the past tended to see literature as rigidly structured and controlled by a dominant discourse hostile to disability. Having established a theoretical context within which to approach the object of study, I will use close readings of several carefully selected texts to elucidate and test this new approach. The final aim of this thesis is to apply the conclusions drawn from this methodology and these readings in order to posit what this subject of study reveals about, and offers to, the broader field of literary studies.

This thesis will make a number of contributions to knowledge which are intimately inter-related. Firstly, it will test and analyse the strengths and weaknesses of current models of disability both in their application to the disability experience and to literature. Secondly, its synthesis of a more robust model for a literary approach to disability will enrich both broader disability studies and the sub-category of literary disability studies. Thirdly, in its exploration of what is missing

in previous disability studies approaches to the literary analysis of disability life-writing, this thesis will turn its focus to the body as a source of 'voice': that combination of language and identity, style and content. This focus on the body in writing that disability brings in turn raises the question of a broader appreciation of the writing body in the wider field of literature. A beneficial side-effect of this focus on bodily identity will be to highlight the reductive nature of the identity politics that have dominated and calcified the study of disability into the orthodoxy of 'disability studies', and to show ways in which disability may be studied and theorised in a more universal, less separatist fashion, not as an end in itself, but as a topic which challenges and offers new modes of conceptualisation throughout the humanities with regard to the body and embodiment.

The research approach for this thesis involved two inter-related strands. My initial research on the inter-relation of disability and literature led me to the first prominent applications of disability studies theories to literature from the 1990s such as those of Lennard J. Davis, David T. Mitchell and Sharon L. Snyder. I focused on their analysis of narrative genres, in particular autobiography, noting their conclusions that narrativising disability through writing, and in particular through an autobiography with its emphasis on the individual, would be undesirable because it would, through the formal conventions of the genre, allow the rendering of the disability experience only in the traditional, oppressive terms of dominant discourse. Yet, in my examination of a traditional and popular autobiography by a person with a disability, Christy Brown's *My Left Foot* (see Chapter 1), a close-reading revealed an alternative frame of reference within the text in the shape of persistent reference to, and attempts to express, a disability experience outside of

the plain, simple, discourse in which the text was related, which was continually addressed by a vocabulary which invoked the trope of the physical. These impressions were strengthened by an examination of the autobiographical work of 1987 Whitbread Award winner Christopher Nolan, where the same themes were evident, albeit in an acclaimed literary text to which an odd, poetic style, full of archaic, portmanteau and neologistic language, subverting dominant discourse, was essential. Having cemented my view of the disabled body as an integral part of the origin of this alternative discourse, and the role of language in its expression, my research turned to the examination of these issues in disability studies. This swiftly led to a disenchantment with the inadequacies of the social model with regard to its conceptualisation of the body and embodiment, and thus with the early theories of Davis, Mitchell and Snyder that my reading of *My Left Foot* had challenged. My interest in the struggle to express a disabled identity led me to contemporary disability identity politics and the debates over political versus personal, experiential approaches to a disability identity. Critiques of the latter, such as Shakespeare's dismissal of a social, communal disability identity, lent a further urgency to my exploration of the writing of a personal, embodied identity. Identity politics did lead me to the profitable area of study provided by anthologies of writing by people with disabilities, which is addressed in Chapter 5, and to the issues of representation, authenticity, and authority, contentious is a political sense, but also in a literary one, that prompted my study of the works of Ruth Sienkiewicz-Mercer and Christopher Reeve, in Chapter 3 and 4 respectively.

In the rest of this Introduction, I will lay out the complex theoretical basis of this thesis, giving an overview of the development of the disability rights movement,

its influence on the development of disability studies, and the first prominent applications of disability studies to literature. I will show how one model which has in particular dominated disability studies, the so-called 'social model', is inadequate in two particular areas: individual experience, and consideration of the body. Although these shortcomings are problematic for disability studies, they cause even more acute difficulty in considerations of disability autobiography, where individual experience, particularly of the body, is often the central concern of the text. This chapter will then move on to evaluate various attempts within the disability movement to address, remedy, improve upon or supersede these flaws, in order to fashion a theoretical model which will offer a more satisfactory approach to the literary aspects of disability. This is necessary because a disability identity politics based on the social model has sometimes been taken as a given in approaches to disability writing. Paul K. Longmore, for example, has argued that disability writing of the early 21st century is part of a move 'to explore *or to create* a disability culture' (my emphasis) as the next stage of the disability rights and disability studies movements (Longmore 2003, 215). G. Thomas Couser has been more circumspect, carefully distinguishing between writing 'from inside a distinct disability culture' and writing 'from inside the experience of disability' (Couser 2002, 110). Taking Couser's distinction as my cue, I will then embark on detailed readings of several key texts in order to explore the literary processes involved in writing the experience of disability, as distinct from writing from inside disability culture.

In Chapter 1, I examine Christy Brown's autobiography *My Left Foot* (1954) and compare it, thematically and stylistically, with both his first autobiographical effort 'Reminiscences of a Mental Defective' and his later autobiographical novel

Down All The Days (1970). In sharp comparison to these works *My Left Foot* is a written in a plain, simple style. I attribute this to the influence of Dr. Robert Collis, an established author, playwright and autobiographer, who schooled Brown in modern writing, and oversaw his redrafting, and the emergence of the text into the public sphere. Although the text thus appears more conventional than Brown's other works, I argue that *My Left Foot* nevertheless manifests a disability aesthetic. It does so by laying bare the limits of conventional language through repeated reference to the frustrated physicality of Brown's attempts to express an apparently inexpressible experience within it. In Chapter 2, I address two works by Christopher Nolan (like Brown, an Irishman with Cerebral Palsy): 'A Mammy Encomium' (1981) and *Under The Eye Of The Clock* (1987), winner of that year's Whitbread Award. In particular, I focus on Nolan's distinctive style, replete with neologisms and archaic words, frequently as poetic as it is dense, and attribute it to the influence of his body. I note the role that a shift in both politics and aesthetics (as well as a development in medical and prosthetic technology) has played in enabling Nolan both to develop and to employ a language and style that stretches the limits of dominant discourse to reach at meaning, and yet have his work received as art rather than deviance, in a way that Brown, writing decades before, could not. I will also consider the influence of the emergent disability rights movement on the sense of identity explored in Nolan's text, and the opportunities his treatment of that theme offers for a reconfiguration of notions of disability identity.

The influence of the disability rights movement on the shaping of personal narrative is a theme which continues in Chapter 3, with a consideration of Ruth Sienkiewicz-Mercer's autobiography, *I Raise My Eyes To Say Yes*. This text

emerges specifically from the context of the disability rights movement, as the text was only made possible by access to interaction programs as a result of her involvement with the Independent Living Movement, key players in the evolution of disability rights in 1970s America. Although contemporaneous with Nolan's text, Sienkiewicz-Mercer perhaps has more in common with Brown, as her struggle for self-expression is translated into plain language through a long and complicated (both practically and ethically) partnership with her able-bodied co-author, Steven B. Kaplan. Yet, due to her long-term incarceration in a state hospital and lack of exposure to education or therapy, Sienkiewicz-Mercer is barely literate and extremely limited in her ability to communicate, and thus the implications for authenticity and authority in regard to her story are even greater than that of the Brown's. In its demonstration of how the personal and the political interact, particularly in regard to the notion of 'voice', the case of Sienkiewicz-Mercer foreshadows the consideration of anthologies of writing by people with disabilities to be addressed in Chapter 5.

Before this, however, the personal and the political voice are considered in a rather different way in Chapter 4, which considers the two volumes of autobiographical writing by a particularly divisive figure in the recent history of disability: Christopher Reeve. Perhaps the most famous of all the disabled autobiographers featured here, Reeve is also, paradoxically, perhaps the least representative, and perhaps the least 'disabled', in a number of senses: his wealth and status arguably protected him from the poverty and stigma most people with disabilities experience, his access to the very best of medical care and equipment gave a 'normality' to his daily life experienced by few of his putative peers, and

facilitated a writing process that was arguably smoother – and more oblique – than any other considered in this thesis. Most significantly of all, however, according to the rationale of the disability rights movement (such as Mary Johnson in *Make Them Go Away*), Reeve was not 'disabled' because he refused to identify with the movement, showing little interest in their agenda but instead devoting himself to 'cure', seen by them at best as a fool's errand, at worst as a negation of the value of the life of every person with a disability. According to this perspective, therefore, the tremendous popularity of Reeve's two autobiographical volumes, *Still Me* (1998) and *Nothing Is Impossible* (2002) was a disaster for disability rights as a social movement. In the light of his reputation, I will consider these two works, not just thematically but stylistically. I will argue, using Sparkes and Smith's theory of narrative, that *Still Me* manifests a failure to adjust to his new disabled identity, but that *Nothing*, more a collection of short essays than an autobiography, has a formal similarity to the personal essay style championed by Couser as discussed in Chapter 5. This surprising revelation can, I argue, be attributed to the impact of the body on the writing process and the writing voice: regardless of the political identification (or lack thereof) on the part of the author.

Finally, in Chapter 5, I will analyse several anthologies of disability writing, much of which relates personal experience of disability. These volumes cover a period which extends from the emergence of an identity politics based on the social model in the late 1970s to the crisis in disability identity politics at the end of the 20th century. Keeping in mind Longmore's comments regarding the manufacture of disability culture, I will seek to determine whether these collections offer a forum for new considerations of experience, and new styles of writing, and thus act as a

means to expand the limits of discourse as Nolan has, or whether they in fact serve

to disseminate an identity politics that homogenises disability experience as

something political and social rather than personal and embodied, thus laying

themselves open to the charge of Birkenbach, as cited by Shakespeare, that: 'There

is no unifying culture, language or set of experiences; people with disabilities are

not homogenous, nor is there much prospect for transdisability solidarity'

(Shakespeare 2006, 76).

Theoretical background and context

In the 1990s, volumes by American disability studies scholars such as

Lennard J. Davis' *Enforcing Normalcy* (1995) and *The Disability Studies Reader*

(1997) and David T. Mitchell and Sharon L. Snyder's *The Body And Physical*

Difference (1997) marked the first prominent applications of the principles of

disability studies to literature. These principles are, as Tom Shakespeare has shown,

heavily influenced by the UK 'social model' conception of disability which

emerged in the 1970s and became the dominant ideology in the British disability

rights and disability studies movements from the early 1980s (Shakespeare 2006,

70). Indeed, Mitchell and Snyder observe in their most recent book, *Cultural*

Locations of Disability (2006), that the social model 'both preceded and

substantively influenced U.S models' to the extent that even in 2006 disability

studies in the U.S. had not articulated 'its own analytical methods distinct from

those of the British social model practitioners': a problem which they seek to

address via what they term a 'cultural model', as will be shown (Mitchell and

Snyder 2006, 6). Shakespeare argues that the social model was revolutionary for

disability studies in its splitting of 'disability' into 'disability/impairment'. This reconfigured disability as something which is not inherent in the individual (the traditional view), but which is rather constructed and imposed by a disabling society onto individuals with physical impairments (Shakespeare 2006, 29). This model allowed contemporary disability studies to develop as a form of cultural studies by shifting focus away from the individual (and, it is important to note, the individual's bodily impairment) to broader social and cultural processes, in emulation of other theoretical schools linked to social movements, such as feminism (30).

Shakespeare notes that social model advocates have attributed the belief that disability is inherent in the individual to what many still refer to variously as the 'individual model' or the 'medical model' of disability, which they claim the social model challenges. Yet he observes that Michael Oliver, who first posited the idea of a medical model in (binary) opposition to the social model in 1983, had renamed this model first as 'personal tragedy theory' and then 'social oppression theory' by 1990, and by 1996 had 'admitted that "there is no such thing as the medical model of disability, there is instead an individual model of disability, of which medicalisation is one significant component."' Shakespeare observes that nobody in disability studies has ever advocated or affiliated themselves to either a 'medical model' or 'individual model' (15). He concludes that the 'individual/medical' model is in fact nothing more than a 'straw person', a threat invented by social model advocates to bolster the claims of their own perspective (18). The consequence, he notes, has been a disability studies of narrow scope, where all approaches that do not conform rigidly to the social model are deemed individual/medical and therefore irrelevant at best, oppressive at worst (24). This

attitude is typified by the comments made in the mid-1990s by Vic Finkelstein (founder of UPIAS, the activist group who conceptualised the social model) that personal accounts of individual disability experience had 'diluted' the disability rights movement (Marks, 612). In the light of these observations, the limits that the influence of the social model has placed on the early work of Davis, Mitchell and Snyder can be considered. Not only did they approach literature as one of the social and cultural processes implicated in the construction of 'disability', but in doing so, they also displayed a profound distrust of any conception of disability that links it to the individual. This is evident in the way that Davis' exhaustive study of the modern cultural construction of disability in *Enforcing Normalcy* condemns narrative literary genres such as the novel and the autobiography on account of their link to the individual. He argues against 'narrativizing an impairment' because it 'tends to sentimentalize it and link it to the bourgeois sensibility of individualism and the drama of an individual story' (Davis 1995, 4). Similarly, Mitchell and Snyder rejected autobiography in their first book, *The Body And Physical Difference*, because of what they saw as its association of disability with a 'lone figure' (Mitchell and Snyder 1997, 9-13).

It is important to note, however, that the influence of the social model over these literary approaches was not complete, and furthermore that the authors of these early works have since revisited and developed their approaches to literary disability. Shakespeare, who calls for such recognitions of complexity, has noted that Davis has himself attracted the hostility of social model advocates because his work does not make a firm distinction between (biological) impairment and (social) disability (Shakespeare 2006, 24). Mitchell and Snyder admitted in their first book

that autobiography had a potential for capturing the 'unique subjectivity' of 'disability as a physical, cognitive, and social phenomenon': an observation that attests to a model of disability far more complex than the social model, not least in its consideration of disability as an embodied experience (Mitchell and Snyder 1997, 9-13). In their next book, *Narrative Prosthesis* (2000), they return briefly to the subject of life-writing as part of much deeper analysis of methodological approaches to disability studies in the humanities. Here, they note the ground-breaking work of what they term the 'negative-image' school of disability studies critics. They credit this school with insights such as the observations that 'individualising' disability removes it from its social and political context, and that the debasement of disabled characters correlates with demeaning cultural attitudes towards people with disabilities (Mitchell and Snyder 2000, 18-9). In acknowledging that the work of this negative-image school focused on the 'metaphoric opportunism of literature' (a phrase they used in their 1997 book), Mitchell and Snyder apparently concede their earlier adherence to it (18). Yet they now highlight the limits of this methodology that 'found literary depictions to be, at best, wanting, and, at worst, humiliating', and conclude that the weaknesses of negative-image criticism lay in its tendency to 'collapse all representations into a sterile model of false consciousness' and to rely on an overly simplistic notion of 'negative' and 'positive' images of disability (18, 20).

Mitchell and Snyder see this methodology as superseded by what they term 'social realism'. They characterise critics in this school as primarily concerned with the function of literary depictions as correctives to social misapprehensions about the specifics of experiences of disability (21). Such an approach positively invites

the study of disability as an individual experience: thus it is unsurprising that this school embraces autobiography, 'as a representational reality that counters artistic metaphors and opportunistic spectacle' (as Mitchell and Snyder classify it with a persistent distrust of metaphor). As an example of this criticism that aimed for 'a more adequate representation…a more substantive, fleshy substitute' they cite G. Thomas Couser's *Recovering Bodies* (1997), observing that he 'analyses the restorative properties of recent disability memoirs not only to the writers but to the literary tradition itself' (22).

Certainly, *Recovering Bodies* is far more positive in its view of life-writing than Mitchell and Snyder's first book, which came out in the same year: Couser championed, and continues to champion, autobiography as the subgenre of literature 'most likely to realize the counterdiscursive potential of disability narrative' (Couser 1997, 183; Couser 2002, 117). Couser's distance from social model orthodoxy is evident in his approach to the body. Although he concedes that 'pathography' (medical narrative with a 'specialized scientific vocabulary') has alienated people from their bodies by objectifying them, he argues that disability autobiography is a means for 'reclaiming one's body from more than just medical discourse' (Couser 1997, 18-9; 34-5). This represents a step away from the social model, which simply characterises any concern with the body, via 'impairment', as being 'medical model'. Indeed, Couser combines the two things the social model abhors by stating that 'personal narrative', as he calls it, offers 'an increasingly popular way' of addressing 'bodies and bodily experience' (29). By taking this view, Couser repositions 'pathography' as simply one of many ways of writing about the body, rather than *the* dominant and oppressive one. As Shakespeare would do later

(and as Laurence J. Kirmayer did before, as we shall see), he observes that 'pathography' in fact serves the essential purpose of objectively validating the subjective experiences of disabled people. Couser's position allows for agency over, and through, the body by the disabled individual via personal narrative. His endorsement of Kathyrn Montgomery Hunter's view in *Doctor's Stories* (1991), that medical and personal narratives often compete in a 'silent tug-of-war over the possession of the story of illness…over who is to be its author and in what language' is particularly useful in considering the doctor/patient writing relationship of Dr. Collis and Christy Brown in *My Left Foot*, to be addressed in Chapter 1, and the collaborative relationship of Ruth Sienkiewicz-Mercer and Steven B. Kaplan in writing *I Raise My Eyes To Say Yes*, addressed in Chapter 3.

Couser's perspective on individual agency through personal narrative extends beyond the body. Such agency, he argues, is key to autobiography's power to challenge 'hegemonic discourse'. This is in direct contrast to the position originally taken by Davis and Mitchell and Snyder, whereby they view autobiography as a rigid category that will subordinate all efforts at expression to the ideologically imposed limits of its conventions.[1] Couser instead sees the category as flexible and open to change through individual agency, and notes especially the fact that autobiography is the literary genre that is 'historically accessible to minorities' (181). In this approach Couser's work can be related to that of Rose Galvin, whose critique of a structuralist view of language reveals a potential for agency and subversion in dominant discourse that is discussed below. This idea

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[1] Mitchell and Snyder later disavow such rigidity, and criticise Davis' location of literature 'within a post-Marxist framework as a tool of dominant ideology and an organ of oppressive politics' when, they insist, '*disability counternarratives* frequently contest this manner of storytelling' (Mitchell and Snyder 2000, 164).

of flexibility and subversion is crucial to this thesis. It allows Couser to argue for autobiography using the very point with which Davis argues against it: that it is *the* 'literary expression of the self-determined life'. Whereas Davis sees the autobiography as binding disability to the individual, Couser simply sees this focus on the individual as offering the 'ideal mode for contesting the association of disability with dependence' by an individual (182). Yet he notes that subsections of the disabled population, such as the Deaf, have placed emphasis on 'interdependence and cooperation [rather] than on individualism and autonomy' and would thus be unlikely to address expression through autobiography (Couser 1997, 228). This idea has arguably expanded into wider disability thinking in recent years: Martha Nussbaum's *Frontiers of Justice* (2007) has identified the concepts of dependence, independence and interdependence as key to the future development of disability studies. This development is reflected in Couser's later work, where he observes that a refutation of dependence on the part of an individual may remove them from the stigmatising category, but does nothing to de-stigmatise the category itself (Couser 2002, 111). In this way the problem of independence can be linked, as a demonstration of its problems in microcosm, to Shakespeare's critique of identity politics, as we shall see .

Couser's position refutes the belief, intimated in the early work of Davis and Mitchell and Snyder as discussed above, that there is a disability experience which cannot be expressed in conventional forms of discourse, such as autobiography. Indeed he argues that autobiography's strength lies in its dissolving of categories, as it 'may enable individuals with disabilities to cross back over the border into the mainstream or, better yet, to cross out-or at least blur-that border' (182). In the light

of this consideration, it is interesting to note that Couser sees the impossibility of embodiment in the text as a positive, arguing that the text acts as 'a kind of neutral space' that conceals the author's disabled body which 'might otherwise trigger stereotypical responses' from the reader (182). In the light of a more recent concern with how the disabled body makes itself known in the text, and the way this concern has become intertwined with the issue of identity politics, to be discussed below, this idea that the inability to express the body may be a positive is crucial. While Couser sees this neutral space as offering the chance to 'escape, extend, or redraw' boundaries, Davis and those who share his perspective might instead see it as a 'neutralising' or 'normalising' space where the subversive, disruptive difference of the author's identity and experience is inevitably subordinated to the conventions of the genre. Couser himself concedes this possibility with his observation that '[n]orms of realism generally govern autobiography…the laws of nature and culture dominate' (182). This happens, he asserts, because disability is a 'master status' which can invoke particular 'master plots' to which even the most conscientious writer can fall prey (Couser 1997, 216).

Couser's early work also addresses other factors which are relevant to the debate over disability identity politics which would come to dominate literary approaches to disability. For example, he observes that disability autobiography is unrepresentative of the broader disabled population: a point which parallels Shakespeare's charge, examined below, that disability studies and the disability movement are similarly unrepresentative. Noting that disability autobiography has, like autobiography in general, thus far been dominated by white middle-class men, Couser argues that the theoretically accessible form is in practice a culturally

specific endeavour, existing only where literacy, individuality, and the idea of life as a plot are valorised: all of which links back to Davis' categorisation of the genre as bourgeois (216). Yet where Davis perceives structure, Couser discerns change. He cites *I Raise My Eyes To Say Yes*, as addressed in Chapter 3, as evidence of this changing of the parameters and conventions of disability autobiography.

Couser extends his analysis of disability life-writing to the practical issues of the matter. First, he notes that the struggle of living with a disability may make finding the time, energy or even means to write about it 'impossible'. Second, as noted earlier, he observes that the life experience of some chronic disabilities may be 'incompatible with plot of any type – and thus seem unnarratable' (Couser 1997, 183). Third, even if an autobiography is written, he observes, it normally only achieves publication on account of its subject's distinction through 'success or celebrity': with disability, he argues, this carries the risk that disability will become the distinction, objectifying the author, turning the text into a 'case study', and ultimately serving only to reinforce marginalisation (181-3). All of these factors, Couser concludes, mean that disabled individuals 'who represent themselves in autobiography may not in fact be very representative' of people with disabilities as a whole (Couser 1997, 183). Couser returns to this notion of the autobiography as published product in his 2002 essay 'Signifying Bodies: Life Writing and Disability Studies' where he notes that the 'rhetorical patterns of autobiographical display' preferred 'by publishers, if not by the reading public' are 'suspect' (Couser 2002, 111). He gives the example of the 'rhetoric of triumph' which he notes is not only unavailable to most disabled people but in being so also further hardens disability as a category of stigma. Another example is the 'rhetoric of nostalgia' for pre-

disability life, something that will be addressed herein, with regard to the comparison of Christopher Reeve's two volumes of disability life-writing, in Chapter 4 (Couser 2002, 111).

A concern with the political consequences of the unrepresentative autobiography marks Couser's later work. He cites Anne Finger's fear, as quoted in Kenny Fries' introduction to the anthology *Staring Back* (see Chapter 5), that the risk of disability life-writing is that '…if you talk about the pain, people will say, see, it isn't worth it. You would be better off dead'. Thus, he concludes, 'candid representation' of experience may reinforce the assumption that disability 'is necessarily, wholly, and universally a negative experience' (Couser 2002, 111). Furthermore, he notes that the over-representation of some types of disability in life-writing (as admittedly can be seen in this thesis, where three chapters are devoted to individual authors with Cerebral Palsy) can actually give the impression that disability is 'less common than it really is' (112). Conversely, he expresses concerns over 'the accessibility of autobiography as a genre to disabled people' (114).

Couser illustrates a crucial point about the application of disability studies to literature by insisting that the critic has a 'responsibility' to rigorously assess the literary merits of disability writing. Observing that to set aside critical values would be 'patronising', he admits that, of the wide range of disability autobiography he has read, 'little of it may prove to have lasting value as literature in the traditional sense – books that require and reward rereading and close analysis'. This is a particularly important issue with regard to disability-themed anthologies and their context in

identity politics, and is discussed more fully in Chapter 5. Couser himself does not appear to appreciate the significance of this declaration, nor that of the qualifying statement he makes, that every disability autobiography has contributed to 'the development of the discourse of illness and disability' (Couser 1997, 292). In fact, what he has illustrated is the way in which a cultural studies perspective on disability has caused approaches to literature informed by it to focus on political rather than literary and other qualities. Sketching out the spaces left unexamined by this inadequacy might be achieved by adapting Shakespeare's model, wherein he highlights the inadequacy of the social model in capturing the quotidian experience of disability, as discussed below.

A way forward that combines elements of both political and aesthetic approaches can be found in Couser's attempt to address the issue of authority and authenticity in disability autobiography. For it is language – which we might take as a marker of literariness - that is the focus of his comparison of Oliver Sacks' account of temporary disability, *A Leg To Stand On* (1984), and Leonard Kriegel's account of a life living with the after-effects of polio in *Falling Into Life* (1991). In noting Sacks' use of words such as '*abyss*, *horror*, and *lurk*…the lexicon and the rhetoric of the Gothic and the grotesque', Couser scoffs at his claim: 'Now I *knew*, for I had experienced myself…'. Instead, he argues that Sacks' persistent prejudice is 'only too obvious in the language and metaphors he chooses to express his experience' (185, 189). In Kriegel's work (addressed in anthologised form in Chapter 5), however, Couser observes an attempt to modify language in order to modify the way the experience of disability is conveyed. In the book as a whole, Kriegel attempts to 'wrest the metaphor of falling' from its negative connotations,

and to use his experience of learning to fall in polio rehab 'to turn it to his own purpose' as something positive (189). Couser notes that while Kriegel rejects the sort of traditional 'allegorical constructions of disability' targeted by Mitchell and Snyder and apparent in Sacks' work, he employs 'creative use of metaphor' in order to 'deconstruct and neutralize a powerfully invalidating trope' (191). This can be related to Galvin's work on subversion of language and to Laurence J. Kirmayer's understanding of how the disabled body makes itself known through language, both of which are discussed below. This also relates to themes to which Couser returns in his later work. Couser traces this link between authority and language in Kriegel's work back to disability's role as his point of origin as a writer: 'being crippled made him a writer and gave him his subject; indeed it made him an autobiographer' (191). The same could be said of Brown and Nolan. Couser expands upon this to argue that Kriegel's use of the essay form is a result of his experience of disability:

> His characteristic form, significantly, is not narrative (…with
> its confident linear progress) but the essay, a tentative form
> that approaches its subject obliquely (191).

Such a form, Couser argues, allows Kriegel to reiterate and revisit key moments in his disability 'in essay after essay, book after book'. Thus, disability is not narrativized but rather something which permeates 'his sense of identity and his trajectory in the world, his point of view' (190-1).

It is at this point in Couser's analysis that we might pause to draw a line between the work that Mitchell and Snyder produced as his contemporaries in 1997 and their development of their ideas in *Narrative Prosthesis* (2000) and *Cultural Locations of Disability* (2006). In making the above point, Couser's analysis

intersects with their dismissal of autobiography as a viable form of expressing the disability experience, which led them to call in 1997 for alternative 'interpretive paradigms' where disability is 'explored as a condition or an experience in its own right' (Mitchell and Snyder 1997, 17-8). Such calls have given rise to two very different and even contradictory explorations of disability identity in writing, which Couser carefully distinguishes between in his 2002 essay 'Signifying Bodies: Life Writing and Disability Studies' as texts written 'from inside the experience of disability' and those written 'from inside a distinct disability culture' (Couser 2002, 110). This is an important distinction for this thesis, because of the implications it has for studying the origins of the writing of the disability experience. As Couser's distinction suggests, writing from inside this 'distinct disability culture' does not comfortably fit with writings of the experience of disability.

The 'disability experience' and 'disability culture'

The reasons for this view begin to become apparent through the perspective of Paul K. Longmore, disabled historian of both disability studies and the disability rights movement. Longmore argues that an early 21st century move 'to explore *or to create* a disability culture' (my emphasis) has been the next phase of a disability rights movement that began with the pursuit of equal rights, access and inclusion (Longmore 2003, 215). Shakespeare offers an insight into why this creation of a 'culture' by a group where activists and scholars intermingle is problematic. He argues that this intermingling is a result of their shared point of ideological origin in the social model, which is reflected in the fact that many disability studies scholars are or were also activists (Shakespeare 2006, 13-4). This has resulted in an uncritical attitude towards disability politics by disability studies that has been

compounded, he argues, by the fact that the 'social model' is not really a theoretical model at all, but a simplistic 'political intervention'. As such, it is too inflexible and unsophisticated to serve as the basis for complex analytic thought on the disability experience (Shakespeare 2006, 33). The consequence has been a politically inflected disability studies which has disavowed explorations of personal experience on the basis of the assumption that an individual's disability will 'automatically define personal identity' in a *political* sense, and that, in this political form, 'disability identity is a given' (Shakespeare 2006, 70).

As a result of this perspective, disability studies academics have often demonstrated an assumption of the field's right to determine a disability identity which applies to all disabled people. For example, David Pfeiffer, founder of *The Disability Studies Journal*, has insisted in 'Disability Studies and the Disability Perspective' (2003) that it is up to 'scholars in the field to set forth the disability perspective' that he believes is common to all disabled people, while Simi Linton has justified such arguments in *Claiming Disability* (1998) on the grounds that the disability movement represents 'a clearly identified disabled community' (Pfeiffer, 134; Linton 1998, 5). Although Linton has conceded that the disability identity on which this cultural project is based 'has certainly not been comfortably embraced by all disabled people', Shakespeare's account of recent and extensive statistics reveal this as an understatement (5). Although these figures are from British studies, these can arguably be taken as representative given that disability studies is a field whose context is primarily Anglo-American, and whose models have been shown to be cross-compatible. They reveal, he observes, that the majority of disabled people would rather be 'free of limitation or classification' than label themselves 'disabled'.

He notes that more than half of those classified as disabled under the Disability Discrimination Act 'did not define themselves as disabled' in a 2003 survey by the Department for Work and Pensions, and that the prominent and vocal Direct Action Network activist group comprises less than 100 of Britain's 6 million disabled (Shakespeare 2006, 72). Furthermore, a 2002 survey by the British Council of Disabled People revealed that only 3% of respondents had even heard of the social model, let alone identified with it (73). Even the UK Disability Rights Commission, he observes, now uses the term 'people who have rights under the Disability Discrimination Act' rather than 'disabled people' (74). While Shakespeare concedes that the majority of people with a disability therefore hold a view of it which fails to address problems of prejudice and discrimination, he refuses to see this position as negative, choosing instead to admire its implicit rejection of both categorisation and the notion of an exclusive 'normality', a theme to which I will shortly return.

Shakespeare argues that the problems with the assumption of control by disability scholars over disability identity, and thus the 'disability culture' that emerges from it, extend beyond their numerically unrepresentative status. The limitations of the dominant social model have, he argues, stunted the disability studies conception of disability identity, primarily as a result of the model's exclusion of impairment (76). This is apparent in Linton's insistence that people with disabilities 'are all bound together, not by this list of…collective symptoms but by the social and political circumstances that have forged us as a group' (Linton 1998, 4). This position is typical of those Shakespeare criticises for formulating a disability identity that 'becomes voluntaristic and difficult to define or police', as those who are not impaired cannot be definitively excluded, nor can the majority

who have impairments but refuse to identify as disabled be definitively included (Shakespeare 2006, 77). This problem is evident in Linton's position, as her exclusion of impairment forces her to cede 'a certain credibility' to the idea that somebody is disabled simply if they say they are (Linton 1998, 12). In her awkward attempt to qualify this by insisting that someone is disabled only if their 'difference' significantly affects their daily life, the presence of impairment, and the inadequacy of the social model highlighted by Shakespeare, are both clearly apparent (13).

Without impairment, Shakespeare argues, the only universal experience available to disability studies as a basis for identity politics is a sense of 'shared oppression' (Shakespeare 2006, 76). He argues that this vague claim leads to an emulation of other identity politics which is inappropriate to disability, and cites a 1995 study by P. Rose and G. Kiger in order to illustrate the formulaic way in which such identity politics develop. He notes their observation that a 'hitherto excluded community' will acquire a 'voice' through social action in order to improve its constituents' status. Such an approach is not only apparent in Linton's claim that the disabled community has recently found 'a voice' (Linton 1998, 4). For Rose and Kiger continue:

> To bolster their self-image, a group exaggerates and values
> its members' distinctiveness. A sense of injustice and
> resistance leads to increased identification with the group,
> which also promotes the self-esteem of its own members
> (Shakespeare 2006, 75).

This exaggeration and valuing of distinction can be seen in Pfeiffer's claim that people with disabilities are 'unique' in possessing a 'disability perspective' that makes them 'more humane', and possessed of an enhanced empathy 'with other

disadvantaged people' (Pfeiffer, 134-5). Likewise, a sense of injustice can be seen in his insistence that people with disabilities have a unique 'sense of justice [and] a yearning for justice' because each of them is a 'survivor' (135). This is also apparent in Linton's insistence that the 'voice' of people with disabilities emerges from a shared 'outrage at [their] social positioning' (Pfeiffer, 134; Linton 1998, 4).

Such identity politics, Shakespeare argues, are not only unsatisfactory on account of their insecure foundations and failure to accommodate the specific somatic complexity of disability. He cites the hidden dangers of identity politics that have been revealed by Foucauldian approaches to disability such as those of Helen Liggett and Dennis Riley. Liggett, he notes, has observed that:

> [I]n order to participate in their own management disabled
> people have had to participate as disabled. Even among the
> politically active, the price of being heard is understanding
> that it is the disabled who are speaking (Shakespeare 2006, 78).

Shakespeare compares this to Riley's view of 'the dangerous intimacy between subjectification and subjection' in the Foucauldian subject. He also cites Rose Galvin's observation that the adoption of an identity created through the processes of hierarchical differentiation and exclusion means that 'subjugated peoples reinforce their own oppression and restrict their hopes to the belief that they can demonstrate how positive it is to be identified as such': an observation that arguably applies to Pfeiffer's work on the 'disability perspective' (78). Shakespeare concludes from these last approaches that disability identity politics is in fact simply 'victim politics', built on the social model's notion of oppression, which denies agency and alienates subjects from their bodies in much the same way as the 'medical model' has been accused of doing (79). The result, he argues, is a

reassuring but self-defeating 'us and them' attitude, that has become an end in itself rather than a means to an end.

Shakespeare offers Nancy Fraser's analysis of radical social movements, 'From Redistribution To Recognition' (1995), as a model for change. He cites her observation that such movements combine two conflicting challenges (one to cultural injustice and one to socio-economic injustice) that have conflicting solutions (the politics of recognition and the politics of redistribution). Fraser's solution is to abandon the politics of recognition because, as per the Foucauldian models above, recognition will at best leave hierarchies intact, and at worst risk stigmatising the disadvantaged class or force individuals to conform to a group culture that discourages debate. Instead, socio-economic justice should be pursued (80). Such an approach, Shakespeare argues, will lead to an end to 'the prison of identity politics' which, he argues, 'leads to the politics of victimhood and the celebration of failure'. He insists that the goal of disability politics should be to make impairment and disability irrelevant wherever possible. He argues that an 'ethnic conception' of disability identity promotes a 'separatist notion of disability pride' (82).

Although this account of Shakespeare's analysis and arguments may seem somewhat of a tangent, because of its emergence from, and focus on, a sociological context of disability, his work on the influence of identity politics on the analysis of, and shaping of, disability culture is crucial to an understanding of the part played by disability writing in the early 21st century concern with a 'disability culture' identified by Longmore. This is reflected, as was shown above, by Couser's careful

distinction, in 2002, between writing from the disability experience and writing from a distinct disability culture. Couser notes that the early 21st century has seen an increase in not just the quantity, but also the sophistication of disability life-writing. In a move reminiscent of his analysis of Kriegel's essay-based work, he cites Nancy Mairs, Irving Zola and Anne Finger as exponents of a 'personal essay' style that enables them not only to 'narrate the conditions in question' but also to 'reflect critically and politically on disability and culture' (Couser 2002, 115). If this seems dangerously close to the cultural studies approach criticised by Shakespeare, Couser is quick to point out that he does not believe that a political perspective makes these works 'automatically superior' to more traditional narratives. He does state, however, that these pieces tend to include 'higher-order thinking' and 'arguable propositions' rather than presenting 'existential truths'. This statement might be interpreted as privileging an academic, disability studies perspective of disability (and thus one that has been shown above to be politically inflected) over a more experiential, personal exploration of disability. The consequences of such a position have been addressed by Jim Swan in his own analysis of the recent trend towards the 'personal essay' style. Swan cites Lennard Davis' approach to editing the anthology of theory and writing, *The Disability Studies Reader*, as one based on a cultural studies approach to disability. He argues that this approach causes Davis to reject 'the kind of disability writing that appears to be addressed to people without disabilities in order to inform or "sensitize" them about what it is like to be disabled': a result, we might infer, of identity politics and its influence on disability culture (Swan, 285). Swan argues that such an approach means that 'accumulated stories of embodied subjects and voiced bodies' have been discounted, curtailing explorations of the cognitive, experiential aspects of disability. Only through a

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cognitive rather than cultural approach, Swan concludes, can the revelations disability brings to 'the writing of the embodied subject' be addressed (285). His approach to the shortcomings of disability studies' approaches to literature is precisely the sort invited by the inadequacies highlighted by Shakespeare.

Although less critical than Swan, Couser carefully delineates the writing from within 'disability culture' that he has set apart from writing from within the 'disability experience'. He notes that it is produced by writers who 'identify as disabled', and that the development of this subgenre in the early 21st century has been 'stimulated' by the disability rights movement. He also predicts that this style will become more widespread 'in the future'. Like Longmore, he hails this development, arguing that such writing explores the 'positive ways' in which disability 'may create culture' and shape identity (Couser 2002, 116). He refers to this practice as 'autoethnography' because of the way in which such works 'foreground the roots of identity in disability culture'. Couser reveals an attachment to the social model convention here (which perhaps explains his sympathy for 'disability culture' writing) in arguing that the construction of a disability culture through writing serves to 'resist or undermine objectification by some presumptive medical or medicalizing authority'. Nevertheless, Couser leaves some room to manoeuvre by insisting that such writing should be seen as 'defining rather than confining' (117).

An explanation for Couser's enthusiasm for early 21st century 'disability culture' life-writing might be found through comparison of his assessment of the disability life-writing field 5 years earlier in *Recovering Bodies*. Here, he observed

that the majority of disability autobiographies were written by white, middle-class, and formerly able-bodied men: much like the members of UPIAS to whom Shakespeare attributes the rise of the theoretically limited social model of disability. These works, Couser notes, overwhelmingly displayed a 'concern with individual autonomy and freedom'. None of them 'affirm solidarity with a marginalized group' or even 'question the cultural ideals of individualism and independence'. Like Davis, he attributes this to the 'intrinsic individualism' of autobiography (Couser 1997, 198). Yet he highlights two notable exceptions in John Hockenberry and Irving Zola. He observes that Hockenberry's *Declarations Of Independence* (1995), an account of his post-ability career as a journalist, appears on the surface to conform to a fundamental disability stereotype: 'an Inspirational Disabled Person who overcomes impairment through pluck and willpower' (203). Yet, in a subplot which sees the author uncovering the hidden disabled history of his family, Couser observes Hockenberry's determination to 'assert his solidarity with the community of people with disabilities'. In doing so, *Declarations* demonstrates 'the need to attack the basis of stigma as well as to escape it through demonstration of one's "ability" – to assert freedom collectively as well as individually' (205). A similar discovery and attainment of a group disability identity is central to Couser's appraisal of Irving Zola's *Missing Pieces*. Originally intended as a sociological study, the book details how Zola, an American polio survivor who passed for normal by using leg braces, began using a wheelchair in order to experience Het Dorp, an experimental Dutch community designed specifically for wheelchair users, from the residents' perspective. Couser observes that the sudden change in social attitudes Zola experiences on account of using a wheelchair leads him rapidly 'to identify with other disabled people in a way he had previously not'. The resultant text, Couser

observes, is 'almost wholly political rather than conventionally sociological', with Zola calling 'explicitly' for 'collectivity, self-assertion and self-representation' by people with disabilities (212-4). Given Couser's observations about Zola and Hockenberry's sense of community, it is no surprise to learn that one of the first anthologies of literary disability, *Ordinary Lives* (1982) was compiled and edited by Zola, and published in the same year as *Missing Pieces*, or that Hockenberry's work features in Kenny Fries' anthology of writing by people with disabilities, *Staring Back* (1997). Many of the authors discussed by critics in relation to issues of writing the disability experience are featured in such anthologies. Such collections (addressed in Chapter 5) are perhaps the most obvious illustration of the way in which a sense of community, and an identity politics, can manifest itself in literature, particularly in regard to Longmore's observation about the exploration and creation of a culture. Yet they also show how an arrangement of disability writing according to literary principles can offer surprising disruptions to the sort of disability politics that have arguably spawned them.

Arguably, the chief strength of such literary anthologies is that they legitimise the expression of personal experiences of disability, even as they exist under the auspices of identity politics and the disability rights movement. Collections of different voices and varied experiences, they perhaps avoid the mono-vocal end that identity politics threatens. An illustration of this threat can be found in Linton's call for the appreciation of the 'active voice of the artist, writer, and theorist with a personal disability perspective'. As alluring as this sounds, Linton assumes (or demands) that this voice will be subordinated to the interests of the disability rights movement, that it will be used to show how 'oppression is not

experienced as a bodily force but a political force' (Linton 1998, 113). Thus, the

personal and political voice are conflated, and the former effaced. Thus, ironically,

while Linton calls for 'radicalizing voices' to be 'admitted into the canon', the

radicalizing, challenging voices of a disability experience that does not suit these

political ends is itself disavowed (115). This irony is strengthened by Linton's

account of her attempts to give voice to her own personal experiences of disability.

She writes of 'struggling to find the words to describe these phenomena adequately',

and even concedes the role of the body by admitting a need to develop ways 'to

articulate the ways impairment shapes disabled people's version of the world' (140).

Although Linton attributes this lack to a 'deficit model' of impairment, it could be

said that the words to describe her experiences are unavailable precisely as a result

of the social model identity politics upon which she insists, which efface the

personal voice with the political, and disavow the body and thus any theory that

language could emerge from it. In adhering to a political conception of disability as

oppression Linton occupies a similar position to that originally held by Mitchell and

Snyder, with their politically-inflected insistence that literary metaphors of

disability can only ever be oppressive (125). As she views things from this

perspective, it is unsurprising that Linton is unable to conceive of the possibility of

access to the body through metaphor that Galvin and Kirmayer propose below. This

illustrates the manner in which the implicit identity politics of social model-based

approaches limits approaches to disability in disciplines beyond that model's

political origins.

Beyond the social model: the body and carnal experience

Rose Galvin aligns herself with a 'growing number of theorists and activists' interested in personal disability experience for whom the social model is inadequate (Galvin 2003, 161). In its focus on language, her analysis of 'disabled identity' is particularly useful for the purposes of this thesis (162). As with other critics of the orthodox conception of this identity, Galvin takes the Foucauldian equation of subjectification with subjection/subjectivity as her starting point, but emphasises the role language plays in the relations of power/knowledge exercised over bodies to produce subjects, particularly in respect to disability's nature as the only 'othering' that can happen to anybody at any time (163). This consideration of language prompts Galvin to link Foucauldian subjection/subjectification to Saussurian linguistics, which she notes is also a model 'which defines identity through difference' (164). In this way, she seeks to illustrate not just how language functions to stigmatise, but how it might be challenged. Galvin casts Saussure's *langue* and *parole* as analogous to Foucault's subjection and subjectivity. She argues that subjection, like *langue*, relies on the existence of a socially governed system while subjectivity, the tie to one's own identity by a conscience or self-knowledge, is reminiscent of *parole* (212). This model explains how, for example, Politically Correct language does not change behaviour: the signifier of a sign may change, but the concept, the signified, does not (166). By the same token, there is no inherent meaning in the term 'disabled': rather, it is a sign that signifies the ascription of 'a set of oppressive associations which stem from the hypostatisation of an abstract concept' (167). Crucially for an understanding of the enduring appeal of the political disability identity, Galvin notes that the threat of having no identity may

trigger an 'existential crisis' so threatening that even a negative one, proffered by what she terms the 'oppressor', may be preferable to none at all (168).

Thus far, Galvin's work offers little that is not covered by standard social constructionist views of 'disability'. Yet the true value of her work is not in her focus on the way in which labels stigmatise, but on the way in which 'discourses silence'. She argues that dominant discourse leaves disabled people 'with no language with which to express themselves', that it 'renders them invisible' as a result of the way in which it 'invalidates their narratives and, therefore, their subjective realities' (169). Here, too, she follows a Foucauldian approach, citing a 1988 interview with Foucault where he denied the possibility of rehabilitating the Other through attention to subjugated language: 'he replied "How can the truth of the sick subject ever be told?"' Further to this, she cites Pierre Bourdieu's claim that a subject will internalise forms of perception and expression to the extent that they will impose themselves on all of the subject's expressions, leading to a form of silencing beyond even conscious self-censorship. As examples of this, Galvin cites the Newspeak of Orwell's *1984* and the Sapir-Whorf hypothesis that language not only delimits what can be said, but what can be thought. This situation, Galvin argues, means that even those who can look beyond 'dominant rationality' to recognize and question their oppression will have 'little opportunity' to articulate their observations because, within the framework which governs acceptable patterns of thought and speech, these articulations would appear as nonsense and thus risk further social stigma (170). To take this further, this process can be seen in microcosm within disability studies, in the dismissal of personal testimony as irrelevant.

In conceptualising these limits of discourse, Galvin's work covers similar ground to Davis and Mitchell and Snyder. She observes that dominant discourse produces standard 'personal narratives' by which the liberal philosophical conception of our selves as 'unified beings whose lives form a cohesive whole' is constituted. She identifies one such narrative form as finding its basis in:

> the belief that our society is a 'level playing field' and that everyone has the same chances to succeed. Adversity is met with a strong will to triumph and those who 'suffer' from 'personal tragedy' will often serve as examples to the rest of society in their ability to succeed in life (171).

We might identify this model as the basis for the conventional autobiography originally critiqued by Davis and Mitchell and Snyder. Like those critics, Galvin notes that this model does not allow for values other than 'neoliberal qualities such as independence, autonomy, a priority for ritualised work behaviour, fitness, attractiveness and wealth'. She concludes that this model allows neither for a conception of 'social oppression', or the possibility for forming 'a legitimate alternative narrative' (171). Like Mitchell and Snyder with their call for other 'interpretive paradigms', she concludes that disabled people need a 'new language, and, therefore, new discourse to provide the means with which to speak' (172).

In attempting to locate this new discourse, Galvin abandons Saussure, seeing the notion of *parole* tethered to a stable *langue* as a limit to agency. She turns instead to the work of the phenomenologist Maurice Merleau-Ponty, citing his conception of speech as a form which desires to escape its limits, and his call for 'truly expressive speech' which is 'open to the initiatives of the subject' (176). She

notes Merleau-Ponty's belief that 'new speech' exists within the current structure of language, 'silently waiting to be brought to life'. This, she reasons, is proof that the 'silenced voices' she traces *can* indeed find the words and phrases 'to express the concepts which already frame their lives'. The fact that 'the words are yet to be found' does not make the 'experiences, the feelings, and the subjugated knowledges' of disabled people 'less real'. Rather, she insists, it simply proves that 'the dominant discourse, the sedimented langue, is retaining its hegemony'. Galvin notes, however, that while this hegemony will persist until new language emerges, 'the limitations of existing language' can, according to Merleau-Ponty, be overcome through 'the use of imagery, [and] metaphor in particular' (177). Given this definition, we can see the vital role that literature, through literary language, can play in the uncovering of new discourses, which Galvin advocates through the use of subversion and slippage to exploit language's 'fluid and polysemic' nature in a way that will 'bring forth alternative narratives, subaltern voices, subjugated knowledges' (178). In this way, metaphor and subversion can be used to express the disability experience in a non-oppressive way 'within existing logics while new language can undergo its halting burgeoning evolution' (180).

Galvin's work on language can be usefully linked to the body via the work of medical anthropologist Laurence J. Kirmayer, who notes that the 'significance of bodily felt meaning' has been neglected in recent Western thought as a whole, as a result of a 'postmodern loss (or abuse) of textual tradition'. Writing in the early 1990s, he perceives a growing weariness with the resultant 'radical abstractionism and relativism' and a growing recognition of an 'inescapable circularity between the order of the body and the order of the text' (Kirmayer, 323-4). Thus, just as it is

through language that bodily experience is most conspicuously elaborated and communicated, so language itself is, he argues, grounded in bodily experiences which provide common referents for a lexicon. Kirmayer notes that common theoretical 'bodies' - the individual body-self of lived experience, the social body of symbolic representation, and the body-politic of power, domination and control – can be cross-translated precisely because of the fact that they are just different textual versions of the same real body in which they have their lexical origins. These texts and the body 'stand in dialectical relationship to each other': a position which fits with Galvin's work as discussed above (324). A further compatibility with Galvin's position is apparent in Kirmayer's distinction between the text of the body which 'stands for a hard-won rational order, imposed on thought through the careful composition of writing' and the real body which provides 'a structure to thought that is, in part, extra-rational and disorderly' (324-5). We may see the former as an analogue for Galvin's conception of Foucauldian subjection through the language of dominant discourse, and the latter as the site for the subversive potential of an agent subjectivity theorised by her in line with the theories of Merleau-Ponty: indeed, Kirmayer perceives this 'extra-rational dimension to thought' as a space which can offer 'important information about emotional, aesthetic and moral value' (325).

As he is not from a disability studies background, it is interesting that Kirmayer should note the characterisation of these extra-rational 'passions' of the body as 'deviance' by medicine, psychiatry and cognitive science: disciplines that prize 'an ideal, disembodied mentality'. Even in the face of such suppression, he observes, 'the body drives us to seek meaning' (325). This assessment can be seen

as a link between the potential for agency espied by Galvin, and the resisting body of Shildrick and Price as discussed below. Kirmayer's analysis focuses on illness but his observations are certainly applicable to disability. He argues that '[b]odily suffering distorts the landscape of thought, rendering our previous constructions incoherent and incomplete' (329). Like Couser, Kirmayer observes the clash of discourse that occurs when patients try to express their experience of pain to a medic in a non-medical discourse, with the result that the doctor sees their testimony as irrational. He observes the same effect in psychoanalysis, noting that its discourse reduces the complex irrationality of the body to a 'basic biopsychodynamic structure' comprised of 'a few core conflicts' onto which culture, 'a layer of shared beliefs', is 'plastered' (330). Medicine and psychoanalysis, Kirmayer argues, both replace the body itself with a representation of the body which 'exaggerate[s] the coherence of [their respective] meaning systems' (331–2). Thus, the patient trying to express her bodily experience in her own discourse will come into conflict with such discourses whose practitioners hold the position of 'the interpreter of truth and meaning', and thus of power, over the meaning of the patient's body, to the extent that the their dominant interpretation may obstruct the individual's self-expression (340).

Evidence of this can be found in research conducted by Deborah Marks. While sympathetic to the ideology behind it (as illustrated by her acceptance of the idea that disability must be associated with oppression) she finds the social model to be inadequate in theorising her own field, psychotherapeutics, which requires an understanding of disability as 'the complex relationship between the environment, body and psyche' (Marks, 611). Rejecting 'the usual individual/social binary' she

instead focuses on disability as 'an embodied relationship'. In a step towards the conclusion Shakespeare eventually draws, Marks observes that the social model and what she terms the 'individual' model are each 'necessary for the survival of the other', and that they leave 'a theoretical vacuum' filled by a 'decontextualised perspective' (611). Marks' research on the medical establishment's reception of personal testimonies by patients with mental disabilities and sickle cell anaemia lead her to concur with Drew Leder's claim in *The Absent Body* (1990) that a patient's 'own experience and subjective voice become inessential to the medical encounter' and with Susan Wendell's assertion in *The Rejected Body* (1996), that modern medicine has a 'tendency to ignore, minimise the importance of, or deny outright any... bodily experiences that it cannot explain' (such as ME): both are positions which can be related to Kirmayer's theory. Marks notes that personal testimony is rejected not just by medicine and psychoanalysis, but also by prominent advocates of the social model of disability such as Michael Oliver, Colin Barnes and Vic Finkelstein. She characterises their rejection of personal testimony as being based upon the belief that it is at best irrelevant to the disability rights movement and at worst, as Finkelstein has argued, something which has actively 'diluted' it (612).

Insisting that such a proscription of personal testimony is just as oppressive as the forces against which the social model claims to position itself, Marks cites Mason's 1992 definition of 'internal oppression':

> 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 (614).

Significantly, Marks emphasises the focus as much on the conscious (and unconscious) relationship with the self as relationships with others (615). She concludes that, in the two very different impairment groups she studied, common experiences that were neither entirely social nor physical could be observed, as results of the dismissal of the groups' personal testimonies. As well as an internalised 'social oppression', causing 'compliance, anxiety and despair', she observed 'physical corollaries' such as 'the experience of intensified physical pain and an attack on the capacity to think' (623). Like Shakespeare, she cites this effect as evidence of a crossover of the social and the corporeal that requires greater complexity than the social model can offer. She calls for research into the 'physiological effects of social and emotional experience' and in the 'growing recognition among some psychoanalysts that materially embodied oppression shapes both conscious and unconscious experience' (624).

Kirmayer's broader argument about the self-expression of a different bodily experience, and its relations to dominant discourse, becomes specifically relevant to literature when he, like Galvin, links expression of this 'irrational' expression to metaphor. This is all the more crucial because Kirmayer ties metaphor to the body. He argues that all meaning in speech is created by metaphor, even the 'static and conventional…dead metaphors we call conventional speech' and that metaphors emerge from 'salient perceptual similarities – elements of which are universal' (Kirmayer, 332-3). Meaning, he states, 'emerges from the capacity to use bodily experience (including socially embodied experience) to think with metaphorically': more simply, metaphors 'are tools for working with experience' (334; 335). The

agency Galvin identifies can be seen in Kirmayer's claim that it is possible for an

individual to 'unpack new meanings [and] open up the situation' by re-arranging

conventional language with new metaphors, and that 'injury or alteration' of the

body will therefore change 'not only the content of thought, but also its form' (335-

6). This is arguably precisely the process we see occurring in the writing of

Christopher Nolan as addressed in Chapter 2 (although it does not explain his

neologisms, Galvin's theories about new language serve to bridge this gap).

Kirmayer does note, however, that an individual's 'search for his own metaphor'

will bring him into contact with dominant discourse (340). This might perhaps be

what literature has to offer: a locale where difference in metaphor is not discounted

as irrationality, but celebrated as artistic innovation. In this view, the work of Anita

Silvers and Ato Quayson, to be discussed shortly, is particularly significant. It is

important to note that Kirmayer insists that the use of new metaphor can be, and

often is, unconscious: so, we can see that dominant discourse can be defied even

unconsciously (340). This ties in with the theories of Shildrick and Price as

discussed below, and also offers food for thought regarding the space between

disability politics and the disability experience. Kirmayer's theory also sheds light

on the term 'metaphorical opportunism', coined by Mitchell and Snyder (Mitchell

and Snyder 1997, 17-8). They use this term to describe the way in which the arts

have traditionally incorporated disability, not realistically as a condition or

experience in itself, but as metaphorical material with which to convey various

meanings, often negative. Kirmayer notes that the power of dominant discourses

over the meaning of metaphors might mean that we view their 'interpretations as

oppression': his distinction between the *trope* as oppressive and its *interpretation* as

oppressive thus allow for the possibility that literary metaphor may be used in a

different, more positive, capacity, if different interpretations are allowed for (340).

We can see that 'metaphorical opportunism' is not an inevitable outcome of the use

of metaphor, but a result of its use in unequal power relations, which, as the theories

of Kirmayer along with Galvin show, can in fact be subverted by metaphor.

Certainly, this understanding offers clues, as Kirmayer notes, as to 'how to place the

socially constructed and bodily given on the same map' (341).

The work of Galvin and Kirmayer offers a useful context to further consider

the approach of Swan briefly addressed earlier. Swan argues that much

contemporary life-writing by writers with disabilities, shows that writing 'is not

only *about* the body but *of* and *from* the body too' (Swan, 284). He cites Nancy

Mairs, whose work is featured in some of the anthologies addressed in Chapter 5

and is arguably typical of the contemporary 'personal essay' style identified by

Couser. Swan focuses on Mairs' statement: 'No body, no voice; no voice, no body'.

Swan sees in this declaration disability's revelation: that the writer is 'first and

foremost, an embodied voice' and, in turn, a 'voiced body' (284). By contrast, he

cites Mairs' observation that a body which is 'unacknowledged, disowned and

hidden', which is not voiced by 'the self that writes', is lost in what she terms

'shameful silences'. These shameful silences can be seen as being equivalent to the

stigmatised, inexpressible experiences currently beyond language that are identified

by Galvin above, or the response of the patient deemed 'irrational' in Kirmayer's

model. In Swan's call for literary disability studies to address 'cognitive difference'

alongside its current concern with 'cultural difference' by addressing the writing of

personal embodied disability experience, the contribution that the theories of Galvin

and Kirmayer might make is clear: they offer precisely the 'new ways of thinking

about culture, language, and the body' that he asks for (286). Like them, Swan observes that the disabled body 'simply overruns the categories of an ableist, stigmatizing discourse to find its own expressions', and the same consideration of agency is apparent in his insistence that the body 'made present in language' positions the speaker as 'an agent of negotiable meanings' (287; 294). As suits the purposes of this thesis, Swan, in a move which reflects his rejection of the simplistic political nature of the social model, sees the appreciation of the 'action of the voiced body' that disability promotes as something that is useful to society as a whole (287). He argues that the conception of 'disabled' and 'nondisabled' as binary opposites is redundant, and that they should instead be conceived of as 'variable positions on a multidimensional gradient' (293). This position invites a pertinent comparison with another gradient model: Sherry's model of impairment and disability as positions along a 'fluid continuum', as championed by Shakespeare, whose views on theorization of the body we shall now discuss (Shakespeare 2006, 37).

Impairment and embodiment

Shakespeare's view of the role of the body with regard to theories of disability is a complex one. He cites the lack of consideration and analysis of the impairment part of the social model's core disability/impairment binary as one of its major flaws. In turn, he argues that the identity politics based on this binary inherits the flaw, ignoring the disabled body and thus becoming generic 'victim' politics. Conversely, he argues that work by post-structuralists, such as Diane Fuss' *Essentially Speaking* (1989), has shown that 'an essentialist theory of identity,

however attractive, is ultimately not a secure foundation for politics' (79). Of course, this statement does not discount the possibility of impairment shaping *personal* identity. Similarly, Shakespeare's attack on the simplicity of the social model focuses on the fact that 'impairment' and the (disabled) body are not necessarily interchangeable. Shakespeare's criticism begins with the social model's separation of disability and impairment which, he insists, ignores the fact that there 'can be no impairment without society, nor disability without impairment'. He observes that impairments may result from social practices such as war, poverty and malnutrition (34). Conversely, 'impairment' is 'only ever experienced in a social context' and is, he insists, not pre-social or pre-cultural:

> The words we use and the discourses we deploy to represent impairment are socially and culturally determined. There is no pure or natural body, existing outside of discourse (35).

This view is shared by Shelley Tremain, who insists, after Foucault, that 'impairment and its materiality are naturalized *effects* of disciplinary knowledge/power' (Tremain, 34). She cites Foucault's analysis of the modern 'docile' body as result of the application of discipline to the body in the form of 'biopower', by which a body can be 'subjected, used, transformed and improved' (36). She notes that Foucault 'regarded "normalization" as the central component of the regime of biopower', and that technologies of normalization are 'instrumental to the systematic creation, classification and control of "anomalies" in the social body' (36-7). She argues that the contemporary concept of 'normality' serves as a means 'through which to identify subjects and make them identify themselves in ways that make them governable' (37). As a result of this subjects with 'impairments' are produced 'because this identity meets certain requirements of contemporary

political arrangements'. This prompts Tremain to reject the social model's use of 'impairment' as a category because, she insists, it actually works '*in accordance with* requirements of the political configuration which that model was designed to contest' and thus 'will inadvertently *extend* those relations of power'. This perspective concurs with that of Liggett, as discussed by Shakespeare above. Tremain concludes that 'impairment has been disability all along' (in the sense of an oppressive social construction), its apparent 'prediscursive' quality an illusion (42). Although Tremain is right to query 'impairment' as a given, her analysis of Foucauldian power is coloured by her clinging to the social model's notion of oppression. Her own implication in power/knowledge is apparent in her call for personal insights into 'lived experiences…of corporeality' – provided that they come from 'those of us involved in disability studies and the disabled people's movement' (45). This is precisely the position Mairian Corker argues against when she suggests that theory should instead grow from 'disabled people's experience' rather than prescribing it (Corker, 639-40).

The positions of Tremain and Shakespeare appear to sharply contradict that of Galvin, Kirmayer and Swan: that the body is not only outside of discourse, but can alter and subvert it. Yet it might be argued that Tremain conflates 'impairment' (which, with its implicit value judgement, arguably fits her description as something socially constructed and imposed onto physical characteristics), with the 'body' or 'embodiment', which is something rather more complex, as Shakespeare appears to appreciate. While Tremain concludes that impairment and disability are the same thing (an oppressive, entirely social, construction) Shakespeare is not so swift to disregard 'the problematic reality of biological limitation' (Shakespeare 2006, 38).

While he appears to agree with her by arguing that 'it is hard to separate impairment from disability', the important distinction between the two comes in the fact that Shakespeare focuses on the 'everyday lives' of those with disabilities. He attempts to address the experiential aspect of impairment, rather than the theoretical aspect of it which Tremain addresses. That Tremain reaches an apparently logical conclusion in the arena of theory in deciding that impairment has no reality perhaps says more about the flaws of such an approach, and the limits of the theories involved, than it does about the nature of impairment. This is not say that Shakespeare's examination of the relationship of disability and impairment is un-theoretical. Nor does he disregard a social element to impairment. Indeed, he emphasises the complexities involved in trying to discern an experiential model by noting the difficulties in, for example, distinguishing between psycho-emotional problems that result from impairment and those that arise due to social responses to the impairment and its effects (36). Shakespeare's endorsement of Mark Sherry's model of disability and impairment as 'a fluid continuum, not a polar dichotomy' is thus arguably more satisfying both experientially and theoretically than Tremain's insistence that if impairment does not fit the model, it must therefore not exist (37).

Shakespeare is also distinct from Tremain in identifying how the assumption of oppression, which is implicit in many social model-based approaches, prevents them from exploring the nature of impairment. He notes that impairment is problematic even without social barriers or oppression: a point supported by the accounts in this thesis of the impact impairment has on the act of writing (41). By looking beyond the issue of oppression, Shakespeare is able to approach the topic of impairment in a different context from the traditional 'us and them' attitude. Thus,

he is free to observe that even the so-called able-bodied experience physical limitations (42). This observation provides a clue as to how a literary disability studies can be useful to the wider literary studies community in the way indicated by Swan. By considering the 'disabled' body's influence on the act of writing, we can progress to considering the influence of other bodies on the act of writing, and the way in which even the supposedly able writing body may be limited in its expression through 'real', non-social barriers.

The able body

With their collaborative essay 'Bodies Together: Touch, Ethics, and Disability' (2002), Janet Price and Margrit Shildrick are arguably ahead of the curve in abandoning disability identity politics and considering the wider significance of disability studies in a world where the boundary between disabled and nondisabled is erased: they achieve this by deliberately writing in a manner that conceals which of the two is speaking, with the aim of demonstrating that through an acknowledgement of 'the permeability between bodies and between embodied subjects…disability studies might move forward' (Shildrick and Price 2002, 62). Explicitly discarding what they see as a liberal humanist concern with identity (a perspective that Shakespeare and Davis in his later work arguably share) they instead seek to address notions of 'encounter,…relationship and becoming-in-the-world-with-others' (62). Like Tremain, the authors pursue a postmodernist feminist approach to conclude that the body is 'materialized *through* discourse'. Unlike Tremain, however, with her insistence on the oppression of the normal, the authors insist that this process means that the body exists 'not as a stable entity but as

something that is always in process', and that identity will always therefore slip. Thus, they insist, it becomes impossible to conceptualise disability 'as the property of an/y individual' and the disabled body must be seen as 'much more than the result of unequal power relations' (63). Instead of Tremain's oppressor/oppressed, these authors insist that disability is equally an issue for the nondisabled, and reject the idea that there is 'some privileged standpoint from which disabled people alone can speak' or that theirs is 'the only "authentic" understanding of the specific embodiments in question' (64). In attempting to forge a new writing on the basis of this perspective, the duo emphasise the 'necessity' of 'writing together' (64). They seek to replace 'unified stories' characterised by clearly delineated subjects, different categorisations of embodied being, and fixed points of view, with an emphasis instead on 'multiple points of interchange', the blurring of categorical boundaries, and the 'discontinuities that make up experience before narrative is imposed on it'. Their focus on narrative especially brings to mind the assessments of Davis, Mitchell and Snyder and Couser of the problematic nature of narrative for the disability experience.

Yet Shildrick and Price also attack conventions in contemporary disability life-writing. Citing work featured in anthologies such as *Mustn't Grumble* (1994) and *With Wings* (1988) (addressed in Chapter 5) they note that such writing focuses on 'experience of bodily restrictions, discomfort and limitations, and of the physical and social barriers that disabled people face' (65). They attack this focus as conveying 'the assumption…that what counts is the experience of the disabled person alone' (66). They also note that such narrative is inherently contradictory, encouraging the reader to see the author/protagonist as 'distinctly other…whilst at

the same time striving to attain standards of normativity'. The result is a portrayal of the body as a 'troublesome possession', as something which may be normalized, for example through rehabilitation, but will never be normal (67). This effect is apparent in Christy Brown's experience of rehabilitation in *My Left Foot*, as discussed in Chapter 1. After Foucault, Price and Shildrick conclude (as Tremain fails to) that power always contain the means to undermine it. This leads them to the same conclusion as Kirmayer and Swan: that there is a 'resistance [to discourse] exercised through the body's refusal as much as through the conscious will'. To illustrate this, they cite Mary Duffy's poem about prosthetic arms, 'Making Choices' (in *Mustn't Grumble*), and note the way in which, through the prism of disability studies, degenerative conditions of the body such as MS have revealed the instability and unpredictability of identity (a point which recalls Shakespeare's critique of the social model's inability to accommodate MS) (68).

Some of the key points of Shildrick and Price's position can be addressed through the theories of Merleau-Ponty, as Miho Iwakuma shows in 'The Body As Embodiment'. She focuses on his conception of the *lebenswelt* (the life world), which includes not just one's body, but also relationships, self-image, worldview, and a sense of temporality (Iwakuma, 80). Only when all these elements are in 'equilibrium', and one takes one's body image into account unconsciously, is the subject successfully embodied. Iwakuma focuses on the example of the new wheelchair user, still accustomed to the *lebenswelt* of the walker, adjusting to the *lebenswelt* of wheels. Yet this model might also be applied to the disabled subject as they write. On the one hand, her work suggests that a writing process in which the body makes itself known *unconsciously* will be liberating for the writing individual.

An example of this from Chapter 1 is the moment when Christy Brown abandons the lengthy, and (we can now see), disembodying process of narrating to an amanuensis, in order to write with his left foot once more: an action he specifically describes as a return to 'being [him]self'. On the other, it suggests that analysing the body in writing is in some way self-defeating, that it will inhibit embodiment: this perhaps explains Shildrick and Price's observation that descriptions of bodily difference tend to objectify the body as a 'troublesome possession'. Iwakuma also observes that Merleau-Ponty's concept of embodiment extends to reading, allowing the reader to 'shed tears when reading a novel, [or to] understand a metaphor…to sympathize with another's feelings' (82). Her linking of metaphor to embodiment reminds us of the work of Galvin and Kirmayer, yet adds a startling new dimension. If people with disabilities have, as per the arguments of Swan, a greater sense of voiced embodiment, might they therefore have a greater sense of metaphor, and of sympathetic and empathetic processes, and thus be innately better writers?

Kevin Paterson and Bill Hughes combine the sort of collaborative process employed by Shildrick and Price with another, slightly different approach to Merleau-Ponty's phenomenological theories. They seek to replace the redundant social model with a model of disability suitable for a 'somatic society' where the body is 'shaped by social relationships, but…also actively contributes to the shape that they take': a position that aligns perfectly with Shakespeare's (Paterson and Hughes, 598-600). In a move that recalls Kirmayer on the disruption of illness, Paterson and Hughes argue that the 'unwanted consciousness' of impairment brings the body to the fore, yet in a social way. A physical barrier, they reason, will cause both a physical *and* social confrontation, as the body is 'stunned into its own

recognition by its presence-as-alien-being-in-the-world' (603). This is a result of a world shaped by 'a specific hegemonic form of carnality, which excludes as it constructs' and where oppression is not just social, but extends to 'bodily discomfort' (604). Hughes and Paterson argue that each instance of 'carnal self-recognition' through exclusion is different, as the body is temporally and spatially specific: there is 'rarely a constant in the ways in which one reacts upon one's body and how, in turn, one's body is received' (605). This observation brings to mind Couser's claim that the essay, with its potential for constant re-evaluation of a specific moment, is the genre best suited to documenting the experience of disability. Hughes and Paterson argue that the *lebenswelt* is 'structured and coded' by a 'carnal order' set by dominant 'normal' bodies, which determines 'carnal performance', and which is therefore 'predisposed to the exclusion of people with impairments'. The lebenswelt model, they argue, can describe the exclusion of people with disabilities from 'the everyday, mundane, sensate minutiae of the lifeworld' in a way that the social model cannot (605).

Hughes and Paterson relate how one of them experiences such exclusion through Cerebral Palsy, noting that a common experience in encountering carnal barriers is the sense that they have been 'annihilated as subject' whilst paradoxically experiencing an extreme sense of embodiment 'at the very level of being that is denied by the process' (606). In particularly, they note how 'carnally informed orders of time' work to preclude 'opportunities to communicate'. For example, they recall choosing not to answer a question in a lift, because the only outcomes available to them, mediated by time and carnality, were to break off the conversation or to prolong the journey to the chagrin of other passengers (606). In

choosing to simply give 'a smile or a nod of the head' the author writes, 'I am "reminded" of my body'. This, the authors insist, is oppression, enacted in a 'subtle interplay of micro- and macro-relations of power…felt in the flesh and the bones' (606). Hughes and Paterson see further evidence of this carnal oppression in the prescription of physical therapy, or through the wearing of prostheses such as false limbs, which are often uncomfortable, impractical, or achieve little (607). Yet they conclude that no approximation of physical conformity by the disabled person will be sufficient, and that change must instead be made to 'the scripts' by which non-disabled people 'judge and bestow social competence'. Yet they note that such scripts are exclusionary, solely delineated by the 'abnormal' bodies that 'are inscribed by and resist them (608). In this way, they assert, all '[i]ntercorporeal encounters become "demands" for disabled people to normalise themselves'. Arguably, this might be applied to the writing process, especially in regard to Christy Brown's writing process as addressed in Chapter 1. Similarly, this argument might explain why disability writing offers insights into both writing and the body: because, unlike the able body, the impaired body 'is permanently stunned into its own recognition as a consequence of the disablism which permeates everyday life' (608). Lastly, Hughes and Paterson's account of an oppressive carnal world offers an explanation of the attractions of the bodiless world of the text, as touched on by Mitchell and Snyder and by Couser. It should be noted, however, that their persistence with the idea of oppression leads them to state their model in the limited terms of disabled/nondisabled. In line with the arguments of Shakespeare, it can be seen that, even if that dubious binary is maintained, the 'nondisabled' are just as limited and affected by this carnal order as the 'disabled'.

<u>Revising the social model</u>

Tobin Siebers is notable as a disability studies critic who has consistently attacked inadequate theorisation of the body, particularly the sort of abstract, postmodern approach attacked by Kirmayer. In 'Tender Organs, Narcissism, and Identity Politics', he addresses the topic of personal accounts of disability. Although his approach can be seen to emerge from a social model context, his conclusions are the very opposite of the orthodoxy against personal testimony. In examining a cultural backlash against the growing confidence of disability rights in the 1990s, he notes that such attacks have a common theme: the supposed narcissism of people with disabilities, which he traces back to Freud's belief in the egoism and narcissism of the suffering or the ill (Siebers 2002, 43). In a typical social model move, Siebers reconsiders this as oppression, arguing that this supposed narcissism is actually 'a form of violent hyperindividualization imposed on victims by political bodies and other groups' (48). In his concern that the individualising of disability has been central to 'making a common purpose difficult to recognize and advance as a political agenda', Siebers at first appears to follow the traditional social model discounting of individual experience. Yet he allows for a reconsideration of individual expression by observing that the problem is not individuality itself, but the 'perception' of it (48). This might be further qualified: it is the *dominant* perception of disability as an individual experience that is the problem. Individual self-expression, he notes, is 'a foundational concept in American politics': it is the characterisation of the self-expression of people with disabilities as narcissistic that turns 'a principle enabling political action into an impediment' (49). This arguably explains Couser's seemingly paradoxical opinion that individual

expression is good for the individual with a disability in proving their independence, but bad for the disabled community. Siebers notes the belief that disabled people's self-expression is 'somehow more narcissistic than those of able-bodied people' is widely held, even amongst people with disabilities. He observes (as do some of the editors of the anthologies covered in Chapter 5) that the opposite is actually true; as Anne Finger notes, 'we cannot tell our stories because they reflect badly on our personalities or make other people queasy' (50). This prompts Siebers to invert conventional social model thinking. Although his call to find 'other ways of telling our stories' in order to 'communicate the truth of our existence as a group' and be 'recognized politically' smacks of identity politics, he goes out of his way to eschew the separatism Shakespeare fears (50; 51). Rather, he reasons that 'human beings make lives together by sharing their stories with each other' and stresses the need to 'tell stories in a way that allows people without disabilities to recognise our reality and theirs as a common one' (50). He concludes by evoking the idea of interdependency that disability points towards, as he notes that, contrary to narcissism, disability in fact encourages an awareness of, and appreciation of, one's interdependency with other people (53).

Mitchell and Snyder have also, as mentioned earlier, recognised and sought to improve upon the shortcomings of the social model. Building on their endorsement of life writing as an expression of the experience of disability in *Narrative Prosthesis*, as mentioned above, they attempt in *Cultural Locations of Disability* to delineate a 'cultural model' of disability (Mitchell and Snyder 2006, 5). They do so as an attempt to address what they see as the weaknesses of the social model on which, they rightly argue, disability studies is even now too reliant, and

which fails to recognise disability 'as a site of phenomenological value that is not purely synonymous with the processes of social disablement' (6). They note that 'key theorists in disability studies have overlooked opportunities to theorize this interactional space between embodiment and social ideology' (7). They cite Tremain's observation of how the social model has left impairment to the rule of medical discourse, and like her, argue that the disabled identity and the disabled body are constructed (11, 7). Yet they appear to diverge from her position by claiming that impairment exists as 'both human variation encountering environmental obstacles *and* socially mediated difference', implying that impairment has a 'real' quality outside of discourse, as Shakespeare does (10). In employing this double notion of impairment, they can be seen to be attempting to bridge the gap suggested by Couser's distinction between a disability experience and a disability culture. This is particularly apparent in their claim that their 'cultural model' allows not just a 'phenomonological perspective' but also a 'group identity' (10).

This notion of group identity connects Mitchell and Snyder's 'cultural model' to the problematic issue of identity politics examined earlier. They assert that their model 'allows us to theorize a political act of renaming that designates disability as a site of resistance and a source of cultural agency previously suppressed – at least to the extent that groups can successfully rewrite their own definition in view of a damaging material and linguistic heritage' (10). These references to 'resistance' and 'suppression' obviously bring to mind the analysis by Rose and Kiger of how minority groups define and assert their identity (see p26). Furthermore, Mitchell and Snyder's use of the term 'us' illustrates once again the risk Shakespeare identifies with regard to the identify of a large group

such as the 'disabled' being defined by a tiny minority of scholars. This position can be seen to be one that Mitchell and Snyder have carried over from the earlier *Narrative Prosthesis*. There, they acknowledge that 'cultural groupings always occur in reaction to prior exclusionary definitions' and that this reaction leads to 'a process of identification itself among those who forward the critique': in other words, academics (Mitchell and Snyder 2000, 43). In disability studies, they note that this has led to the construction of 'a formidable disability "identity."' It is formidable, they argue, because the identity in question 'does not consist of a "positive" content'. By this, they mean that it 'does not simply replace a less acceptable representation with another equally fictive but alluring one'. Instead, it is 'reactionary' (44). In this way, it might be seen that Mitchell and Snyder carefully avoid the problems of effacement and misrepresentation inherent in the championing of a political identity, as discussed earlier in regard to Linton and Pfeiffer.

Mitchell and Snyder's persistent concern with the risk of identity politics is apparent when they return to the topic in *Cultural Locations of Disability*. They observe that people labelled with their disability by medical discourse, as if it were the truth of their social identity, 'often find themselves resisting the effort to identify their diagnoses, in order to complicate medical definitions with the more nuanced stories of their own experience' (Mitchell and Snyder 2006, 11). Such a dilemma can, of course, be seen to be closely related to the risk of the imposition of a disability identity that has been defined by scholars, which Mitchell and Snyder's refusal of a positive identity avoids. A similar point of comparison with Shakespeare's distrust of identity politics can also be seen in Mitchell and Snyder's

doubts over the institutionalisation of disability studies within the academy. They observe that an institutionalisation process that 'churns out more knowledge about disability while resisting reflexive inquiries about whether or not more is inherently better' is one that 'threatens to reproduce some…problems' (185). What is problematic for Mitchell and Snyder is the way in which this process brings to mind arguments by Foucault 'that excessive diagnosis and the evaluation of bodies within categories of pathology proved to be the characteristic form of oppression in the modern period' (193). In this respect, their concern invites parallels with the earlier discussion of Shakespeare's application of Foucauldian ideas in his critique of the drive to establish a disability identity politics, with the apparently inevitable categorisation that entails.

Mindful of these risks, Mitchell and Snyder make what they call the 'heretical claim' that 'people-based research practices' are exhausted, and that 'textually-based analysis is the only *absolute* remedy' to this exhaustion. Texts, they argue, provide 'access to perspectives that inevitably filter disability through the reigning ideologies of their day'. A practise of textual analysis, they suggest, is 'tantamount to turning social beliefs into an object of investigation'. Such an approach would appear to offer a way of avoiding the pitfalls of identity politics and a prescriptive disability culture, by utilising the reactive, flexible, non-'positive' identity they describe. It would, they argue, offer 'an opportunity to reformulate our attitudinal milieu immediately – and in the most pragmatic and visceral manner' (203).

Although, as we have seen, Mitchell and Snyder have over the course of their work come to embrace personal narrative and its capacity for capturing disability as a phenomenological experience, they maintain a view of the relationship between the body and the text which sometimes makes it hard to see how the two might interact positively. Their description of this view is the focus of *Narrative Prosthesis*. The title is their term for what they see as the 'perpetual discursive dependence upon disability' in literary texts. This is due, they argue, to the fact that the disabled body promises 'to lend a "tangible" body to textual abstractions': a function they term 'the *materiality of metaphor*' (Mitchell and Snyder 2000, 47-8). By literary, they mean 'those texts that not only deploy but explicitly foreground the "play" of multiple meanings as a facet of their discursive production'. Within such texts, they argue, disability 'serves as an interruptive force that confronts cultural truisms' (48). Its force comes, Mitchell and Snyder argue, from the body's role as an 'other' both to text and to culture, 'an object with its own undisciplined language that exceeds the text's ability to control it' (49). While this would seem to place them in philosophical agreement with Kirmayer, they insist elsewhere that 'the body itself has no language, since language is something foreign to its non-linguistic materiality' and that it must thus 'be spoken for if its meanings are to prove narratable' (64). It is perhaps this conflict in their thought which leads them to avoid an exploration of the body as a source of language.

Whether the body has an alien language or is alien *to* language, Mitchell and Snyder assert that because of this alien quality, the disabled body '*operates as the textual obstacle that causes the literary operation of open-endedness to close down or stumble*' (50). In this way, it functions as 'the literary object par excellence',

provoking 'a process of explanatory compensation wherein perceived "aberrancies" can be rescued from ignorance, neglect, or misunderstanding for their readerships': a literary narrative (53). Mitchell and Snyder acknowledge that narrative might try to remove or even obliterate difference: the 'negative-image' school of criticism, as described earlier, has documented many instances of this (53-4). Yet they reject that school's 'dismissive critical stance that narrative merely replays retrograde politics of disability': a charge which, as illustrated earlier, they have also levelled at Davis (164). They insist that 'many fictions, particularly modernist and postmodernist anti-narratives, seek out means for disrupting the popular disability expectations that accrue around normalcy narratives' (164). They note that the idea that any narration is impinged upon by the subjective and partial nature of the individual perspective that controls the story is foundational to modernism. In this respect, they perceive many key characters in modernist novels as individuated by reference to "wounds" or wounded identities and their corresponding frailties. In postmodernist narrative they detect an urge, not to repair or resolve a character's impairment, but to delve 'into the social, personal, political, and psychological implications of impairment as bequeathing a social awareness'. The result, they argue, is a literature 'teeming with disability as a matter of identity, perspective, and subjectivity' (165). This analysis of a postmodernist approach is particularly applicable to the writing of Christopher Nolan, as addressed in Chapter 2.

Such developments in the recent history of literature lead Mitchell and Snyder to conclude, 'in contrast to the claims of many scholars of disability', that there is an 'insurrectional drive in art toward an interrogation of repressive norms'. Indeed, they assert that literature, of all discursive spaces, provides 'a unique space for contemplating the complexity of physical and cognitive differences' (166). They

resist the urge to criticise what they term the 'impersonation' of disability in literature by able-bodied authors, arguing that such works demonstrate an 'attempt to cross the threshold of disabled subjectivity' (174). This 'willingness to imagine disability', they insist, 'proves tantamount to a literary revolution within the cultural imaginary' as writers risk entry into 'this seemingly unimaginable or uninhabitable universe' (175).

These possibilities for literary revolution are also expanded upon by Anita Silvers in 'The Crooked Timber of Humanity: Disability, Ideology and the Aesthetic' (2002). She agrees that 'the idea of the normal holds so much less sway in art than in ordinary life' and that this allows for 'an aesthetic that makes disability powerful' (Silvers, 230). Like Mitchell and Snyder, Silvers rejects the assumption that art 'valued by a society that discriminates against disabled people' must therefore reinforce this discrimination (236). She observes that art in fact 'broadens what we previously have imagined to be normal, even – indeed, especially - what we consider normal in regard to art itself' (239). This sort of aesthetic shift is documented in this thesis in a comparison, in the first two chapters, of the work of two male Irish autobiographers with Cerebral Palsy: Christy Brown and Christopher Nolan. Brown, published in the 1950s, changed his verbose, wordy draft to a short simple account in plain language in order to make his account of disability accessible to the reading public. Nolan, writing thirty years later, would be celebrated for precisely the elliptical, neologistic and dense style that Brown sought to avoid. Silvers could almost be describing this situation when she writers:

That anomaly presents as originality rather than deviance

> depends on the way we conceptualize the connectedness of
> successors with their heritage and, specifically, on the
> prescriptiveness with which individuals are obliged to
> conform to their predecessors (240).

Although Nolan's work (perhaps carefully) makes no reference to Brown's, the warm reception it received was surely facilitated by the precedent of this earlier success, in the manner Silvers implies. Silvers' work arguably sketches the kind of direction which a model of literary disability, as opposed to a political model of disability studies, might pursue. Instead of denying 'otherness', she argues that 'aestheticizing disability elevates otherness to originality' (241).

Silvers' observation, that 'to be fully appreciated, the human variations we call disabilities must be interpreted as being meaningful', is one shared by Ato Quayson. In *Aesthetic Nervousness* (2007), the theories of Mitchell and Snyder serve as a foundation for Quayson's ideas regarding the relationship between literature and the disabled body. 'Aesthetic nervousness' is his term for the effect whereby 'the dominant protocols of representation within the literary text are short-circuited in relation to disability' (Quayson, 15). This is very similar to Mitchell and Snyder's view (see p59). Quayson argues that this effect can be perceived in 'tensions refracted across…the text such as the disposition of symbols and motifs, the overall narrative or dramatic perspective, the constitution and reversals of plot structure, and so on' (15). He argues that these tensions are also apparent between characters, and between the reader and the text. This 'tension' or 'short-circuit' occurs, Quayson argues, because disability disrupts the 'common impulse towards categorization' forcing a re-evaluation both of that impulse and 'of what it means to be human in a world governed by a radical contingency'. Disability reveals this

contingency by virtue of its nature as something which 'can never be fully anticipated or indeed prepared for' and which reveals that '[e]very/body is subject to chance and contingent events'. The recognition of this, Quayson contends, produces an 'extreme anxiety whose roots lie in barely acknowledged vertiginous fears of loss of control over the body itself' (17). He asserts that this 'aesthetic nervousness', because it undermines assumptions about wholeness and normativity, 'returns the aesthetic domain to an active ethical core', disrupting the surface of representation. Because, Quayson argues, representation cannot assimilate disability, this 'ethical dimension' will always be apparent in attempted representations of disability (19). He cites this as the reason why the literary texts he analyses in *Aesthetic Nervousness* are undergirded, 'not by the binary opposition of normal/abnormal, but by the *dialectical interplay*' between unacknowledged social assumptions and the disabled body as a reminder of contingency (21). Quayson insists that this 'dialectical interplay' can be shown to affect 'all levels of the literary text, from the perspectival modulations of the narrator…and the characters to the temporal sequencing and ordering of leitmotifs and symbolic discourses that come together to structure the plotlines' (21). This notion of play, and of the subversion of dominant discourse can be seen to be heavily influenced by Mitchell and Snyder's appreciation of the possibilities for the approaches to disability made in postmodern texts (see p60).

Disability, Quayson argues, 'elicits language and narrativity even while resisting or frustrating complete comprehension and representation and placing itself on the boundary between the real and the metaphysical'. In this respect, he might be seen as making a similar claim to Davis (and Mitchell and Snyder) in arguing that disability 'inaugurates' narrative. Quayson insists, however, that he

implies something different: inauguration as 'the setting of the contours of the interlocking vectors of representation' (22). Furthermore, he stresses that, while disability produces 'a contradictory semiotics of inarticulacy and articulation' in the literary-aesthetic, it also 'engenders attempts at social hierarchization and closure within the real world' (23). Because of this, Quayson argues, disability serves 'to close the gap between representation and ethics, making visible the aesthetic field's relationship to the social situation of persons with disability in the real world'. Literature 'helps us to understand the complex *processes* of [the real world framing of disability] and the ethical implications that derive from such processes', he argues, citing Mitchell and Snyder once more (24). Quayson offers to add to their work by focusing 'on the devices of aesthetic collapse that occur *within* the literary frameworks themselves' (an analysis we shall see more of on Chapter 2) (25).

Like Davis and Mitchell and Snyder, Quayson recognises that one possible aim of a literary narrative spurred into existence by disability is the resolution or elimination of the perceived 'deviance'. He argues that such an aim is rendered futile both by the way in which the aesthetic domain is short-circuited upon encountering disability, and by the continuing existence of disability 'in the real world' (26). Quayson also takes after Mitchell and Snyder's early work in his insistence that the text and the body are alien to each other. He insists that disability in literature is 'created out of language' and it is this which enables a 'trade' of 'significations' between the disabled and the nondisabled, and vice versa (27). While he concedes that literary representation of disability 'somewhat subtends' real-life treatment of people with disabilities, he insists that the aesthetic nervousness of the literary domain 'cannot by any means be said to be equivalent to

the responses to disabled persons in reality'. Although the literary model provides 'an analogue to reality', he does not consider this 'the same as that reality'. Despite Quayson's qualifications, certain connections may be discerned between his theory of aesthetic nervousness and the theory of phenomenological oppression proposed by Hughes and Paterson (see p52) (30).

Quayson's work on the futility of the literary-narrative-as-correction-of-deviance and the gap between theoretical models and the real-world serves as an excellent context within which to consider Davis' later work, and the apparent disparity it shows with his earlier ideas, as these are two areas that this work addresses. As has been shown, Mitchell and Snyder have substantially revised the position on the power of dominant discourse which they used to share with him, and have criticised him for maintaining it. Davis maintains an interest in power, yet where the social model's political cast once informed his sense of an oppressive dominant discourse, it is now the target of his analysis. In *Bending Over Backwards* (2002),he questions 'the clear line drawn between the socially constructed "disability" and the pre-existent and somatic "impairment"' on which the social model relies (Davis 2002a, 23). He is similarly critical of the identity politics to which the cultural studies approach, facilitated by this disability/impairment split, has led. Like Shakespeare (as Shakespeare has noted), he sees it as a dead end, 'dependent for its motivation and existence on remembering and re-invoking the pain caused by oppression' and concerned only with 'making all identities equal under a model of the rights of the dominant, often white, male, "normal subject"' which focuses on the pursuit of 'autonomy and independence' (100; 28-30). This pursuit of identity will always involve 'marginalizing…*some* group', otherwise

'when all identities are finally included, there will be no identity' (88-9). In this respect, Davis can be seen to have reached the Foucauldian position on categorisation and power taken by Shakespeare and Mitchell and Snyder.

Just as this position prompts Mitchell and Snyder to devise their own version of the 'cultural model' (not to be confused with the 'disability studies as cultural studies' reliant on the social model and criticised by Shakespeare and Davis), so Davis seeks an alternative to the social model. This take the form of what he terms the 'dismodern' which is based on 'dependency and interdependence', in opposition to the independence and autonomy sought by identity politics. In the 'dismodern' era, Davis asserts, everyone is disabled in the sense that they are incomplete without, amongst other things, 'information technology, protective legislation, and globalized forms of securing order and peace' (28-30). In his characterisation of 'modern subjectivity' as a 'wounded identity', unable to 'cure itself' without endless 'cure narratives', direct parallels to Mitchell and Snyder's assessment of the links between disability and modernist literature, as discussed earlier, are clearly apparent (Davis 2002a, 99). Indeed, like them Davis believes that this is what disability has to offer the wider world: he cites Susan Wendell's argument that '[i]f disabled people were truly heard, an exploration of knowledge of the human body and psyche would take place' (39).

The similarity between the views of Mitchell and Snyder and Davis on the nature of modern subjectivity, and to an even greater extent, Quayson's concept of 'aesthetic nervousness' can be elucidated through Robert D. Wilton's analysis of Lacan in relation to disability. Davis has previously referred to Lacan's conception

of the constitution of the subject elsewhere, in work which has much in common with Quayson's theory of aesthetic nervousness (Davis 1997b, 55). Although, as we have seen, the phenomenological theories of Merleau-Ponty are particularly well-suited to the needs of a post-social model disability studies, and Kirmayer's theory of bodily meaning casts doubt on the viability of psychoanalysis for accessing the body as a source of language, Robert D. Wilton's citation of Lacan's reformulation of Freudian castration as offering 'a consideration of the body as culturally constructed' is especially worth considering in the light of Davis' arguments (Wilton, 377). Wilton notes that Lacan replaces physiological castration with a symbolic castration that occurs when subjects enter into language (the Symbolic order) at the Mirror Stage. Here, the subject is constituted through a (mis)recognition of the corporeal self. The cost of becoming a subject is still loss, but it is now a loss of the sense of one-ness that existed in the pre-Symbolic. The individual represses the knowledge of this loss, and the Symbolic order (language) facilitates this by displacing the desire for wholeness onto objects in the world for an 'always already unsuccessful search for that which would complete us'. Thus, the Lacanian phallus is a privileged signifier, created at the point of the subject's entry into language at the Mirror stage, and its signified is that which the subject has lost in the moment of constitution, which cannot exist within symbolic reality (378). This can be seen as the wounded subjectivity that Davis identifies, and narrative may be seen as the signifier, continually shifting in search of reunification with its signified. To this we might add the theories of Galvin and Kirmayer, leading to the conclusion that that which the subject has lost, the referent of the signified which cannot enter into the symbolic order (that is, language), is arguably the body that is insistent on meaning.

In the light of Davis' talk of 'cure narratives' in the abstract sense, Brett Smith and Andrew C Sparkes' sociological survey into the effect of narrative on the lives of people with disabilities is particularly useful for highlighting the real-world practice of a rather abstract idea. Smith and Sparkes employ Kirmayer's theory of metaphor, in particular his emphasis on the body making itself known in unconscious metaphor to an analysis of the language used in their interviews with fourteen English rugby players who had sustained Spinal Column Injuries. Smith and Sparkes classified these narratives according to the definitions used by Arthur Frank in *The Wounded Storyteller* (1995), collecting eleven 'restitution' narratives, one 'chaos' narrative, and two 'quest' narratives. The 'restitution' narrative, based on the belief that health can be restored is, they note, redolent of metaphors of sport and warfare, in phrases such as '*a fight to make a comeback*' (Smith and Sparkes, 616). Such narratives focus on 'medical advances and a cure that will return them to an able-bodied state of being'. For these individuals, 'winning is being cured of disability' with the latter defined as an '*enemy that must be beaten*' (617). This model strongly echoes the position espoused by Christopher Reeve (a keen sportsman, disabled in competition) in *Still Me*, addressed in Chapter 4. The authors observe that such narratives have a narrow definition of success that it is unlikely to be fulfilled, and prevent their subjects from exploring other, potentially more rewarding, identities as disabled men (618). The 'chaos' narrative, according to Frank's definition, lacks narrative order and is 'told as the storyteller experiences life: without sequence or discernible causality'. The authors quote their subject:

> My life is a mess [ten second silence]. I had broken my neck, and, and, and it was awful [ten second silence]. Difficult to

describe [five second silence]. No, it was, even now, back
then; I don't know [ten second silence]. I was, am, am no
more, I'm no more, and then, and then, then I left still in pain,
awful, something, but not a nice time (619).

They cite this subject as evidence that, while narrative and metaphor can help in

reconstructing the self, 'they may also imprison the person within certain storylines'

(621).

Finally, the two 'quest' narratives came from subjects who were able to

'accept impairment and disability and seek to *use* it'. Through journey metaphors,

these narratives employed 'a metanarrative of progress' in which 'risks, difficulties,

uncertainties and descents' all play their part. Significantly, the subjects of these

narratives focused, not on individual overcoming as the others did, but in 'stories

and dialogue – in communication and community – with others'. The link to

Couser's distinction between individual overcoming narratives and those that

embraced a universal outlook is striking, as is the similarity to the way in which

Reeve's narrative changes and eventually resolves itself in *Still Me*. Furthermore,

these subjects were observed to have 'a more communicative relation with the

body', which was perceived as a site of 'possibility' rather than a 'problem': a

distinction which recalls Shildrick and Price's critique of narratives that objectify

the body as a troublesome possession (622). Ironically, given their focus on

personal testimony, Smith and Sparkes attribute this attitude to the subjects'

introduction to the social model, and the counter-narratives, empowering

perspectives, and sense of community they see it as providing. They argue that the

social model facilitates 'restorying the self over time and developing

communicative bodies'. They conclude that disabled people thus benefit from:

> …the individual and collective stories told by other disabled people that deviate from standard plots, provide new narratives, and legitimize the re-plotting of one's own life (623-5).

It should be noted, of course, that this survey focuses on people who acquired disability, rather than being born disabled. In this light, the key word in Davis' phrase 'cure narratives' is 'cure'. Arguably, those born disabled have a very different body experience, having, as per Iwakuma's account of Merleau-Ponty's *lebenwelt*, an unconscious equilibrium as a result of their born experience that arguably results in a very different disability subjectivity. Likewise, as Shakespeare showed in his critique of the social model, much of its inadequacies stem from the assumptions of its formerly able-bodied, stably disabled, founders.

Nevertheless, Smith and Sparkes' survey is useful in showing the positive effects that narrative can have for the disabled identity; if combined with Galvin's sense of the need for identity *and* her sense of the possibility of agency, it provides another facet of the theoretical vocabulary I have established here as a context for the series of close-readings that follow. These readings will thus consider the role of writing as a physical act of embodiment and as a conscious or unconscious expression of physical difference expressed through literary form, most accessibly (but not exclusively) through a subversion of form (most specifically, in language through metaphor and neologism). In turn, this will be considered through the prism of personal and political identity, and the interplay of power relations between different discourses. On these bases works will be analysed in terms of their literary

qualities, relation to convention, contributions to debates about disability, and wider

thought on the role of bodily identity in writing.

CHAPTER ONE: CHRISTY BROWN

Christy Brown was raised in mid-twentieth-century Dublin, Ireland: he thus had no exposure to any readymade conception of his disability as a cohesive political or social identity (although he did develop a sense of this, as we shall see). Though misdiagnosed as an 'imbecile' while an infant, he was integrated into his family and home-schooled to the best of his mother's abilities. Thus, he had a venue and opportunity for self-expression and recognition, which ultimately led to his meeting with Dr. Collis and his access to physical therapy, and the doctor's advice on writing. Given these factors, it is unsurprising that Brown's autobiography, *My Left Foot* (1954, hereafter *Foot*), is very much in the traditional mode of autobiography criticized by disability studies scholars. Nevertheless, or perhaps because of this, *Foot* is a crucial text for the elucidation of this thesis. Although it was written before disability identity politics was formalised by the political intervention of the social model, and was tremendously popular with (and arguably

intended for) mainstream, able-bodied readers, the text remains relevant in a post-disability rights landscape: not only did the book spawn an equally popular and acclaimed film adaptation in the 1980s, but as recently as 2003, disability rights historian Paul K. Longmore has called Brown a 'hero of our struggle' (Longmore, 130). I will argue that such different, contradictory readings of Brown and *Foot* are made possible by a text that is far more complex than it first appears, due to a large extent to its use of conventional discourse to tell a story that continually points to the limitations of that convention. I will link this conflict to the role played by Dr. Collis, Brown's physician, an author, playwright, and autobiographer, in the composition and revision of the text, and consider the implications for authority, authenticity and agency that arise from this. This counter-reading of *Foot* will be further informed by a consideration of, and comparison with, *Down All The Days* (1970, hereafter *Days*), Brown's later autobiographical novel which covers the same period and themes in a very different style. *Foot* was published when its author was only 22 years of age. This may seem a ludicrously young age at which to publish an autobiography, but in the context of Brown's life and career, it makes perfect sense. At this age, the text functions less as a retrospective account of a life of achievement, but rather as an establishment of identity. It also implicitly emphasises the presentation of Brown's difference as exceptionality, a theme which is dealt with more explicitly in the similarly youthful publications of Christopher Nolan, to be dealt with in the next chapter. His age, as well as the interaction of his art and his disability, functions as the 'pre-existing distinction' on the part of the author that G. Thomas Couser identifies as essential to any autobiography seeking publication (Couser 1997, 182). *Foot* has precisely the sort of narrative criticised by Mitchell and Snyder: the book begins with the author's birth, progresses in a linear fashion

recounting his experiences, and concludes with his triumph. Coupled with a plain prose style, this at first makes the book appear deceptively simple.

From the outset, however, the text rewards close reading. The discovery that there is 'something wrong' with Christy Brown at the age of four months, as signalled by the involuntary bodily contortions caused by Cerebral Palsy, is related in a detailed yet detached tone of narration in the opening pages of the text. While this detachment might simply be attributed to a reliance on others' accounts of his infancy, it may also be interpreted as an authorial strategy to achieve a classic Cartesian separation of mind and body: by distancing his authorial voice from this unconscious infant body with its 'habit of falling backwards', Brown locates the authorial voice in Couser's 'neutral space', normalising himself and distancing himself from the stigma of disability (*Foot*, 9-10); (Couser 1997, 182). The same technique is arguably employed in the work of Nolan, as will be shown in Chapter 2, where the latter employs third-person narration to achieve a similar level of authorial control. This early establishment of body and mind as binary opposites may be seen as an attempt to pre-empt the influence of the medical discourse that dominated Brown's early life, and which thus dominates the early part of the linear narrative based on it: early on in the book, doctors misdiagnose Brown's spasms as evidence that he is 'mentally defective' (a diagnosis that inspired the title of his first attempt at autobiography, 'Reminiscences of a Mental Defective') (*Foot,* 10). Writing before disability studies' analyses of medical discourse, and before the controversial validity of the 'medical model', Brown thus demonstrates an awareness of power relations with regard to medical discourse, both implicitly, in his pre-emptive authorial rebuttal of the diagnosis, and explicitly, in his observation

that his mother's refusal to accept it seemed 'almost an impertinence'. The implicit and the explicit critique of medical discourse, and its interplay with his own agency, is subsequently played out symbolically, as Brown learns to write with his foot and proves that he can do so to an 'astonished' doctor by writing with the doctor's 'big red pencil' in his 'big report ledger'. It is hard for him to inscribe his identity here, with the doctor's tools of expression, as opposed to the chalk and slate he uses at home: 'the pencilled letters wouldn't come off as easily as chalked ones!' (22). This difficulty, and this agency, remind one both of Linton's difficulties expressing herself comparatively, and of Galvin's insistence on the possibilities for subversion of dominant discourse through agency, as addressed in the previous chapter.

Before Brown has learned to write, or even to use his left foot, he describes his life as one spent 'imprisoned' behind 'a glass wall', at once within and 'beyond the sphere' of his family's experience (14). The imagery of imprisonment is redolent of a certain sense of corporeality, yet the simultaneous absence evoked by 'beyond' points to a more complex, socially inflected carnality that brings to mind to socio/carnal oppression addressed by Hughes and Paterson. Certainly, as Brown relates the key moment of the text – the first use of his left foot – the account he gives points to an interaction of, and blurring of boundaries between, mind and body that is far more complex than the Cartesian dualism referenced at the start of the text. This is no break*out* from the body-as-prison, but an epiphany, marking Brown's entry into language, that is far more complex. One day, 'fascinated' by the spectacle of his sister's play with chalk and slate, Brown feels a desire to copy her actions. Suddenly, 'apparently on its own volition', his left foot snatches the chalk, and an 'impulse' drives it to make a 'wild sort of scribble' (15). This is not an

account of mind overcoming body – Brown stresses that he acts 'without thinking'.

Yet, triggered as it is by his desire, neither can it be called a spasm. The ambiguous

'impulse', suggestive simultaneously of the conscious, the unconscious, and the

(involuntary) body is a particularly apt word choice. It can be seen that Brown's

experience of his left foot fits with the various theoretical approaches based on the

work of Merleau-Ponty addressed in the previous chapter, as it allows him a 'living-

through-the body' experience:

> [For the individual] who has attained the dialectic of subject
> and object, the body is no longer a cause of the structure of
> consciousness, it has become an object of consciousness
> (Davis 2002a, 9).

This offers an explanation for Brown's claim that he comes to rely on the foot 'for

everything': it is not just how he writes, but an extension of his subjectivity, as other

passages will demonstrate (*Foot*, 21). An alternative, but not necessarily

contradictory, interpretation of Brown's account of this epiphany relates to Couser's

identification of 'distinction' once more. Arguably, Brown cultivates the ambiguity

of this episode in order to emphasise his exceptionality, and in turn, that of the text.

This perspective gains credibility from the fact that such epiphanies punctuate the

text: a stylistic tic perhaps inherited from Brown's first avowed influence, Dickens.

This first epiphany marks Brown's entry into language, a point which brings

to mind Wilton's consideration of Lacan as addressed in the previous chapter.

Wilton notes that entry into language, the Symbolic Order, is marked by a

'castration', a loss of that which cannot exist in the Order (Wilton, 378). I suggested

that that loss might be the 'irrational' body that Kirmayer identifies and that, rather

than being lost, this body in fact survives and can be accessed from (or rather makes itself known) within the Symbolic Order by the means Kirmayer outlines: for example, metaphor. In this respect, the Symbolic Order can thus be conceptualised as the same system as Galvin's dominant discourse. This becomes evident in the immediate aftermath of Brown's epiphany regarding his left foot. Recognising that Christy is trying to communicate, his mother immediately begins trying to instruct him in conventional language, urging him to copy the letter 'A' (16). The physical effort required of his unconventional body to produce conventional writing is stressed: Brown writes that he 'strained every muscle' in order to reproduce the letter as required. Even though the 'A' is '[s]haky…awkward, wobbly…and… uneven', it is recognisable: and Brown himself is now recognisable to his family as a conscious, cohesive subject.

Certainly, from this point on Brown the subject and Brown the writing subject are inextricably linked in the manner which gives *Foot* its odd dynamic. Brown views writing as 'the thing' that will give his mind a 'chance of expressing itself'. He celebrates it as 'more lasting' than speech, which is not yet available to him (17). Yet it is important to note that towards the end of the text he inverts this hierarchy, insisting that, whilst 'immortal', the written word lacks the ability to 'bridge the gap between two human beings as the voice may'. When he qualifies his new appreciation of speech by highlighting the importance of temporality – stating that he would prefer 'an hour's fierce argument' or 'a few moments of soft chatter' to writing 'the greatest book on earth' – the notion of carnality (with particular regard to temporality) espoused by Hughes and Paterson appears applicable once

again, and this time prompts us to consider the limitations of the written word in that respect (161). Brown's language, especially that regarding writing and self-expression, displays exactly the physicality of metaphor addressed by Kirmayer. He writes of his consciousness as a 'tense, taut thing…which panted for expression behind a twisted mouth' (17). Writing is a pleasure for Brown specifically as an expression of his personal identity. He writes his initials 'with a great flourish', and feels 'proud' and 'quite important' upon writing his full name. This empowering attraction might of course be viewed from a social model perspective as dangerous bourgeois individualism, giving a false sense of power and status to a disabled author who is in reality in thrall to an oppressive ideology. Such a manifestation, in the act of writing, of the sort of socially embodied oppression defined by Hughes and Paterson might be detected in a number of episodes in *Foot*: such as when misspelling (in other words, defying the convention of spelling) hampers written supplementation of his distorted speech, causing Brown to fly into a rage; or when his feet are normalised by footwear, and he writes of feeling 'as any normal person might feel if his hands were tied behind his back' (18-21).

The next key scene in *Foot* centres on Brown's mastery of the language he has acquired. As a slightly older Christy gazes at his mother, her attention devoted to a new infant, he is moved to inscribe a word, the identity (and thus meaning) of which is deferred until the passage's end. Due to a 'vague' feeling that he must master this word without her, he does not seek her help. When he finishes the word that has 'puzzled' him for so long, he seeks her 'approval' of it. She stares 'silently…still and thoughtful' at the word - 'M-O-T-H-E-R' (25). On the surface the scene appears sentimental: a touching display of communicated affection

between Brown and his mother that seems to highlight and affirm their bond. Sentimentality is a key issue in Davis, Mitchell and Snyder's dismissal of autobiography as a viable means of expression: they attack it for eliciting a stock emotional response (such as pity or admiration) from the reader, rather than a political one (Davis 1995, 3-4); (Mitchell and Snyder 1997, 9-13). Yet there is arguably much more to this scene than simple sentimentality: an impression that is strengthened by Brown's attacks on the inadequacy of sentimentality later in the text (see below). Simultaneously, an alternative, symbolic reading of the scene is readily available: that Christy has mastered language, and has displaced his mother as the arbiter of language, the dominator of discourse. He has mastered *her*, placing her in the patriarchal hierarchy of language and re-defining her identity solely based on a role ascribed to her through gender. The moment of apparent communion is in fact a moment of separation. In its symbolic aspect, the scene is clearly connected with the earlier 'A' scene regarding the acquisition of language. This might be seen as evidence of a meta-narrative strand about writing and the establishment of the authorial identity, with Brown emphasising his development as a writer both within the narrative and outside of it. This scene also reflects on the role of the reader: Brown is writing about writing for an audience (his mother), and for his audience (the reader). This strand becomes particularly prominent later in the text, when Brown details the writing process for the text *within* the text itself.

As he grows older, Christy is driven by an 'unconscious determination' to copy his siblings: 'to feel what they felt and know what they knew' (45). If this recalls the 'A' incident, it also points to the kind of social carnal experiences Hughes and Paterson have addressed. Christy is able to socialise with his siblings by

using a prosthesis (a cart) to travel outside the home. When people 'stop and stare',

he feels a sensation that 'there was something wrong somewhere', but represses it

(39). When the cart breaks, however, Christy is effectively disembodied:

immobilised, he becomes housebound. It is now that the repressed 'queer idea' of

his difference returns to haunt him (47). Brown describes himself as 'a cripple who

had only just discovered his own affliction' (50). Such language reveals not just that

Christy has taken on the negative social construct of disability, but that he

recognises it: years before the social model's orthodoxy. Yet, as with his mother's

rejection of the doctors' diagnosis, Christy resists. In not being able to understand

'what' makes him different, or 'why it should', he both questions and challenges the

assumption that such treatment is a given (49). The direction of Christy's

questioning is particularly important. Language is integral to his concerns, and

much of his distress comes from the fact that he cannot 'reason' or 'think clearly

about [his difference]', but can only 'feel it deep down' (49). His anxiety here

recalls Galvin's observations about identity anxiety, and the need to cling to an

identity no matter how marginalised or oppressive. Brown recalls: 'I had never

thought about myself' (50).

　　　　The visual field is integral to Brown's new disabled identity. He grows to

hate first his reflection, and then mirrors in general, because they allow him to see

'what other people saw'. This recalls the observation made by sociologist Erving

Goffman, in his pioneering work *Stigma* (1963) that, for the individual socially

stigmatised because of their undesired differentness, 'self-hate…can also occur

when only [the stigmatised] and a mirror are about' (Goffman, 133). This visual

sense of self is the basis of Brown's new experience of his body, an experience that

is Uncanny, in the Freudian sense of the familiar made unfamiliar: 'I had never thought I looked like that'. This identity also has a Foucauldian element, as per Marks in the last chapter, in that it is constituted by a certain discourse: without 'knowing what to look for', he had seen 'nothing peculiar', but now Christy is 'leered' at by a 'grotesque face' when he looks in the mirror. Such descriptions reveal that he has absorbed the idiom of the disability-as-grotesque that Couser identifies in the writing of Oliver Sacks. Yet Christy's agency, apparent in his questioning of the identity, is stressed again when he uses his left foot to smash the mirror: using his own carnal self-expression to reject the system of representation imposed on him (*Foot*, 50-1).

Although Brown displays a sense of disability as something socially constructed, in a manner that prefigures the eventual solidification of such ideas into the political tenets of the social model, he also explores an internal, individual aspect of the disability experience in a way which recalls the perspectives of Shakespeare and Hughes and Paterson on the difficulty of separating the physical and the social. He writes that '[s]omething had gone out of [him]', and that he had developed 'nerves as sharp as broken glass'. Social pressure has altered his mental state: 'I had become as different in mind as I now knew I was in body'. Furthermore, this mental discomfort is experienced and expressed in physical terms as a 'tautness' and 'mental tension'. It is the physicality of this experience that drives Brown to self-expression through art. He finds that his current means of expression, the simple copying out of words, is not enough for this newly complex experience of identity. Feeling that he needs 'some other way' to 'express' himself, he is drawn to his brother's paints much as he was to his sister's chalk. As he paints for the first

time, he connects these two incidents, noting that both involved the discovery of a 'new way to communicate with the outside world' (51-6).

Painting broadens Brown's 'range of expression' and his 'choice of subject', allowing him to develop a more complex subjectivity. Creativity and agency are inter-related: Christy feels happier because he has 'something to make each day, a thing to look forward to'. He is an agent subject, creating meaning, rather than the passive object of another's (negative) discourse. Merleau-Ponty's theories of the application of consciousness (whereby objects only come into existence when consciousness is directed at them) are particularly applicable here. As his painter's eye turns outwards from introspection Brown notes that he 'learned to forget [him]self', taking the pressure off of his own identity and thus lessening the need (as identified by Galvin) to subscribe to any identity that drives him to accept even a negative one. Painting gives him 'a feeling of pure joy' within which he is 'unconscious of everything' including himself (57). Furthermore, in giving him something to achieve every day, painting also gives Christy's life a narrative, with all the therapeutic qualities as identified by Sparkes and Smith which that entails (and something which becomes more apparent below). Painting becomes 'everything' to Brown, allowing him to 'articulate all that [he] saw and felt' (68).

Yet there is a danger to painting in the way it disconnects Brown from an outside world that, he admits, 'hadn't yet become a reality' to him. He finds himself falling into daydreams, sensing nothing, 'thinking' instead. His individuality becomes extreme: he now lives '*with*' but '*apart*' from his family, a development that mirrors his existence before the 'A' incident (68-9). It is in this state that he

meets Katriona Delahunt. Although she is described sentimentally as a 'dream-girl', her effect on his burgeoning artistic self-expression is tremendously significant. In another superficially sentimental episode, where she helps the young Christy make a 'get-well-soon' card for his hospitalised mother, Delahunt teaches the boy to narrow down his self-expression to the demands of an audience and a specific message. Noting that for the first time his painting was motivated by a desire 'to please someone else', Brown records the pleasurable 'feeling of being useful' (62). The exploration of such motivation is significant with regard to the later account of the autobiography's construction in the text: might the autobiography itself be tailored to its audience's preferences (especially in comparison to the much more complex, explicit, non-linear, surreal and angry *Days*)? In helping to make the card 'better', Delahunt acts as Brown's first collaborator and editor. She also instils in him a sense of practicality regarding his art, insisting on the 'necessity' of rising 'above the ordinary standard of thought and activity' in order to bring a 'securer balance' to his life: comments that hint at writing as a career for him (59).

This meta-narrative about catering to convention in fact has a thematic correlative in the portrayal of Delahunt. Brown characterises her as a 'dream girl', establishing a deliberately unrealistic view of women that persists throughout *Foot*. It is as if women, and indeed the other characters, do not have bodies at all, or at least are less embodied than Brown: a common effect whereby disability seems somehow more physically real than ability, as noted by Mitchell in the previous chapter, and by Tobin Siebers in his comment that, in contemporary art 'broken bodies and things are more real than anything else' (Siebers 2001, 749). Certainly, the physical aspect of sexuality is sublimated in *Foot*, arguably in order to conform

to the asexual role required of people with disabilities and make Brown's narrative more socially acceptable, as part of a subordination to convention to be discussed below. Thus, libidinal energies are masked and transferred to the titular foot:

> I centred my interest more in my left foot than in any other
> part of me – my heart included (61).

Anger and hatred are also sublimated in this fashion, presumably for the same reason. When Brown's next 'dream girl', a flirtatious neighbour, eventually abandons him, he finds himself:

> painting crazy little pictures that had neither pattern or
> theme…haphazard slices of…boiling mind dashed on to the
> paper wildly and recklessly (73).

Such self-expression unregulated by the formal requirements of social interaction presages both the *style* and the *content* of the later *Days*, with its non-linear narrative, insubstantial plot and stream-of-consciousness passages, and its frank handling of sexuality and rage as themes. In *Foot*, however, Brown restrains himself in both respects, responding to his erstwhile dream-girl's '*look of pity*' (his emphasis), with the carefully measured observation that he 'almost hated' her for her behaviour. In the context of the book, this is a strong statement. Indeed, Brown rejects not just pity, but 'sympathy' also, arguing instead that that people like him need 'genuine human affection' (74-6). Given that Davis, Mitchell, and Snyder have argued against disability autobiography as a form precisely because, they claim, it inevitably provokes pity/sympathy with reaction to disability, Brown's aims for his autobiography appear limited on account of his conformity to convention.

This rejection alerts Christy to the fact that he has been living in an 'impossible paradise', content in his belief that his 'difference' is only a state of mind. The reminder of the physical aspect of his difference is 'all the more violent and bitter' as his consciousness is directed at it once more. As he enters adolescence, he observes that for his peers, mind and body interact as an 'integrated whole', with the latter a 'natural outlet' for the energies of the former. Yet for Christy this link brings only a 'terrible *narrowness*' akin to being 'suffocated'. Like copying before it, painting ceases to satisfy him as an outlet. He feels a 'new need' for a 'broader medium to speak though', and the lack of one eventually drives him to contemplate suicide. With a symbolism particularly appropriate to autobiography as a form, it is only in plotting to annihilate his identity, to give it a finite conclusion, that Brown masters it by discovering creative writing. As he pens his suicide note, Christy discovers that his earlier pleasure at writing his name extends to writing creatively: he takes pleasure in writing 'grandly' and 'magnificently', concocting 'a splendid opening phrase'. This is his first act of autobiography. Its formal requirements make him review his life as an ordered narrative, giving significance and meaning to various events: he makes sense of his past, recalling happy moments, and shapes an aspirational sense of the future, as he thinks of seeing his 'dream girl', Katriona Delahunt, again (78-82).

In a development that lends credence to the theories of Davis and Mitchell, discussed in the previous chapter, that the need to ascribe meaning to difference is the basis of all narrative, Brown's thoughts after abandoning suicide and taking up writing turn to the question of why he was made 'different'. Yet the cultivation of the image of genius apparent with the earlier 'A' epiphany is also apparent here:

regardless of the implicit explanation of his adoption of creative writing, Brown attributes his sudden interest in creative writing to another epiphany. He remarks, simply: 'suddenly one day I had an idea'. As the creative urge expands to fill his mind, he begins to write compulsively. His first attempt at fiction recalls his frustrated painting:

> I hardly knew what I was doing. I just sat there, writing
> down whatever came into my head. It was a crazy jumble
> of words…It was just like mixing my paints and letting
> them all run into one mass of colour. I played with words
> like a child fascinated by a new toy, writing them down on
> to the paper and then looking at them in a sort of wonder
> (*Foot*, 83).

This untutored approach can be attributed to Brown's working-class upbringing as much as his disability: he remembers growing up in a house where books were 'a rare phenomena'. This can be seen as an explanation for his settling on autobiography, for, as noted with regard to Couser in the previous chapter, this has traditionally been the one literary genre available to writers from a non-literary background (Couser 1997, 181).

Brown claims that he initially saw writing, like painting, as a way to 'live alone, independent of others…[in] a grand new world of thoughts and ideas' (*Foot*, 84). Yet his accounts of his first writings can in fact be seen as an attempt to express the inexpressible physicality that was evident in his suicidal desperation. Throughout his amateur experimentation with genre, from westerns to romances and detective thrillers, body issues are a clear concern. When depressed he writes 'morbid descriptions of decomposing corpses…'. Sublimated violence is projected onto his early characters - Brown recalls 'I sliced them up into little pieces and scattered their remains about. It was very gory' (86). This is his apprenticeship in

the shaping of the body through representation, with the gore in particular suggesting a preoccupation with deconstructing the body as an object. This can also be linked to subjectivity: Davis has noted that the 'normal' body of the subject is the result of a (mis) recognition of fragmentary body parts as a unified whole subject during Lacan's Mirror Stage, and that the disabled body acts as 'a direct imago of the repressed fragmented body', threatening normal spectators by causing them to re-experience their former 'fragmentation' (Davis 1997b, 52). Managing the body through writing is therapeutic for Brown, like 'letting all the pent-up bubbles escape'. Yet these dismemberment fantasies can only do so much: he continues to feel 'an almost physical sense of pain' at being 'imprisoned' in his body, and longs to 'break loose and escape' (*Foot*, 86). The problem is temporal: each day is 'merely a repetition of the last, without any change or hope of change'. Simply put, his life lacks narrative structure – it is 'patternless, without purpose', in a way that is reminiscent, as his purpose in painting was, of the work of Smith and Sparkes on the therapeutic qualities of narrative (85-9). This observation offers a point of connection between Smith and Sparkes and Hughes and Paterson: if narrative is therapeutic, and time is one area of embodied social oppression, it might be argued that a narrative redefined for a disabled embodiment could be both therapeutic, pleasurable, and free the subject from oppression. Might this offer another, new explanation for the growing popularity of the personal essay in modern disability writing? This might fill in the theoretical background behind Couser's observation that the essay style offers freedom from narrative progress by allowing the re-visiting of the same experience at different times.

At around this time, a pilgrimage to Lourdes, driven by a hope for a cure, despite his 'lack of interest in religion', introduces Brown to other disabled people for the first time. Initially he is disconcerted to discover 'so much suffering in the world'. He objectifies his fellow pilgrims within the language of the grotesque, referring to 'them' as 'looking like living corpses as they lay under the newly risen sun', and comparing the sight to 'the Court of Miracles' in *The Hunchback Of Notre Dame*. Here again, the idiom of monstrosity that Couser identified in the work of Sacks is apparent. Yet his individualistic disability identity is profoundly challenged. He suddenly feels 'very small and insignificant' as he emerges from the bath waters feeling, symbolically, 'reborn' (92-7). This 'brotherhood of suffering' of which Brown now finds himself a part shares many of the qualities of today's more sophisticated political identity of disability. For example, Brown claims that the community has a shared 'story'. Furthermore, he identifies the transgressive possibilities inherent in disability's nature as a permeable category, noting that all 'barriers' are swept away by 'the common need for understanding and communication which we all felt…'. Perhaps most significantly of all, Brown argues that there is something unique about this identity, something which 'suffering alone could have inspired', and which finds its roots in 'a common heritage of pain'. It is interesting that Brown should focus on pain, which is arguably, as Shakespeare has pointed out, the area where the boundaries between the physical and the social are most blurred. If a communal identity is to be established, this would, in the light of the dismissal of essentialism and social construction seen in the last chapter, seem the point at which it could be most likely to flourish.

On his arrival home, Brown has arguably become politicised. He displays a nascent form of the separatism that Shakespeare fears is the logical result of identity politics, stating that he feels separated from his mother and family, as if by a 'new kind of glass wall', and that, in the place of the bond they once shared, his mother can now 'only vaguely' comprehend his feelings. He has also become an activist of sorts, convinced by his experiences that his life needs 'to have a purpose, a value'. It is at this juncture that Brown encounters Dr. Collis. The doctor fixes Brown with eyes that 'while they looked at me, seemed at the same time to look *into* me' (101-4). This, then, is not simply the medical gaze critiqued by Couser as objectifying the patient (Couser 1997, 19). Collis, it is later revealed, is a doctor *and* an artist (and autobiographer). As such, he functions simultaneously in two discourses, seeing Brown as both object and subject. Collis diagnoses Brown's Cerebral Palsy and offers him physical therapy. It is here that their collaboration is born, as Collis insists that Brown work 'with' the medics. Collis' words give: 'the past some significance and the future some promise, some definite purpose…' (*Foot*, 107). Thus, along with his newly acquired sense of the commonality of disability, Collis' intervention gives Brown's life the narrative structure he has been craving. For all its dynamism, this episode thus represents the genesis of the key conflict in both Brown's life and the text's production. For Collis insists that Brown subordinate his narrative to medical discourse and its 'mystic-sounding words' in order to become a *tabula rasa* from which the medics can 'make' a normal person. He must relinquish the self-expression he has developed. In particular, the left foot must be silenced because its use strains his body and prevents 'normal' behaviour. Brown realises the high price he must pay: 'I would be lost, silent, powerless'. The choice presented to

him by the doctors is unambiguous in its opposition of abnormal artistry and normal health:

> 'If you continue to use your left foot you may one day become a great artist or writer with it – but you'll never be cured' (123).

Brown acquiesces, believing that the 'new life' which will come from this 'complete new mode of thinking and acting' will be 'worth any sacrifice'. This process of normalisation is apparent in his first visit to the clinic, where he observes other disabled people in much the same way as he did in Lourdes. '[I]t was a treatment in itself, just looking on', he observes, noting his 'near-horror' at the 'twisting, twining babies with crooked little limbs, misshapen heads, distorted features' that he sees. It is an out-of-body experience. Seeing 'no reasoning, only helplessness' in the infants with Cerebral Palsy, he remarks: 'I realised for the first time what I myself had looked like as a child' (122-132). Yet Brown's political awakening in Lourdes overcomes his normalised response of horror. His 'brotherly insight' enables him to 'see and to *feel*' the 'imprisoned minds' of the children. As when first confronted with his own disabled identity, Brown finds in this sense of commonality something that 'no words of [his] could describe'. As he questions the significance of this feeling ('What does all this mean to me…what have I to do with all this?') he realises for the first time that his 'affliction' brings 'a strange beauty' into his life.

In this transitional time at the clinic, Brown begins a friendship with an employee, Sheila. Unable to use his foot to communicate, and embarrassed by his slurred speech, he recruits his brother as an amanuensis in order to write to her. In making this choice, Brown reveals a concern with presentation. As he insists that he

can 'express on paper' what he 'couldn't say', he observes that '*[t]he* greatest barrier' [his emphasis], is not speaking, but the social context of the speaking act (134-5). In this claim, two critical positions from the previous chapter are brought into play. Firstly, Brown's claim is directly related to Hughes and Paterson's account of carnal oppression, particularly in regard to their example of a person with Cerebral Palsy having difficulty interacting due to socialised norms of the body regarding time and politeness. Secondly, this recalls Couser's championing of the disembodied nature of the text as a neutral non-visual space in which the disabled writer may present himself (Couser 1997, 182). This correspondence also mimics Brown's relationship with Delahunt, as Sheila responds to Brown's 'dreamy, fanciful letters', with pragmatic missives 'full of wisdom'. This pragmatism is reflected in Brown's realisation that however much his body was rectified, his 'emotional life…*could* never really be "normal"' (136-7). This last point weighs heavily on any interpretation of Brown's writing, as we shall see.

His experiences at the clinic give Brown a 'mind full of ideas'. He feels that he has discovered 'the key to something' that he has sought since becoming self-aware. The exact nature of this 'key' is strangely obscure, as if inexpressible, and repeatedly deferred. Brown's new sense of a communal disabled identity is an integral part of this revelation: he states his desire to share the key with those who are 'similar' to him by virtue of living 'a narrow suppressed life'. This phrase hints once more at a political conception of disability identity, and also at the all too permeable nature of a political approach to identity as criticised by Shakespeare. This political element persists in Brown's insistence that the revelation offers a way of 'breaking loose' from such a life and of 'playing [a] part in the world along with

the able-bodied'. This obscure key would appear to be, finally, self-expression: that is, the establishment of a context which enables the voice of the disabled subject to speak on an equal footing with the able-bodied one. Brown writes of feeling an 'urge' to tell 'the world as a whole' about his revelation, and this is the genesis of his autobiography (139). The choice of genre can be seen to result from a combination of his desire to reach a large audience, the personal nature of the experience that he wishes to present, and the accessibility of the genre, as noted earlier. The latter is particularly important as Brown is limited not just by his own lack of education and experience, but by his reliance on a younger and even less educated amanuensis.

The issue of the amanuensis is clearly a sensitive one for Brown, perhaps because he is now writing on behalf of the 'suppressed' community he has allied himself with. He is careful to point out that that his brother the amanuensis is simply a 'fool' who will 'just hold the pen' (139-141). A concern for authenticity is perhaps the reason that much of the rest of the text is taken up by an account of its own production. This attention to the writing process is very useful for this thesis, not least in Brown's detailed recollection of his first attempt at autobiography, written at age eighteen and entitled 'The Reminiscences of a Mental Defective'. Brown is harshly critical of this effort, particularly its style. He mocks his earlier tendency to turn 'a simple statement' into 'a complex one', to use a whole paragraph 'to express a single thought', and to indulge in repeated 'digressing' (142-4). Brown includes a sample of the text to illustrate this point:

> It is when we are released from the turbulence and feverish
> activity of the day that we fall, without conscious effort or
> mental volition, into a reverie mingled with regrets and

> mellow joys…All the happy and tearful scenes of the
> forgotten past crowd before our inner eye (144-5).

According to *Foot*, Brown abandoned this version because he felt that he was writing 'mechanically' and that the product lacked 'an intelligible form' (145). He immediately identifies a collaborator as the solution to this problem:

> If only I had someone to advise me, to show me how to
> write clearly and constructively with no gaps between or
> holes in the middle! Someone who would know what he
> was talking about, who would put me onto the right path.
> I needed a guiding hand; I needed someone not only with
> brains but with a heart as well (146).

With the intervention of such a collaborator, fulfilling the exacting specifications that Brown sets out, this original style is eliminated from *Foot.* Yet it, or something like it, re-appears in *Days*, an occurrence which gains significance from the fact that the novel is essentially based on the same material. For example:

> He heard only his own loud chaos and nowhereness, saw
> only the tangled ways of his exile, the mouth of night
> engulfing him, the key forever turning in the lock, the lonely
> footfall forever turning upon the hill, the leaf falling in the
> forest (*Days*, 222-3).

The re-emergence of this style for the telling of the story reveals two things. Firstly, that it is not inadequate *per se*, but simply unsuitable for the purposes of *Foot.* Secondly, in being the distinguishing feature of what is in effect a supplement to *Foot*, it suggests that style is integral to a lack that the novel's very existence implies. Arguably, the nature of this lack might be explained by a comparison between the writing style in 'Reminiscences' and the 'exemplary' style Gayatri Chakravorty Spivak employs in her theoretical writing on problems of representation and authority. In such writing Spivak employs a verbose, digressive style as an attempt both to illustrate and to find a way around the fact that, as she sees it, 'plain prose cheats' (Danius and Jonsson, 33). One of her central concerns in

such writing is the impossibility of representing, in dominant discourse, communities that are silenced and denied by it: a concern that is, I would argue, implicit throughout *Foot*, not least in Brown's declaration that 'there are some emotions that cannot be conveyed, that cannot be "felt" through the written word alone' (*Foot*, 161).

Yet Brown, perhaps inspired by the pragmatic advice of Delahunt and Sheila to use his creativity practically, and bound by his need to reach a wide audience, as well as his unconscious yearning for a narrative structure for his life, seeks a collaborator, and settles on Dr. Collis. Arguably, he may have been unaware of the consequences for authority and power that this decision would have for his work. Couser has observed that the 'monological' nature of a text will always obscure the 'dialogic' process of any collaboration that produces it, and that this concealment makes it hard to gauge power relations in the collaborative relationship (Couser 2004, 35-7).He conceptualizes all collaborative writing relationships as existing in a continuum, ordered according to their power balances (54). At one extreme he places the ghostwritten celebrity autobiography as an example of a text dominated by the identity of the subject (50). At the other, as an example of a text dominated by the identity of the writer, he positions ethnographic life writing, such as slave narratives, or so-called American Indian autobiography (where the interests and agendas of the European American writers shape the life stories of their Native American subjects) (42). The Brown/Collis relationship does not appear to fit into Couser's continuum because the text, in its form as a traditional autobiography, is credited to Brown alone, and it is thus impossible to judge the extent of Collis' contribution. Yet Couser's continuum does highlight the role of status and power

relations, not just work done by collaborators. With this in mind, it should be observed that, according to *Foot*, Collis was Brown's first and only choice when he realised his need for a collaborator: '…a name suddenly flashed across my mind, so suddenly that I almost fell off the chair: "Collis!" I heard myself saying out loud, "Collis!"' (*Foot*, 146-7). This apparent epiphany invites questions. Following the internal logic of the text, it might be argued that Brown simply makes the connection between the need for order and productivity in his writing, and the doctor who had recently instilled these qualities into his life by enrolling him at the Cerebral Palsy clinic. Yet Brown appears to protest too much against another possible motivation: 'It was only later that I found out that he was…Robert Collis, the author too, the man who had written the famous play, *Marrowbone Lane*, *The Silver Fleece*, his own autobiography, along with other plays and books' (147). It should be noted that Brown's emphasis is as much on Collis' fame as his writing experience. Although Collis' role as authorial mentor is detailed in the text, and considered below, the issue of his fame, and thus status, merits further investigation, especially as Brown downplays its importance as a factor in his selection. It may in fact be seen as crucial to the book's genesis. The book's conclusion, a charity concert arranged by Collis to raise awareness of Cerebral Palsy, is in reality the book's beginning, at least in terms of its popular appeal. For it is here that *Collis* reads the first chapter of the book aloud to the public. He contextualises it in the public arena by emphasising its authenticity and authority, offering it as 'something that will give you an inside view of a person crippled with cerebral palsy' (182). In vouching for the text and augmenting it with his fame, Collis thus contributes to public demand and interest, all of which would arguably have shaped a book that was still being written. Indeed, it should be noted that the crowd's enthusiastic

response is the focus of the book's conventional, reader-pleasing 'happy ending'. In reaction to their response Brown remarks: 'I was at peace, happy' (177-84).

Whatever the suppositions about Brown's selection of Collis as collaborator, the account of his role in the production of the text given in *Foot* offers considerable detail. Collis reads 'Reminiscences' and pronounces it 'awful', but not without moments of promise. He recruits a tutor to teach his protégé 'good modern English', so that he might write a story that a reader 'can live in…himself' (thus, we might infer, broadening and normalizing the subjectivity of the text in considerable contrast to Brown's earlier observation that his emotional life could never be normal) (148-50). Brown writes that he re-drafted the text with Collis 'behind' him (151). The doctor's instruction is didactic, as he lectures on the 'forms…standards…principles and conventions' of literature. Brown states: '[H]e did all the talking, and I did all the listening'. Simultaneously, Brown employs a new amanuensis, his brother Francis, who 'thought about what he was writing' and thus offered more input. Thus, Brown's input into the text is arguably diminished in two areas, due to his dependency on Collis' approval, and his dependency on his brother's input. The next draft has a more 'clear-cut' theme, 'more orderly' construction and a 'more mature' level of thought behind it, but Collis deems it '"still too literary"' and requests another. Brown concurs, finding it 'pompous and unnecessarily dramatic' (166-8). This implies that he believes that a disability autobiography should be simple, humble and prosaic, which *Foot* certainly is. That a wok of disability autobiography should be considered 'too literary' is of particular significance given the examination of the work of Christopher Nolan, and in

particular his self-consciously flamboyant literary style, that takes place in Chapter 2.

Initially, Brown is exhilarated by the literature Collis schools him in, and his delight with language has an expressly physical dimension: Shakespeare gives 'an almost physical sense of joy' while Bernard Shaw is 'as brisk and stimulating an exercise…as a morning run…'. Yet, as he grows more absorbed in texts he detects a 'danger' in the 'black magic of constant reading', and longs for the true physical experience of 'climbing' or 'strolling' (173). In accordance with this, he begins to find composition via amanuensis stifling. One night, struggling to express himself through dictation, but finding that his words are 'all wrong and twisted', he has a revelation: 'suddenly I remembered my left foot' (173-4). In a flurry of violent physical activity (having 'flung' himself onto his bed, 'ripped' off his sock, and 'seized' a pencil) he dismisses his amanuensis and writes with his left foot once more. He writes 'without consciousness' for hours, feeling 'free' and like a 'different person'. He remarks: 'I could think, I could live, I could create'. He feels 'released, at peace', at the fact that he can 'be [him]self sometimes'. He writes of 'the ecstasy of creating' as being a substitute for 'the joy of dancing' (175). Brown's joy prompts recollection of Hughes and Paterson's notion of carnal oppression once more: in this moment, Brown is not only free of the conventions of dominant discourse in his writing, but is also free in his embodiment. Significantly, when Collis finds out, he urges his protégé: 'don't use it except when you must' (175). The evocation of Brown's pact with the clinic doctors is appropriate: he admits that 'the old pen had a lot to do' with his laziness in rehab (164). Taking into account the internal tensions revealed by the above analysis of the account of the

writing process, it is unsurprising that concerns over authority and authenticity should come to the fore at the text's climax, especially, as we have seen, because the climax is also the beginning of the text's public life. When Collis asks to read Brown's first chapter aloud, he insists that Brown appear onstage with him so that 'they'll know it's your work not mine'. As Collis reads the piece aloud, Brown wonders:

> Had I really written all that stuff? Did all that really come
> out of my mind? It seemed as if I was dreaming (183).

Foot is, then, a far more complex text than might be expected from its young author and concise, simple and plain style. Certainly, it justifies the attention given to it here, and casts doubt on the social model-inflected literary approaches that would characterise it, in its apparently traditional form, as victim to and perpetrator of an oppressive view of disability. Although on many levels the text is conventional, and treats disability conventionally, it can be seen that this very conventionality is foregrounded by Brown's account of the writing process, thus establishing a certain critical distance between himself and the text's version of his life story. The wide-eyed, asexual, placid and jolly Christy belies Brown the author, carefully establishing his genius through the series of mysterious epiphanies that give the narrative its backbone, from 'A' to writing to Collis. Through these epiphanies concealing structure, through these 'dreamgirls' urging him to be practical in using his creativity and to learn to please his audience, and through his achieving fame and establishing himself at the age of 22, disabled and working-class in the 1950s, we glimpse Brown the author.

And yet an alternative frame of reference is clearly provided: in every sentimental scene there is a symbolism pointing to a richer meaning, a disability experience that is scarcely expressible, yet makes itself known in the desire for expression. Brown's work proves that the social model, and indeed the 'medical' model are as redundant as Shakespeare has claimed, because, writing years before them, he shows resources for dealing with medical discourse, and for recognising and challenging the socially imposed aspects of the disability experience, that are more than adequate. Furthermore, Brown shows precisely the kind of awareness of the inadequacy of separating mind and body in disability experience that preoccupies much more recent (and more celebrated) writing. The phenomenological theories that are becoming popular are more than evident in his use of physical metaphors, and by his careful choice of terms such as 'impulse' that suggest experience without falling either to body or mind. Thus, even in conventional discourse, he brings a sense of the abstract and the unspoken to the text. His account of pain relieved by self-expression is particularly useful in gaining a sense of what the possibilities for the writing body might be. It is particularly interesting that, in the nascent identity politics he explores, Brown circumvents immediate redundancy by focusing on that 'common heritage of pain': in pain's blurring of the physical and the social there lies the possibility for a viable disability identity that is stymied neither by the generalities of political identity nor the rigid specificity of essentialism.

CHAPTER TWO: CHRISTOPHER NOLAN

Like Christy Brown, Christopher Nolan is an Irish author with Cerebral Palsy who came to prominence at a young age on account of his writing. Yet a number of qualities separate these two authors and their writings, not least the simple matter of time. In the 27 years between the publication of Brown's *My Left Foot* and Nolan's *Dam-burst Of Dreams* (1981, hereafter *Dreams*), the disability rights movement had been born, medical technology, particularly in assisted communication, had improved, and social attitudes to disability had changed considerably, as indicated by the fact that *Dreams* was published in the United Nations' International Year Of Disabled Persons. Nolan's work reflects changing attitudes not just on the part of the reading public and society at large, but also on the part of the author himself. Even by the standards set by Brown's publishing of *My Left Foot* at 22, Nolan was precocious: after finding fame by winning the British

Spastics Society literary award in 1979 at the age of 12 with the autobiographical fiction of 'A Mammy Encomium', he published this and other works in *Dreams* only two years later. This early acclaim was only overshadowed six years later, when Nolan's expansion of 'Encomium' into *Under The Eye Of The Clock* (1987, hereafter *Clock*) won that year's Whitbread Award, marking his work as exceptional not just within the narrow context of disability literature, but literature as a whole. An examination of Nolan's work is therefore crucial to this thesis, not only for its intersection with Brown, or its emergence at a time when disability rights was dispersing into broader society, but for its expressly literary quality, which arguably emerges from, rather than in spite of, Nolan's disability. For Brown, as we have seen, the key to success was a simple story, told in a plain style. Nolan's style is the very opposite of this (if not of the more self-consciously literary *Down All The Days*): dense, poetic and verbose. Yet context is also crucial for the literariness of Nolan's work: both *Dreams* and *Clock* are prefaced by introductions which contextualise not just the text but also the author, presenting his difference as genius. Apparent in this process is the reluctance to admit any authors as influences, or to place Nolan in any literary tradition.[2] As such, no hint of an encounter with Brown's work is to be found there, despite Nolan's repeated references to his voiceless disabled forebears en masse.

The introduction to *Dreams* is provided by the journalist Marjorie Wallace, who interviewed and profiled Nolan for the British *Sunday Times* after his Spastics Society award, and thus brought him to world-wide attention. As might be expected from her profession, her focus is on Nolan's biography and interviews with those

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[2] Wallace does note, however, that Nolan 'has begun to be familiar' with the work of Gerard Manley Hopkins (xii).

close to him, but her introduction does also explore the themes and style deployed

in his writing. In *Clock*, Joseph Meehan, the protagonist, encounters the media after

winning his award and embraces journalists as 'imaginative people' who 'tuned

quickly' to his message and who treated him with 'graciousness, delicacy, fairness

and faithfulness' (*Clock*, 90; 92). Wallace's introduction, which focuses as much on

the author's biography and writing process as upon his literary value, reflects such

sympathy by foregrounding and emphasising Nolan's literary talent. She notes that

although Nolan communicated with his family through a system of noises and

gestures as a child, his literary talent was only revealed at the age of 12, when he

was given Lioresal, a new muscle-relaxant. This allowed him to type using a head-

mounted pointer. Wallace recounts the story that Nolan almost immediately began

typing poems which he had already composed and memorised. Kathleen Ryan,

Nolan's teacher, is quoted by Wallace as being 'surprised by the strange language'

of the poems: not only did she have 'no idea whether he could write or spell' but

she never suspected that he knew 'such long words' (*Dreams*, viii).

Wallace portrays the teenage Nolan as a genius. She notes that Nolan 'does

not like having poetry read to him' wishing instead to 'keep his mind unconditioned

and develop his own ideas' (xi-xii). Similarly, she notes that his very first poem,

typed days after trying Lioresal, 'contains the alliteration which characterizes much

of his work'. Indeed, she notes that Nolan was prolific, writing his second poem

within two days of the first; this idea of Lioresal freeing a pre-developed flow of

work is the collection's titular 'dam-burst', plucked from Nolan's own description

in 'Encomium' (16). Thus it can be seen that Wallace amplifies Nolan's

fictionalised version of his genesis as a writer, a version where the extraordinary

nature of his talent is emphasised. His mother, Bernadette, contradicts this image

considerably. She is unsurprised by Nolan's talent, and to an extent undermines the

mystery of it with her recollection of teaching him 'all the time'. She recalls

facilitating his first system of communication by decorating the family kitchen with

the letters of the alphabet, illustrated by her drawings:

> He learned how to spell by accumulating groups of letters.
> He used his eyes to indicate which letter came next in the
> word which he was attempting to spell. He memorized the
> look of each word and was always fascinated by the rich
> sound of unusual words (viii).

Wallace attributes the 'extraordinary style and vocabulary' of Nolan's writing to the

unusual experience of language that results from his disability. She quotes

Bernadette's description of her son as 'playing with words…as other, able-bodied,

children play with toys'. It is this context, she posits, that leads Nolan to 'cherish

them, to savour their sound, to explore their meaning' (ix). Of particular interest is

Wallace's observation that Nolan's sense of grammar is one in which words are

placed 'in relation to one another like friends round a dinner table'. The idea of the

structure of language being rearranged in this way recalls Galvin's work on the

possibilities for personal agency as discussed in the Introduction. Furthermore, in its

sense of interdependency, this view of language might be seen as a linguistic

analogue for Davis' 'dismodernism', with its emphasis on interdependency, also

discussed in the Introduction (ix). As Davis perceives 'dismodernism' as a social

paradigm shift of the early 21st century, the analogy is particularly appropriate,

given that Nolan's play, and the reconfiguration of language that results from it, is

an indirect result of the shift in attitudes to disability that gained momentum in the

1970s. For, unlike the doctors who misdiagnosed Brown (and, in Chapter 3, Ruth

Sienkiewicz-Mercer), the doctors at the Central Remedial Clinic in Dublin

'accepted without question' Bernadette Nolan's belief that her son was intellectually normal, and encouraged her to expose him to stimuli like the kitchen alphabet (ix).

Even with Bernadette's account of Nolan's education, Wallace is drawn back to the idea of genius. She notes that although not well-read, nor even 'able to reach for a dictionary', Nolan's writing is peppered with classical allusions. She theorises that his language, along with the 'archetypal images' that characterise his early works (such as the short story 'Perangamo') originates in 'his subconscious'. She extends this apparent allusion to Freud by describing Nolan's early work as 'uncanny'. This is a reasonable assertion. Robert Wilton, in his insightful analysis of the relevance of Freud and Lacan to disability, has observed that '[f]or Freud, physical disability is a source of uncanniness' (Wilton, 371). The archetypes which Wallace identifies in Nolan's early work are 'exotic, in turn threatening, doom-laden and hopeful' (*Dreams*, x). Wallace's approach might itself be analysed here, as the archetypes which she identifies (perhaps unconsciously herself) can be readily identified as stereotypes of disability: fear, pity, and inspiration. Furthermore, what is in fact interesting about Nolan's archetypal figures, such as the protagonist of 'Perangamo', is that they are archetypes of *ability* rendered uncanny through their rendering in the idiom of disability. Thus, Perangamo is a fit, strong and normal, if thuggish, young man, but Nolan writes of him walking with 'faltering footsteps, loose limbs lagging lazily, non-cooperatively behind', or making 'his lonely way home fighting madly maddening undercurrents of electric thrombosis in his brain' (44; 46).

For a literary perspective, Wallace refers to Christopher Ricks, Professor of English at Cambridge University. Ricks takes the grotesque style of Nolan's early work and analyses it, asserting that the author 'animates dead metaphors and expressions in a startling way'. Continuing with this theme, Ricks notes that while this early work is marked by 'grim and dead' landscapes and characters 'frozen into postures as in a Beckett play', the language Nolan uses is nevertheless 'young and energetic'. The disparity between form and content is a theme upon which Ricks expands:

> He uses words as though he were passing electric shocks
> through a dead body. Old clichés and disused words are
> brought horrifyingly to life by the sinister and the
> supernatural (x).

That Ricks should connect Nolan's language use to the body in such a way is remarkable, and can certainly be taken as evidence that the physical aspect of Nolan's disability makes itself known in his writing. Language is rendered uncanny, or, in the Russian Formalist sense, defamiliarised, by Nolan's disability. That the body makes itself known in this uncanny way demonstrates the ways in which Nolan's writing upsets or avoids dominant discourse's ways of dealing with the bodily, in a manner that recalls Galvin's work on subversion of dominant discourse as discussed in the Introduction.

That Nolan eventually abandoned the grotesque style of his early work suggests that he, perhaps in an awakening of disability politics, became aware of the negative quality of such language, as emphasised in the Introduction by Couser's attack on Sacks for employing the idiom of the grotesque with regard to disability (Couser 1997, 185; 189). This problem is apparent in Ricks' use of the same style in

his analysis: his description of Nolan as 'passing electric shocks through a dead body' risks being read as an allusion (quite possibly unconscious) to the spastic convulsions resulting from the author's Cerebral Palsy, that in turn reveals a rather negative view of Nolan's relationship with his body. The consequences of this are apparent when Wallace seizes on what she describes as Ricks' 'Frankenstein' imagery to assert that it 'explains a lot about Christopher'. She puts it simply: 'His written words are his only means of "zombieing" paralysed limbs and encumbering body into life'. The simple contradiction of this phrase, given that Nolan's words are in fact only 'brought to life' by his body, not vice versa, reveals the inadequacy of the perspectives on mind and body available to Wallace. This is made all the more apparent by her contradictory statement that, on one hand, words are Nolan's 'totality', while on the other she observes that his words allow only a 'glimpse' into his 'encapsulated mind' (*Dreams*, x). Wallace rightly argues, however, that Nolan's writing is unconventional, because he 'has never had the opportunity to learn conventions'. This point could be refined in order to consider the disabled body more fully as the source of this lack of ability to absorb convention, or rather, in the view of Shildrick and Price, the source of resistance to an overlaid discourse. Similarly Wallace's attempt to link Nolan's 'surrealistic' style to his disability, although not expanded upon, is admirable, for this is precisely what Kirmayer does in his argument for metaphor as the means by which the body makes itself known in language (x).

Wallace also raises the issue of 'voice' in Nolan's work. As he has 'no voice of his own' she wonders 'whose voice he hears pounding out those melodic lines' (Steven B. Kaplan asks almost exactly the same question of his disabled

collaborator in Chapter 3) (x). She notes that 'euphony' drives Nolan's writings as much as meaning, and concludes that in the case of a neologism such as 'sapespered' and 'dankerous' the word is often 'primarily selected' for its sound (xii). Wallace identifies a constant movement in Nolan's work between the 'universal' and the 'intimate' and between narrative styles of 'cacophony laced with the dissonances of contrast and conflict' and the 'taut…and simple'. The 'universal' and the 'intimate' might be interpreted as the social/political and the personal. The 'simple' and the 'cacophony' might in turn be interpreted as dominant discourse and what lies outside it. Thus might Nolan's work be seen as an attempt to reconcile, or mediate between, these elements. The attempt to balance dominant discourse and that which is outside of it recalls Brown's allusions, in the plain prose of *My Left Foot*, to an inexpressible experience. Such mediation in Nolan's work is further evident from John Carey's observation, in his introduction to *Clock*, that the development of Nolan's writing style has been marked by the interspersing of his typical style with: '[p]lain statement and straightforward reportage' (*Clock*, x). If Nolan's style does represent, on one level, a mediation between the personal and political, his preference for moving between cacophony rather than allying himself to a single definable 'voice' can be seen as a way of successfully avoiding the problematic conflation of the personal voice with the political voice that Shakespeare has identified in disability writing that allies itself to a disability identity politics. Indeed, in his openness to cacophony, Nolan arguably rejects not just dominant discourse, but the domination of *any* discourse. This is perhaps a reflection of the factors that Wallace perceives as possible influences on the young Nolan's unusual language: 'conversations overheard, snatches of Gaelic, doctors' whispered consultations…items from radio and television' by a young man

unusually sensitive to language. Thus medical discourse, in line with Couser and Shakespeare, is cast simply as another discourse, rather than the great oppressor (*Dreams*, xii).

Insightfully, Wallace examines the effect of the body, not just as a cache for the unconscious, but on the writing process itself. In this way, she brings to the fore the social aspect of embodiment that Hughes and Paterson, for all their preoccupation with oppression, have rightly highlighted. She notes that while disability has shaped Nolan into an unusual talent, 'handicap's advantage becomes a cruel barrier' in the act of writing. Initially, each word typed with the unicorn wand took 10 to 15 minutes. Thus, Wallace observes, 'sheer labour' has an 'effect' on his work by:

> creating a discipline in which every word must play
> many parts, through its meaning, the evocation of its sound,
> its shape and rhythm and, most important, its relationship to
> its neighbours (xiii).

The resultant work is thus 'extraordinarily dense in texture'. The effect of this process perhaps reveals the reason for the difference between Nolan's work and that of Brown (and thus, the problem of finding commonality in the variance in experience even between those with the same disability): Nolan is far more reliant on assistance in the physical act of writing than Brown is. This is the point at which his image as genius is at risk for, as Wallace observes, the 'success' of Nolan's writing process is 'largely due' to Bernadette, his 'patient amanuensis' who 'steadies his head to make typing possible, checks unusual spellings in the dictionary for him and struggles to understand what he wants'. This role arguably sheds light on the fact that 'A Mammy Encomium' is, by both title and content, a

work devoted to her. Yet even at this early stage, frustration is evident: Wallace recalls an occasion when Nolan wanted to use the word 'masochistic' only for his mother to be unable to interpret his version, 'masokiz', learned by sound alone. He was temporarily forced to use 'cowardly' as a substitute, before discovering the correct spelling and restoring the original word ten days later (xiii).

'Encomium', written at age 12, declares itself as Nolan's 'autobiography' (3). Despite its author's youth, the work establishes much of the distinctive style that is refined in *Clock*: it is a work of autobiographical fiction centred around the character of Joseph Meehan whose disabilities and life experiences are similar, but not the same as, those of Christopher Nolan. Its fussy and stilted, staccato style, that would be improved upon in *Clock*, can arguably be attributed as much to a lack of sophisticated transcription equipment (such as the computer used then) as to a lack of sophistication on the part of the young author. Thematic naivety however, can only be attributed to the latter; 'Encomium' often succumbs to a sentimental and clichéd view of disability, for example describing 'horrendously handicapped' children trying 'to conquer their horrid handicaps' at Joseph's special needs school (14). In *Clock*, this is replaced by a far more nuanced treatment of disability and disability identity. 'Encomium' is also explicitly religious, an element that is not apparent in *Clock* and which complements the sentimentality: Nolan writes that Joseph 'happily accepted crucifying handicap' (17). This religiosity is important because it imposes a meaning on a key scene. In the account of Joseph's writing breakthrough in *Clock*, it is Lioresal that allows him to type. In 'Encomium', however, the focus is on Joseph 'praying and begging God to have pity on him' and

a recounted dream which implies that his ability to type is a religious miracle (16; 18).

The role of Joseph's mother, Nora, in 'Encomium' is far broader than mere amanuensis. It is she who teaches Joseph how to reconfigure language to the requirements of his disability, explaining 'how to leave out the unimportant letters and get the sound of the word from the remaining letters' (a shorthand similar to the 'word seeds' employed by Ruth Sienkiewicz-Mercer, to be discussed in Chapter 3) (11). Similarly, when Joseph's first attempts to type with a wand after taking Lioresal flounder due to 'milling defeating spasms', it is Nora 'instructing astounded Joseph to carry-on' while supporting his chin and rigging the paper in the type-writer for him, who allows him to type his first poem (16; 20). Significantly, even as Joseph feels 'power' for the first time as he ventures into 'literary fields', he relies on Nora to bring 'added focus' to these first writings where he is '[g]roping Medusa-like' without direction or purpose ('Oftentimes the trip was for nothing') (21). Yet, as with Brown, the power of authority takes hold and cultivates Joseph's ambition, he turns to his schoolteacher for advice on 'how to outline his stories'. One day he sees an advertisement for a 'Literary Contest For The Handicapped', which arouses his '[i]nterest in schooling his carefree, careless concatenate mind'. His ambition is thoroughly focused: '[l]ively close attention to the closing date exacerbated Joseph's battling brain' (22).

One passage in 'Encomium' is crucial for a consideration of the impact of the disabled body on writing. As we have seen, Wallace has stated that Nolan pre-

composes his work in his head, with the act of typing a process of transcription rather than composition. Yet, in 'Encomium' Joseph composes *as he types*:

> as he typed thoughts, brilliant, bright, boiling words
> poured into his mind, sometimes with such ferocity that he
> felt spoiling confusion creep across his turbulent, creative
> mind (23).

If the fictional Joseph bears any relationship to Nolan, this passage has several implications. Although improved technology means that Nolan may well, by the time of *Clock*, have been able to compose 'on the fly', this account comes in 'Encomium', written in a period when typing was, as detailed by Wallace above, a laborious process. If, like Joseph, Nolan composed as he went along, the physical barrier posed by his disability can be seen to have even more of an impact, given that temporality, as he tried to pin down these thoughts, would become much more significant. Hughes and Paterson's work on social norms of temporality as evidence of carnal oppression is particularly relevant here: given his disability, Nolan would arguably not be able to harness spontaneous inspiration via the conventional transcription he attempts to approximate through his Lioresal-assisted typing as an able-bodied writer would. Thus his disability becomes far more important to the act of writing. In fact, there is a hint of a feedback loop: for it is the act of typing, an act shaped and necessitated by his disability, that prompts or at least plays a part in his creative thoughts. This also makes Nolan's creativity less a thing of the Cartesian mind, composing in its prison and choosing the moment for its escape, and more a thing of a *living-through-the-body* experience, reflecting the phenomenological approaches influenced by Merleau-Ponty (as discussed in the Introduction).

In the six-year interval between the publication of *Dreams* and *Clock* a discernable paradigm shift had occurred: identity politics was in the ascendant in 1987, and international definitions of disability now largely recognised a disability/impairment model that legitimated the view of disability as a thing of social construction (and thus political identity) rather than an inherent fault. It is surely this subtle shift that facilitated the reception of *Clock* as remarkable not simply due to its author's disability, but because of the way this aspect of his identity informed his art. In winning the Whitbread, Nolan earned the status of equal among his literary peers. Further evidence of this can be gleaned from the tone of the book's introduction, provided by the literary critic John Carey. The first thing the latter insists upon is that the text 'does not need a preface by me or anyone' (a rather neat example of the paradoxical nature of the supplement as per Derrida). He insists that he provides one solely as a favour to an author he admires. Thus Nolan is accorded literary peer status and authority, and the text is validated (*Clock*, ix). In crediting *Dreams* as the foundation of this status, Carey refers to the latter's 'jubilant, lawless' quality as its strength: a point which raises the issue of the subversion of convention mentioned by Wallace earlier, and of the subversion of dominant discourse as per Galvin and Shildrick and Price, as well as Silvers' notion of art's receptive attitude to difference. Despite praising this lawlessness, it is significant that Carey positively notes Nolan's subsequent concessions to plain speech: perhaps lawlessness is something to be set aside in exchange for status. If the latter point betrays a sense of qualification in Carey's praise, this may be linked to the persistence of certain stereotypical, clichéd attitudes to disability in the latter's introduction. His conclusion that Nolan's intense relationship with language stems from its function as 'his one escape route from death' recalls the resort to

cliché by Ricks and Wallace in their reception of *Dreams*: his reference to 'the coffin of [Nolan's] body' cements this image (ix).

Carey's close focus on Nolan's relationship with language is productive, however. Like Wallace, he notes the use not only of rare 'found' words, but of tailor-made (or 'bespoked' as Nolan writes) neologisms. In a move that appears to allude to Nolan's working at the limits of dominant discourse, he locates such language 'far beyond charted usage'. In indicating the limits of such discourse, and thus the limits of its knowledge and power (as per Foucault), such language is innately subversive: thus, as Carey argues, any attempt to read the book in the traditional mode of disability-as-tragedy is undermined 'by the resourcefulness of the very language which expresse[s] it'. This supports Shildrick and Price's citation of Foucault's insistence that all power contains the potential for its own subversion, and undermines the notions of the rigidity of the autobiographical form originally offered by Davis, Mitchell and Snyder. Although Carey is referring to *Dreams* in his elucidation of Nolan's style, the argument also applies to *Clock*. In this style, idiom (and thus the accepted order) is 'constantly subverted and remade', pushed 'askew' to the extent that '[c]ertain words…have…special meanings for Nolan'. Carey notes that the meanings of Nolan's neologisms are often hard to fathom because of their multiplicity of allusions, as in his example of Joseph's thoughts of his future:

> '[H]e had long ago snapped shut his challenging, fees-fashioned future and humanhinded his woodway as a celibate pilgrim through life'…It is deceptively like, and bitterly unlike, 'humankinded': but what does it mean? Is the 'hind' element 'hind' as in 'behindhand', or as in 'hindrance', or as in 'hind' (simple country fellow)? Or all three? This sense of language expanding beyond its own

boundaries, and beyond our reach, is a typical Nolan effect,
and one thing that prompts the frequently made comparison
with Joyce (x).

Although Carey identifies this effect, a disability studies perspective might allow an

analysis of the cause. This refusal to privilege one meaning over another recalls

Wallace's earlier analysis of Nolan's relation to 'static', and points to Kirmayer's

view of how dominant discourses control the interpretation of metaphor, and thus

the meaning of the body from which such metaphors spring. In this way, Nolan's

style might be seen as a conscious or (as per Kirmayer once more, and Shildrick and

Price) even unconscious reaction to, and resistance to, the demands of dominant

discourse. Carey's assessment is a particularly good illustration of Silvers' point

regarding art's more receptive attitude to disability through its appreciation of

aesthetics. Carey, as a literary critic, can be seen to approach Nolan's language in a

much different way to Dr. Collis or, in Chapter 3, Steven B. Kaplan. Unlike the

latter, Carey's never presents the possibility that Nolan's strange language is an

error, an abortive communication. This is made all the more apparent by the fact

that what could be interpreted as small typographical and semantic errors, rather

than artistic reconfigurations of language, although un-remarked upon, are actually

apparent in both *Clock* and *Dreams*. For example, in the account of Joseph's birth,

Nolan writes of a 'knife used to prize him out'. Should this perhaps read 'prise'?

This could be interpreted as a deliberate pun, a misprint, or evidence of a reverence

towards Nolan's artistic powers on the part of his editors that grants him the benefit

of the doubt over spelling (50).

Despite this reverence for Nolan's unusual use of language, it is interesting to note that Carey applauds *Clock*'s incorporation of '[p]lain statement and straightforward reportage' as a sign of the author's 'development' as a writer. This might bring to mind our comparison of Brown to Spivak in the last chapter. Carey argues that this variation allows the author 'new kinds of tonal contrast, a new capacity for extended narrative, and a new realism'. These last two points are important, for in making them Carey implies that Nolan's customary style – his disability-forged aesthetic – is unsuitable for either 'extended narrative' or 'realism'. This suggests that a certain breeziness, lightness - *disembodied-ness* - is desirable as an effect of extended narrative, but *not* in a short one. This issue of form might be seen to extend into genre, for example to the personal essay style as identified by Couser in the Introduction, and examined in Chapter 5. The second point interrogates this first one: in increasing the gap between the conditions of writing (difficulty, physicality, effort) and the conditions of reading (ease, disembodiedness) how can an *increase* in realism be achieved? Rather, it is Nolan's submission to a dominant, able-bodied version of reality represented in a certain way in literature that is increased. I would argue that Nolan's earlier style is far more deliberately 'realistic' to his experience. Nolan has not, however, abandoned his earlier style in favour of convention. Rather, as Carey notes, *Clock* is a text of tonal contrasts. This again hints at Nolan's deliberate avoidance of one particular discourse, thus avoiding the perpetuation of hierarchy that Shakespeare warns against in the pursuit of identity politics (x).

It is worth noting that Carey himself stresses that Nolan's writing style is 'a fruit of his disability' (xii). The critic's exegesis of this cause and effect is based on

what he sees as the author's combination of 'a child's weird fanciful sympathy' with 'the mind and vocabulary of an adult'. Looking past the obvious slide into cliché in this conflation of disability with infantilism, we can tease a more useful outcome from Carey's point. A reversal of Carey's assertion that Nolan realized 'the terrible truth about his body' at an early age [based on a passage where the latter writes of Joseph crying 'the tears of a sad man' at the age of three] reveals a fault-line to be exploited (xii). What if Nolan (Carey reads Joseph as Nolan) did not 'realize' the terrible truth of his body at all? From a Lacanian perspective, we might rather argue that instead, the 'terrible truth' of the body was never covered by the action of the Mirror Stage, as this socialisation process could not function on Nolan's body. Thus physical disability might allow a person to retain their pre-social relationship to their body, as their body is never recognised as a subject, whilst simultaneously socialising into so-called 'adult' language (xii). There are other elements to this terrible truth in the theories of embodiment addressed earlier.

If Carey is unable to see this, it is only because he is of his time: the late 1980s marked only the beginning of a problematisation of body theory, and in judging Nolan's disability as 'a positive factor which adds immensely to the book's value and significance', Carey is keeping reasonably abreast with the progress of the shifting paradigm of disability in 1987 (xii). He shows enough awareness of disability as a political identity (if not of the history of disability writing) to recognise Nolan's authorial voice as 'a voice coming from silence, and a silence that has, as Nolan is aware, lasted for centuries' (xii). He emphasises his impression that Nolan writes as a representative of the disability community further by citing the author's 'keen sense of the generations of mute, helpless cripples who have been

"dashed, branded and treated as dross"' (xii). This quotation of Nolan explicitly refers to people with disabilities as an oppressed minority, yet Carey's finer interpretation of it is troubling. If he shows sensitivity to the importance of voice, he seems reluctant to link the silence he perceives to any social system, or even oppressor. Rather, the blame is softly redirected to people with disabilities themselves, via a reversion to the model of disability as personal failing: they are oppressed because of their lack of 'a voice to tell us what it feels like' (xii). This is naïve in the extreme. Such voices have always been there, but they have usually been ignored.

In Carey's estimation, with Nolan's work, 'we know' what it is like to be disabled, because the author 'tells us' (xii). This is an interesting claim, not least in the way that it recalls Couser's sharp criticism of Oliver Sacks' claim to such authority for his own account of temporary disability in *A Leg To Stand On*. Carey's assumption that Nolan's work is *completely* representative of one of the most nebulous, diverse and permeable identity categories recognised amply illustrates the reason for Couser's concern over how representative one account of a life with a disability can be. Not only does such a judgement immediately deny such complexity, but it effaces the testimonies of different disability experiences. This may be seen as an effect of reading, rather than writing, but it does remind us uncomfortably of the original stand of Davis and Mitchell and Snyder against autobiography as individualising disability: for that is arguably what Carey's reading of Nolan suggests has happened. There is the ring of effacement to his conclusion that, after reading the book, it 'should not be possible…ever again to think as we have before about those who suffer what he suffers' (xii). Yet this is

arguably a misreading, over-writing other voices in just the manner that Nolan

implicitly refuses to.

Like 'Encomium', *Clock*, (subtitled *The Life Story of Christopher Nolan*) is

a work of autobiographical fiction related in the third person detailing the

experiences of Joseph Meehan, a fictional character with the same disability and a

similar background to Nolan, who like him, goes on to become a writer (the books

he publishes share titles with Nolan's work). If this is, as its subtitle might suggest,

the life story of Christopher Nolan, why is it written as autobiographical fiction?

One obvious reason for this approach is the freedom it provides from the generic

and stylistic constraints of first-person autobiography, a decision perhaps informed

by the sensitivity Nolan has previously demonstrated to the constraints of discourse,

and to discourage the sort of effacing misreading carried out by Carey. Another

motive for this choice might be the elephant in the living-room: Christy Brown.

Nolan's mode might be seen as a conscious move to pre-empt comparisons with *My

Left Foot*. Yet Brown's own work of autobiographical fiction, *Down All The Days*,

may be seen as a reference point (albeit unacknowledged) for the power of this form

in overcoming the limits of conventional autobiography.

Clock begins with success, as Joseph returns home after winning a prize (the

same that brought Nolan to prominence). In this way, the text utilises the flexibility

of autobiographical fiction to sidestep the restrictions of the autobiographical form

such as the familiar tendency towards a narrative of progress and 'overcoming' (as

seen in *My Left Foot*): Joseph is already a success. This triumphant opening is

reinforced by a robust sense of the character's disabled identity: Nolan writes of

how 'a cripple came to vie with able-bodied man...in the area of...literature' (2). The empowerment which comes as a result of this is evident in Joseph's attitude. On the plane home, Nolan writes, Joseph 'enriched himself by exhibiting his drunken, drooling body for all to see', defiantly celebrating his difference. This powerful opening swiftly expands from the personal into a broader political context:

> Century upon century saw crass crippled man dashed, branded and treated as dross in a world offended by their appearance, and cracked asunder in their belittlement by having to resemble venial human specimens offering nothing and pondering less in their life of mindless normality (3).

Such contextualisation demonstrates not only a sense of the oppressive nature of 'normality' characteristic of a political sense of disability identity, but also ascribes to a process of subjection ('having to resemble') reminiscent of the Foucauldian approach to disability raised by Tremain in the Introduction. For not only does Joseph see himself as part of a disabled community struggling against a 'hostile, sane secretly savage' able-bodied world, but also as someone whose identity is socially constructed, just as 'normality' is constructed. Yet this identity is, contrary to Tremain, open to the sort of agency Galvin perceives: 'accept me for what I am and I'll accept you for what you're accepted as', Joseph thinks (4).

The political precision of the terms Nolan uses are integral to his ability to relate Joseph's disability experience fluently. In utilising the vocabulary of identity politics to create a character that recognises himself as 'disabled' and others as 'able-bodied', and wonders 'Can I climb socially constructed barriers?', Nolan situates himself on the other side of a paradigm shift to Brown, and even his approximate contemporary Sienkiewicz-Mercer (see Chapter 3). This political

precision can be seen as an extension of the neological aspect of Nolan's writing: his attempts to capture the nameless, the unspoken and the voiceless in language. Or perhaps it is his political sense that informs his neologistic urge. Certainly Nolan traces Joseph's linguistic pioneering back to his childhood on the margins of language and experience. The young Joseph observes that even as his disability 'obliterates [his] voice', it results in him knowing 'something more' than his family (4). Joseph feels the urge to 'communicate with…that great able-bodied world', but it is not the urge to prove himself 'normal' that motivates him. Rather, Joseph mythologises himself and his linguistic quest, which he hopes will take him to 'destinations man never knew existed...no-man's land'. (4). Here, we can see Silvers' aesthetic appreciation of disability in play once more. We might also perceive the dangers of Brown's solipsism and the separatism identified by Shakespeare.

Joseph's confident political identity can be seen to stem from the more disability conscious society in which he grew up. After the 'caring collective society' of the Central Remedial Clinic School he is, after some initial difficulty, successfully integrated into a mainstream Dublin secondary school (8). Here, his struggles to express himself are (unlike those of Ruth Sienkiewicz-Mercer, as we shall see in Chapter 3) recognised as communication, and teachers and students delight in 'deciphering his coded communication', involving him in all activities (10). Joseph establishes with the teachers the sort of relationship Sienkiewicz-Mercer is only able to establish with one other patient. They succeed with an 'almost telepathic degree of certainty' in *reading* 'his facial expressions, eye movements and body language'. The whole class functions as a microcosm of a new

model society, with the able-bodied members working to facilitate communication, even if this means working outside their 'normal' discourse of expression (11).

Just as such early experiences of communication are shown to have shaped Joseph's use of language, so might a similar experience have shaped Nolan's own work. His struggles with non-verbal communication have familiarised him with giving voices to experiences apparently beyond words: something which no doubt informs his penchant for rare or synthesised language. His experience of efforts to decipher his language have given him confidence in both the possibility and the validity of his self-expression, and the co-operation of a multiplicity of voices to establish meaning. If this recalls literary Modernism, *Clock* is certainly marked by passages reminiscent of the stream-of-consciousness style utilised by Joyce and Woolf. These passages in particular recall the account of Joseph composing 'on the fly', and the sense of bodily urgency of the early poetry that method produced:

> Who'll have you, who'd be fool enough - maybe you're
> biting off more than you can chew - chew damnblast chew,
> if I could chew I could call myself normal, imagine, can't
> chew, can't swallow, so why chew? can't call - can call, a
> famished moan maybe yet it suffices; can't chew, can't
> chew, can't smell - can smell - can't chew, can't control
> bowels - can, can, can control, can't control bladder – can
> control, can control; can't chew though so what… (12).

This particular passage concerns Joseph's difficulties on finding a mainstream secondary school willing to accept him. In an excellent example of the switching of style that Carey observes, Nolan juxtaposes Joseph's frantic physical ranting with a cool, plain political analysis of the situation. His rejection is not portrayed as rare, uncharacteristic ignorance or meanness on the part of an individual, but as prejudice

and oppression (however concealed), rooted firmly in the hierarchical binary opposition of 'normal' vs. 'abnormal' and as something to be consigned to history:

> Someone always vetoes his application...someone normal; someone beautiful; someone blessed by normality; someone administering the rusty mind's rules of yesteryear...one of the head-strokers (12-3).

Joseph's delight at finally being accepted has the same robust, almost militant air as his victory at the start of the novel, as he celebrates 'bursting asunder all man's renegade constraints in dealing with disabled man' (16). Similarly, this episode also leads him to consider his place in the disabled community, and indeed, disabled history. He urges himself: 'Think of the others gone before you…stored away in a back room, dirty, neglected, frowned upon'. Yet again, his triumph is theirs, a small step towards redressing years of oppression. Thus, Joseph explicitly places himself in the history of the disability community. He sees himself as an inheritor of a suppressed history, poised at the correct time to unearth it: 'years heard the silent cry of those bashful babes and cuteness cogitates years' findings'. His sense of belonging gives him 'nerve' and 'resolve' (19-20). In return, he feels a debt to his disabled 'brothers', which he repays by 'resurrecting them'. He lambasts the 'crones [that] caused their banishment' (26). For Nolan, the word 'crones' appears to be a shorthand for social prejudice regarding disability, for when describing Joseph's birth, he writes of 'crones' insisting that he would be '[b]etter dead' (50).

Nolan provides a detailed account of the physical act of Joseph's writing with the unicorn wand. He writes of how Joseph 'bashfully brought forth droned, bespoked letters bested onto a page by a bent, nursed and crudely given nod of his stubborn head' (26-7). The word 'droned' recalls the repetitive, stumbling quality of

Nolan's language; 'bespoked', his need for neologism, recombination and reconfiguration – for what one might call 'prosthetic' or 'orthopaedic' language (in a very different sense, of the body as an agent of discourse, to the phrase 'narrative prosthesis' as used by Mitchell and Snyder in the Introduction to this thesis to refer to the body as an object of discourse). The use of 'nursed', meanwhile, evokes both the familiar medical paradigm of disability, and simultaneously a maternal tenderness that addresses both the literal (his mother supporting and augmenting his head movements as he writes) and the figurative (the assistance in the birth of his text). There is also an explicit sense of struggle here: words are to be 'bested', as is his 'stubborn' unresponsive head (26). A sense of involuntariness or reflex is conveyed by Nolan's description of the writing process as 'falling words plopping onto his path' and this is expanded upon in an ironic reference to Joseph's 'powers' of writing. Yet Nolan writes of 'typewritten words selected especially to describe a glorious bountiful nightmare' (28). Is the former an ironic undermining of the author as agent, and a playful recognition of the apparently rigid conventions of narrative form which Davis, Mitchell and Snyder were initially so pessimistic about with regard to their non-oppressive possibilities? Similarly, is Nolan's description of Joseph's writing in a 'numb-lost language' a reference to the alternative discourse he is unearthing, or the ideological limitations of dominant discourse? (27).

When Joseph becomes a writer, *Clock*'s status as a work of autobiographical fiction grows more complicated, becoming self-reflexive and displaying a postmodern quality. Nolan describes Joseph's choice to write 'using the third person' as a way to emphasise that he is a 'storyteller'. By doing this, Nolan writes,

Joseph 'thereby cast[s] renown upon himself by dangling disability before the reader'. Nolan writes of Joseph the writer 'begging' the reader to 'look', 'feel', 'sense life's limitations', 'cry the tears of frustration', and 'above all…laugh' (28). This self-reflexivity, along with the contradiction apparent in Joseph's artfully 'dangling disability' before the reader that he is 'begging' only moments later, invites consideration. Certainly, Nolan implies a calculating self-consciousness on the part of Joseph the author. In doing so, he deliberately invites an examination of his own intent, 'dangling' it before the reader. Nolan is demonstrating not only his artfulness and self-awareness, but his awareness that the reader will be aware of this. In this way, he sets up the sort of 'play' that Mitchell and Snyder cite as essential to literary texts, as we saw in the Introduction, and also echoes their work in his drawing of attention to the way in which disability can disrupt the conventions of narrative (28).

This disruption is, of course, what Quayson seeks to analyse further with his concept of 'aesthetic nervousness', and his work offers further insights into Nolan's use of autobiographical fiction. Of particular use is Quayson's analysis of two works by Samuel Beckett, his novel *Molloy* (1955) and the play *Endgame* (1957). Quayson observes that *Molloy*'s entire narrative 'is governed by a scrupulous stream-of-consciousness narrative method' which makes it 'impossible to differentiate between what occurs in Molloy's own mind and what is actually in reality outside of it' (Quayson, 63). This mode, Quayson argues, means that although Molloy is a character with many impairments, the narrative 'serves to almost dematerialize his body…[disability/impairment] is abolished' (63-4). This means that the reader is 'confronted with a problem of the structure for

interpretation…[e]verything seems liable and elusive, even Molloy's impairments themselves' (64). The parallels with *Clock* are clear. In *Clock*, however, Joseph's narrative does have an external dimension, in the form of the third person narrative and Nolan's commentary. Furthermore, this itself is underscored by the meta-narrative qualities resulting from the description of Joseph's practise as a writer. While this arguably provides a firmer structure for interpretation that *Molloy*, it nevertheless leave in place enough levels of complexity to allow multiple interpretations, thus avoiding the fixity of a specificity of disability experience.

Quayson also recognises this need to avoid specificity. In *Endgame*, he notes, the 'physical manifestation of disability is perpetually on stage' and its 'specificity' is 'only assuaged by the elusive play of language that we are made alert to as if pursuing the threads of an inexhaustible enigma' (64). Quayson cites Hamm as an example, noting that while the audience is 'never allowed to forget his disability', his final soliloquy 'produces a mode of transcendence for the disabled character' through its 'rapid oscillation…among various vectors of performative identity'. By this means, Hamm eludes any one limiting identity, suggesting a 'transcendent…intensified consciousness' (78). The parallels with the analyses of Nolan's style already offered earlier in this chapter are clear: as we have seen, Nolan too 'oscillates' between the 'universal' and the 'intimate' and 'cacophony' and the 'simple' in order to avoid identity specificity (see p107). But there is an important difference. Quasyon concludes that the impairments of Beckett's characters are 'ciphers of the frailty of the human condition and not to be read as markers of any real disability as such': it is this lack of 'phenomenological specificity' that makes them 'easily assimilable to philosophical categories' and

enables his works to function by maintaining their essential absurdity (83-4). In the case of Nolan, however, as has already been discussed, things are more nuanced. We have seen that Nolan (unlike Beckett) is able, by switching between styles, to convey a narrative that is both disembodied and embodied (see p115). In material already discussed, a particularly obvious example of this is the account of Joseph's struggle to find a secondary school in *Clock* (see p121). This passage combines an experiential stream-of-consciousness narrative on the part of Joseph with a cool, clear socio-political analysis of the situation by Nolan.

<center>*   *   *</center>

Even as Joseph struggles to find his own authorial voice in his teens, he refuses to accept that his own language of body movements and expressions 'as being anything other than perfectly normal for him' a description which recalls Iwakuma's observation in the Introduction that a disabled individual's habituation to their *lebenwelt* is necessary in order for them to obtain a subjectivity that is in equilibrium. Yet in his initial period at secondary school Joseph experiences the power of language to hurt and oppress him, as his at first hostile schoolmates discuss his inferiority 'openly': the dominant, disablist, discourse they employ effacing him 'as if he were not really present'. Nolan reports that they 'chose tags' by which they would address him. The power of these terms 'weirdo, eejit, cripple, dummy and mental defective' (the latter, of course, the term Brown willingly accepted for himself in his first autobiography) is evident (*Clock*, 29). This experience spurs Joseph on in writing the first version of an autobiography. His intent is to 'rescue crippled man from pits of oblivion and set about shattering the

sacred-held image of handicap as being godsent'. Thus, he shares a concern with the disability studies academic community, not just for a re-appraisal of disability history but for a contemporary re-conceptualisation of a notion of disability that is 'cruelly wanting'. Joseph positions himself at a paradigm shift: Nolan writes that, as he penned his draft, he 'bygoned the past and cheered the future' (31). When he completes it, Joseph decides to enter the autobiography for the Spastics Society Literary Contest, the award he has won in the novel's opening and which Nolan of course also won.

Even as he shapes and perfects his literary voice, Joseph maintains links with other discourses. His school-friends learn to read his eyes, following in the footsteps of his sister to interpret 'his nodding-headed, eye-darting language' (36). Around this time, he makes the first of a number of visits to a Gaelic-speaking part of Ireland for the first-time, and the text becomes littered with Gaelic-words (37). As these trips continue, the children are encouraged to 'speak their native Irish language' (136). This is the place, Nolan writes, where 'their culture was for the first time recorded in written words of their own Irish language': a point that gives the impression that a post-colonial sensibility has informed Nolan's sensitivity to the limits of dominant discourse (138). This intertwining heritage of language and history combine to direct the non-linear narrative back to Joseph's rural early childhood, where Nolan writes of Joseph's first encounter with literature upon hearing his father recite a poem about a donkey. The poem strikes Joseph precisely because it resonates with his sense of his own disability:

> Joseph listened to the whole poem, he formed the image of
> the little wobbly donkey in his mind. He looked at his own
> limbs, his head lolled back, the stirring of the muse took

hold that day (31).

In keeping with Wallace's point about his having few or no literary influences, Nolan's artfulness is on display once more as he stresses that, in Joseph's upbringing, 'Literature was never mentioned' and 'writers and poets were seldom mentioned'. However, when poets are mentioned, it is in the context of history and tradition, such as when he notes how his father's '[l]ove of history…threshed out names of Irish poets like Francis Ledwidge, Padraic Colum, Joseph Mary Plunket, William Alingham, Yeats or Patrick Kavanagh' (31).A sense of Irish literary tradition is perhaps what shaped Nolan's own search for a tradition of disability, yet his reluctance to acknowledge it is arguably due to the fact that to do so would threaten to remove the sheen of erudite genius from his writing, removing the prestige which his disability has if it is perceived as the source of his talent by those such as Wallace and Carey. Another motivation may be his sensitivity to accusations of fraud: an issue which arises later in the story (39). Such sensitivity explains the treatment of Joseph's father, Matthew. His own literary interests are downplayed: he is said to have 'meddled' in literature, and Nolan insists that he 'would be the very last to sense that his broad rambling murmurings might be beneficial to his children'. Nolan concludes that Matthew 'never detected…that his own erudite mind nutshelled evergreen bunting' (that is, his own literary talent). This provides a contrast to Joseph, who is forced by his disability to maintain his 'silence', his developing muse 'unknown' to his parents (41). He suffers the double agony of being unable to express himself either idiomatically or creatively. He waits, his 'gossamer gift snuggled still in his cubby-hold mine' (43). However much Nolan deprecates Matthew as a literary influence, it is worth noting that the author uses similar language in describing the father's motivations as those ascribed to the

son. For example, he writes of the former 'rescuing history' in 'poetic' accounts to his son (43).

The non-linear narrative of *Clock* places Joseph's biological birth after his literary one. As if in rejection of the pretence to realism offered by medical objectivity, Nolan describes a determinedly un-realistic birth. Crucially, he places the infant Joseph in the position of agency at the moment of birth, having 'decided' to take up an unusual position in his mother's womb with a vow that he 'wasn't going anywhere'. Upon realizing that 'life demanded to see him' Joseph 'had decided to choose death, but fate decided otherwise' (50). This might be seen as another ironic touch on the part of Nolan, a complete inversion of the traditional 'survival-of-the-fittest' arguments concerning disabled neonates, especially as he quips: 'Better dead said the crones, better dead said history'. When the infant Joseph does come under the jurisdiction of medical authority, a paradigm shift in attitudes to disability is apparent, as documented in Wallace's introduction to *Dreams*. Nolan commends the doctor who 'wisely' chooses to assess the infant Joseph through 'cutely constructed games' rather than standard examination. Using such methods, he 'never found Joseph wanting' and instead confirms his 'normal intelligence'. The 'brave doctor' recommends 'physiotherapy, speech therapy, occupational therapy and in time, schooling' (51): a considerably more progressive diagnosis than that presented to Ruth Sienkiewicz-Mercer in the United States less than twenty years before, as discussed in Chapter 3. Yet the fact that Nolan should praise the doctor emphasises the transitional nature of the shifting paradigm: in his progressive attitude the doctor is evidently not typical. It is, however, shared by another medical professional, in the form of the psychologist who is similarly

crucial to defining the identity that Joseph will carry through life. Unlike those whose inability (or refusal) to see outside of dominant discourse threatened Brown's opportunities and had, as we shall see, dire consequences for Sienkiewicz-Mercer, she is willing and able to interpret Joseph's 'bowing-headed, eye-pointing, foot-peddling language' (52). It is surely such stamps of authority approval that forge Joseph's confidence in his own identity and methods of communication that sees him begin writing as a schoolboy determined to 'break free from society's charitable mould' and show people 'what they never thought existed' (53). This vow can be seen as another textual reference to our central concern: that un(der)-theorised space outside dominant discourse, and its use as a resource for a challenge to, and reconfiguration of, disabled identity. As Nolan writes later, Joseph is determined to do away with 'the sob-storied views of the past' (89).

Yet as Joseph's interest in his disability fuels his urge to write, so to does it frustrate it. As he operates a typewriter with his 'unicorn wand', Nolan writes that 'great spasms gripped him rigid and sent his simple nod into a farcical effort which ran to each and every one of his limbs' (54). Medicine is on hand to offer him help – a therapist works with Joseph in 'trying to *discipline* his bedamned body' (my emphasis). This development is interesting in two ways: firstly for the allusion, once again, to a Foucauldian approach to the body, and secondly for the way in which it raises the issue of collaboration. As we have seen with Brown, and will see with Sienkiewicz-Mercer, collaboration can be a crucial element in disability writing. In the case of Joseph, he needs the hand of an assistant to support and guide the fitful gestures of his head and the attached wand. Nolan adroitly captures the fine balance between assisting and interfering in the creative process that his first assistant, the

therapist Eva Fitzpatrick, faces: 'Gumption was hers as she struggled to find a very voluntary tip coming to the typewriter keys from his yessing head'. Yet, as with Joseph's bobbing head, this authorial finesse is followed by the clumsiest of disability clichés, the heroic able-bodied person without whom the disabled individual would be nothing. In this case, without Fitzpatrick, Joseph 'would never have broken free' (54).

Lioresal retains its credit for Joseph's breakthrough, in the form of 'the mustard seeds of his and Eva's hours of discovery' (55). Yet, as noted earlier, the input of the author's mother is remarkably and ruthlessly effaced, as was that of Brown's mother and his fraternal amanuenses. The basis for Nora Meehan's lack of authority, and Joseph's surfeit of it, rests on the unknowability of the disability experience. In yet another evocation of Foucault, power and knowledge are conflated:

> Feeble Joseph was just eleven years old, but before long he
> would be taking on Nora, schooling her to see what he
> could see, instructing her to steady his head for him while
> he typed beauty from within, beauty of secret knowledge so
> secretly hidden and so nearly lost forever (56).

Despite all his confidence and secret knowledge, Nolan describes Joseph's first writing as 'bashfully typed green words, frail poems and childish prose'. He writes of the young author's immersion into a 'Word-Wold' of obsessive writing, a development that recalls Brown's early slip into artistic solipsism. Yet Nolan perceives this as Joseph simply biding his time, having 'for years clustered his words' in preparation for the day that a 'Cyclops-visioned earthling would stumble on a scheme by which he could express hollyberried imaginings'. The latter phrase could be an allusion both to the inability of the able-bodied to diverge from the path

of dominant discourse, and to the need for a disability-informed perspective (an impaired, or one-eyed, perspective). More deeply, it is perhaps a reference to the Cyclops of classic literature, famous for their skill in manufacturing powerful weapons for use by mythical heroes, such as Zeus' thunderbolt (57).

The apparent passivity and dependence implied by the above phrase appears to contradict the previous independence and confidence shown by Joseph, whom the author describes as 'confident enough to feed himself on fame' and ready to 'compete with other writers'. Apparently, such confidence is not misplaced: at the age of 12, 'Encomium' wins the Spastics Society literary competition, amid comparisons to Yeats, Joyce and Dylan Thomas (thus placing him, however unwillingly, in a Romantic/Modernist literary tradition once more). Suddenly famous, Joseph is feted by the British press (58). Nolan describes the unprecedented public platform presented to the young writer: '[H]e spoke now not only to folk in Britain, but…countries all around the world' (82). Although this sudden fame brings him to the attention of '[e]xperts in the field of neuro-study and linguistics', Joseph wonders whether 'any sane, able-bodied person [can] sense how it feels to have evil-intentioned limbs constantly making a mockery of you'. He doubts the capability of even the 'greatest expert' to 'rescue truth from [his] meagre writings', and wonders how 'they' (the able-bodied) can 'hear [his] cry for life' (82). This last passage might be seen as a development, perhaps informed by a more sophisticated politics, of Brown's doubts over the possibility of self-expression, reminiscent of the concerns of Galvin and Kirmayer over non-dominant discourses being dismissed as irrational. Yet Joseph eventually decides that he has 'underestimated the power

of the adult intellect' of those 'heaping understanding on his ribald rantings' (82).

Of these experts, one computer engineer is crucially sympathetic to Joseph's:

> dedication to re-writing the saga of helpless, crippled man,
> rejected by society and suspended in time, and to all intents
> and purposes seen to be waiting listlessly for the call to even
> greater oblivion (83).

This engineer devises a computer system which enables Joseph to use a chin switch to select letters and build words. Nolan's ironic evaluation of the apparently simple scheme ('There and then disability would be conquered') is apt. As with Ruth Sienkiewicz-Mercer in the next chapter, Joseph finds such communication devices problematic. When he tries to get in sync with the machine his body freezes and he has to be paced by the engineer. Eventually he is able to type his own name, but, in a development which is significant for the social ethics of disability, only with 'the reassurance of the human hand' (83). With his fame and his communication device in place, Joseph ponders his new position as a figurehead for the disabled community:

> Can I, he pondered, crippled as I am, spearhead a new drive
> to highlight the communicative needs of tongue-tied but
> normal-notioned man? silently [sic] he mulled over his
> aspirations - if computer science can give me a voice, then
> everyone else who is similarly afflicted stands a chance of
> being freed (84).

With this aim in mind, he re-directs the generous proceeds of a *Sunday Times* appeal to a research-fund for scientists 'to bring to fruition an as yet trestle-dead dream to find a voice for the voiceless'. In doing so, he seeks to 'head-first' the scientific community (an odd, but allusive phrase, resonating as it does with both his new position, and his new-found way of expressing himself via the chin button). Another allusion is also at work here: 'trestle-dead' brings to mind both the inanimate state of Frankenstein's creature, with all the implications of monstrosity

and control that suggests, and also recalls the allusions to that creature, and Ricks'

sense of them, in Wallace's introduction to *Dreams*. Furthermore, the notion of the

scientific (de facto medical) community 'finding' a voice for people with

disabilities is as troubling as Steven B. Kaplan's attempts to 'find' a voice for Ruth

Sienkiewicz-Mercer that will be addressed in Chapter 3.

However politically motivated or altruistic, Joseph is also keen to exploit the

media attention to secure his own future as an 'independent writer' (86). He

embraces journalists as 'imaginative people' who 'tuned quickly' to the message

behind his 'sparse and brief' and 'staccatoed' style. Authenticity is a prime concern

here: Joseph invites the journalists to watch him write, and furthermore, to cup his

chin as he types with it 'in order that they could feel the undercurrents of electricity

running and molesting his attempts to strike a letter'. Their understanding of the

physical act of his writing is crucial to its meaning, Nolan asserts: 'Only thus could

he convey his briefness in language, only thus could he explain why his rhythm of

sound was jumpy and jarring on the ear' (90). The media, including Wallace,

respond with 'graciousness, delicacy, fairness and faithfulness'. Nevertheless, he is

'wary of being exploited' and 'silently [keeps] his weather-eye upon all and sundry'.

Simultaneously, he is canny: 'foraging for himself was always to the fore of his

mind' in the shape of his plan 'to have his fool's findings published…a book of

poetry by Joseph Meehan standing by itself on a shelf in his study'. His cultivation

of prestige through the media is enough to secure himself a publisher that counts

themselves as 'privileged' and 'honoured' to have him (92). Once again, the shifting

levels of identity Nolan the author has set up using the character of Joseph the

author are in evidence.

At this moment, as a published author, Joseph's distancing of himself from his mother is complete. Nolan writes that Nora 'wanted to free her son from her', arguably absolving himself, at a remove, of his own actions in removing the role played by the mother-figure in the writer's development. He even effaces the biological link, referring to Joseph's publishing as 'his moment of birth'. He refers to Joseph as someone who had now 'defeated dyed death and bestowed birth to himself. He birthed an author' (92). The new identity acts as a prosthesis to his status, as Nolan writes that Joseph the author 'now shared the same world as everyone else'. The inter-relation of power/knowledge and his authority, manifested through control, is now his explicit concern: he can now choose 'how much to tell and craftily decide how much to hold back', an observation which invites further scrutiny of this apparently candid text. Intriguingly, Nolan states that Joseph's 'voice would be his written word' – a view which is clearly congruent with Brown's views - and sees his former language of movement and expression effaced by the written word, in an explicit acceptance of the latter as the lingua franca of the nondisabled world in which he seeks agency (93). Nevertheless, Joseph's language bears the marks of his experience, as Nolan's account of his London-based editor's response shows. Accustomed to dealing with 'free-voiced' authors, she is nonetheless 'startled' by 'words which had been lifted from the depths of numbness' marked by the 'surrealism of a creativity which had, chaos-like, nearly clung forever to the lip of the abyss of hell' (96).

The book Joseph publishes is, like Nolan's, titled *Dam-Burst Of Dreams*. The sight of the book as a physical object, emblazoned with his name as the author,

is 'truly intoxicating', making him feel 'dignified' (96). This recalls, of course, Brown's similar pleasure in the status of the author. The physical image of his words fascinates him; 'how his words looked in print, how his poems sat upon the page' (100). This pleasing physicality is almost fetishised:

> His fingers secretly licked the hard shiny cover, he mentally calculated the yield, but his gripping fingers hesitated a moment and then splayed open, dropping his lovely golden harvest on the kitchen floor (101).

His status confirmed, Joseph is finally happy to concede his place in literary tradition, proudly taking his place 'amongst the greats of literature'. The author's status modifies his identity: 'this book made sense of his life', Nolan writes, describing it as 'a reason for his being given a second chance at birth'. This idea of the book as an extended imposition of meaning recalls the work of Kirmayer, and also invites remembrance of, and comparison with, *My Left Foot*. The latter is especially recalled by Nolan's declaration on the inextricable link between life and life-story in Joseph's 'foolproof account of his desperate disabled life' (101-2). He nevertheless acknowledges the limits of his text even as he reveals his authorial intention regarding 'the doubting Thomases':

> book or no book, they never deviated from their pitying assessment of him. He never hoped to alter their thinking. His book was not for them… (102).

Even as Joseph crows over the book as the summation of his identity, he finds that his lack of voice leaves him unable to promote his text with his authorial identity during the promotional campaign around it. Nolan writes that the media 'stepped into his void and provided a voice for his mercurial, soundfilled words'. The

contradiction of the 'void' and the 'soundfilled words' suggests a definition of voice as a passive vessel, rather than the 'disability voice' we might see evidenced in Nolan's distinctive style (97). The dangers inherent in allowing such ventriloquism are made apparent when Joseph finally encounters a hostile journalist. This character's '[s]lowness to grasp positive statements' and the fact that he 'seemed to be missing the point' during the interview evokes Galvin's point as to the impossibility of non-dominant discourse being recognised (98). The journalist doubts Joseph's authenticity, 'looking for genius' in 'past generations', and questioning 'anyone and everyone' but him. Joseph deduces the journalist's 'naked dislike for the fools of fate', when he refuses to observe the writing process, or to accept the resulting poem (99). The resulting article implies that 'Joseph Meehan the fraud' who 'never allows folk to see him typing', is assisted by a ghost-writer (107). Learning a lesson from this, Joseph is ironically forced to call on his mother for help for the rest of the media campaign. He reinstates her as his 'amanuensis…his risen voice'. Her voice on the radio, speaking on his behalf 'nulled his handicap' and 'highlighted his boy's genius', as 'his disability for once played second fiddle to his art' (103).

The genius identity is an obvious way of protecting Joseph's authority and authenticity, as well as turning the momentary interest in his writing into a career. Scholars and reviewers admire his 'boy's boldness - bumpkin - fashioned, but vested with cloyish cleverness'. As the book becomes a bestseller, Brendan Kennelly, Professor of English at Trinity College, Dublin, in a moment that recalls the function of Carey's introduction, confirms the change in Joseph's status when introducing him to a public audience. 'Nobody can make a poet', he explains, 'but

when we look at that fella in the wheelchair there, we are looking at a poet, a pure

poet, he's a poet now' (104). Furthermore, he is voted one of the People Of The

Year for his 'outstanding contribution to Irish society' at the age of 16 (119). As he

accepts the award, he muses inwardly on his position in this society in the midst of a

paradigm shift in attitudes to disability where, on the one hand, the 'future for

babies like him never looked more promising', while on the other 'society frowned

upon giving spastic babies a right to life'. He ponders how an unidentified 'they'

plan 'to burrow through the womb and label them for death, to baffle their mothers

with fear for their coming'. He notes the irony that disability actually precludes anti-

social behaviour: '[T]he spastic baby would ever be the soul which would never kill,

maim, creed falsehood, or hate brotherhood'. He concludes by asking: 'Why then

does society fear the crippled child and crow over what may in time become a

potential executioner?' (119). This sharpening of political thought becomes

increasingly apparent after Joseph's success. For example, on the subject of

institutionalisation, to be addressed in Chapter 3, he concludes '[b]etter dead' (127).

Similarly, he refutes the assumption that his life is miserable, noting that when

'least expected…something else would happen to heap glory on his boyhood' (128).

Yet even in these moments of happiness he thinks of the 'crippled brothers and

sisters who had gone before him' and feels 'hurt for their never having had a chance

to experience' what he has (129).

After finishing school, Joseph goes to Trinity College to study literature.

Here he (supposedly) encounters the literary canon for the first time. Nolan

describes this encounter in adversarial terms: Joseph is 'challenged' by the Anglo-

Irish literary tradition. He also undermines the authority of the canon by stressing

the subjective nature of its merits, composed as it is of 'the fashionable greats in literature'. Nevertheless, he comes to embrace (an unspecified) Brontë, Dickens, Conrad, Sterne, O'Casey, Beckett and Synge, who '[kindle] munificent mullings in his ribald mind'. He is no longer 'a boy-writer, undisciplined and gauche' (156). Nevertheless, Joseph is not in thrall to the greats, achieving excellent marks for an essay on Beckett by 'reading what he wanted to hear into Beckett's rolecall to awareness'. Likewise, Nolan writes that Joseph 'frowned at the greatness of Joyce', a turn of phrase which almost seems designed to rebuff the comparisons made with Joseph's teenage work. This impression is reinforced by Nolan's observation of Joseph's desire 'to emulate him [Joyce] for boyhood's fame' (161). The answer is perhaps revealed in Joseph's ambitions for his future:

> [H]e nadir-aspired to mould his only gift into briny,
> bastardized braille so that fellows following never had to
> nod yes to mankind's gastric view that man speechless and
> crippled must forever be strolling as underlings to the
> yapping establishment (161).

In conclusion, it can be seen that Nolan's work offers clear examples of the sort of language use that a combination of the work of Galvin and Kirmayer traces back to the body. Similarly, it can be seen that Nolan deploys a sophisticated awareness of, and handling of, dominant discourse and the resources available to him to circumvent it. His use of the mode of autobiographical fiction to emphasise his artifice by laying it bare, a choice which in turn reveals and undermines the assumptions, conventions and shortcomings of literary approaches to disability, is crucial in this respect. By deploying it he displays traits, such as his sense of oppression, that would appear to link him ideologically to the contemporaneous

disability rights movement. This is not made explicit, however, but is instead addressed within the more general terms of a body seeking to express itself regardless of *any* imposed interpretation. Nevertheless, developments in social sensibilities, as well as aesthetic ones, can be seen to have had a marked impact on the way in which Nolan writes, and indeed was able to be read. This is especially true when he and his work are considered in comparison to Brown. In Chapter 3, we will examine a piece of writing that was published in the same period as *Clock*, but whose long gestation period means that it was produced in a considerably different social and aesthetic milieu, all of which is apparent in its form as much as its themes.

CHAPTER THREE: RUTH SIENKIEWICZ-MERCER

I Raise My Eyes To Say Yes (1989, hereafter *Eyes*) is an account, given in the first-person, of the life of Ruth Sienkiewicz-Mercer. Born in Massachusetts, in 1950, Sienkiewicz-Mercer was struck by encephalitis as an infant, which resulted in a form of Cerebral Palsy much more severe than that experienced by Brown or Nolan, leaving her not just unable to speak, but with very little control over her limbs. The book is an account of her life from her birth up until its publication, covering her early childhood at home and in progressive institutions, her long incarceration in the hellish Belchertown State School from the early 1960s, and her gradual transition to independent living in the late 1970s. The text thus deals both with a *personal* disability experience and, through her involvement with the campaign for independent living, an explicitly *political* sense of disability identity.

This is complicated by the fact that the text emerges from the context of her political involvement: the 'FREE' education program through which she was able to write the book operated under the auspices of the independent living movement. The book itself, as its afterword suggests, can thus be seen as an extension of her political interests:

> the publication of this book will provide [Sienkiewicz-Mercer] with the opportunity to engage teachers, speech therapists, doctors and nurses, social services providers, even politicians, and to raise their consciousness about the lives, needs and aspirations of [people with disabilities] (224).

Matters are further complicated by the impact of Sienkiewicz-Mercer's disability on the writing process. Although she developed a system of communication through facial expression as a child, she was diagnosed as an 'imbecile' upon institutionalisation, and thus denied not only therapy and education, but any capacity for communication, for much of her childhood (38). Thus, even when her ability to communicate was finally (re)discovered and nurtured, it was irrevocably stunted. Nevertheless, before entering the 'FREE' program in 1979 she had in fact already attempted to compose an autobiography. Although, as with Brown, her account of this first autobiography is available to us only through the filter of its successor text, it is nonetheless insightful. Begun in 1976, while she was still institutionalised, Sienkiewicz-Mercer reveals little about the motivation behind this first attempt other than that it developed out of the speech therapy classes she was at last receiving as part of sweeping reforms at Belchertown. She 'spent a lot of time talking…about different ideas for [the] book' and began 'to outline the basic elements' using a TIC communication device (171). This project apparently stagnated due to the laborious process of typing using this device, although the text acknowledges that her illiteracy was an 'even greater problem'. By the time she

enrolled in the 'FREE' program in 1979, after living independently for some time, she was frustrated by 'the total lack of progress on this project' (172).

Through the 'FREE' program, Sienkiewicz-Mercer met Steven B. Kaplan (a volunteer) and they began work, over 2000 contact hours for nearly a decade, on what would eventually become *Eyes* (xxv). The text is credited to both of them, yet the introduction and the afterword are both written by Kaplan alone, a fact which is especially significant given that these two sections give an account both of the composition of the text and its context. Ironically, it is the very transparency with which Kaplan details his involvement in the text, and the large amount of material regarding him that it provides for analysis, which leaves him open to the sort of enquiry that the more oblique collaborations of Brown and Nolan are spared. Couser, for example, has classified *Eyes* as being 'akin to a slave narrative' (Couser 2004, 38). He bases this on Sienkiewicz-Mercer's lack of physical ability and education which, he argues, places her 'among "those who do not write" ', according to Philip Lejeune's term for the subjects of ethnographic life writing (37-8). *Eyes* might thus, along with other ethnographic writing such slave narratives and so-called American Indian autobiography, be located at one extreme of Couser's continuum of collaborative relationships, which we briefly addressed in Chapter 1 (42). At this extreme, Couser argues, the division of labour where one collaborator 'supplies the "life" while the other provides the "writing"' becomes particularly apparent (36). The defining characteristic of this ethnographic category is the lack of power on the part of the subject as a result of their inability 'to review the manuscript and mandate changes' (37-8). Thus, however altruistic and committed Kaplan is, he possesses most of the power in the collaborative relationship.

Furthermore, as Couser notes, such volunteers tend to be amateur writers, who are 'not necessarily conscious of ethical constraints' (54). Given the voluntary nature of the 'FREE' program, it might also be argued that Sienkiewicz-Mercer had only a very limited choice of collaborator, and was not able to be as selective as, for example, Brown. These concerns can be balanced against the credit Kaplan gains from displaying the sort of transparency with regard to the composition process that Couser takes as a likely indicator of 'ethically sound collaboration', in the shape of his lengthy introduction (35).

Yet the vacuum in Sienkiewicz-Mercer's half of the relationship, implied by Couser's continuum, is often impinged upon by Kaplan's attempt to contextualise the text and its process of production. For example, he describes Sienkiewicz-Mercer's abilities thus: 'She has never spoken a word, never written or typed a sentence. She has had little formal education, and reads, at best, at a first-grade level, recognizing only simple words placed before her in a familiar context' (*Eyes*, vii). This description appears simple and straightforward: that is the problem. Although all of the above is 'true', Kaplan, perhaps demonstrating his training as a lawyer, turns shades of grey into black and white. In fact, as the text proper insists, Sienkiewicz-Mercer did 'write', used recognisable sounds to communicate, and was of average intelligence. However noble his intentions are, Kaplan apparently misrepresents the abilities (and thus the contribution) of his collaborator. He is arguably, although perhaps unconsciously, following a traditional individual-overcoming-adversity model of autobiography: over-emphasising her disability in order to underline her achievement. This unconscious adherence to tradition is also apparent in his use of negative language to describe his subject as a 'victim' of

Cerebral Palsy, 'confined' to her wheelchair by a 'functionally useless' body (vii). However unwittingly, such language undermines Kaplan's earnest efforts to emphasise that the book is 'recounted by' Sienkiewicz-Mercer, and that it is 'her autobiography, written with [his] assistance' (viii). This extends to his apparent dismissal of her earlier attempt at writing, as he insists that she has 'never written or typed a sentence' (vii). However narrowly true this statement may be, 'writing', as Couser has noted, is a term that can cover anything from invention to copy-editing, and is thus applicable as a description of her 1976 attempt (Couser 2004, 36).

Regarding the composition of *Eyes*, Kaplan is far more precise. He describes how Sienkiewicz-Mercer would initiate an anecdote with a word, either spelled (in a 'very rudimentary' fashion) by indicating letters on a spelling board, or selected from words on two other boards. Kaplan would respond by asking questions to establish the time and location of the event, and capture precise details (x, xi). Next, he would ask a 'few dozen' follow-up questions, 'coloring' the story according to her responses via facial expressions and sounds. The equivalent of five minutes' conversation would take 'about an hour'. Importantly, Kaplan notes that he would supplement Sienkiewicz-Mercer's account with interviews with friends, relatives and staff, and by using official records, a trait more common in biography than autobiography, as Couser notes, and one that arguably further undermines the authenticity of the text as 'her' story (Couser 2004, 45). Next, he would write a draft 'from Ruth's point of view' which he would read aloud to her. Having 'carefully explored her reaction', to make sure that she was 'comfortable with the descriptive language and commentary' he would write a final draft (*Eyes*, xi). In the text proper, written in conventional prose, the 'seed words' (e.g., 'SHARI.GRETL.SOAP'.) are

used as the titles of various sections, presumably as a reference to the text's point of

origin and as a mark of authenticity (25).

Although the resultant text is largely written by Kaplan, he insists that the

'thoughts and emotions, the impressions and observations' contained within are

Sienkiewicz-Mercer's 'alone'. Yet he appears to recognise that this state of affairs is

somehow unsatisfactory. He wonders, much as Wallace does of Nolan, what

'idioms, vocabulary [and] tone' she would use if she could 'express herself on

paper' (xii). Although he notes that she has claimed to possess an inner voice that

'talks in words and phrases, sentences, even paragraphs', Kaplan is strangely

dismissive, stating that this voice would be more likely to feature 'internal sounds

and evocative non-verbal images' (xii-xiii). He perhaps makes this judgement on

the basis of her limited external voice, able only to produce 'ten distinct sounds'

(vii). Furthermore, he appears to suggest that Sienkiewicz-Mercer's subjectivity is

so radically internalised by her disability that she may perceive this inner voice only

as 'some disembodied intelligence that drops by for frequent chats' (xii). Kaplan's

dismissal of Sienkiewicz-Mercer's inner voice perhaps stems from an inability on

his part to understand the unconventional subjectivity arising from her disability,

thus supporting the theories of Galvin and Kirmayer that unconventional

expressions of experience will be deemed irrational by those more accustomed to

operating within dominant discourse. Although this undermining of her authority

and viability is again unintentional, it once more raises the issue of Kaplan's

suitability as a collaborator. It might be argued that this is the inevitable outcome of

the unusual composition process, and that Kaplan at least attempts to make the

difficulties of the process transparent. He writes, for example, of his attempt to

avoid 'unwittingly embod[ying] too many of [his] own projections'. In a move that might seen as an attempt to avoid the doubts over agency that prompt Couser to categorise the text as ethnographic, Kaplan also stresses Sienkiewicz-Mercer's agency over the process, stating that the duo often 'floundered over an obscure detail' due to her insistence on getting it 'just right'. He even tested her by providing 'plausible, [but] partially inaccurate' summaries which she refused to accept (xv-xvi).

Kaplan insists that the textual voice he creates is 'close enough' to Sienkiewicz-Mercer's own, functioning as an 'accurate…reconstruction of her viewpoint'. Nevertheless, he acknowledges that it 'wasn't really her own' (xvii). This is reminiscent of Galvin's point regarding the need for identity, which will prompt a subject to accept even an unfavourable identity over the absence of one. A paradox is apparent in Kaplan's observation that via her experience of hearing drafts read aloud, Sienkiewicz-Mercer is 'tasting…real talking-about-things-going-on language, for the first time' (xviii). In this 'real' language, and especially in the way in which it effaces Sienkiewicz-Mercer's 'inner voice', we might observe a parallel with the 'plain prose' of *My Left Foot*, and the way it limits and effaces Brown's attempts to express his experience. Couser has observed that Kaplan's narrative voice raises 'questions of authority and authenticity' and argues that however 'scrupulous' Kaplan may have been, the narrative voice of the text cannot be regarded as Sienkiewicz-Mercer's because it does not accurately reflect her limited verbal skills. Nevertheless, he defends it for representing 'a hidden population' of those unable to write because of disability (Couser 1997, 218). He later expands upon this argument, defending the text more robustly and insisting that if it had

accurately reflected Sienkiewicz-Mercer's level of literacy it might have 'given a misleading indication of her sensibility and intelligence'. Furthermore, he argues that such a text 'might have been unpublishable (and virtually unreadable)' (Couser 2004, 38). This argument might be refuted using the closing passage of *Eyes'* afterword, where Kaplan for the first and only time in the text presents an extended sample of the 'seed words' from which he has extrapolated his narrative. He reproduces Sienkiewicz-Mercer's notes for a speech that he gave on her behalf at a rally for deinstitutionalization, for the purpose of illustrating both her capacity to express herself and the validity of his translation:

> .I.FEEL.(CLUE).TRASH.BELCHERTOWN.
> .OLD.HOUSE.STINKS.
> .(CLUE).HOT.BELCHERTOWN.
> .I.GETTING.LEARN.
> .I.GETTING.FOOD.MYSELF.
> .PCA.ASK.ME.WHAT.WHEN.
> .PATIENTS.MOVE.OUT.
> .MONEY.PEOPLE.OUT.
> .BROKEN.THEY.BUILDING. (224).

Kaplan's account of this is:

> 'I was treated like garbage at Belchertown. The Infirmary stunk and the whole place was like hell. Now I am getting an education. I go grocery shopping for myself, and my personal care attendants ask me what I want to do and when I want to do it'.

> 'All of the people still living at the State School should be moved out, and all of the money now being spent at the institution should be directed to the handicapped people living in the community. The State School should be torn down, brick by brick' (225).

Although they are not necessarily evidence of a viable long-form text, these 'seed words' are not only readable, but possess a certain poetic quality, and thus literary value, as Kaplan himself notes in his introduction (xiii). Yet, in stating that it is

'better to have a somewhat misrepresentative text written from her point of view than none at all', Couser ignores and effaces the only words of Sienkiewicz-Mercer that are made available to the reader in the finished text without (significant) mediation, much as Kaplan effaces her 'inner voice' with his ersatz one (Couser 2004, 38). His use of the term 'unpublishable' is critical to an understanding of this apparent oversight. In employing this term, Couser reveals the values that he applies, however unconsciously, in assessing the text's viability (38). These become more apparent in his suggestion that Kaplan's 'misrepresentation' of his subject is justified by his creation of a text that is 'accessible to a reading public that requires a fluent, detailed narrative' (39). Here, we can see parallels with Brown, and his ambition to write a narrative that would reach the 'whole world'.

In his haste to justify Kaplan's 'translation' of Sienkiewicz-Mercer as an act that simply serves to 'amplify' her voice, Couser raises the issues of ethics, but only to question why anyone would see Kaplan's practice as unethical (38). Although Couser clearly appreciates that there might be a problem, he does not fully explore its consequences. Yet these are hinted at by his observation that Kaplan's translation serves to 'hypernormalize' his subject as it 'masks or erases the disability that has so profoundly shaped its subject's life' (39). This observation illustrates a refinement of Couser's earlier view, as discussed in the Introduction to this thesis, that the 'neutral space' of a normalised text language was, in its masking of an author's disability, a positive thing. Yet more might be made of the problem of 'hypernormalization' with regard to Kaplan. For example, the link between a reading public's (supposed) demand for the fluent, detailed narrative that such a 'translation' represents, and the broader context of a society's demand for

conventional expression and behaviour, which arguably played a part in Sienkiewicz-Mercer's incarceration and mistreatment, might be examined. Couser also clearly appreciates that there might be other ethical problems with Kaplan's work, but similarly fails to fully explore their consequences.

He observes that the political and mimetic senses of representation 'seem somehow at odds' in the Kaplan/Sienkiewicz-Mercer relationship, and that the former 'inevitably mis-speaks [the latter], giving her his voice'. Yet he simply concludes that this effect is 'more of an irony than an ethical lapse' (39). Although he concedes that 'harm' can be done to the subject of ethnographic writing, his conception of harm extends only to damage to their 'privacy, to their reputations…to their integrity as individuals' (41). Although the latter phrase again recalls Galvin's point about the need for identity, it is deployed without the sense of a potential for oppression that she recognises. Indeed, Couser reasons that ethnographic subjects 'are less liable to damage by the product' because they may well 'never confront their published alter egos': a statement which arguably ignores the real-world effect of such texts (42). Although he does note the danger in 'the appropriation of a life story for purposes not shared, or understood, or consented to by the subject', this is not a charge that he levels at Kaplan (48). Arguably, Couser believes that as Kaplan and Sienkiewicz-Mercer have the same end (independent living) in mind, the former cannot be misappropriating the latter's story. Yet, as Shakespeare's work on the stagnation of disability rights has shown, an attention to the means, as well as the end, is crucial.

The seriousness of this problem can be illustrated by some of the imagery employed by Kaplan in the introduction. Presumably as an attempt to emphasise the text's significance (and thus its popular appeal), he strives to expand the personal into the general, just as Collis urged Brown to, by metaphorically transfiguring Sienkiewicz-Mercer's disability-based distinction. External to the text proper, this cannot be excused by the aesthetic appreciations of Silvers. In this practice, Kaplan reveals a profound misapprehension of key disability issues. He claims that Sienkiewicz-Mercer's 'very existence embodies the predominant symbol of our century: the concentration camp' (*Eyes*, xxv). With all the inadequacies Spivak ascribes to 'simple' language, this phrase consolidates the traditional assumptions about disability of the sort apparent throughout the introduction, and reveals the risk of the imposition of meaning that Kirmayer identified. That Kaplan should appropriate his co-author's 'very existence' as a useful symbol for 'our' dominant /ableist discourse is deeply troubling. In a way, it is fortuitous that he should couple this with concentration camp imagery: the symbolic appropriation of disability has gone on long enough to be widely accepted without question, but the removal of the concentration camp, in a similar fashion, from its established social-historic specificity and meaning is more likely to raise eyebrows. This juxtaposition reveals the same concealment of real social oppression that is similarly concealed when Sienkiewicz-Mercer's disability is appropriated. The paradox of Kaplan's image in implying that she is oppressed (the notion of oppression is clearly suggested by Kaplan's own imagery) by her own body–her self, in other words, rather than the society that incarcerated and abused her–is thus thrown into sharp relief.

The mingling of disability and concentration camp imagery brings to mind the early-twentieth century popularity of eugenics that reached its peak in the Nazi

Holocaust: a vivid illustration of the fact that suffering and oppression is a social condition, rather than an individual one (the eugenic link is further strengthened by Kaplan's unfortunate decision to further describe Sienkiewicz-Mercer's body as a 'natural' concentration camp). The associative leap to her incarceration at Belchertown requires little imagination. Yet Kaplan does not make it. Despite the book's origins in a political project, and his oft-stated commitment to expressing Sienkiewicz-Mercer's experience, a precise focus on disability as a political identity is missing from the introduction, even as it features thematically in the main narrative. The link between Sienkiewicz-Mercer's institutionalisation and the concentration camps is apt and, in its shocking nature, might have revealed something to the nondisabled reader about their own, and wider, attitudes to disability in the last century. Instead, her suffering is blamed on her body rather than the social system, dividing her against herself. Her disability is individualised and symbolised for a story which suits 'our' (nondisabled) purposes.

There is a possibility that the fault-lines in Kaplan's statement are the remains of an initial intent to draw such explicit parallels between Sienkiewicz-Mercer's incarceration and the Nazi concentration camps. Perhaps this position, revealing the nightmare of failed independence in Sienkiewicz-Mercer's blameless incarceration, was suppressed in favour of a story that would boost and reassure society through the story of an individual's triumph over the tragedy of her disability. Might the desire to give the memoir a mass market (and therefore nondisabled) appeal motivate such a move? Coincidentally, in the text proper, Sienkiewicz-Mercer herself, musing on the content of a charity appeal film, notes that 'the general public's attitudes…had a great deal to do with determining the tone of the film' (21). Even so, the proffering of Sienkiewicz-Mercer as a symbol, an

embodiment of somebody else's values and ideology, negates both her humanity and agency. It also undermines and contradicts the purpose and point of ensuring that Sienkiewicz-Mercer tells her story in her own terms: if her identity truly is inscribed in her body, why would it need the exegesis of a memoir?

Kaplan's symbolic appropriation of Sienkiewicz-Mercer might simply be seen as an extension of the issues of symbolism and meaning that arise from the composition process. As noted earlier, he acknowledges a difference in language use resulting from Sienkiewicz-Mercer's disability that is arguably literary. He notes that she must 'choose her words more carefully than anyone' and is thus forced to 'utilize an economy of language'. Thus, she avoids the 'trivial verbiage found in casual conversation'. Furthermore, she avoids 'meaningless or misleading statements' which might 'waste the attention of her audience'. She is 'innovative …yet always blunt' and uses conversation 'to reveal, not to mask, her thoughts'. From one perspective, this might seem the very opposite of literary language: the terms 'misleading statements' and 'trivial verbiage' could have been coined for a work such as *Tristram Shandy*, for example. Yet if Sienkiewicz-Mercer's 'economy' of language is linked to Wallace's description of Nolan's work as 'dense', it might arguably be seen to share a certain literary quality. Kaplan describes Sienkiewicz-Mercer's communication as 'in the most fundamental sense, pure poetry'. He bases this judgement on his belief that her limited communication system means that she 'speaks symbolically' by necessity. He elaborates: 'Her every verbal utterance engages language at its most compressed, essential, yet suggestive level' (xiii). Kirmayer would of course argue that *all* language use is symbolic, and this reminds us to consider his two key observations: that meanings

are often imposed onto such symbolic speaking by dominant discourse, and that such speaking is rooted in the body. As noted above, Kaplan himself seems aware of this risk in his description of the composition process. Not only did he at first feel that Sienkiewicz-Mercer 'settled too quickly' on his meaning, but also that she 'appropriated [his] suggestions as her original thoughts' (xiv). This can be seen as the sort of subjectification through language that Galvin mentions, and the imposition of meaning by dominant discourse that Kirmayer mentions. The disabled body, too, plays a role in delimiting meaning. Kaplan states the possibility that sometimes 'Sienkiewicz-Mercer was simply tired and thus willing to accept my earnestly offered semi-truths' (xiv).

Instances in the main text indicate the problem of differentiating between Sienkiewicz-Mercer's deliberate use of symbolism and Kaplan's imposition of symbolic meaning for effect. For example, the seed words 'GRAY.HAIR.BROOM.BACK'. prompt a passage describing one of Sienkiewicz-Mercer's fellow patients at Belchertown with a deformed spine and long grey hair as being reminiscent of 'the mean old witch of whom I had heard of so often in fairy tales' (51). It is clear from the seed words that the symbolic association was Sienkiewicz-Mercer's not Kaplan's. From this negative association springs another: 'The hunchbacked witch quickly became a symbol of Ward 4'. One might argue that Sienkiewicz-Mercer's use of this idiom of the monstrous regarding the disability of others reflects the sort used by Sacks, as criticised by Zola. On the other, it might simply be argued that, as with Kaplan's analysis, her disability means that she has to use language economically, and resort to stereotype is one method available to her. The similarity to Sacks in describing other patients is not an

isolated incident. Tom Shakespeare has referred to Sacks as 'the man who mistook his patients for a literary career' (Shakespeare 1995, 137). With this in mind, we might also recall the theories of Davis and Mitchell regarding the idea that deviance serves as the initiating point of all narrative in our consideration of another passage detailing Sienkiewicz-Mercer's account of fellow patients. Here, the narrative reduces these people to their most crudely 'interesting' features. Kaplan arguably plays a role here too, turning '.IMAGINE.VOMIT'., '.CLOCK.MILK'., and '.CAR.POLICEMAN.SOUND'. into the more allusive 'The Retch', 'Daisy' and 'The Siren' (*Eyes*, 52). Yet, after describing these 'extraordinary characters', the memoir adds that the State School was 'the one place where they should have received empathy and understanding', in the process revealing the way in which the passage, subject to the conventions of narrative, has undermined the political purpose of the book (54). In mitigation, it might be argued that Sienkiewicz-Mercer's experience on Ward 4, her second ward at Belchertown, occurred when she was a child, and with its population of the severely mentally and physically disabled patients, must have served as a shocking experience after the relatively high-functioning Ward 1. It is interesting to note that the description of Ward 4 recalls Brown's first account of seeing other disabled people for the first times, at Lourdes and the clinic: 'Ward 4 seemed a human wasteland. It presented a staggering array of crippled bodies and damaged minds, a living picture of pain and madness' (49). Like Brown, it might be argued that the text documents Sienkiewicz-Mercer's perspective changing over time. For example, although she later observes the apparently constant pain of a severely retarded hydrocephalic girl with a sense both of 'grotesqueness' and 'pity', the text adds:

> I'm sure that a lot of people would look on me just as I

viewed that girl, believing that life couldn't possibly offer
me anything worthwhile on account of my 'pathetic'
physical condition. I know far too many people who are
enjoying their lives fully, yet appear to others as pitiful (90).

As if to illustrate this point, she describes the relationship between Terry, a blind
and dumb girl, and Diane, her therapist. She notes that the pair 'interacted on a level
that very few people would have thought possible', and concludes that her
experience of living for so long 'with people who have been totally rejected by
society', and of being 'written off by nearly everyone' has made it 'very difficult to
draw the line at which life is no longer worthwhile'. She concludes: 'I choose not to
draw that line at all' (92).

Thus, just as the conventions of narrative threaten to undermine
Sienkiewicz-Mercer's political aim for the book, so is communication one of her
central thematic concerns. She insists that her 'inability to speak' is 'the single most
devastating aspect' of her condition and has the same wish as Brown, to 'be able to
talk, if only for one day, or even one hour' (12-3). As a child, she frowned to say
'no', raised her eyes to say 'yes' and combined the two for 'maybe', adding
emphasis with 'a number of different vocal sounds and facial expressions' (6-7).
Thus, she did not have 'much of a chance to develop…skills of self-expression', as
most conversations were like 'playing a perpetual game of twenty questions' (7).
Furthermore, she has always been dependent on others in her efforts for self-
expression and communication. The consequences of the failure (or refusal) to
understand her are considerable and felt throughout the text, in particular on her
arrival at Belchertown at the age of eleven in 1962. Previously accustomed to
progressive care, she is eager to meet the people that she is going to 'work with'.

Instead, she is misdiagnosed, yet again, as an 'imbecile' by the school's head physician: something she 'cannot view…as an understandable mistake' (38, 39). The attendants make 'little effort' to communicate with her, and talk 'disparagingly' about her to her face as if she were an object, treating he like one as they do, leaving her bed-bound and force-feeding her (41). She notes: 'As long as these people considered my brain useless and my facial expressions and sounds meaningless, I was doomed to remain "voiceless"' (42). This comment can be seen to illustrate precisely the points made by Kirmayer and Galvin about 'irrational' discourses not being recognised. It also powerfully illustrates the existential and political reality of Sienkiewicz-Mercer's understanding of voice: for her it is not an abstract concept, but absolutely crucial to gaining power over her situation.

This withholding of communication even applies to Sienkiewicz-Mercer's relationship with her family. During her first few weeks at Belchertown, her one comfort is the constant stream of letters from her mother. When she finally visits the school, Sienkiewicz-Mercer attempts to communicate to her mother the appalling nature of her treatment. Yet, she is unable to initiate dialogue, and is instead 'forced to rely on her mother's questions in order to communicate specific information'. Thus Sienkiewicz-Mercer is unable to express the abuse she experiences at the hands of the staff:

> I was unable to tell her…that I was being fed on my back
> through a watering can, or that the attendants preferred it if
> I cried during feeding because this made it easier for them
> to shove food down my throat (60).

Sienkiewicz-Mercer reports that her mother understood that she was unhappy, but 'did not understand how bad things were' (60). If it seems charitably doubtful to

believe that her mother did not pick up on her daughter's distress, a subsequent event confirms this. One month later she is taken swimming by her parents. The physical evidence of her decline is undeniable, as her body speaks: 'The previous summer that bathing suit had fit snugly; now it hung on me like a sack...Any further questions about how I was faring were unnecessary' (61). Sienkiewicz-Mercer insists that she would have given 'an unmistakable answer' if anyone had asked her if she wanted to leave the school. But as nobody does, and she 'could find no way to make such a statement spontaneously', she is trapped (61). As with the abuse by the staff, it can be seen that this impossibility of communication is not accidental, but rather a result of imposed values: as Sienkiewicz-Mercer is ruled an imbecile her utterances are interpreted as nonsense, while the eventual revelation that her father insisted upon her staying at the school explains her mother's refusal to ask questions that could prompt unwelcome answers.

Unable to communicate, or rather to be recognised as communicating, Sienkiewicz-Mercer retreats from her hellish situation, embracing a more extreme form of the solipsism experienced by Brown. She enters a 'private world of memory and imagination' where time becomes 'a blur'. She notes that this experience is un-narratable, as 'that period is a fog of people and behaviour that [she has] tried very hard to forget' (56). When trying to remember the details of this period in order to write the book, her words recall the warnings of Davis, Shakespeare and Mairs regarding the re-inscription of pain. She states: '[I]n order to write this book, I have strained to recall details of those intentionally lost memories; very few events of those days seem worth remembering' (85). When placed on Ward 3, with the most radically damaged and disturbed patients, her sense of externality attracts her to the

notion of abandoning any attempt at rational communication whatsoever: 'In an occasional moment of weakness, or just to let off some steam, I allowed myself to join the chaos with a yell or a shriek'. Only 'pride' keeps her from making this a habit (77). Yet gradually, she learns to fashion her own internal narrative, in the form of daydreams where '[n]obody was the least bit handicapped' (77). Over time, these narratives became more complex, with a conscious technique. Sienkiewicz-Mercer would cast herself as both author and protagonist in tales reconstructed from her memory of the *Nancy Drew* books she had read as a child. As she puts it:

> When it came to the crunch between the horrible realities of
> the ward and the wonderful adventures of my imagination,
> the world of Ruth Drew won out enough to keep me afloat
> (78).

Although amongst girls of her own age, Sienkiewicz-Mercer refutes the idea that it was 'any kind of peer group', noting that all of the other patients were 'totally incapable of interacting in any way with the world around them' (79). She views them simply as 'a nameless group of immobilized people' whose mental condition 'cut them off from the world' (80).

Yet *Eyes* also presents another, more hopeful portrayal of the positive possibilities for interaction between disabled people themselves and between disabled people and progressive able-bodied people, such as that between Diane and Terry addressed earlier. This is evident even upon Sienkiewicz-Mercer's arrival at Belchertown, in Ward 1, where she recalls the relationship of the mildly retarded April with Theresa, a wheelchair user. While the former dresses and feeds her partner, the latter reciprocates by 'constantly advising and instructing her with gentle, understanding firmness'. Sienkiewicz-Mercer observes that 'the spirit of

their relationship was not unusual' on the ward (45-6). Ironically, she theorizes that her own friendship with Goldy, a 'retarded' woman, was only possible because the latter was unable to comprehend the abstract concept of Sienkiewicz-Mercer's supposed 'imbecility' (46-7). Perhaps the most significant example of alternative communication is the relationship that develops between Sienkiewicz-Mercer and another patient with Cerebral Palsy, Theresa Ladue. Ladue is described as her 'physical duplicate' who 'showed [Sienkiewicz-Mercer] how [she] must look to other people'. After some time in the same ward, Sienkiewicz-Mercer becomes aware of Theresa using sounds 'precisely' as she does, and also that she is seeking a 'response'. They begin to '"talk" to each other…through sounds and facial expressions'. This communication grows sophisticated enough for them to share 'opinions and feelings about living on the ward' (63). Crucial for this thesis is Sienkiewicz-Mercer's insistence that this exchange finally developed into a simultaneous experience for the pair of an 'extraordinary insight' that they 'shared', and that, furthermore, 'no one who was *not just like us* could possess' (my emphasis) (64). This insight is strongly reminiscent not only of Brown's account of his revelation after his time at the clinic, but also of Kirmayer's argument that a common experience of embodiment leads to a shared bodily lexicon, upon which all meaning in language, via metaphors of the body, is based. Just as Kirmayer acknowledges that bodily difference will affect how the body is used metaphorically, so it might be argued that such metaphors can be adopted by a group who share physical difference, forming a new lexicon. This is arguably what Sienkiewicz-Mercer and Ladue achieve.

Sienkiewicz-Mercer and Ladue develop their own 'special language' over the following months, constructing a 'basic, yet effective, system of communication'. They use events as opportunities to reveal to each other what their individual vocabularies of sounds and expressions mean. They become attuned 'to every change of tone and pitch', familiarizing themselves 'with what each sound meant in terms of emotion, opinion, or thought', and studying each other's faces for expressions (65). Thus, when Sienkiewicz-Mercer makes a noise and purses her lips upon being read a letter from her sister Shari, Theresa later repeats the sound and expression in order to refer to Shari. Similar, they name residents and staff by tagging them with sounds or expressions, and begin ('[a]lmost without realizing it') to supplement the system with simple hand gestures, in a manner that again suggests Kirmayer's theories about the embodied basis of language (66). For example:

> a sideways movement of the hand and forearm indicated
> that the subject of discussion involved emotions; an up-and
> -down movement indicated that the subject was a person;
> an upward movement alone meant 'man,' a downward
> movement alone meant 'woman'; raising the hand towards
> the face meant 'I'; an abbreviated movement of the hand
> towards the face meant 'who?'; a more rapid movement of
> the hand toward the body meant 'I'm mad at myself'.

Sienkiewicz-Mercer goes on to describe a 'typical conversation' that the pair might share:

> I would raise my arm to show that I wanted to talk about a
> man, then purse my lips to show that I loved this person.
> After Theresa answered with an affirmative sound, I would
> go on, perhaps following up with a babyish cry or gurgle.
> This might confuse Theresa, because I had just identified the
> subject as a man I liked. To clarify the point, I would look
> over at Theresa's teddy bear. Once she caught the object of
> my gaze, she would understand, I hoped, that I was talking
> about a baby boy (67).

As revelatory as this account of a new language sounds, Sienkiewicz-Mercer is quick to admit that the system had severe limitations. She reveals that the pair's attempts at communication often failed. More significantly, she notes that, 'by the very nature' of the system, neither party could ever be sure 'whether a message had been interpreted correctly'. Understanding relied upon eye contact and 'intuition', but even so there were times when: 'one of us could tell that the other one didn't know what the hell we were talking about'. Here, the limits of discourse provide a useful safeguard. As Sienkiewicz-Mercer succinctly puts it, '[h]alf the battle was to keep the topic of conversation within the limits of what we reasonably could expect to tell each other' (68).

Conversely, she observes that the more the two conversed in this way, the more sophisticated and yet simple they became in their use of it. Indeed, 'there were occasions when we stared into each other's eyes and communicated messages without making any sounds, expressions, or signals of any kind. In these instances our eyes did all the talking...and all the listening too'. Is this perhaps the return to the lost state of wholeness, pre-Symbolic order, in line with Wilton's analysis of Lacan? Certainly, it is an escape from the socially constructed carnal oppression that Hughes and Paterson describe in social encounters: by 'sharing the experience' with Ladue, Sienkiewicz-Mercer finds that she has 'eased her pain and frustration'. In this context, their misunderstandings and incommunicable thoughts ceased to matter: 'What mattered was that we each had someone who was trying to understand, someone deeply interested in our feelings and willing to share those feelings totally' (69). The viability of this system of communication is demonstrated later in the text, when Sienkiewicz-Mercer is able to successfully tutor another

patient with Cerebral Palsy, Donna, in its use. She achieves this through simple repetition: 'I just kept repeating basic expressions to her, communicating simple messages about how I felt about a particular person, or a meal, or anything else around us'. When Donna eventually learns the language, Sienkiewicz-Mercer is surprised at 'the depth of Donna's personality and intelligence'. Given that Sienkiewicz-Mercer feels 'more sensitive to her than most people' because of their 'similar physical attributes', and yet only begins to know her after months of communication, this leads her to wonder: '[H]ow could a "normal" person be expected to understand her?' (118 -21).

The above question prompts another: given the nature of the composition process and Sienkiewicz-Mercer's insistence that nobody else could understand the communication she shares with Ladue and Donna, how could Kaplan give such a detailed account of it? Arguably, however, the two systems of communication are not incompatible, as Sienkiewicz-Mercer's eventual breakthrough at Belchertown illustrates. After a successful lawsuit over horrific conditions at the home, brought by friends and families of the residents, the home is placed under direct control of the federal district court in 1973, resulting in 'drastic reforms' (viii). A new generation of more considerate staff are employed, and one nurse, Wessie, finally notices that Sienkiewicz-Mercer gestures with her eyes:

> She put the spoon down and thought for a few seconds, then asked, 'Ruthie, are you trying to tell me something?' With a broad grin on my face, I looked at her squarely. Then I raised my eyes up to the ceiling again with such exaggeration that I thought my eyes would pop up through the top of my head. Wessie knew she was onto something,

but she wasn't sure just what. She pondered for a few more seconds...then it clicked! A silent conversation flashed between us as loud and clear as any spoken words. Even before she asked me a dozen times over, and before I exuberantly answered a dozen times with my eyes raised skyward, Wessie knew. And I knew that she knew. I was raising my eyes to say yes (110).

Although this is apparently a massive breakthrough, Sienkiewicz-Mercer notes that it was still impossible for her to make spontaneous statements without engaging in 'a frustrating guessing game'. As with Ladue, she chooses to embrace this limitation, in order to 'avoid going crazy with frustration', by becoming 'very selective' in choosing what she would attempt to communicate. Even so, her attempts relied on the listener's intuition, and free time (112). This dependency is made all too obvious when another member of staff accidentally breaks her leg by lifting her roughly. Sienkiewicz-Mercer notes that staff member did not report the injury 'because nobody confronted her about it' (132). Even when her pain is noticed, she is unable to direct attention to her hip. She thus endures months of hip pain because the doctors 'couldn't be bothered to let [her] know what was going on, or even ask [her] how [she] was feeling' (133). She notes that this 'inability to communicate…made the physical pain worse' (145). The ultimate realisation of her dependency and powerlessness as a result of this institutional attitude to communication comes when the pain causes her to contemplate suicide, only for her to realise that not only can she not do it herself, but that she 'couldn't even ask someone to do it for [her]!' (135).

Now sharply aware of the intersection of language and dependency, it is unsurprising that Sienkiewicz-Mercer takes an interest when she overhears another patient, Diane, talking about an independent living program. It appeals to her

greatly: '[H]earing her talk about the independent life she would lead quickly convinced me that this should become my goal as well' (142). With a new focus on independence, she begins to take advantage of new advances in communication therapy that are made available at Belchertown in the mid-1970s. As a result, her expressive capabilities 'took huge leaps forward'. Key to this is her relationship with the speech therapists, not least their status as 'partners', open to negotiating the structure and function of communication techniques with her. This relationship can be seen as the model for her relationship with Kaplan, and also recalls the sort of reconfiguration of language that Bernadette Nolan offered her son in Chapter 2. On beginning the program, Sienkiewicz-Mercer is able to spell one-syllable words, selecting from an alphabet chart via eye or noise signals. An initial introduction to a more complicated system of 'ITA graphemes', utilising symbols to represent sounds rather than letters, proved too taxing for her to master. In describing the process of learning, she reveals how closely intertwined speaking, reading and writing are:

> It's difficult to learn how to spell when you can't talk or write, when you can't feel the sound of words coming out of your mouth, can't watch the letters take shape on paper at the point of pen or pencil. I could only sound out the letters in my head and write them out longhand in my mind. As a result, I had a tough time spelling words that used different letters but sounded alike.

Like Nolan, she is forced to memorize words in lieu of writing them down (153-4). As her limitations are explored, Sienkiewicz-Mercer is introduced to a range of communication devices. The first is a simple word board of ten items. Next, she is given an experimental device known as 'the expressor'. Basic messages were inscribed around a ring of flashing lights. A mercury switch triggered by Sienkiewicz-Mercer's raised forearm stops the sequence at a particular bulb (155). The device is unwieldy and unreliable, yet she observes: '[I]t was exciting for me to

produce messages, even such simple ones, without anyone's assistance'. With the coming of the age of the personal computer in the 1980s, her options increase greatly. She now uses a head-switch to select words and phrases on a screen, which could be stored and actually spoken aloud by a voice synthesiser later. By 1987, a refinement of this system uses allows symbols to represent the phrases more economically (156).

Just as Sienkiewicz-Mercer begins to find her personal voice through speech therapy, so too does she begin to locate her political voice. One of her speech therapists, Chris Dendor, is 'a strong advocate of the women's movement' and in the course of their discussions, Sienkiewicz-Mercer remembers becoming 'increasingly enthusiastic about it too'. It is important to note that these discussions are a revelation for her not just for their content, but also for their structure: unusually for staff members, Sienkiewicz-Mercer remembers that Dendor 'viewed communication with me as a two-way process, and she gave me plenty of opportunities to express myself' (158). It is important to note that her newly gained ability of self-expression is in many ways an end in itself for Sienkiewicz-Mercer: she recalls the relief simply in being able to declare, '*in words*', something as simple as '.I.FEEL.BAD' (160). She soon begins to master language, customising her word boards to her identity (181). Not long after this she makes her first attempt at autobiography. The timing of this brings to mind the words of Davis and Couser regarding the association of autobiography with independence, and also the role autobiography can be seen to play in the shaping of the authors' identities in the work of Brown and Nolan. There can be little coincidence in the fact that this development comes at a time when, after making contact with independent living advocates Carol and Paul Shelton, Sienkiewicz-Mercer moves to Alpha House, a

halfway house in the school grounds designed to acclimatise patients to living in the community (184). Indeed, she remarks of the move that the resultant privacy made her 'feel more like a real person' (186). Furthermore, at this time she encounters Sue, a wheelchair-using student, who gives the residents 'peer counselling' lessons on living out in the community (193). Sienkiewicz-Mercer is 'inspired' by her, not least because she recognises Sienkiewicz-Mercer's identity as made up of inter-connecting elements, rather than as monolithically *disabled:* '…she treated me like a woman' (194). Although it is not made explicit, this subtle reference to feminism serves as Sienkiewicz-Mercer's introduction to the wider field of identity politics. Soon after this meeting, Sienkiewicz-Mercer makes her 'first public appearance as an advocate for the rights of the physically handicapped', on March 10th, 1978, addressing an audience at International Women's Week at the University of Massachusetts. Of her speech she recalls: 'One of the themes I stressed was my lifelong dependency on other people and the fact that I was rarely respected as a woman and as an individual'. She also stressed the expansion of her communication techniques, and of the efforts made by many 'people with a disability…to become a useful and productive member of society' (199). When she finally leaves Belchertown in 1978 to move to independent living in Springfield, the narrative notes that the 'worst chapter' of her life 'had just ended'. Whether this turn of phrase is Sienkiewicz-Mercer's or Kaplan's is hard to tell, but it certainly has a resonance: Sienkiewicz-Mercer has mastered both narrative and her own narrative (201). Tellingly, shortly after leaving Belchertown, she grows frustrated by the lack of progress on her autobiography, and enrols in the 'FREE' program, where she meets Kaplan (210). The resultant text states, in its opening pages: 'Despite my unavoidable dependency on others for physical assistance, I am a very independent

person in thought and spirit. I have always striven to be as self-reliant as possible'
(12).

Sienkiewicz-Mercer's last act of independence, however, is contained in a
meta-narrative involving her parents that emerges towards the text's end (a feature
also apparent in the autobiographies of Brown and Nolan, as we have seen). The
earlier portion of the text records that her parents 'weren't very happy' about
sending her to Belchertown when they were unable to afford better care for her (35).
A degree of sarcasm is apparent in the text's subsequent observation that her parents
'failed to mention' the high death rate amongst residents at the school, and also
'neglected to tell' her that she could be admitted there only upon the proviso that
they accepted a misdiagnosis of their daughter as 'mentally retarded' (36). Despite
her account, detailed above, of being unable to communicate with her mother, she
later observes that it 'probably wouldn't have changed anything'. More explicitly,
she finally observes: 'I have always believed that my parents could have worked out
a way to care for me at home' (73). At the conclusion of the text however,
Sienkiewicz-Mercer reveals that the subject of her parents offered the 'only real
difficulty' she encountered in telling her story to Kaplan. She notes that her excuses
for them 'sounded true enough' and that she 'almost sold' Kaplan on this version of
events. Yet the text reveals that Kaplan probed for further details until she admitted
to asking her parents 'several times' to take her home permanently, and that they
had 'undoubtedly' understood this request. When Kaplan pushes as to why her
parents didn't agree to take her home, she gives 'no reply' (210). He responds by
'gently but persistently pursing 'the whole story'. Sienkiewicz-Mercer faces a
dilemma common to those with disabilities: she cannot afford to alienate those upon

whom she relies. She notes that her parents 'had read some of the early parts of the book' and were 'enthusiastic' and supportive, and admits that she 'didn't want to hurt [her] father's feelings' with her comments, but adds that after 'thinking the whole thing through', she decided 'not to pull any more punches'. She now states, unequivocally:

> .D.A.D.\$?*!(*Asshole*)
> It was my father's decision to send me to Belchertown, as well as to keep me there. He made that decision against Mother's wishes (211).

The conclusion of the text is not exclusively concerned with individual independence, however. Indeed, Sienkiewicz-Mercer's account of her first experience of independent living focuses on the fact that it took place in the context of a small community of people with disabilities. This is reflected in her use of language, with much of the account being related in the first person plural:

> We always had turnover problems....
> In our first few months at Linden Towers...
> …[W]e had nobody to blame but ourselves if somebody turned out to be unsuitable (207).

Similarly, she involves herself, as an assistant, in the 'augmentative communication' workshops of one of her therapists, Dr Howard Shane, and becomes an advocate for highlighting 'the distinction between receptive language ability and expressive language handicaps'. This in turn leads her to adopt the position that mainstreaming of disabled children in education is 'essential in order to prevent a handicapped child's life from being wasted' (216-7). As mentioned earlier, *Eyes* is, according to its afterword, intended as a part of such advocacy. From '.I.HOPE.TEACH.DOCTORS'., Kaplan extrapolates Sienkiewicz-Mercer's desire to 'address, and educate, professionals in all disciplines that deal with the

physically handicapped' in the areas of deinstitutionalization, mainstreaming and communication (224).

In conclusion, it can be seen that *I Raise My Eyes To Say Yes* is both an insightful and a problematic text, and that both these qualities arise from Kaplan's role in its composition. In telling his subject's story, he does, as Couser argues, inevitably mis-speak it. Yet at the same time, much of the thematic content shares the same connection that the works of Brown and Nolan do, which suggests a certain degree of authenticity. It is hard not to feel however, especially in comparison with the life-writing of disability activists to be addressed in Chapter 5, that Kaplan's perspective on Sienkiewicz-Mercer's quest to gain her voice is distorted by his focus on the individual element, a focus which is a result of the traditional progressive autobiographical narrative form he deploys to tell her story. In this way, the hints of an alternative disability identity experience, such as is suggested by her analysis of inter-disabled inter-dependencies and the Kirmayer-style bodily lexicon that she shares with Ladue, cannot be adequately addressed.

CHAPTER FOUR: CHRISTOPHER REEVE

Christopher Reeve has been called 'the most recognized person in a wheelchair ever' (Johnson, 129). When the famous, indeed famously able-bodied, actor was rendered quadriplegic as a result of a horse-riding accident in May 1995, he received a tremendous amount of media interest and public goodwill in the aftermath of the accident and throughout his rehabilitation. His subsequent re-invention of himself as an advocate for those with spinal cord injuries might have been taken, by a disability movement emboldened by the 1990 Americans with Disabilities Act, as a sign that it had found the prominent spokesperson it had long sought, someone who 'would begin to talk publicly about the disability experience as a political one…to champion disability rights' (255). Indeed, Reeve himself stated, in *Nothing Is Impossible* (2002, hereafter *Nothing*), that '[i]t would take the leadership of a public figure to raise awareness and make the difference in the lives

of victims without a voice' (*Nothing*, 87). He did become involved in disability and politics, but in a way which had little to do with the 1977 San Francisco sit-in.[3] For his focus was not on disability rights, but rather on a cure for his disability. Indeed, Mary Johnson has argued that Reeve's very public pursuit of cure can in fact be implicated in the campaign *against* disability rights that she documents in American politics and media in the decade following the ADA, in *Make Them Go Away* (2003). She attributes this both to a complex interaction between the public perception of Reeve and disability, and to his manipulation of this perception for his own ends. Johnson notes that, while '[n]early a quarter of a million people in the U.S. had spinal cord injuries' at the time of Reeve's accident, media reaction to the event was typified by Sharron Churcher of *Penthouse* magazine, who wrote: 'I don't know how the rest of us would cope'. This effacement effect can be recognised as a classic example of the danger of individualising disability which the social model addresses. Amongst 'thousands' of articles covering Reeve's disabling she notes that only one, by Art Blaser, an associate professor of political science (and, like Reeve, quadriplegic), made a connection between him and disability rights (Johnson, 7).

A post-ADA America, Johnson argues, continues to understand disability as 'a medical tragedy whose solution is cure', and 'does not understand [or] believe' that the 'prism of rights' is the 'correct way to understand' it (52). Reeve, with his campaign for cure, thus fit perfectly the comforting stereotype of the disabled person who is '"an inspiration" - "brave" and "courageous"' (60). By way of

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[3] This 25 day occupation of a branch of the Department of Health, Education, and Welfare was part of a campaign by the American Coalition of Citizens with Disabilities (ACCD) demanding the implementation of section 504 of the 1973 Rehabilitation Act, widely regarded as the first civil-rights statute for people with disabilities, protecting them from discrimination in federally funded programs (Scotch, 3). It was a foundational moment for 'grassroots' campaigning that would eventually lead to the 1990 Americans with Disabilities Act. For more on this see Joseph Shapiro's *No Pity: People with Disabilities Forging a New Civil Rights Movement*. Personal experience of this sit-in is also addressed in Chapter 5.

contrast, disability rights activists (at least as those who campaigned against the ADA in the media and the public arena sought to characterise them) were people 'who would blame society for their problems [and who] seemed like isolated whiners' (125-6). Boosted by the media-friendly symmetry of his previous incarnation as Superman, it is therefore unsurprising that in the late 1990s '[w]hen someone thought of a spokesperson for disabled people, they thought of Christopher Reeve' (125). Reeve's view was that disability was 'a temporary setback rather than a way of life', which was 'how most people felt about a life with a disability' (128-9). Shakespeare notes that upon Reeve's death mainstream media obituaries consistently represented him as a hero and an inspiration, while the disability movement largely criticized him (Shakespeare 2006, 114).

The fact that 'disability rights seemed to hold no interest' for a man who had campaigned for freedom of speech in South America and on many environmental issues is, Johnson argues, remarkable. She quotes excerpts from an interview Reeve gave to *New Mobility* magazine's Sam Maddox:

> People say to me, 'why don't you give up on that [cure business] and work for better conditions for people with disabilities? Work harder for the ADA, bring up people on charges who fail to meet the [access] codes?' I can't do both effectively, in my opinion (Johnson, 128).

Johnson notes that while Reeve has stated that he never said he 'would take on the mantle of representing all people with disabilities', he did indeed often talk of his desire to 'help speak up for the whole disability movement': at least when arguing that they shared his desire for cure (146). However uninterested in disability rights he claimed to be, Johnson alleges that Reeve's focus on cure and the individual:

> …bolstered the case against disability rights by offering a

> story of the disability experience that concurred with those who insisted that what people with severe disabilities faced were personal, medical problems, that what they needed was compassion - and a cure (129).

This motif of Reeve's version of disability as a 'story' persists, apparently unconsciously, in Johnson's criticism of him. Reeve's story of disability is, she implies, a fiction. She notes, for example, that '[t]he facts [on the possibility of spinal cord regeneration] in the speech he gave on *Larry King Live*, on *The Today Show*, to Barbara Walters were mostly invented…' (130). She also cites the case of the $5 million 2000 Super Bowl commercial for an investment company, viewed by 'over a hundred million viewers' in which Reeve appeared to walk. While many were moved to tears, she observes, 'others had felt it deceptive, misleading': they recognised Reeve's story of disability as fiction. Arguably, it was a harmful fiction: some spinal cord injury groups subsequently received calls 'from people convinced the ad was real and wanting the cure themselves' (147). While Reeve defended the advert as 'a motivating vision of something that can actually happen', *Time* magazine commentator and medical practitioner Charles Krauthammer, a wheelchair user, described it as 'nonsense' and speculated that other paralysed people:

> …might end up emulating Reeve, spending hours on end preparing their bodies to be ready to walk the day the miracle cure comes, much like the millenarians who abandon their homes and sell their worldly goods to await the Rapture on a mountaintop (147).

Like Sienkiewicz-Mercer, Reeve's life-writing is an extension of his political campaign: in his case, for a cure. Yet, as the above examples from Johnson indicate, Reeve's 'story' potentially has more in common with the fictional story of

disability that suits tradition than the actual experience of disability. In this respect, it is useful to look ahead to the next chapter, and Irving Zola's introduction to his anthology *Ordinary Lives* (1982), wherein he positions the writing contained within it as a riposte to the dominant, determinedly unreal view of disability that Johnson would recognise as persisting decades later, and which, by her implication, Reeve perpetuates.

Reeve published two pieces of life-writing: *Still Me* (1998, hereafter *Still*), and *Nothing*. The former spent eleven weeks on the *New York Times* bestseller list, and his audio version earned him a Grammy for best spoken-word performance. Reeve might also therefore be seen as the most recognized autobiographer in a wheelchair ever. In this respect, he is not anomalous: Couser has, after all, observed that the majority of disability autobiographies up until the mid-1990s were written by white, middle-class, and formerly able-bodied men. Given Johnson's analysis of Reeve's view of disability, it would be little surprise if his work shared the qualities that Couser identifies in such books, such as a 'concern with individual autonomy and freedom', a disregard for 'solidarity with a marginalized group' and a failure to 'question the cultural ideals of individualism and independence' (Couser 97, 198). Even more pertinent to a consideration of Reeve's 'story' is the Smith and Sparkes' study as addressed in the Introduction, because of its more precise focus on spinal cord injury, and its application of Kirmayer's theories regarding the body making itself known through metaphor. Given Reeve's dedication to cure, we might expect to classify his narrative, along with those of most of the study's subjects (and thus proportionally, most of society) as a 'restitution' narrative. The 'restitution' narrative is, of course, based on the belief that ability can be restored and is, they

note, characterized by metaphors of sport and warfare, with phrases such as '*a fight to make a comeback*' (Smith and Sparkes, 616). It focuses on 'medical advances and a cure that will return [the subject] to an able-bodied state of being'. For these individuals, 'winning is being cured of disability' with the latter defined as an '*enemy that must be beaten*' (617). Smith and Sparkes observe that such a narrative has a narrow definition of success that it is unlikely to be fulfilled, and will prevent their subjects from exploring other, potentially more rewarding, identities as disabled men (618). Such narratives 'may also imprison the person within certain storylines' (621).

As the following analysis of Reeve's life-writing will show, however, his books also contain elements of the other narratives mentioned in the study, such as the 'chaos' narrative (which lacks structure, order and causality), and the 'quest' narrative, where subjects come to 'accept impairment and disability and seek to *use* it', using journey metaphors to create 'a metanarrative of progress' in which 'risks, difficulties, uncertainties and descents' all play their part. This is especially significant to Johnson's analysis of Reeve, and the relating of him to Couser's analysis of conventional individualistic autobiography, because Smith and Sparkes link the quest narrative to the re-construction of identity via 'stories and dialogue – in communication and community – with others' (619; 622). The irony is that Smith and Sparkes attribute the genesis of quest narratives to the introduction of their subjects to the social model: the basis for the political perspective from which Johnson attacks Reeve. Nevertheless, their talk of 'restorying the self over time and developing communicative bodies' and of the benefits of stories 'that deviate from standard plots, provide new narratives and legitimize the re-plotting of one's own

life' arguably explains the way in which the later *Nothing* re-visits the events of *Still* with both a different perspective *and* a different style (623-5). The same could, of course be said of Brown's *My Left Foot* and *Down All The Days*, and Nolan's 'A Mammy Encomium' and *Under The Eye Of The Clock*. In this respect, we might recall Couser's idea of the essay style's strength as lying in its re-visiting of the same situation from different perspective, and also remember Davis' words on the 'cure narrative' and its inevitable failure. Ironically, this links to a further criticism Johnson makes of Reeve: that any pursuit of cure is ultimately doomed, as people will always be incapacitated and thus disabled in some way 'whether Christopher Reeve gains his cure or not' (Johnson, 229). This in turn connects to Shakespeare's words on the physical limits of even the so-called able-bodied (and similarly his words on how a disability will always be a disability) as addressed in the Introduction. Nevertheless, in this process of re-visiting his experience in *Nothing*, I will argue that Reeve's later writing shows that his long-term experience of disability altered not just his world-view but the very way in which he wrote, to a degree that is recognisably comparable with the ways in which the disabled body has made itself known in the works discussed in previous chapters. Given that Reeve was able-bodied for much of his life this is particularly interesting for what it suggests about the disabled body's influence as measured against his socialisation as able-bodied.

Reeve's work is also crucial for a consideration of the writing process. Unlike the other authors thus far covered, Reeve not only had hi-tech equipment, but a multitude of assistants to transcribe his dictation and compile his book, as well as the backing of a large and well-organised international publishing house

(Random House). Johnson also reports that Reeve also had *Time* magazine journalist Roger Rosenblatt as a un-credited collaborator (128). These resources can be seen as an extension of a disabled life that was very unlike the majority of his disabled peers: his fame ensured a persistence of status, and also of relative wealth. Shakespeare, writing after Reeve's death, notes that he 'reportedly spent £270,000 on treatment and therapy every year, had eleven attendants, and benefited from donated equipment' (Shakespeare 2006, 112). In the 'Acknowledgments' to *Still*, he thanks June Fox 'who became much more than a transcriber of my thoughts. I literally could not have written this book without her'. Likewise, he thanks his three personal assistants who 'helped…proofread, and worked tirelessly managing daily crises', enabling him to 'shut the door and concentrate on this book' (*Still*, Acknowledgments). In *Nothing*, he thanks his assistants for 'the time they spent sitting next to me at the computer, patiently waiting for the next sentence', and also for their 'invaluable comments and suggestions as we proceeded' (*Nothing*, Acknowledgments). He goes on to refer to his 'team of nurses, aides, equipment vendors, and accessibility advisors', without whom he could not live his daily life, 'let alone write about it' (*Still*, Acknowledgments).

Johnson has suggested that Reeve's need for such a 'team' was over-stated, and that this was a manifestation of his medicalisation of disability which arose from his view of his life as a pursuit of cure. For example, she notes that he bemoaned the expense of hiring registered nurses to attend to him, when in fact many of them were 'hired for jobs that do not require a registered nurse's training - changing catheters, suctioning tracheas' (Johnson, 233). This medicalisation might also be seen in his nod to 'equipment vendors', which foreshadows the product

placement which is evident in both books, with Reeve going as far as to eventually become a spokesperson for various pieces of expensive rehab equipment. He readily endorsed such equipment even though its sole use was, as noted by Krauthammer above, to prepare a disabled body for a day that will probably never come. In *Nothing*, Reeve's debt to corporate sponsorship is even more evident, as he offers his thanks to:

> …Therapeutic Alliances, Inc., for the ERGYS 2 bicycle; to Pulmonetic Systems, Inc., for the LTV Pressure Support Ventilator; to Nellcor for the Pulse Oximeter and computerized carbon dioxide meter; and to Bioflex, Inc., for the FES Stim Machine (*Nothing*, Acknowledgments).

Still begins with a narrative inside a narrative - an account of Reeve's idea for a film 'about a quadriplegic who lives in a dream' (*Still*, 3). Newly paralysed, he finds solace in a dream where he is 'whole again and able to do anything and go anywhere'. Each night the dream becomes progressively more realistic, as the man finds himself leaving the hospital to go sailing (the sport metaphor from the 'restitution' narrative), and sneaking back each morning to wake. Although his daily demeanour improves, the man worries that he is losing his mind (4). Nevertheless he considers 'sailing down the path of the moon, as far as he possibly could go, and leave everything and everyone behind him' (the individualism Couser identifies) (5). But his renewed relationship with his family enables him to abandon this fantasy life - 'he has an entirely new basis for the future with his family and toward recovery'. Although Reeve insists that that the tale comes from his experience but is 'not [his] story', he later recalls that in intensive care after the accident he would indeed dream that he was 'whole again' and that he would 'go off and do wonderful

things' only to be shocked anew to awake paralysed (5; 47). This story can be seen

as an early attempt to establish a re-storying in the way analysed by Smith and

Sparkes (and by Davis in his critique of the a cure narrative). Yet, as Reeve's

reluctance to accept the story's proximity to his own shows, this attempt is

unsuccessful. Although this story's conclusion implies reconciliation with his new

state, his subsequent statement that 'it's always a shock in the morning when you

wake up' undermines this (5-6). It is important to note that the sailing dream returns

in the conclusion of the book, but this time it is openly Reeve's own. This suggests

that it is an attempt to re-story his life in a different way, as what would appear to be

a 'quest' narrative. The journey metaphors and the sense of community and

dialogue that Smith and Sparkes identify as characteristics of this are clearly

apparent:

> Reluctantly I turn away from my fascination with the wake
> behind us and concentrate on what lies ahead. But now the
> boat is damaged, I've been injured, and we've lost our charts.
> Everyone is fully alert, gathered together on deck, quietly
> waiting to see if we can navigate to shore. Off in the distance
> is a faint flashing light; it could be a buoy, another ship, or
> the entrance to a safe harbour. We have no way of knowing
> how far we have to go or even if we can stay afloat until we
> get there. We agree to try, and to help each other steer (278).

Yet it can be seen that this attempt is held back by the persistence of elements from

the restitution narrative, both in the sporting/sailing metaphors, and the persistence

of cure as the goal:

> In the morning, if we stay the course, our beloved *Sea Angel*
> will be tied up safely at the dock and together we'll start
> walking home (278).

This metaphorical structuring is followed by an attempt to apply similar narrative to

his disabled life, beginning with his accident. In describing the horse-riding accident

which snapped his neck, Reeve appears determined to prove that he did not deserve

disability. He gives a detailed account of his equestrian career and the precautions he took, even to the extent of withdrawing from a previous competition upon discerning a 'risk' (9). Once more he invokes the 'restitution' narrative as he gives an account of his pre-disability athletic experience as a sailor, pilot, skier, diver, tennis player. In all of these, he insists, he always 'stayed within...self-imposed limits' and in 'all aspects of [his] life...enjoyed being in control' (9). The implication is obvious: it was his individual responsibility to ensure that he did not become disabled, and he fulfilled it. This can be seen as the logical counterpart of his post-disability experience, where it is his responsibility to ensure that he becomes able-bodied again. This is recognisable as congruent with the traditional attitude to disability described by Johnson earlier. Yet Reeve's description, as it progresses, highlights the unrealistic view of disability this presents, as per Johnson and Zola.

This unreality is neatly illustrated by Reeve's later reflection on his need, while portraying Superman, to take care to avoid the headline 'Superman Hit By Bus'. He remarks: 'How could I have let it happen?' (46). Such unreality is the reason why the narrative that Reeve seeks to apply to the accident does not work: by the logic of that position if he was being a responsible individual, according to the rules of personal responsibility, how could he possibly be disabled? Perhaps as an unconscious response to this, a contradictory narrative emerges, offering a different meaning for the accident in the form of simple bad luck. Thus, Reeve stresses that his decision to compete that day was 'a fluke', yet at the same time wonders whether he failed to observe 'warning signs' before the accident. These two contradictory narratives of disability fail to be reconciled in his absurd summary: 'I've since learned that this sort of impulsive decision is typical of many accidents'

(15). Accidents are of course atypical by definition. Rather than dwell on this contradiction, Reeve is concerned simply with moving ahead. Yet the narrative is disrupted by this unresolved issue, which insists upon returning. Thus, a few paragraphs later he comments: '[s]omeone said that a rabbit ran out and spooked Buck. Someone said it could have been shadows' (19). Still later, after a brief medical and factual description of his 'hangman's injury', he interjects: 'Rabbit or no rabbit, shadows or no shadows, I think I may have done something to cause the accident, and I have to take responsibility for it' (21).

Arguably, it was in the weeks after Reeve's accident that this pattern of contradictory narratives became established. When he realises the extent of his injuries his first thought is: 'Why not die and save everyone a lot of trouble?' (31-2). He expands upon this utilitarian view of life, stating: '…[I]t had dawned on me that I was going to be a huge burden to everybody, that I had ruined my life and everybody else's. Not fair to anybody. The best thing to do would be to slip away' (34). It is important to note that, removed as they are from the context of extreme shock after a catastrophic event, these words are presented as a statement of fact rather than feeling. Reeve is eventually swayed by his wife's words which, he writes, 'saved my life: "You're still you. And I love you"' (32). Eventually, he begins to feel more positive: 'Maybe it can be okay. I mean, life is going to be very different, and it's going to be an enormous challenge, but I can still laugh, and there's still some joy' (36). Yet it is at this point that Reeve's fateful pursuit of cure is initiated. An overly optimistic doctor, Dr. Jane, assures him that he can eventually expect his arm function to return (43). It transpires that this claim is based on little more than wishful thinking, an ironic development given Reeve's own subsequent

spurious claims for spinal cord research. Dr. Jane's prognosis arguably interferes with Reeve's adjustment to disability. As he notes: 'It took a while to get used to the idea of being fed...It takes time, even though everybody is so willing to help' (40). The conflict between cure and adjustment arguably plays a part in causing him to spend his first month in recovery 'floating among various moods and feelings - gratitude, horror, self-pity, confusion, anger', a situation that can be seen as corresponding to the description of the 'chaos' narrative described by Smith and Sparkes (44). Yet he eventually moves onto the cure narrative, a fact he appears to recognise himself, as he looks back at his thoughts during that time and perceives a narrative structure to them: 'It always began with: This can't be me. Then it went to: Why me? Then to: There's got to be a mistake. Then finally: Oh God, I'm trapped, I'm in prison'. Cure is the only possibly conclusion to such a narrative, where a Cartesian separation of mind and body has reduced the latter to nothing more than a prison. Thus, the narrative he describes ends with the cry: 'Somebody, please, let me out. Just let me out' (49).

It is at this time that Reeve has his first experience of being a disabled person in society, when he is shocked to be addressed by a doctor 'as if [he] were three'. He finally snaps and yells '"Fuck you, I'm a forty-two-year-old man. You treat me like one or don't come in this room again."' Yet, despite the fact that she 'increased [his] feelings of despair and loss, humiliation and embarrassment', Reeve insists that she 'intended no harm or discomfort', and fails to view this exchange as indicative of the existence of a social component to his disability, in its disabling quality (45). This inability to perceive the social element of disability is also apparent in Reeve's account of the letters he received from well-wishers. He praises

the letters from other people with spinal cord injuries that fit his restitution narrative by urging him to 'fight on' (a war metaphor, as per Smith and Sparkes' analysis). Yet he mocks the 'long, compassionate letter from a woman who said she could identify with [him] completely because for many years she had suffered from chronic indigestion' (52). Even at this stage however, he wonders of his future life: 'Is there a way to be useful, maybe to other people in my predicament?' (53). Yet his first face to face encounter with other disabled people reveals his ambivalence over the idea of disability identity.

When he meets these others in rehab, Reeve perceives them as 'damaged people', part of the 'institution' which he brands 'a place for the ill' (another example of his insistence on medicalising disability). On the notion of having to mix with 'the disabled' he bluntly states: 'I couldn't accept myself as one of them' (97). He acknowledges the 'difficult adjustment' he faces to 'become one among many' (98). Reeve notes that his celebrity was a factor, as he was kept in 'glorified isolation' with 'many special privileges', and that this was 'not a good thing'. It is interesting to note his observation that he was 'unique' to the staff because he 'came from the world of the quoted and the photographed'. The implications of this point can be connected to Johnson's argument regarding the focus of media and public attention on Reeve: that he was exceptional amongst people with disabilities *because* of his power, *because* people paid attention to and listened to him (98). This is of course also the very opposite of the effect Zola experiences in blending in, and identifying politically as disabled, in *Missing Pieces* (1982)*,* where he is shocked at the loss of status he experiences.

Nevertheless, Reeve begins to integrate at rehab and finds that it is 'fulfilling to share experiences and feelings' with other patients. He finds himself 'connecting with many of them in ways that [he] would never have thought possible' and finds himself 'becoming less resistant to being one of them' (102). Yet he still fits this occurrence into a restitution narrative, seeing it simply as 'acceptance…an essential first step in rehab'. This is apparent in his deployment of the sport metaphors cited by Smith and Sparkes, as he views rehab as 'a new sport', vowing to be 'disciplined about [his] body' in order to 'master [his] situation' (114). It is at this time that he re-enters public life, making his first appearance at a fund-raising dinner in aid of the American Paralysis Association. The occasion prompts him to consider advocacy and public speaking as a new career. Again, he refers to this in terms of a life narrative, musing that through such work he has 'an opportunity now to make sense of this accident' and to 'give it meaning' (126). This might prompt a recollection of Kirmayer's analysis of the way in which meanings are imposed onto the body by dominant discourse. In Reeve's case, we can see that this meaning is the dominant conception of disability as medical problem in need of a cure. It is this which shapes what Reeve refers to as his role as 'an advocate for research and the quality of life for people with disabilities' (*Nothing*, 86).

More practically, a career as a public speaker provides Reeve with an income. Even with his comparative wealth he, like others with disabilities, finds money a constant worry. His celebrity is no defence against the greed of medical insurance companies, and he becomes embroiled in 'ongoing battles about insurance' (*Still*, 127). He recounts disputes over his stay in rehab, extra nurses, and a back-up ventilator, noting that the insurer's refusal to pay $3,500 for the back-up

(that he eventually bought himself) meant that he could have been prevented from travelling to speaking engagements, and thus from earning income. In this way, Reeve has a taste of the experience of other people with disabilities. As he would observe when re-visiting the ventilator dispute in *Nothing*: '[W]hat about others in a similar situation who simply don't have that kind of money?' (*Nothing*, 90). Yet Reeve's celebrity status affords him opportunities unavailable to other disabled people, such as free medical equipment from medical companies, which he promotes, not just in the 'Acknowledgments' section, but throughout the text itself:

> Electrologic of America provided me with a bicycle, which allows me to maintain the strength and mass of my leg muscles while giving me a cardiovascular workout…The benefit of this bike is tremendous…(*Still*, 128).

Reeve concedes that much of this equipment is prohibitively expensive: $100,000 for the bicycle, $30,000 for a StimMaster to exercise his leg muscles, $15,000 for a tilt table to decompress his spine. He argues that such facilities 'should be available to anyone with a spinal cord injury', but he does not state how this might be achieved, although writing in the context of his battles with insurers, he appears to suggest that they should pay for such items (128). To recall Krauthammer's comments however, it can be seen that the ultra-expensive equipment which Reeve lists is all dedicated to preparing the paralysed body for cure, rather than accommodating disability. Similarly, Reeve does not address the fact that equipment vendors and insurers are essentially involved in the same industry, or that, by virtue of his product placement, he is also.

Furthermore, Reeve's entreaties to the insurers are based once again on the traditional perception of people with disabilities as a burden which he displayed

upon realising his predicament after the accident. He appeals to them on the basis

that their hunger for profit and his hunger for cure are in fact compatible aims.

Paying out for expensive cure-preparation equipment, he argues, would mean that

'in most cases patients would improve dramatically or even be cured and no longer

require costly reimbursements' (129). Reeve later returns to this topic, describing

the $8.7 billion 'spent annually merely to maintain spinal cord patients' often in

institutions, as a situation whose 'economics…make little sense'. He balances this

'social obligation' against its contribution to the national debt, and seeks to tip that

balance by insisting that such care is 'failing to improve the quality of [patients']

lives' (140). Yet, as Johnson's analysis shows, Reeve's perception of the quality of

life with a disability is not particularly representative. Furthermore, his

characterisation of people with disabilities as a drain on resources, as reliant not on

their civil rights but on 'social obligation' is deeply demeaning, as is his use of such

imagery to appeal to those who customarily use it. In the light of this, his claim to

speak '[o]n behalf of people around the world who suffer from serious illnesses or

disabilities' in stating that disability through spinal cord injury is an 'an emergency'

in urgent need of cure can be seen at best as politically dishonest (143). In *Nothing*

Reeve cites an excerpt from his testimony to Congress on the issue of budget reform

for the National Institute of Health's research programs which is very similar to the

position espoused in *Still*, but with even more negative language. He describes how:

> …spinal cord *victims* will continue to *sit* in wheelchairs,
> *draining the resources* of insurance companies as well as
> Medicaid, Medicare, VA hospitals, and nursing homes. [Yet]
> it is very possible that within the next three to five years
> people who are now *afflicted* with a wide variety of
> disabilities will be able to *overcome* them. They will *regain*
> *their rightful place in society*, rejoin the workforce, and at
> last be relieved of the *suffering* they and their families have
> had to endure. The plea for adequate funding cannot be

ignored (*Nothing*, 95) (My emphasis).

Reeve's language here clearly plays to a stereotype of disabled people as members of a passive underclass, who are a burden to their families and a drain on society's resources, and of disability as something wholly negative and inherent in the individual, which it is the individual's responsibility to overcome. This is the argument Reeve makes while lobbying for the 1995 Harkin/Specter bill that would force health insurance companies to donate 1 percent of every premium paid to research. Yet Reeve discovers that the access his celebrity gives him to high-level politics is not even as effective as the grassroots disability movement that brought about the ADA:

> When Harkin and Specter called for a sense of the Senate
> on the bill, the result was 98 to 0 in favour. Gratified by this
> response, they called for an official vote. It was defeated 65
> to 33 (*Still*, 244).

Reeve attributes this defeat to 'the duplicity of most politicians' in the face of pressure from 'a powerful special interest group such as the insurance lobby' (244). In *Nothing* he details the failure of another bill he lobbied for, (for rather more altruistic and disability-conscious reasons) to raise lifetime insurance caps beyond the $1 million cap set by Congress in the 1970s which, he observes, would be eroded within three years by a 'catastrophic illness or disability' thus consigning even insured patients to institutions he terms 'human parking garages' (*Still*, 91). Although he writes personally to each senator, the bill is defeated 56 votes to 42. A perhaps rather more jaded Reeve observes that he has been 'assured a number of times' that the issue will be revisited, but that 'so far nothing has come of it' (92). His *Still* incarnation is rather more naïve as regards the reality of the political

situation of people with disabilities, a factor which can again be attributed to his adherence to a version of disability that is determinedly unreal and unrealistic. Even so, he vows to continue his campaign, characterising it as his opportunity to 'do something', not just for himself, he insists 'but for everyone else in the same condition' (*Still*, 130). In *Nothing* he characterises his role of self-appointed spokesman as less of a choice and more as something that has been thrust upon him: '[L]ike it or not', he writes, his role is 'to speak on behalf of other patients who will never be heard' (*Nothing*, 105). Thus he appoints himself a spokesman for millions, and effaces their voices.

Yet Reeve chooses to pursue this role through his personal obsession, cure, and in the most individualistic fashion: '[M]y ability to adjust to life in a wheelchair might depend on my spirit and determination, but my future would lie with medical science' (*Still*, 131). Thus he medicalises disability once again, leaving the quotidian experience of living with a disability to the individual to overcome personally with 'spirit and determination' rather than through social and political change. His individualistic view of his role as disability spokesman is especially evident in his decision '[t]o create a sense of urgency, and to give the quest a human face' by declaring his intention to walk by his fiftieth birthday, only seven years away (135). This unrealistic aim was never achieved, yet in *Nothing* Reeve insists that he achieved his goal, which was to 'provoke a reaction from scientists, politicians, and the media by proposing a difficult but not necessarily impossible challenge' (*Nothing*, 169). Yet the consequence of appointing himself as an individual figurehead in his new career as public speaker, advocate, lobbyist and fund-raiser is apparent in a *Newsweek* article which delights him. The journalist

signs off with the quip: 'We should all be so disabled' (*Still*, 140). Superman has become a 'Supercrip': the person with disabilities who overcomes them through personal effort and so proves that there is no discrimination, and that any disabled people who do not achieve similar feats are simply not trying hard enough (Haller, 2000).

Perhaps because Reeve has declared their non-existence or effaced them by speaking for them in pursuit and support of his personal desires, dissenting disabled voices are notably lacking in *Still* and *Nothing*. In the former, he briefly acknowledges in the Afterword that his 'optimism about the future' of spinal cord recovery is 'often criticized', but does not go into detail about such criticism, or indeed who has offered it (*Still*, 285). In the latter he writes of '[o]ccasionally' receiving letters from 'people with spinal cord injuries'. It is interesting to note that Reeve employs similar language to that he used in his testimony to Congress as he implies passivity, laziness and inertia by describing how some of these critics have 'been sitting in a wheelchair for as much as twenty-one years'. He also subtly presents them as pessimists by describing their argument as a claim that 'there is no point in searching for a cure'. His incredulity, and the implication that the reader will share it, is apparent in his observation that some 'even say they are happy with life they way it is and don't want to be cured'. He admits to being unable to 'understand their point of view' yet concludes by remarking that he respects such a position, but only as long as 'those individuals…don't try to interfere with progress' (*Nothing*, 17). His final unconscious verbal insistence on them as 'individuals' apparently underlines the fact that Reeve is firmly established in an individualistic model of disability, and thus perhaps explains why he is unable to understand their

argument: because he is unable to see disability as something with a socio-political element. His comment about individuals interfering with progress can arguably be linked to a passage in *Still* where Reeve expresses his outrage at President George W. Bush's use of disabled people in media appearances expressing his ideological opposition to stem cell research. In particular, he notes the President's appearance on April 10th, 2000 with an acquaintance of his, former New York City police officer Stephen McDonald. Reeve notes that McDonald, a long-term wheelchair user and a devout Catholic who believed that his shooting (an 'accident' as Reeve unconsciously mis-labels it) was "God's will", was opposed to such research on religious grounds. Reeve writes:

> I felt great sympathy for Stephen…That's why it was painful
> for me to see him strategically placed next to the podium on
> television that day. I felt he was being used. Politicians do
> this sort of thing all the time (162).

Apparently it does not occur to Reeve that he himself was 'used' by politicians for his disabled celebrity status during his own engagement in politics, or by the companies donating expensive medical equipment to him. That he is unable to allow for the possibility of agency, or the determination of disability's meaning, on the part of another disabled person emphasises once again the effacing quality of his role as self-appointed spokesman.

This effect is apparent in the brief accounts of his pre-accident encounters with disability that Reeve provides in *Still*. He recalls that his first acting role after appearing in *Superman* (1978), was playing a bilateral amputee in a theatre production of Lanford Wilson's play *Fifth of July* (1979). Faced with the task of 'learning to simulate walking on artificial legs', he is coached by a Vietnam veteran

amputee (*Still*, 210). Reeve remembers being 'awkward and self-conscious' around

him, but observes that the injury 'had given meaning to his life'. This is, of course,

precisely the view that Reeve takes of his own injury, and can be interpreted in two

ways: either Reeve took the man's experience as a model for dealing with his own

later disability experience, or he is imposing his own meaning onto the man's

disability. The fact that Reeve again, as he did with Stephen McDonald, mis-labels

the man's war injury as an 'accident' evokes this latter possibility. As noted earlier,

an 'accident' is the very opposite of meaning, while in the Introduction,

Shakespeare observed that disabling through, for example, war, reveals the social

element and context of disability. In labelling it an accident, then, Reeve is once

more applying a perspective which refuses to see any social element to disability. In

an 'accident', nobody is to blame. This denial of the social element of disability is

especially ironic, given that Reeve's detailed description of how he performed

disability serves as an excellent illustration of the dynamic nature of this social

element. For, while he focuses on the 'physicality' of mimicking his coach's

movements in order to get him 'into the part', his attempt to be 'spontaneous,

truthful, and "in the moment"' means that his acting of a scene where his character

loses his balance changes with each performance:

> Sometimes I felt anger and denial. Then my attitude was:
> Don't help me, I don't need anybody. Sometimes I cried, and
> would reach out for help. Sometimes I tried to pretend it
> hadn't happened (210-1).

Just as with Couser's critique of Sacks in the Introduction, it appears that Reeve's

encounters with disabled people serve only to harden his prejudices. Thus, when he

is assigned another disabled coach for a film role as a paraplegic (before the

accident), his abiding thought as he watches her struggle through rehab is: 'Thank God that's not me' (241).

Reeve's account of his film projects after his accident offer further insights into his understanding of disability, and his narrativisation of it. They also serve as useful points of comparison for *Still* and *Nothing* which are, after all, also creative endeavours. There is also an obvious interaction between Reeve's advocacy work and his art. He states in the Afterword to *Still* that they are 'two equally powerful sources of satisfaction' which allow him to experience a sense of 'fulfilment'. Indeed, the 'separation anxiety' he feels at finishing the 'intensely personal work' of writing *Still* is what spurs him to appear in the remake of *Rear Window* (1998). Yet Reeve's first film project after rehab is as a director. He selects the project partly because its location in one set is logistically manageable for his disability, and partly because he feels that the 'emotional content of the story' is 'perfect' for him (245). The film, *In The Gloaming* (1997), is the story of 'Danny, a young man suffering from AIDS who comes home to die' (246). Reeve's reference to his connection with the emotional content of the story is clearly a reference to his disability. At first such disability solidarity on his part, making the leap between paralysis and AIDS, seems unlikely. Yet, given Reeve's obsession with viewing his relatively stable disability as a medical emergency, it is not so surprising. However, given Reeve's obsession with research and cure, it is odd that innovations such as anti-retrovirals and other medications, which had certainly by the date of the film in the mid-1990s greatly extended the lives of many people who were HIV positive, are largely ignored.

The inexorable quality of the main character's death, as related by Reeve, seems essentially an outmoded, melodramatic, sentimental device. In this respect, the 'emotional content' of the story that he is attracted to can once more be seen as the determinedly unreal and unrealistic fiction of disability that exists in the public imagination. Arguably Reeve's interpretation of what the film means to him says less about the realities of living with AIDS, paralysis or indeed any disability than it does about the fiction that any state other than able-bodied is equivalent to death. This imposition of Reeve's own view of disability prompts him to change the script. He finds the main character 'too sarcastic, bitter and judgmental', and rewrites him with 'a quiet dignity [that] would make him much more sympathetic' (246). Here we might recall Johnson's distinction between the public image of Reeve and that of disability rights activists discussed earlier. The 'quiet dignity' he calls for is arguably related to his repeated characterisation of people with disabilities as passive, and the lack of voice he exploits in his 'speaking for' the millions like him who supposedly desire cure. This is also reminiscent of the issue of the supposed narcissism of people with disabilities, as addressed by Siebers in the Introduction. Yet the justification he provides is entirely based on his individual experience: 'Perhaps I felt a strong connection with Danny because of my own experience. After having nearly died twice, I felt no anger towards any of my relatives' (246).

Reeve also returns to acting in a remake of Hitchcock's *Rear Window* (Jeff Bleckner, 1998). Yet as producer he brings his advocacy to the project in his determination to have it 'highlight the courage and resourcefulness of a severely disabled individual' (288). Indeed, he states that his 'justification for the project' was the focus in the first half of the film to the protagonist's progress 'in rehab and

starting to rebuild his life'. The film was, in effect, to be a form of advertisement for the medical equipment he endorsed, aimed not just at the 'average viewer' but at the 'many disabled individuals [who were] not aware of the equipment available for exercise'. Rejecting a documentary format on a channel such as 'PBS or the Discovery Channel' because it 'would reach only a relatively small audience', he argues that 'demonstrating' rehab equipment 'within the context of a compelling story' would be 'much more effective', reaching twenty to thirty million people. Viewers, 'drawn in by the anticipation of a good thriller, would also be exposed to a life that is unfamiliar and perhaps even intimidating to them'. Yet this consciousness-raising is tailored to Reeve's own cause: 'the latest devices that promote ability within a disability and allow the patient to lead a more normal life' (288). Quite what investment the able-bodied would have in such information is debatable: the only logical conclusion is that they would again be exposed to the idea that disability is a personal medical problem that can be overcome by the individual who strives to 'lead a more normal life' (as long as they can afford expensive medical equipment). This perpetuation of fiction extends even to Reeve himself, when he subsequently admits that he himself does not use any of the equipment he is pushing:

> I am somewhat embarrassed to admit that…the only high-tech device that we adopted was a voice activated computer. I rarely even see it, however; it lives downstairs and is used almost exclusively by my assistants (289).

This hypocrisy is heightened by Reeve's justification for not using the computer: 'I could dictate five letters…in the time it would take me to complete one using the microphone at the computer' (289). Thus, Reeve once more shows that social accommodation (here taking the form of his personal assistants) is actually a far

more practical, realistic adaptation to make with regards to disability than the purchase of costly equipment which offers a cosmetic individuality. His defence, that '[n]ot everybody has three assistants' is particularly ridiculous given his dedication to pushing for expenditure on equipment and dubious, intangible resources such as spinal cord research. Nevertheless, one particular incident Reeve recounts with regard to the filming of *Rear Window* highlights the reality of the social element of the disability experience. As with the *Fifth Of July*, Reeve is determined to be 'in the moment' when acting. Thus, in a climactic scene where the villain is to cut the protagonist's ventilator hose, he suggests that the actor should actually do so. The result is all too real, precisely the sort of experience of disability as a social embodiment as analysed by Hughes and Paterson in the Introduction:

> In one instance, after slicing the hose, he crouched down in front of me and mocked my efforts to breathe. He looked and sounded like a dying fish. In response the expression of humiliation and anger on my face could hardly be described as acting (291-2).

As *Still* comes to a close, Reeve arguably demonstrates that he has learned some lessons about being 'in the moment', and addressing the social rather than medical side of his disabled existence. Yet this conflicts with his restitution narrative. Thus, while he seeks to remind himself that 'being is more important than doing, that the quality of relationships is the key to happiness', and that he believes 'those things are true' he also states that in claiming these things he is 'putting on a brave face' (272). A factor in this disconnect is arguably Reeve's inability to attain the sort of 'living-through-the-body' experience necessary to attain wholeness that was discussed with regard to the work of Miho Iwakuma in the Introduction. Thus, he insists that 'we are not our bodies…our bodies are like houses we live in while

we're here on earth' yet also states that he takes no comfort in this concept, finding it 'more of an intellectual construct than a philosophy I can live by on a daily basis' (274). This perspective, Reeve reveals, cultivates a fear that 'the best moments of [his] life are behind [him]', and thus causes him to 'look back longingly' on his past (276). Yet he also recognises that a retrograde narrative is destructive: 'I have to stop this cascade of memories…There is no other way to survive except to be in the moment' (278). In this way *Still*, with its mixed accounts of his pre- and post-disability life, and the inevitable looking-back required of the autobiography form, can thus be seen as part of the problem.

As we saw in the Introduction, Couser has recognised this problem with traditional narrative and has embraced the potential for an essay style which frees the author from fixing one moment with one specific meaning, and allows them instead to return to it again from a variety of locations and perspectives. This is arguably what occurs in *Nothing*. Originally envisioned as a collection of Reeve's speeches and interviews, Reeve soon discovered that 'improvised remarks don't always translate well onto the written page' and decided instead to write a collection of essays (*Nothing*, Acknowledgments). As we have already seen to some extent, each of these essays revisits areas covered in *Still*. Thus, the first essay, 'The First Decision', re-examines Reeve's life immediately post-accident. Here a progression from the restitution narrative is apparent. He now writes: 'Whether you succeed or whether you encounter adversity…you always have to believe in your worth as a person. That's what counts' (4). Noting that this comment came from a speech given in February 2001, Reeve is quick to admit that, in intensive care in June 1995, he had 'no such belief' (5). Furthermore, in a passage that recalls his immediate

insistence in *Still* as to the worthlessness of a disabled life, he now concedes that his reaction was solely based on prejudice: 'I knew absolutely nothing about living as a vent-dependent quadriplegic' (6). He writes that he soon began to accept 'the new reality', but, in an apparent admission of his earlier adherence to a restitution narrative, he acknowledges that this happened 'in spite of [him]self' (13-4). Although, in 'Humor', Reeve maintains that a 'longing for normalcy' permeates 'every aspect' of his disabled life, a greater social awareness is perhaps apparent in the place of the rugged individualism on display in *Still*. He now writes of struggling to find 'the right balance between managing my own needs and meeting my obligations to others' (29).

Reeve devotes a whole essay to the topic of what he calls 'Mind/Body'. However, although he states that his disability has led him to a 'reconsideration' of his previous belief that 'our overall health is affected by our state of mind', this is not supported by the essay (37). He insists, for example, that the mind 'can both create a physical condition and enable us to recover from it' (40). In support of this, he claims that 'overwhelming evidence' from '[m]any researchers' shows that stress can cause 'hypertension, ulcers, and a compromised immune system', and that 'repressed anger' can cause or exacerbate cancer, without citing any sources for these claims. Although such thoughts might at first appear to provide a welcome reconsideration of a traditional Cartesian separation, it can be seen that Reeve's quasi-mystical argument is nothing more than a re-statement of traditional myths about disability that imply that it is somehow a result of a negative attitude on the part of an individual. We need only recall Reeve's re-writing of Danny for *In The Gloaming*, or Johnson's assessment of the public image of disability activists in

order to see something dishonest and sinister in the prohibition of anger. It is no surprise that this apparently new perspective leads back to familiar territory for Reeve: that of 'overcoming' his disabled reality. In a passage that recalls the Nolan's differing accounts of his first attempts at writing in 'A Mammy Encomium' and *Under The Eye Of The Clock*, Reeve attempts to support his theory of mystical overcoming through an anecdote about the healing of an ankle wound. Although he does not 'claim to understand precisely why' the wound healed, and concedes that 'Fortaz, the prescribed antibiotic, is an aggressive therapy', without which he 'wouldn't have recovered', he nevertheless insists that the wound could not have healed 'without an ironclad agreement between [his] mind and [his] body' (42-3). Ultimately, this is just the same Cartesian thinking which Reeve displays in *Still*: the idea of 'trying to overcome the limitations of a disability [with] exercise and discipline' (45). Thus, he writes of 'learning to control manifestations in [his] body with the power of [his] mind' (47).

Significantly, however, there is evidence elsewhere in *Nothing* of changes in Reeve's attitude. Although he sticks rigidly to separation of mind and body in 'Mind/Body', it is apparent in the essay 'Parenting' that, however unconsciously, the social element of the experience of disability and to an extent the body as known in that social experience, are making themselves known. Reeve notes that, just as with his own father, his relationship with his children was defined pre-accident by physical activity (55). Initially concerned that he will have nothing to contribute as a disabled father, he is surprised to find that sport is replaced by conversation. He writes: 'We spent most of the time talking. I quickly realized that we'd never really done that before' (58). This new form of interaction allows Reeve to embrace the

idea that that 'sometimes *being* is more important than *doing*' in a way in which he

was unable to at the end of *Still*. Although his advocacy work in that book means

that his observation that 'even if you can't move, you can have a powerful effect

with what you say', is unsurprising, a new tone is apparent in this declaration (59).

For this line of thought leads to passages which contrast sharply with the rest of

Reeve's work, as when he writes that:

> …words can only have a positive effect on others if and
> when they are ready to listen. And we have to choose our
> words carefully, particularly when we are the voice of
> authority for people who are vulnerable (60).

Reeve makes this statement while reflecting on the opinions given to him by doctors

after his accident, but they may well be seen to serve to illuminate his own

responsibilities as self-appointed advocate for the wider disabled population. In this

vein, his insistence that 'none of us has a right to refute someone else's experience

or perception' is of particular relevance (62). He could almost be referring to the

view of mainstream society on disability when he states: 'The worst thing we can do

is to say, "That's wrong, you're exaggerating, you're re-writing history"' (63).

Although arguably not consciously intended as such, these words and the social

positions they reflect, can be seen as a renunciation of Reeve's role in effacing and

denying other experiences of disability in his role as self-appointed disability

spokesperson.

However unconsciously, a suggestion of how he has reached this position is

perhaps contained in the essay 'Recovery'. This is an account of how, after years of

intensive exercise, Reeve regains control of one of his fingers (110). Although he

insists that this proves that his 'daily regimen had been worthwhile', he admits to

'the reality that nothing in my everyday life had changed' (125). Arguably, the fiction of cure is finally dispensed with and the reality of his disability experience is finally accepted: at this time, the Christopher Reeve Paralysis Foundation board vote 'to allocate more money for quality-of-life grants' than to research (126). A new, philosophical and analytical attitude to the social and physical reality of his disability is also apparent in the essay 'Hope'. Reeve notes that what he had termed 'irrational anger' at his disabling has 'left a residual effect that still informs the way I look at the world today: I want to see fair play' (159). This arguably suggests that Reeve, however unconsciously, now recognises that the anger of people with disabilities is not bitterness, but is rather a justified response to injustice. This shift of social and political priorities due to his disability experience is evident elsewhere too, in his account of abandoning or modifying longstanding ideological positions: as a committed Democrat, he would pre-disability 'never have imagined siding with Jesse Helms on *anything*'. Now, however, he finds that 'the most effective way to change policy in Washington is to join forces with the most influential allies on a case-by-case basis' (161). Given that the cases in question are disability issues, it is thus possible that, however unconsciously, Reeve has abandoned the traditional, mainstream 'overcoming' ideology apparent in *Still*, and begun to develop a sense of politics based on a social and physical experience of disability.

In conclusion, it can be seen that Reeve's two books inform this thesis in complex yet illuminating ways. *Still* can be seen as precisely the sort of traditional autobiography that Davis and Mitchell and Snyder criticise, and indeed wears its individualist, traditional view of disability as a badge of honour. Furthermore, the book can be seen as part of Reeve's 'story' as it existed in public life, sharing many

of the qualities which lead Johnson to implicate Reeve the man in the perpetuation of a harmful fiction of disability. Nevertheless it might be argued that *Still* - as a narrative of disability as individual overcoming - lays bare that narrative's quality as a story: that is, as a *fiction*. This is particularly apparent in Reeve's conclusion, where he himself implicates the book's retrospective nature, essential to the autobiography form, as something oppressive and threatening to him: the traditional narrative of the individual overcoming does not fit the reality of, and cannot be imposed onto, the reality of his disability experience. This fiction is something which traps him and will not allow him, in the words of Smith and Sparkes, to re-story himself. In this respect even the title of the book is redolent of this dreadful feeling of being caught. By way of contrast, it can be no coincidence that in *Nothing* he finds freedom in the essay form to return to and re-address his disability experiences in a way he could not in the traditional autobiography form of *Still*. In both its style and its nascent concerns therefore, it will be seen that Reeve's second book shares qualities with the anthologies to be examined in the following chapter.

CHAPTER FIVE: ANTHOLOGIES

Anthologies of disability writing appear to offer a simple solution to the main problems which disability studies critics cite with regard to disability autobiography. In place of the individual voice which risks both the perpetuation of the idea of disability as personal misfortune and the effacement of others' experiences of disability a variety of voices are instead presented in one volume. Meanwhile an overarching narrative, judged by Lennard J. Davis, David D. Mitchell and Sharon L. Snyder and G. Thomas Couser to be incompatible with the reality of disability, tends to be rejected in anthologies, possibly as a result of their format, in favour of the 'personal essay' style. Indeed, many of those writers championed by Couser as exponents of this style feature in more than one anthology. These traits are arguably shaped by the fact that anthologies have a different purpose to autobiographies. In taking 'disability' as a unifying theme, and soliciting

disabled contributors, they implicitly create a form of identity politics: whereas autobiographies are defined by the exceptionality of disability, anthologies tend to be defined by its commonality. In this way, they may be more accessible for, and indeed attractive to, people with disabilities both as readers and writers. Yet this in turn may mean that they exclude nondisabled writers and also mainstream readership, threatening to produce the kind of ghetto effect of which Shakespeare warns. All the attendant dangers of identity politics are thus potentially implicated in anthologies, in their very nature as supposedly representative collections of writing on the disability experience. In this regard, the intent of the editor of a collection is particularly important, as is their selection of material and contributors. This is especially true if we recall Longmore's distinction between *documenting* and *creating* a disability culture: each anthology potentially creates that which it may claim to document. In this way, a rigidly conceived anthology may be just as unrepresentative and effacing as an individual autobiography.

This chapter examines four anthologies of writing by people with disabilities: Irving Zola's *Ordinary Lives* (1982), Marsha Saxton and Florence Howe's *With Wings* (1988), Lois Keith's *Mustn't Grumble* (1994), and Kenny Fries' *Staring Back* (1997). Over their 15 year span, shifts and developments in the conception of disability are clearly apparent from volume to volume, as their titles suggest. Thus, it is possible to trace the development of the relationship between disability and writing from Zola's apparent disavowal of identity politics, through the clear influence of feminist identity politics in Saxton and Howe's collection of 'literature by women with disabilities', and its subtle development in Keith's anthology of 'writing by disabled women', to the explicit alignment with Longmore's notion of 'disability culture' made in Fries' introduction to his collection.

In his introduction to *Ordinary Lives* (1982), Zola observes that the

collection is being published at a time when there is new interest in disability in

wider society, as evidenced by the fact that his year of writing, 1981, is a year

'officially designated by the United Nations as the International Year of the

Disabled' (Zola 1982b, 11). Just as this wider interest in disability can be seen as a

result of the advances in civil rights and independent living achieved by the

developing disability movement in the 1970s, so can Zola's own perspective on

disability be seen to have a political element. In the same year as *Ordinary Lives*, he

published *Missing Pieces* (1982). This text, in line with Couser's analysis as cited in

the Introduction, shows how Zola had come 'to identify with other disabled people

in a way he had previously not' during a field-study spent living in an experimental

community of people with disabilities, Het Dorp, in Holland. *Missing Pieces* is,

Couser notes, 'almost wholly political rather than conventionally sociological' in

calling 'explicitly' for 'collectivity, self-assertion and self-representation' by people

with disabilities (Couser 1997, 212-4). This sense of collectivity is also apparent in

Zola's introduction to *Ordinary Lives*, where he identifies himself as one of a group

of 'crips' who feel uneasy about the contemporary treatment of disability in the

'novels, plays and movies' of their time (Zola 1982b, 11). Like later critics such as

Davis and Mitchell, Zola seizes on the stereotypical representations of people with

disabilities as either figures of 'superhuman heroism and courage' or as 'poor

unfortunates' in such works (11).

However, unlike Davis, Mitchell and others influenced by the social model,

Zola does not see such representations as acts of oppression. This is perhaps

because he does not make a firm distinction between the disabled and the nondisabled, arguing instead that 'most' members of society will at some point be disabled in some way (11). Zola instead attributes stereotypes to a deliberate disconnection between the reality of disability and the way it is represented. He perceives this is arising from a pervasive need in 'the Western world' to deny disability by displacing it 'as happening to someone else'. From this perspective he sees society as a whole, rather than people with disabilities, as the victim of such representations because such fantasies mean that people will never learn to develop the ability to cope with 'inevitable fallibility, in either the self, or in others' (12). As Johnson did in her analysis of Reeve, Zola observes the role stories play in maintaining such fantasies. He cites the example of the classic narrative of overcoming, whereby the disabled person regains their normality, and comments:

> [L]ife … for those of us with a chronic disease or disability,
> is not like that. In fact it's just the opposite. It is in the nature
> of a chronic disability or a chronic disease that it essentially
> lasts forever...it is a continuous struggle – not a battle to be
> won once and for all (12).

Zola's perspective invites comparison with Couser's view, as addressed in the Introduction, that traditional narrative is ill-suited to representing disability. This is especially interesting because Couser suggests replacing narrative with the personal essay, which he argues has a greater flexibility more suited to expressing the complexity of living with a disability. Zola, however, in detailing the selection process he employed in compiling his anthology, states explicitly that he deliberately rejected authors who have 'written essays about his/her issues, not stories describing his/her experiences' (14). This would appear to suggest that, rather than simply being unaware of, or unfamiliar with, disability identity politics,

Zola in fact knew of it and rejected it. This rejection is apparently based on precisely the element of such work that Couser praises: the fact that such essays do not just 'narrate the conditions in question' but also 'reflect critically and politically on disability culture', presenting 'higher-order thinking' and 'arguable propositions' rather than presenting 'existential truths' (Couser 2002, 115). The explanation for this discrepancy perhaps lies in Couser's use of the phrase 'disability culture'. To use Couser's distinction, it might be seen that Zola is concerned with the disability *experience* rather than disability culture.

Swan has described Davis' intent in editing his anthology, *The Disability Studies Reader*, as based on rejecting 'the kind of disability writing that appears to be addressed to people without disabilities in order to inform or "sensitize" them about what it is like to be disabled'. He attributes this decision to Davis' pursuit of disability studies as a form of cultural studies, rooted in identity politics (Swan, 285). Zola's intent is completely the opposite. He states that his aim is to allow people to understand 'the emotional issues of daily living' with a disability:

> Sometimes you may think we are just the kind of person
> you'd like to have for a friend, and sometimes you would
> rather have nothing to do with us (Zola 1982b, 12).

In this regard, Zola's position can be seen as one which is congruent with Swan's call for an exploration of disability as cognitive experience, rather than cultural identity. Indeed, although Zola makes no claim that the essence of the disability experience is 'inherently incommunicable to the able-bodied world', he *does* perceive an effect that 'mutes the vocabulary of experience' whenever disabled

people try to express themselves. Yet he attributes this to 'society's denial and...distancing', thus demonstrating a similar conception of dominant discourse imposed onto experience as per Galvin and Kirmayer, but one which finds answers in the cultural, rather than the cognitive (13). This perspective is further apparent in his statement that disabled people are 'in a better position to write about what [disability] is like' *at his time of writing*, suggesting that as dominant discourse is a result of society's denial it could change if that denial was relinquished. In accordance with this interest in what disability reveals 'about the human condition', Zola observes that because most people with disabilities tend to be 'socialized' as able-bodied, with customary prejudices and expectations, disability 'does not automatically qualify' a person with a disability to be either 'an expert witness or a writer' (13).

Zola writes of the difficulties he faced in finding suitable material for the anthology. Although he dismisses essays about 'issues', he makes little mention of positive criteria for selection. His focus is largely on excerpting material from established pre-existing texts, such as *My Left Foot*, and works by recognised authors such as Flannery O'Connor and Alexander Solzhenitsyn. This could be interpreted as a sign of a requirement for a certain literary status on the part of the work he incorporates. Intriguingly, Zola observes that many of the works he wanted to include were 'unexcerptable', highlighting an issue of form on which he fails to elaborate further (14). This is arguably a result of the retrospective cast of the text: the pieces eventually included in the anthology date from as early as 1948, and cover a wide range of disabilities and chronic illnesses, from deafness to Cerebral Palsy. Given that Zola writes of deliberately excluding political essays, it would appear likely that this retrospective range is a result of selection, rather than a

paucity of available material. Alongside extracts from fiction, poetry and memoirs, three pieces by Zola himself also feature. 'And The Children Shall Lead Us' echoes his comments in his introduction regarding the possibility of social attitudes changing, and of the extent to which people with disabilities are socialised as able-bodied themselves. It is an account of how his nine-year-old daughter and her friends encounter and accept his post-polio use of leg braces in a way in which he, a middle-aged man, has until then been unable to. 'With Hieronymous Bosch in India' can in many ways be seen as a companion piece to *Missing Pieces*. It tells of Zola's experiences when his leg brace breaks on a trip to India, forcing him to visit a local clinic for repair. Here, he is confronted by the other patients in a moment that recalls Brown in Lourdes and Reeve in rehab, as he regards 'a Hieronymous Bosch painting in all-*too*-living color' (107). Zola notes once more his socialisation as able-bodied in his observation that the sight of the patients was not actually 'grotesque' but rather 'felt like' it was (108). Similarly, he also demonstrates the difference between the representation and the reality of disability which he discusses in the introduction in the story's resolution, where it is revealed that the apparently pathetic patients were actually the technicians fixing his brace: an act which, ironically, allows him to 'pass' for normal once more. He observes his relief at this:

> I was sure that I was fleeing [sic] something but I didn't
> know what. Perhaps guilty…that I felt quite restored to
> normal society, even whole again (111).

This episode captures the porosity of the border between disabled and nondisabled which serves to explain the apparent contradiction between Zola's identification

with his fellow 'crips' and the disability experience, and his lack of interest in an identity politics.

Zola's avoidance of politics contrasts sharply with the complexities which comprise the context to *With Wings*, which followed his volume six years later. Not only do its American editors Marsha Saxton and Florence Howe provide an overall introduction, an introduction to each of the book's three sections and a preface, but Merry Cross provides an additional preface for the British edition. An anthology of literature by women with disabilities, the book's gendered slant reveals its debt to feminism in both its formulation of disability and its purpose. In this way, it can be seen as a snapshot of the way in which the evolving disability identity politics of the 1980s modelled itself, as Shakespeare argues, on foregoing models of identity politics in ways that were not necessarily productive. Indeed, Cross begins her preface to the British edition by arguing that the book is proof of 'a viable international disability movement', thus implicating all the material within in a political movement. Likewise, she embraces a conception of people with disabilities as an 'oppressed group'. She attributes the international cohesion of this group to the fact that women with disabilities 'can speak to each other in a common language of experience' even across markedly different cultures (Saxton and Howe, i).

The implicit subjection that Shakespeare sees as arising from identity politics' concern for categorisation is apparent in the way Cross agonises over terminology. Although she claims to prefer the term 'physically challenged' because of its reference to 'bodily reality' what she perceives as 'the barriers thrown up by society in our paths' are primarily economic, in an approach to disability identity from a Marxist understanding. Her focus is on how people with disabilities

'are pushed aside' into unemployment in the name of the fast production 'of wealth by the masses for the few'. It is in response to this economic 'vanishing trick', particularly impacting on 'female crips', that Cross situates the anthology as part of an attempt to redress this 'vanishing' through the finding of disabled 'voices' (ii). Her Marxist approach could arguably be seen as the primary function of Cross' preface for the British edition, reflecting as it does the greater political concern in the British wing of disability studies which led to the birth of the social model as political intervention, as compared to the civil rights model more evident in the American wing. In this way, it can be seen that the Cross' claim of a commonality of experience that connects the British and American movements is to an extent undermined by the apparent need for translation which the presence of her preface implies.

However awkward the connection is, Cross' examination of the role of 'voice' in identity is insightful nonetheless, particularly in her calls for an analysis of how the 'individual and collective voices' of disabled women are 'found' (a phrasing used by Nancy Mairs elsewhere, as we shall see) (ii). Like Linton, Cross is unable (or unwilling) to separate the personal and the political, conceiving of voice primarily in the context of intra-community interaction: 'When we meet we inevitably share our experience, and learn and grow at both a political and personal level' (ii). Crucially, Cross acknowledges that this modus operandi is learned from 'the women's movement' wherein many disabled women found their 'political selves' (ii). Cross makes an interesting point that might be related to Silvers' work on aesthetics when she notes that, at her time of writing, the voices of disabled women were 'strongest in the arts' while being marginalised politically (iii). In this way, her words seem to imply that disability art is a refuge: a position which

appears to affirm Shakespeare's critique of identity politics (and thus the notion of a specific identity culture based on it) as a dead end, rather than a means to an end. This impression is strengthened by Cross' implication, in her characterisation of the volume as full of 'familiar stories...with which those of us with similar disabilities can particularly identify', that the intended reader of the volume is a disabled woman (iii). This declaration also carries intimations of the re-inscription of pain and the failure of endless cure narratives for which Shakespeare and Davis both criticise identity politics. Cross insists that 'anyone outside the disability arena' might not appreciate the collection, taking the opposite position to Zola (iii). The contradictory nature of this as a basis for commonality is apparent in her subsequent declaration that:

> [O]ur oppression has divided us from each other in
> numerous ways, so that the very act of bringing us together
> across disabilities, and across *literary standing,* is a unifying
> and healing one (my emphasis) (iii).

Thus, the sole basis for her conception of common experience, oppression, is that which she seeks to eliminate. Meanwhile, Cross' reference to literary standing reminds us of Couser's words regarding the applications of standards of literary merit to disability writing. She appears to imply that the literary quality of the work is less important than the fact that it is written by someone with a disability: a position that surely smacks of the patronisation which Couser seeks to avoid (Couser 1997, 292).

Cross hails the role that the women's movement has played in 'nurturing the much younger disability movement' (Saxton and Howe, v). Yet her application of

the former's models to the latter demonstrates Shakespeare's point with regard to the assumption that identity politics are interchangeable. Thus, after insisting on a common experience of disabled women, Cross goes on to call for anthologies by men with disabilities, and by Afro-Caribbean and Asian women with disabilities, illustrating the endless subdivision of identity categories criticised by both Davis and Shakespeare. This approach also reveals the extent to which Cross' application of a feminist model has reduced her disability identity to a secondary, hyphenated subcategory of her feminist-informed gender identity. Thus, whilst bemoaning the fact that the term 'disabled' is 'misleadingly simple', she advocates a hyphenating of it which in fact serves to draw analysis away from the term itself via endless subcategorisation (v).

Saxton and Howe's own preface contradicts that of Cross in several ways (thereby undermining further her claims of commonality). Where she glossed over the 'literary' nature of the anthology they focus on it, insisting upon their desire to produce a 'fine literary volume' celebrating the 'disabled female' as 'literary artist'. They seek to provide 'a literary forum for the exploration of the experiences' of disabled women in order to 'challenge the literary community to follow suit'. Finally, they intend that this 'literary volume' should encourage 'readers to confront their *own* feelings' (their emphasis) regarding disability (vii). Yet, for all their use of the term, the editors do not elaborate on their understanding of the literary in relation to disability. It appears that they seek to use the term simply as a marker of status, perhaps motivated by the lack of status traditionally given to testimonies of disabled people (as argued by Tobin Siebers and Anne Finger). For all their ostensible concern with style, as intimated by their reference to the literary, Saxton

and Howe appear more concerned with content, as they arrange and order their anthology into three 'thematic parts' (vii).

Like Zola, Saxton and Howe detail the problems they faced in compiling their anthology. Originally aiming to provide the 'broadest representation of types of disabilities', they were eventually forced to focus on conditions that 'directly affect ...fundamental activities' such as walking, seeing, hearing and breathing, and 'physical difference in appearance' (viii). Thus, 'chronic pain and illness' could be included, but mental illness and learning disabilities are not. In their emphasis on the body, Saxton and Howe clearly differ from Cross, with her social model focus on oppression as the basis for commonality. Like her, however, the editors call for separate anthologies on these subjects, a move that illustrates once again the endless possible subdivisions of identity that Davis attacks. Aside from their concern with 'literary quality' the editors sought work that portrayed the lives of disabled women 'accurately', addressed 'important issues', challenged stereotypes, and presented 'fresh perspectives'. They actively sought authors diverse in class, ethnicity, race, age, and sexuality. Importantly, they also highlight their selections of works from 'traditional', as well as feminist perspectives, demonstrating a less rigid political attitude than that espoused by Cross. Also, like Zola, Saxton and Howe found their search for material 'arduous'. They note the preponderance of biographies where an author's disability is omitted, and of writers who are reluctant to refer to their own disability. They attribute this to the stigma of disability, and to its internalisation. Because of this, they find that their best research tool was 'word of mouth': they recall asking disabled associates, including disability rights activists: 'Do you know of any disabled women writers, or writers who write about disability?' (viii). Like

Cross, they note the power of such asking as a 'consciousness-raising' act in itself (ix). Here, we can see another illustration of Shakespeare's point regarding the unrepresentative nature of the disability rights movement: if the writers who are asked to give an account of their disability experience are plucked from the movement, it is natural that they will define their disability experience, and thus the anthology, in the (political) terms of that movement, when in fact the number of people with disabilities who identify as such is actually comparatively small.

Saxton and Howe explicitly link literature to disability rights in its capacity to document both 'the details of daily living' and 'the deepest meanings of this experience' simultaneously (xiii). In this regard, their perspective can be linked to Couser's analysis of the personal essay style emerging in the context of 'disability culture'. They see the act of writing itself as 'empowering' (as do others, as we shall see), specifically in regard to the 'need' of people with disabilities 'to name the physical pain': a point which recalls Kirmayer, Galvin, and Shildrick and Price and their accounts of how the body makes itself known, as well as the danger of its re-inscription (xiv). Connected to this is their observation that disability may in turn impact on the act of writing:

> A writer's disability may have interfered with her work. It
> may have stimulated or contributed to it. Or it may not have
> affected it at all, at least no more than the many other aspects
> of her life experience (xiv).

Saxton and Howe see the anthology form as crucial in representing this variety. As a 'collection of many voices', it allows for a 'rich diversity of … perspective'. They conclude: 'No one contributor can speak for all, but each voice is important and needs to be heard' (xv). In stating this, they open up further distance between

themselves and Cross, with her emphasis on the political voice that does, as for Linton, indeed speak for all.

Like Zola, Saxton and Howe observe the 'cultural denial of the reality of chronic illness and disability'. Yet, while Zola sees this as society's loss, Saxton and Howe view it as oppression, arguing that this denial serves to 'silence the voices of those who cannot deny [their disability]' (1). As evidence of this they cite the 'puzzling myth', as addressed elsewhere by Siebers and Finger, that people with disabilities 'are always talking about their problems', and like them argue that the opposite is true:

> Just as we learned at an early age not to acknowledge
> disability in others…so too we learned not to confront others
> with our own disabilities – 'Don't tell'.

In response to this, the first section of their anthology is dedicated to 'works that *do* tell' (1). This sense of the importance of the social element of disability is further evident in the other two sections of the book. The second part is devoted to 'the impact of other people's feelings about our disabilities, as well as how our disabilities affect the way we feel about and behave towards others', the third to the battle against so-called internalized oppression (47; 105).

This sense of the social element of disability, and its relation to the writing body, is developed further in Lois Keith's introduction to her anthology of writing by disabled women, *Mustn't Grumble* (1994). Whereas Cross, and to a lesser extent Saxton and Howe, viewed disability as a sub-category of their feminist identity, Keith, upon finding herself transformed into a wheelchair-user '[o]vernight', discovered that her old friends' commitment to 'equality and justice' did not extend

to disability (Keith, 1-2). She expands upon the notion of silencing espoused by Saxton and Howe, complicating it beyond oppression, for she finds not only that her old friends found it 'hard to listen', but that she 'didn't want to talk' about her new disability experiences with them. Rather, Keith decided that to 'make sense' of her new life, she would have to 'become a member of a new community' (2). Like Saxton and Howe she embraced 'word-of-mouth', with similar consequences: having 'heard many stories from newly disabled people' and through 'reading what little there was by disabled writers' she apparently embraces the social model: 'I began to understand that my inability to be a full part of this society was not, in fact, my fault' (1; 2). Comparable to Shakespeare's analysis of the development of an identity politics, Keith subsequently gains a conception of herself as oppressed, noting that her nondisabled colleagues began to suggest that she consider 'applying for early retirement' after her disabling (2).

Like Saxton and Howe, Keith sees writing as important for its capacity to allow her to 'name' her new experiences 'in order to be able to handle them'. She develops this idea by observing a therapeutic quality to writing similar to the 'restorying' of Smith and Sparkes. She observes that her own writing enabled her to make a transition from a focus on 'personal pain and loss' to later attempts 'to make sense' of the society she lived in (3). Although she does not address the topic of dominant discourse explicitly, Keith does, like Mitchell and Snyder, insist on the need for 'the disability movement' to make its voice heard through 'its own literature'. Yet the problem of the unrepresentative, effacing nature of this 'movement', evident in Saxton and Howe's reliance on activists for contributions and the way in which she herself was politicised, is further evident in Keith's

selection process for her anthology. Her 'grass roots' approach saw her gather work from women she had worked with in writers' groups, and supplement this through a 'small network of disabled women friends'. Yet in contrast to Saxton and Howe, Keith also invited contributions through the press and disability press, describing the compilation of her anthology as 'an organic process' (4). Furthermore, she portrays this process as a 'dialogue', with many pieces changing as a result of discussions between author and editor (such correspondence is included in an appendix). As well as pieces which were 'creative and original in style and form', Keith also included those that were 'simple and direct': a step away from the 'literary' emphasis of Saxton and Howe and Zola. In another move that can be seen as a development on the earlier attitude of Cross, Keith writes of her intention to give equal footing to exploring both 'personal and political change for disabled people' (5).

Like the other editors, Keith poses the question: 'Who is this book for?' Yet another development on the position of Cross is apparent in her answer, much like Zola, that 'this anthology is about universal experience'. However, this supposed universal experience is in fact tied to the assumption that the experience of being a *woman* is universal among women. Thus, she argues that able-bodied women will relate to the themes explored by disabled women such as independence, appearance, inequality and illness and pain. Nevertheless, Keith is quick to emphasise the fact that there is no 'party line' as to how (or whether) disability should be politicised. For example, she concedes that her inclusion of writing about chronic illness and disease may perpetuate what she terms 'the medical model': the 'stereotypical view of ourselves as weak and sick' (6). In response to this point, she states her belief that

disability already has enough 'hierarchies' imposed from outside, and rejects 'simple categories' (7-8). Nonetheless Keith can be seen, like Cross and Saxton and Howe, to fall victim to the perpetuation of hierarchy simply through her insistence on maintaining identity categories. Thus, she identifies the intended reader as a woman who will give a 'sigh of relief' at the fact that 'other women have shared [their] experiences and felt as [they] do' (7). This insistence on category ultimately lends Keith's position the confrontational, separatist air bemoaned by Shakespeare and, as we shall see, by Shildrick and Price (see below):

> It is self-critical, self-aware writing, which says: 'You might choose to see me as passive and quiet, or bitter and twisted, but here are the ways I am fighting back. This is how *I* see things, this is how *I* choose to describe them' (8-9).

This perspective is evident in one of Keith's own contributions to the volume, her poem 'Tomorrow I'm Going To Rewrite the English Language'. Here, her bold intention to discard 'all those striving ambulist metaphors/of power' in a bid to 'construct new ways to describe' her 'new, different strength' might invite a link with Kirmayer and Galvin, yet the piece proves to be more bluster than insight, with Keith simply concluding: 'Somehow I will learn to say it all' (57). In such bold claims and failure to deliver, we might see a parallel with Shakespeare's assessment of the social model's strength in politics and failure in analytical thought.

At first glance, Kenny Fries' *Staring Back* might seem to be similarly confrontational, not least in its title, a reference by Fries both to how people with disabilities have traditionally been defined by the 'stare' of the able-bodied and to how this balance of power is shifting. 'In these pages', he writes, 'we are staring

back' (Fries 1997b, 1). Like Saxton and Howe, Fries notes that people (not just authors) with disabilities 'have been silenced', and attributes this to an oppressive able-bodied community 'who did not want to hear what we have to say'. He also concurs with them in his view that disabled people have played along with this silencing, citing Anne Finger's 'fear that if we told our stories people would say: "See, it isn't worth it. You would be better off dead."' As with all the other editors, Fries observes the difficulty he faced in 'searching for the words with which to begin speaking about [his] own experience'. Spurred on by the inadequacy of a medical explanation for his experience ('congenital deformities of the lower extremities'), he writes of taking the:

> …initial steps of finding the language, unearthing the images, shaping the forms with which I could express an experience I had never read about before, so that my experience as a person with a disability could become meaningful to others (1-2).

As an account of the problem of language and form, this can be seen as a far more sophisticated approach than that taken by Keith above (and indeed of any of the antecedent anthologies), far closer in its understanding and description of both expression and meaning as problematic to the theoretical approaches of Kirmayer and Galvin. A similarity with Kirmayer's account of meaning as imposed by dominant discourse onto the irrational body is especially apparent in Fries' recollection of his inability to see his first attempts at disability poetry as poems at all: he recalls 'wanting to throw all those drafts away, not thinking them poems'. With no disability role model in writing he feels 'unsure of [his] identity as both a writer and a person who lives with a disability' (2). He finds himself 'unable to successfully meld on the page the nondisabled world [he] lived in with [his]

experience of being disabled in that world' (2). In an another advance on other anthologies, Fries recognises that this disjunction between form and content also means that in transcribing his experiences he risks *in*scribing disability as negative in the way described by Finger. In a sentence that recalls Keith, he worries that even his closest friends, having seen the pain he had gone through, will be unable to 'believe [that] there was so much more to living with … disability than pain'.

As with Zola and his interest in the 'human condition', Fries writes that his volume is bound together by 'the theme of human connection – connection with the past, connection with one another, connection with our bodies, connection with our selves' (3). Like Saxton and Howe and Keith, Fries observes that 'old models die hard'; yet, while he notes that his anthology contains 'literature that clearly espouses the social model of looking at disability', he argues that literature 'does not, and should not, conform to the dictates of current political or social discourse'. Yet a certain dismissive social model perspective is apparent in his description of some works he has included as containing the 'vestiges' of 'moral and medical models of disability' that have been 'internalized', in a way that recalls Shakespeare's criticisms of the dismissal of anybody who does not accept the social model as a victim of 'internal oppression' (8). Yet Fries does allow for agency on the part of the individual contributors, insisting that each piece is a 'product of a disabled writer's encounter with his or her disability experience'. Like Saxton and Howe, he highlights the effect of disability on the writing process, noting how poet Larry Eigner's disability 'profoundly affected the work's actual composition', how Marcia Clay's Cerebral Palsy experience is 'strikingly rendered' in her fiction, and how Andre Dubus' disability is apparent in his work even when 'the work's central

focus is not disability or a disabled character' (8). In respect to the latter description, we can see a similarity to the early work of Nolan, with its application of the lexicon of disability to the world of the nondisabled. Fries appears to be arguing for such a lexicon, or for an aesthetic with its roots in the cognitive experience of disability, in a manner similar to Swan.

Yet, arguably because of his adherence to the social model, Fries is unable to maintain the careful distinction between disability experience and disability culture that Couser does, or the similar distinction between disability as cultural studies and disability as cognitive experience that Swan seeks to address. Instead, he cites Longmore's conception of a new, post-ADA phase in the consolidating of disability politics: a 'quest for collective identity', in which the task is 'to explore or to create a disability culture'. Fries explicitly aligns his anthology to this disability culture, insisting that it in 'many ways…mirrors this quest' (9). Crucially however, rather than hyphenating identity like Saxton and Howe and Keith, Fries argues that this production of culture should occur within mainstream culture, and indeed *needs* mainstream culture to inform it. He writes of a need 'to bring the lives of those of us who live with disabilities closer to the center where a truer understanding of the richness of our lives can be forged' (9-10). In this respect, it is no surprise that *Staring Back* should feature the work of John Hockenberry, whose work fits especially well into this context: his 'Walking With The Kurds', excerpted from *Declarations Of Independence* for this anthology, sees the author argue, as Couser has noted, 'that his experience of disability is not so different from the common conditions of life for a large number of people worldwide' (Couser 1997, 204). In such a call to appreciate disability as a universal rather than exclusive experience

one can find traces both of Swan's call for a focus on the cognitive experience of disability and Silvers' plea for an appreciation of disability aesthetics. In regard to the latter, it is interesting to note that *Staring Back* foregoes the complicated thematic divisions of *With Wings* and instead groups works according to genre, thus demonstrating a new appreciation for the importance of form, with less concern for thematic categorisation.

The works of a number of contributors, such as Mary Duffy, Merry Cross, Leonard Kriegel and Nancy Mairs, span these four anthologies and their editorial agendas. This thematic compatibility is especially interesting in the case of Kriegel and Mairs, as both have been offered as exemplars of literary disability by the likes of Couser and Swan. Both feature in *Staring Back*, while the former features in *Ordinary Lives* and the latter in *With Wings*. Kriegel's contribution to *Ordinary Lives* is an excerpt from *The Long Walk Home* (1964), his account of polio rehab as a young man, which can thus be viewed in a 1960s pre-disability rights context. His contribution to *Staring Back*, comes from the later *Falling Into Life* (1991), after this watershed. The Kriegel of *The Long Walk Home* gives an account of himself as a young man in polio rehab which is redolent of the kind of macho, individualist, overcoming attitude Couser has identified in many disability autobiographies. Although Kriegel displays a sense of group identity in rehab, this extends only to his group of wheelchairs users ('lions') and is in fact based on a rivalry with, and exclusion of, another group of polio patients with arm braces ('birds'). In writing, Kriegel captures a sense of the replication of hierarchy that Shakespeare and Foucauldian critiques discern in a supposedly empowering identity politics. Of excluding the 'birds', he writes:

> … even though I felt that I was betraying the birds, I excused
> myself…'It's nothing personal. It's just that the plan is only
> for guys in chairs. None of the birds are coming' (73-4).

In *Falling Into Life,* the older Kriegel revisits his time in rehab. In doing so he demonstrates his propensity, as identified by Couser, for returning to key moments in his disability 'in essay after essay, book after book' (Couser 1997, 190-1). Couser has, as we have seen, linked this to Kriegel's use of the essay form in *Falling Into Life*, because it allows such an approach where narrative 'with its confident linear progress' does not (191). This form, Couser argues, allows Kriegel to portray disability, not as something to be overcome, but as something ever-present which permeates 'his sense of identity and his trajectory in the world, his point of view' (190-91). In this regard, it might be seen that Kriegel's later work fits with Zola's editorial intention to showcase writing that represents the reality of the disability experience rather than the traditional narratives of overcoming. Yet Zola has, of course, disavowed essays about 'issues'. Furthermore, he has argued against the idea that disability guarantees a writer's authority on the subject, while Couser insists that Kriegel's disability 'made him a writer and gave him his subject; indeed it made him an autobiographer' (191). Thus, it might be seen that in excluding essays for their political qualities, Zola loses the capacity for insight and analysis that they offer and also makes the mistake of assuming that narrative form is ideologically neutral (even as the problems with expression of the reality of the disability experience in dominant discourse are raised in his introduction).

Indeed, there is much in Kriegel's work as featured in *Staring Back* that fits with, and offers solutions to, Zola's analysis of the problem of unreality in the representation of the disability experience. For example, the older Kriegel now

recognises his younger self as a 'pragmatic American for whom survival was method and strategy' (Fries 1997b, 39). We might see this, as per Kirmayer, as the imposition of meaning and order onto the body through the dominant discourse of overcoming. This connection to Kirmayer's theories is further apparent when Kriegel reflects on how his relationship with his body has changed, after experiencing a fall from which the techniques he learned in rehab do not help him to recover:

> My body had decided – *and decided on its own, autonomously* – the moment had come for me to face the question of endings. It was the body that chose its time of recognition (48).

While the young Kriegel was a 'novitiate of the possible', the older Kriegel is left 'pondering limitations and endings and summations' (41; 48). Nevertheless, he feels 'curiously buoyant' that 'mortality had quite suddenly made itself a felt presence' (48). In this example of the body making itself known, in line with Shildrick and Price's assessment, another aspect that connects with Zola's editorial intent is apparent: Kriegel has embraced and demonstrated the reality of both disability and mortality and it is not dreadful.

This cross-anthology congruency of work is also apparent in the work of Mairs as it appears in both *With Wings* and *Staring Back*. Like Kriegel, Finger (and, ironically, Zola), Mairs has been categorised by Couser as one of the exponents of the 'personal essay' that does not just relate the author's disability experience but also reflects 'critically and politically on disability and culture' via 'higher-order thinking and 'arguable propositions' (Couser 2002, 115). Yet Mairs has also been championed by Swan, who has a different appreciation of the personal essay style. He cites her essay 'Carnal Acts', as included in *Staring Back*, as evidence of how

disability can be used to address 'the writing of the embodied subject' (Swan, 285). Such writing, he argues, illustrates how 'accumulated stories of embodied subjects and voiced bodies' that have previously been discounted might be expressed, through a focus on the cognitive rather than the cultural. In this way, it can be seen that Swan perceives Mairs as more aligned with the writing of the 'disability experience' than the 'disability culture' within which Couser positions her. In his insistence that disability writing 'is not only *about* the body but *of* and *from* the body too' he facilitates a focus on the literariness of disability writing, away from the political limits of disability culture.

Swan's sense of Mairs' focus on writing arguably also applies to her much earlier contribution to *With Wings*, 'On Being A Cripple' (1986). This essay is positioned by editors Saxton and Howe in the section titled 'Transcendence' which according to them focuses on the tackling of what they term 'internalised oppression' (Saxton and Howe, 105). In this essay Mairs is concerned with language and identity. Whereas fellow contributor Joyce Davis implicates language in internalised oppression in 'Lame', dismissing 'crippled' as an 'ugly and stumbling word' that 'blots out the power and the hope of the spirit', Mairs embraces the term 'cripple', in much the same way as Zola embraced 'crip', declaring: 'I am a cripple. I choose this word to name me' (Saxton and Howe, 43; 118). Although she acknowledges that the meaning of the word is 'complex and not entirely flattering', she seeks to harness its power, noting that '[p]eople – crippled or not – wince at the word *cripple*, as they do not at *handicapped* or *disabled*'. She continues: 'Perhaps I want them to wince. I want them to see me as a tough customer … As a cripple, I swagger' (118). In this declaration we might see an example of another aspect of identity politics criticised by Shakespeare and

Foucauldian approaches: the attempt to harness an imposed, negative category as positive which, these critiques argue, is inevitably doomed to failure because, however positive its appearance, this act ultimately re-inscribes categories, and thus hierarchies.

Mairs champions the term 'cripple' for being 'straightforward and precise', as opposed to the vagueness of 'disabled', which, in a parallel to the complaints of Zola, she perceives as 'widening the gap between word and reality' (118). In an apparent contradiction of her claim to redefine the word 'cripple', Mairs criticises terms such as 'differently abled' for their 'semantic hopefulness', insisting that '[s]ome realities do not obey the dictates of language' (118-9). In this way, Mairs might be seen as taking a rigid structuralist position, apparently insisting, contrary to Kirmayer and Galvin, that language is finite and fixed, and thus that namings that are negative in origin, such as 'cripple', are the only ones available and so must be adopted (the latter position of course recalls Galvin's observation that even a negative identity is preferable to no identity). In accepting this rigid, limiting language, Mairs appears to find an analogue to the limits imposed by her disability: to term herself 'differently-abled', she writes, would be to 'to deny that [she has] lost anything' as a result of her encroaching MS (119). She appears to acknowledge the reductive nature of such labels in her attempt to view positively the fact that vague terms 'at least hint at the truth'. In implying that the appropriate language to capture her experience is not yet available, she can be seen to take a position similar to that of Zola, in linking, however insubstantially, what she sees as the inadequacy of the term 'disabled' with the fact that society is not yet ready 'to accept crippledness' (119). The sense of conflict and dissatisfaction with her own argument

apparent in this essay is further evident in a final contradiction: while Mairs insists on delicacy, stating that she 'would never refer to another person as a cripple', she nevertheless does so only a few pages later, referring to 'other cripples' (119, 122). Be it slip or contradiction, this occurrence serves to illustrate the political implications of language even when apparently used subversively, and the dangers of effacement inherent in the ease with which writing on the disability experience can slip into the inscribing of a disability identity politics, due to the vocabulary the two share.

As with Kriegel, Mairs' contribution to *Staring Back*, with her piece 'Carnal Acts', can be seen as a considerable development on her position in the earlier anthology. The genesis of the essay comes from her attempt to consider how her identity as a disabled person and her identity as a writer are related. She concludes that the two are 'interdependent', with an 'intimacy that has for some reason remained, until now, submerged below the surface of [her] attention' (Fries 1997b, 52). She attributes this to the sense of embodied self that has resulted from her disability. Her MS, she writes, has:

> …rammed my 'self' straight back into the body I had been
> trained to believe it could, through high-minded acts and
> aspirations, rise above.

She attributes her original view of her body to a 'Western tradition' of separating mind and body that is almost 'part of our collective unconscious', and furthermore 'an unquestioned element in the social instructions we impose upon infants from birth' (53). This is, of course, the same view espoused by Zola in his introduction to *Ordinary Lives*. Mairs argues that this situation is maintained by the power of

shame in the body (53). She argues that it is possible to 'subvert' the power of

shame:

> …by acknowledging who I am, shame and all, and, in doing
> so, raising what was hidden, dark, secret about my life into
> the plain light of shared human experience (58).

If Mairs' position in 'On Being A Cripple' appeared contrary to that of Galvin, her

position here is clearly much closer, not least in her focus on how one might

'subvert' power. Furthermore, Mairs is clearly referring to dominant discourse as

the source of shame and the target of her subversion:

> What we aren't permitted to utter holds us, each isolated from
> every other, in a kind of solipsistic thrall. Without any way to
> check our reality against anyone else's, we assume that our
> fears and shortcomings are ours alone (58).

This analysis recalls both Siebers' work on the supposed narcissism of people with

disabilities and Kirmayer's idea of a lexicon of bodily experience as the basis for

language. Mairs observes that she had believed her first collection of essays,

Plaintext (incorporating 'On Being A Cripple') to be 'personal', and was thus

overwhelmed by the response from readers exclaiming 'in a tone of unmistakeable

relief, "Oh, me too! Me too!"'. She elaborates:

> It's as though the part I thought was solo has turned out to
> be a chorus. But none of us was singing loud enough for the
> others to hear (58).

In this way, she concludes, her first essays were about 'not merely speaking out but

calling out' (59). In making this distinction, she avoids the position of Keith and

Linton, where the personal voice can only exist to contribute to one political voice

which eventually effaces its component parts. This is possible because she locates

her disability identity in her body, rather than in a commonality of oppression:

> I've 'found' my voice, then, just where it ought to have been,
> in the body-warmed breath escaping my lungs and throat.
> Forced by the exigencies of physical disease to embrace my
> self in the flesh, I couldn't write bodiless prose. The voice
> is the creature of the body that produces it. I speak as a
> crippled woman (60).

It is thus impossible for Mairs to claim, as Linton would, that her bodily

difference is irrelevant. Instead, she insists: 'No body, no voice; no voice, no body'

(61). As mentioned above, 'Carnal Acts' is cited by Swan as an example of a new

type of disability writing that is markedly different to Couser's focus on the

'personal essay' (of which Couser also upholds Mairs as an example). He takes her

interest in the 'embodied voice' and the 'voiced body' as part of a pursuit in writing

by people with disabilities for 'new ways of thinking about culture, language, and

the body' (Swan, 286). In his claim that Mairs' words illustrate how the disabled

body 'simply overruns the categories of an ableist, stigmatizing discourse to find its

own expressions', it can be seen that Swan is approaching the theoretical tenets of

Kirmayer and Galvin, and also Shildrick and Price. Indeed, he shares the same focus

on bodily presence in language as Kirmayer, and on agency as Galvin in his

insistence that the body 'made present in language' positions the speaker as 'an

agent of negotiable meanings' (287; 294). As Mairs herself seems to imply with her

reference to 'shared human experience', Swan sees the appreciation of the 'action of

the voiced body' that disability promotes as something that is useful to society as a

whole, rather than the stuff of segregation (287). This recalls the introductions of

both Zola and Fries, as does Swan's insistence that the conception of 'disabled' and

'nondisabled' as binary opposites is redundant, and that they should instead be conceived of as 'variable positions on a multidimensional gradient' (293). In this way, it can be seen that 'Carnal Acts' fits Swan's model for a disability writing that moves away from disability studies as a mode of cultural studies, towards a cognitive approach to disability experience that is compatible with more complex theories of the writing body and embodied subjectivity.

The development of positions over time is particularly evident in the work of Kriegel and Mairs because their contributions appear in different volumes. Nevertheless, it is also possible to read other contributions in isolation from the editorial context of their particular anthology. Indeed, Saxton and Howe, Keith and Fries all acknowledge that individual pieces in their collections are not necessarily subordinated to their editorial intent. Thus, it is possible to find material that documents the bases of the 'new' positions delineated by Couser and Swan in older material: a phenomenon that suggests that the cognitive/experiential approach the latter addresses does indeed have a presence outside of a 'disability culture' created or imposed later. Thus, the excerpt from Frances Warfield's *Cotton In My Ears* (1948) contained in *Ordinary Lives* shows a sophisticated understanding of the way in which language is implicated in power and identity beyond Zola's own rather under-developed concern with what we can now recognise as the difficulty of expressing the disability experience in dominant discourse. In her account of her hearing-impaired childhood and her attempts to pass Warfield reveals the innate subversion of the impaired body that Kirmayer and Shildrick and Price discuss, for example in her conjuring of an imaginary deaf friend who does not understand speech, not because he cannot, but because he 'liked to make nonsense' (Zola

1982b, 28). Similarly, she recognises the power of language to subject in a manner similar to the Foucauldian approaches we have seen. She lives in fear of being 'outed' as deaf by means of the 'Seven Deadly Words' - 'What's the matter – cotton in your ears?' - to the degree that she believes that 'it would kill [her]' (29). At the same time, as per Zola's position, Warfield is socialised as nondisabled, and does not identify with other deaf people. Rather, she is 'terribly afraid' of them, fearing that their common impairment means that they know her secret (29-30). This fear combines with her learned prejudice to cultivate hatred, as she attempts to kill her deaf neighbour with the words she fears:

> [A]s Aunt Harriet had said, he was so stone-deaf he might as well be dead – so I looked straight into his face and said, quite loud, "What's – the matter – cotton in your ears?"
> It was exciting, and perfectly safe. Old Mr. Bascomb's blank, vacant stare didn't change. He was a dead man. I had killed him with the Seven Deadly Words. I ran home feeling good…strong and brave and full of secret glee (30).

Warfield also negotiates the contradictory stereotypes which Zola addresses, in her account of the treatment of her hometown's one deaf family. Thus, she notes that Mrs. Furness is described as a 'wonderful' person who 'bore her affliction bravely', yet at the same time, her hearing husband is described as a 'saint' for living with her disability (30). Likewise, the partially deaf Miss Eva is criticised by the community as a whole for refusing to 'give in and face reality and get an ear trumpet' whilst simultaneously being accused of 'using her deafness as a convenience' (31).

Ved Mehta's contribution to *Ordinary Voices*, an excerpt from his book *Face To Face* (1957), displays a similar doubt over disability's role as a basis for a common identity. Mehta's notes that upon his arrival at the New York home of his

blind American sponsor, his sponsor's wife appeared to assume that '[h]e was blind and I was blind and … therefore … we would of course enjoy one another's company' (89). This is starkly disproved by the sponsor's assumptions, angrily refuted by Mehta, that the blind in India live in 'primitive' and 'backward' conditions (92). The extract from Andrew Potok's more recent *Ordinary Daylight* (1980), meanwhile, reflects the changing social conception of disability in the early 1980s. Admitting himself to a rehab centre for the blind to prepare himself for imminent sight-loss, the author at first refuses to identify as blind or interact with the other residents (52). Like Warfield, and Joyce Davis in *With Wings*, he highlights the power of language, noting that even the word 'blind' is 'fraught with archetypal nightmare', to the extent that he could not bring himself to say it, and feels a desire to scream upon hearing a doctor describe him as such (53). Similarly, his first encounter with other blind people recalls the first disability encounters of Brown, Reeve and Zola himself: Potok perceives them as existing 'in isolation', appearing 'broken' (53). Yet when he finally begins to interact with them, he finds his prejudices collapsing in the revelation of shared experience:

> Soon everyone was drawn in. We couldn't contain all we had stored for so long. We were finally with people who understood … Soon we were emptying our clogged hearts of the terrible burdens we hadn't been able to share with anyone (58).

For Potok, this shared experience soon translates into a strong sense of group identity. He states: 'I belonged here, and I began to love *my* group. I swore that I'd do anything in the world for any of them. They were *my* people' (60).

An increasing complexity with regard to this new conception of disability as something with a social context becomes more apparent in *With Wings*, with Saxton

and Howe devoting the second section of their anthology to the social element on disability, or as they put it: 'the impact of other people's feelings about our disabilities, as well as how our disabilities affect the way we feel about and behave towards others' (Saxton and Howe, 47). This might, of course be seen as an effect of the social model's ascension in disability studies in the mid-1980s, bringing with it a more politicised, rigid sense of identity, and a conception of disability's social aspect as being dominated by oppression, as per the prefaces by both Cross and Saxton and Howe. Yet there are various perspectives on display. Kay Yasutome's poem 'I Met Florence In Room 43' gives an account of the meeting of two MS patients in simple terms: 'We shared' (75). Such a simple, unanalysed connection recalls the account of Sienkiewicz-Mercer's encounters with her 'double' Theresa Ladue in *I Raise My Eyes To Say Yes*. Meanwhile, Deborah Kendrick's account of a meeting between herself, a blind poet, and the seeing poet Tess Gallagher, in 'For Tess Gallagher' is more complex. Of their moment of meeting, she observes:

> I see clearly laid out before me two alternate routes
> For this sliver of human relating.
> Fantasy skims smoothly over one,
> While masochistic reality creates another (84).

In the fantasy, the two 'talk…share [and] laugh like conspirators' over their common experiences, and over the 'line and phrases and meter' of poetry. However, in reality, the blind narrator finds that:

> I scramble for the spoken syllables,
> Deny my claim to our shared muse,
> And know that the moment's direction is permanently,

pathetically cast.

Here disability disrupts the common identity of the two poets, its imposed social

significance governing the outcome of the interaction:

> All we talk about instead
> Is the only
> Other
> Blind person you have known (84).

This poem suggests that the disabled and the nondisabled cannot write as one.

Kendrick's narrator can be seen as someone whose two identities as writer and

disabled person are not balanced, as those of Mairs in 'Carnal Acts' are. This sense

of segregation is also apparent in Kendrick's short story '20/20 with a Twist'. Here

Kendrick employs the genre of science fiction to imagine an accessible world for

the blind, where:

> Braille had been re-established in the universities…Visually
> impaired children were taught Braille and print
> simultaneously…Street signs, billboards and elevators were
> all equipped with speech –synthesized devices (141).

By way of contrast, the author's present is re-cast as the 'dark-age days of the

nineties', to highlight the ignored crises of dwindling braille teaching and education

facilities (139). The protagonist is one of a group of blind militants who achieve

equality through a 'visionary revolution' of non-violent direct action such as the

shutting down of power grids and the blacking-out of television broadcasts (140).

They are cast against a society that Kendrick imagines as marginalising the blind

through the denial of education and freedom of association. While the militants are

portrayed as passive in their oppressed state (the protagonist recalls that her 'role as revolutionary had never been a conscious decision') the failed attempt by the authorities to cure their blindness is portrayed as an act of oppression designed to cause them to identify politically as 'seeing people' (139, 140). Kendrick's fantasy of disabled revolutionaries can be seen as the logical extension of the foundational self-dramatisation of identity politics analysed by Shakespeare, and an illustration of the segregationist, unproductive victim politics to which it leads.

In stark contrast to Kendrick's lurid fantasy of oppressed disability revolutionaries, Miriam Ylvisaker undermines the notion of unproblematic disability solidarity with her account of a self-help group in her short story 'Significant Others'. Laura, the protagonist, disabled by arthritis, 'does not really like the other women in the group, their hopelessness and despair … She hates looking at them, hates looking at herself (86). The positivity of Mairs' 'chorus' of voices finds its opposite here. The group is un-harmonious, with each member advocating 'a different stance, a better idea' on their condition and responses to it. In this forum for speech (analogous, arguably, to an anthology), speech fails: one woman's speech is 'jerky', while another 'seldom speaks' (87). Tellingly, the group's leader, although 'a good listener', does not have arthritis herself but bases her authority on her experience of 'a long-term illness', and 'does not limit discussions'. In this way, Ylvisaker draws attention to the problems of disability's broadness and porosity as a category, and thus the limits to the possibility of a common experience (87). Arguably, her piece undermines the very anthology in which it is included, a fact which can at least be seen as a testament to the editors' admirable commitment to ensuring that differing voices are heard.

This same accommodation of voices of dissent with regard to the universality of disability identity is also apparent in *Mustn't Grumble*. Indeed, certain pieces can be seen to reflect the line taken by Keith in her introduction, where she rejects the rigid hierarchies and categorisation inherited from feminist identity politics, and insists that the anthology has no 'party line'. Thus, Mary Duffy confidently states in 'Making Choices' that 'disability does not guarantee allegiance or protection' (Keith, 31). Jaihn Makayute goes even further in 'Freedom Fighter', portraying the 'women whose fight is with conviction against the disablers' as oppressors themselves when they declare:

> … '*how dare she say such a thing*
> *how dare she say she wants to walk*
> *again…*
> *how dare she voice that*
> *after all we've done to make*
> *disability a state in which to be proud?*'

Thus, it can be seen that Makayute illustrates the effacement caused by the subordination of individual personal experience to the political voice championed by the likes of Linton. Makayute's words also imply the perpetuation of hierarchy identified by Shakespeare in identity politics, as she identifies those who would silence her with the silencing effect of dominant discourse: '*I'm not scared now of being burnt for voicing my truth … My silenced-by-fear days are done*' (Keith, 187).

Despite these concessions to dissent, it is interesting to note that Shildrick and Price have criticised *With Wings* and *Mustn't Grumble* by name, as we saw in

the Introduction. They take issue with the implicit suggestion in anthologies by disabled writers (typified they argue, by Keith's claim for the authority of her voice in her introduction, as cited earlier) that the only significant point of view on disability is that of people with disabilities. Although they do not explicitly implicate the social model, or an identity politics based on adherence to it, as a factor in this, they attack the majority of contributions to these anthologies for focusing on 'experience of bodily restrictions, discomfort and limitations, and of the physical and social barriers that disabled people face'. They argue that such accounts are inherently contradictory, encouraging the reader to see the author/protagonist as 'other' while at same time striving to attain standards of normativity. In this manner, they argue, the disabled body becomes a 'troublesome possession' that may be normalized, but not normal (Shildrick and Price 2002, 66-7). They include Mairs (presumably for 'On Being A Cripple' in *With Wings*) in this criticism, and as we have already seen, a certain limitation is indeed apparent in this early writing. Shildrick and Price instead champion writing that attempts to capture 'experience before narrative is imposed on it' (65). In this respect, they can be seen to share a similar perspective to Swan in his desire for an expression of disability as a cognitive experience, and to reach the same conclusions as Kirmayer in seeing narrative as a form of dominant discourse imposing meaning on the body.

Yet material from the two anthologies which Shildrick and Price criticise arguably fits their argument. For example, Kate O'Reilly's 'Sight' is a short story related in the third person, which details the experiences of a partially-sighted woman. O'Reilly avoids narrativising this disability by leaving it nameless, and indeed medically undiagnosed, until the story's end. This results in a defamiliarising effect that reveals how a medical diagnosis is necessary to establish the meaning of

her experiences. In this way, 'Sight' can be seen to illustrate Kirmayer's point with regard to the meanings applied to the body by dominant discourse, and the way in which the individual's own meaning, issuing from their bodily experience, will appear irrational. 'Sight' also evokes Shildrick and Price's claim that the disabled body will always disrupt and resist such rigid imposition of meaning. These connections are particularly apparent when the protagonist discovers her disability as a schoolgirl unable to perceive the three-dimensional roundness of the globe, which allows O'Reilly to fashion an analogous allusion to Gallileo Gallelei, with the teacher 'sensing heresy'. As her different experience is deemed irrational, the girl discovers that 'remaining silent' is her only option (Keith, 19). When her reliance on touch to augment her sight leads her to a series of social transgressions at school, she, like Kendrick, begins to see the sighted as 'the enemy'. This hardens her into a segregationsist:

> She learns another lesson. Her sight is maverick, theirs is restricted. She decides to become Gnostic and veer away from their seeing world (20).

The protagonist thus becomes 'accustomed to her playful, vicious sight', a description which recalls Shildrick and Price's idea of a 'resistance [to discourse] exercised through the body's refusal as much as through the conscious will' (Shildrick and Price 2002, 68). Nevertheless, attempts to diagnose her medically persist. The power of medical discourse on a linguistic level is particularly apparent in the doctors' use of 'dictionary terms she can no longer look up' and the fact that her plea to have them speak in 'laywoman's words' leads them to 'laugh, calling her a feminist' (Keith, 22). When the medical diagnosis is finally reached, the protagonist notes how her family delight in 'redefining her with the official label' to

make sense of her past 'idiosyncrasy' (24). In response, she feels only 'unretractable rage' at the lack of authority attributed to her own discourse: 'Why had no one listened? She was misunderstood and maligned' (23). Of her diagnosis as 'only partially sighted', she comments: '"only" has nothing to do with it' (24). This declaration cements the impression of the body as a site of innately rebellious excess as per Kirmayer, Shildrick and Price.

A similar example of writing that attempts to capture experience before narrative is imposed on it can be found in Joan Tollifson's contribution to *Staring Back*, 'Imperfection Is A Beautiful Thing'. Like Zola and Mairs, she notes Western society's demand for silence regarding the reality of the (disabled) body. Tollifson suggests that the reality of 'vulnerable' organic life needs to be approached 'not intellectually, but experientially', as it is only in this manner that one can realise 'how porous and momentary every thing is' (Fries 1997b, 106). A similarity with Swan's call for an appreciation of the disability experience as cognitive rather than cultural is again apparent here, as is Couser's distinction between disability 'experience' and disability 'culture'. Tollifson observes, as per Zola, that she herself sought to avoid the reality of her disability, and that this led her to avoid both 'the image or label of being a cripple' and other disabled people. She recalls: 'I refused to see myself as part of that group' (106). Yet, on joining a disabled women's group she, like Mairs, is surprised to learn that her 'supposedly private hell was a social phenomenon' and that disability was not just her 'personal problem, but a social and political issue as well' (107). Politicised, she participates in the month-long occupation of the San Francisco Federal Building sit-in of 1977 in support of the passing of the first US civil rights legislation covering disability. A side-effect of the campaign is that the squatters form a 'society in microcosm…where being

disabled was no big deal'. For the first time, the author feels 'like a real adult

member of the human community' (107). She concludes:

> Finally identifying myself as a disabled person was an
> enormous healing. It was about recognizing, allowing, and
> acknowledging something I had been trying to deny, and
> finding that disability does not equal ugliness, incompetence,
> and misery (107).

In this aspect of her account, Tollifson might be seen to subscribe to the view of

'internalized oppression' criticised by Shakespeare: namely, that any disabled

person who does identify as 'disabled' is perpetuating oppression.

Yet Tollifson progresses beyond this identity politics. She focuses instead on

using meditation as a means for 'realizing what is before all identities, what is

whole and not limited to or by this body, or any ideas about this body' (108). In this

regard, Tollifson's analysis resonates with Kirmayer. Likewise, a strong similarity

with the position of Shildrick and Price is apparent in her conception of meditation

as a way of experiencing existence 'without adding a storyline, without analysis,

without identification (this is "my" anger, "my" problem, "my" peaceful or

disturbed mind)' (108). The 'storyline', she insists, is what gives the 'illusion of

continuity and of a solid, enduring entity called "me" who is "having" all these

experiences'. Without a storyline, the self is revealed as 'nothing but shifting

thoughts, images, sensations, ideas'. Tollifson argues that the experience of

disability reveals what remains 'without the labels and the stories' (109). She views

the experience of being disabled in modern society as 'a constant embodiment of

[the] basic truth' that life 'is the way it is, not the way we wish it was' (110). This

can be seen to strongly reflect both the claims of Swan, and Shakespeare's call for a

theorising of quotidian disability experience beyond the political intervention of the social model.

Shildrick and Price's insistence that people with disabilities do not have a monopoly on the disability experience can be seen to be problematised by two accounts of transitions into disability resulting from cancer from different anthologies. In 'Colostomy', Helen Kendall's account of drastic bodily change in standard first-person narrative is intercut with passages that strain at the limits of language in their attempt to capture new physical sensations and experiences. For example, between an account of the procedure and her recovery, comes: '*Fingers-trapped-under-a-stone numbness, eyes-closed numbness, everyone-go-away numbness*' (Keith, 43). This might be seen as an attempt by Kendall, socialized as able-bodied, to find a way to give voice to the new reality of her body that disability has made her aware of. She concludes, like Mairs in 'Carnal Acts' and Tollifson, with a return to the body as a source of knowledge, via this new language: '*All-the-senses-inform wisdom, no need-to-travel-afar wisdom, here's wisdom*' (45). Barbara Rosenblum employs a similar, if more analytical approach in *Staring Back*'s 'Living In An Unstable Body'. She finds that, after cancer, 'the body no longer contains the old truths about the world'. Rather, it is necessary to 'learn a new language, a new vocabulary…the deeper structure of [the body's] grammar' (Fries 1997b, 102-3). This perspective strongly recalls that of Kirmayer, particularly in her observation that she 'can no longer rely on the previous systems of interpreting the body…used before' (103). This is the irrational body exceeding meaning, as per Kirmayer and Shildrick and Price, once more:

When you have cancer, you are bombarded by sensations
from within that are not anchored in meaning. They float in
a world without words, without meaning. You don't know
from moment to moment whether to call a particular
sensation a 'symptom' or a 'side effect' or a 'sign' (103).

The consequence of this, however, is that Rosenblum finds that she cannot 'use language to tell how [she] feels' and often feels 'frustrated by the way the limits of language circumscribe [her] ability to communicate events in [her] body' (103). She faces a challenge to 'find words to apply to sensations [she has] never had before' (104). She does not engineer the neologisms of Nolan or the subversions of Galvin, or the metaphor of Kirmayer, perhaps because, disabled relatively late in life, she is subsumed in dominant discourse that does not allow expression. In this way, it might be seen that the possibilities for new language as proposed by Merleau-Ponty (as discussed in the Introduction) and cited in Galvin might be a way in which a cognitive approach to disability experience could contribute to wider human experience in an empowering fashion, as it has been seen that an expression in language in the way Rosenblum cannot obtain (and which Kendall aims for), but as evident in Brown, Nolan and Sienkiewicz-Mercer, is empowering in itself. This last point perhaps reveals something problematic about the anthology form, and also a useful feature of the more traditional autobiographical form. In their tendency towards short, analytical pieces, and their overarching explicit concern with disability it might be seen that anthologies represent an analogue of Iwakuma's unadjusted embodied self: constantly conscious of bodily difference, and thus never successfully unconsciously embodied. In this respect, the more traditional autobiographies arguably possess the strength of having a more closely entwined

content and form without disability as an explicit focus, and might thus be seen as more successful textual embodiments in line with Iwakuma.

In conclusion, this brief overview of four anthologies of disability writing can be seen to have demonstrated that anthologies arguably have as many limitations as autobiography. Their strengths are not as self-evident as they first appear. A polyvocal nature is all very well, but how many voices must a collection contain in order to be representative? Similarly, reflection and analysis may at first appear to be vitally self-conscious and self-questioning, yet can all too easily fall into the pattern of 'creating' rather than 'documenting' a culture. This latter risk is weighted by the implication of anthologies of disability writing by nature of their very existence in a form of identity politics, itself a product of a political intervention: the social model. Although dissenting voices are indeed contained in these collections, these contributions become defined primarily by their dissent. While it is true that certain pieces, as we have seen, offer analysis and insight, and, in the case of Mairs and Kriegel, a discernible thematic progression, the anthology form is ultimately too fragmentary and cursory for these insights to move beyond observation, except when they are subordinated to a strong editorial agenda: which in turn defies the apparent liberational political raison d'etre of such collections. Thus, for a more satisfying unity of content and form, and to remove the disability experience from a limiting political context, it can be seen that the more traditional autobiographical form is arguably preferable.

CONCLUSION

In this thesis I have sought to expand upon analyses of the shortcomings of

the social model of disability by considering their implications for a literary study of

disability life-writing. I have sought to demonstrate that the first literary approaches

to disability life-writing that relied upon the social model were limited by its status,

as evident in Tom Shakespeare's assessment, as a political intervention rather than a

robust theoretical model. This has led, I have argued, to a tendency to assess texts

on political rather than literary grounds. Criticisms of autobiography offered by

Davis and Mitchell and Snyder in the mid-1990s are expressly political: in their

insistence that individual accounts undermine the 'true' political nature of disability

as a communal identity, the political priorities of the social model and the identity

politics spawned by it are clearly apparent.

As recent criticisms of the social model have shown, while its narrow political focus has been useful for the political purposes of the disability rights campaign, it is ill-suited to the wider concerns of the disability studies field, where it has long been the dominant perspective. As Shakespeare has noted in *Disability Rights and Wrongs* (2006), it has threatened to limit disability studies as a field by shackling it to the disability rights movement via identity politics. This identity politics requires a foundational submission to categorisation (and thus to hierarchy and segregation) and to a victimhood that focuses on the 'oppression' it claims to oppose as its sole unifying factor for its existence. This formulaic approach does not adequately address the complexities of the experiential aspect of disability, which denies the rigidity of such categorisation.

As Swan notes, the shortcomings of a cultural studies approach are particularly apparent when it is applied to disability life-writing which, as we have seen, often attempts to explore and express this experiential aspect. Yet that is not to say that one automatically precludes the other in the way Swan implies. It is important to note that early disability studies approaches to literature by Davis and Mitchell and Snyder in the 1990s did not argue against the expression of experience in literature. Rather, they worked on the premise, informed by the notion of 'oppression' integral to the social model, that such an expression was impossible in conventional forms of literature such as the autobiography. As Silvers has argued, they assumed that art produced in a society that marginalises disabled people must reflect that marginalisation. This assumption was flawed in two respects. First, as Silvers notes, art does not operate on exactly the same basis as society. Secondly, as Galvin's theories suggest, the disability experience can indeed be expressed in dominant discourse, both through the admittedly slow evolution of conventional

language, and through the subversion of convention by tropes such as metaphor. Both of these factors are in play in the work of Christopher Nolan; *Under The Eye Of The Clock* can be seen to perform the function of rendering socially undesirable physical difference as artistic innovation in a conventional, if literary, autobiographical form.

Although Galvin's insights into subversion and innovation are vital, they are still couched in the terms of the social model: dominant discourse 'oppresses' people with disabilities as a distinct group. Yet, as Couser has noted, the expression of experience sought in disability life-writing is about 'reclaiming one's body from more than just medical discourse' and other types of dominant discourse (Couser 1997, 34-5) As we have seen in the texts examined in the previous chapters, the very act of expression, be it Brown's painting or Sienkiewicz-Mercer's statement 'I.FEEL.BAD.', is less resistance to oppression, and more an act of affirmation. It is worth remembering that Kirmayer's assessment of the body as the source of new and subversive language is based on the idea that bodily difference will produce a different discourse. I have applied this to disability, but his original argument concerns more general bodily difference, such as illness. This is apparent in the writing we have seen by people disabled by cancer, where the struggle is not with an oppressor, but with the need to articulate a new bodily-originated language that dominant discourse does not accommodate, through the empowering expression that disabled authors such as Brown, Nolan and Sienkiewicz-Mercer have arguably achieved.

In this respect it might be seen that writing that articulates bodily expression is, as Swan notes, disability writing's gift to wider literary studies and society as a

whole. His use of Nancy Mairs as an example is particularly pertinent, as her progressive MS confounds the rigid categories of disability identity politics, blurring the line between disabled and nondisabled. Mairs links her disability to her writing by noting that it has made her aware of herself as a voiced body and an embodied voice. This can, of course, be seen to be applicable to all authors, but is simply highlighted by the attention to embodiment which disability studies can offer. Likewise, the insights of Kirmayer and Galvin into the role of the body in lexical innovation and thus literary creativity can be seen to have implications beyond disability literature.

It is thus perhaps useful to consider once more Zola's position as espoused in his introduction to *Ordinary Lives* (1982): that the perpetuation of myths about disability are harmful to society as a whole, and that writing which conveys the reality of the disability experience and thus in turn reveals the reality of all our selves as embodied subjects is thus of benefit to society as a whole. Such a view not only reflects the large, porous and continually shifting nature of the 'disabled' population that Zola and Shakespeare identify in a far more realistic fashion than the social model's rigid demarcation of 'disabled' and 'nondisabled', but also offers a way for disability literature to be of practical use. As the latter has observed, the identity politics of the social model, with its demands for cultural recognition, will at best leave hierarchies intact, and at worst risk stigmatising the disadvantaged class, or force individuals to conform to a group culture that discourages debate (Shakespeare 2006, 80). Shakespeare insists that the goal should instead be to make impairment and disability irrelevant wherever possible. In raising awareness of the reality of embodiment, disability life-writing can contribute to this goal, in line with the 'dismodernism' of Davis, whose concern is not the 'care *of* and care *for*' the

body linked with 'oppressive subjection', but rather 'caring *about* the body'. The conclusion of this 'dismodernist ethics' is the recognition 'that difference is what all of us have in common' (Davis 2002a, 26). To be more specific: embodiment is what all of us have in common.

As we have seen, Shildrick and Price agree that it is through recognising 'the permeability between bodies and between embodied subjects' that 'disability studies might move forward' (Shildrick and Price 2002, 62). Like Couser, they perceive the disabled body as 'much more than the result of unequal power relations', placing it beyond identity politics as 'something that is always in process', rather than being 'a stable entity' to which an identity might be ascribed. Therefore, they insist, 'disability' should not be conceptualised 'as the property of an/y individual', and people with disabilities should not be seen to have a 'privileged standpoint' or the only 'authentic' understanding of disability embodiment (63-4). Their view does not account for the observations of writers such as Mairs and Tollifson regarding the special awareness of embodiment that their experience of disability gave them. The difference between these two perspectives might best be mediated by Zola's observation that '*at this moment* those of us who have lived with a disability are often in a better position to write about what it is like' (my emphasis) (Zola 1982b, 13). In this way it can be seen that Zola, writing in the early 1980s, allows both for the contribution made by experiential accounts of disability and for the future development of the 'dismodernism' conceptualised by Davis, where the discourse developed in such accounts could benefit, and be adopted by, society as a whole.

Shildrick and Price reject much of the writing in anthologies such as *With Wings* and *Mustn't Grumble* on the grounds that it conveys the belief that 'what counts is the experience of the disabled person alone' (66). The conveyance of such a belief might be seen as a consequence of the implicit identity politics that result from basing an anthology on identity. However, as *Ordinary Lives* and *Staring Back* show, this is by no means inevitable, as Zola's rejection of 'essays about…issues' and Fries' emphasis on moving the focus on disability to the mainstream in order to gain a 'truer understanding' of it demonstrate (Zola 1982b, 14); (Fries 1997b, 9-10). In the light of this, Shildrick and Price's vision for a new type of writing should be viewed with pragmatism. They call for the replacement of 'unified stories' - characterised by clearly delineated subjects, different categorisations of embodied being, and fixed points of view – with an emphasis instead on 'multiple points of interchange', the blurring of categorical boundaries, and the 'discontinuities that make up experience before narrative is imposed on it' (64-5). Their own technique of 'writing together', thus blurring and concealing their comparative ability and disability, might be taken as an example of the style they envision. While such a style arguably works in the setting of critical writing on the subject of disability, it is hard to imagine such work proving accessible or popular: indeed, it might be suggested that such writing would be counter-productive to their stated aims, finding an audience only within disability studies. Not only would such an abrupt break with convention be counter-productively isolating, but is, as Galvin's argument has shown, unnecessary. It might be argued that their goals can be achieved just as easily by looking backwards as forwards: it is not for nothing that Couser has praised conventional autobiography for its construction of a 'neutral

space' that allows authors with disabilities both to cross and to blur the porous border between 'disabled' and 'nondisabled'.

Their argument regarding the need to abandon 'unified stories' based on a clearly delineated subject in favour of attempts to capture the 'discontinuities that make up experience before narrative is imposed on it' poses further difficulties. Such a position surely risks the very objectification of the body for which they criticise anthology writing: it furthermore recalls the nightmarish 'chaos narrative' of Smith and Sparkes, which is also glimpsed in Miho Iwakuma's vision of the maladjusted embodied subject, constantly conscious of their embodiment, unlike the successfully embodied subject, who is unconsciously embodied. In this regard we might again consider the idea that there is a strong case for autobiographies such as *Under The Eye Of The Clock* precisely because, in its closely entwined use of disability in both content and form, it might thus be seen as a textual analogue of Iwakuma's notion of successful embodiment.

For this reason, Couser's championing of the personal essay as the future of disability writing may be overly optimistic: in making analysis its focus, it runs the risk of disembodying even as it addresses the body. This aspect is magnified if such work appears in the context of an anthology by writers with disabilities, with its implicit identity politics, as demonstrated in Chapter 5. In this respect, a middle ground might be found by championing volumes of personal essays, such as Mairs' *Waist-High In The World*, which arguably combine the strengths of autobiography (such as unity of form and content in the empowering expression of the voiced embodied subject) with those of the personal essay style (such as escaping the rigidity of a single narrative) while avoiding the pitfalls of identity politics.

In essence, this thesis has made a number of contributions to knowledge. First, it has tested and analysed the strengths and weaknesses of current models of disability both in their application to disability experience and to literature. Second, its synthesis of a more robust model for a literary approach to disability will enrich both disability studies, broadly conceived, and the sub-category of literary disability studies. Third, in its exploration of what is lacking in previous approaches to the literary analysis of disability life-writing, this thesis has focused on the body as a source of 'voice': that combination of language and identity, style and content. This focus on the body in writing that disability brings in turn raises the question of a broader appreciation of 'the writing body', both as it makes itself known in language, and in its physical influence on the act of inscription, in the wider field of literature. In turn, this highlights the importance of the developing technology of inscription, as evident in the progression from the type-writer of Brown to the word-processor of Nolan. Another consequence of this focus on bodily identity has been its emphasis on the reductive nature of the identity politics that have dominated and calcified the study of disability into the orthodoxy of 'disability studies', and on ways in which disability may be studied and theorised in a more universal, less separatist fashion, not as an end in itself but as a topic which challenges and offers new modes of conceptualisation throughout the humanities with regard to the body and embodiment, bridging the gap between the twin orthodoxies of social constructionist and essentialist models.

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