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Changing bodies, changing narratives and the consequences of tellability: A case

study of becoming disabled through sport

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By

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Abstract

This article explores the life story of a young man who experienced a spinal cord injury (SCI) and became disabled though playing the sport of rugby football union. His experiences post SCI illuminate the ways in which movement from one form of embodiment to another connects him to a dominant cultural narrative regarding recovery from SCI that is both tellable and acceptable in terms of plot and structure to those around him. Over time, the obdurate facts of his impaired and disabled body lead him to reject this dominant narrative and move into a story line that is located on Norrick's (2005) upper-bounding side of tellability. This makes it transgressive, frightening, difficult to hear, and invokes the twin processes of deprivation of opportunity and infiltrated consciousness as described by Nelson (2001). These, and the effects of impairment, are seen to have direct consequences for the tellability of embodied experiences along with identity construction and narrative repair over time. Finally, some reflections are offered on how the conditions that negate the telling of his story might be challenged.

Introduction

According to Murray (1999: 53), 'Narratives do not, as it were, spring from the minds of individuals but are social creations. We are born into a culture which has a ready stock of narratives which we appropriate and apply in our everyday social interaction'. Likewise, in emphasising the dialectic between the individual and the cultures they inhabit, Frank (1995) argues that while people tell their own unique stories of illness or disability, they compose these stories by adopting and combining narrative types that cultures make available to them. In commenting on this social aspect of narrative he states:

> The ill body's articulation in stories is a personal task, but the stories told by the ill are also *social*. The obvious social aspect of stories is that they are told *to* someone, whether that other person is immediately present or not … From their families and friends, from the popular culture that surrounds them, and from the stories of other ill people, storytellers have learned the formal structures of narrative, conventional metaphors and imagery, and standards of what is and is not appropriate to tell. Whenever a new story is told, these rhetorical expectations are reinforced in some ways, changed in others, and passed on to affect others' stories (1995: p. 3).

Personal stories, therefore, are both personal and social at the same time. As Coffey and Atkinson (1996: 61) point out, 'Although the reported biographical events may be unique to the individual, they are structured according to socially shared conventions of reportage'. They go on to emphasise that 'storytelling is culturally situated and relies for its success on culturally shared conventions about language and the hearing of stories' (1996: 77). Mishler (1999: 18) also suggests that storytellers are always working within shared 'social and cultural frameworks of interpretation'. In this regard, from the perspective of discursive psychology, Wetherell (1998) notes the interpretive repertoire that people call upon to talk about objects and events in the world in a recognised, familiar, and relatively coherent way.

Not all stories, however, have equal status. Some are more acceptable than others. Some are heard and some are ignored or silenced. Thus, Frank (1995) points to the medical narrative as the canonical or 'master' narrative that trumps all other

stories in the modern period: 'The story told by the physician becomes the one against which others are ultimately judged true or false, useful or not' (1995: 5). Plummer (1995) also notes the structure of suffering, survival, surpassing and transcendence that characterise the modernist tale. Set against this, in Western societies as Lupton (2003: 70) recognises, 'To despair, to lose hope, are frowned upon as strategies of dealing with diseases such as cancer'.

With regard to the process of emplotment in clinical encounters Mattingly (1998: 79) suggests that therapists and other health professionals work to construct 'success' stories, 'They presume that patients will not be committed to therapy without success, for success breeds hope, and hope is essential'. Thus, in such encounters certain story outcomes are desired and others feared.

> When a story is told, if that storytelling is successful, it creates in the listener a hope that some endings (generally the endings the hero also cares about) will transpire … We hope for certain endings; others we dread. We act in order to bring certain endings about, to realise certain futures, and to avoid others (Mattingly 1998: 93).

Accordingly, depending upon the situation and the audience, some stories are more tellable than others. For Ochs and Capps (2001) tellability is one of the gradient dimensions of narrative and is something negotiated by the teller and listener in particular local contexts. In this regard, Norrick (2005) proposes a two-sided notion of tellability. That is, one that encompasses the familiar lower-bounding side of this phenomenon as sufficient to warrant listener interest and the generally ignored upper-bounding side where tellability merges into the no longer tellable because they are too personal, too embarrassing, or too frightening.

> Some events bear too little significance (for this teller, this setting, these listeners) to reach the lower-bounding threshold of tellability, while others are so intimate (so frightening) that they lie outside the range of the tellable in the current context. Similarly, one narrative rendering of an event may fail to bring out its significance (humour, strangeness), and thus fail to reach the threshold of tellability, while another telling might render the event so frightening (intimate) that the story is no longer tellable. Hence, the more

strange (salacious, frightening) an event (or narrative rendering of it) is, the more tellable the story becomes, seen from the lower-bounding side, but the less tellable it becomes, seen from the upper-bounding side due to the potential transgressions of taboos (Norrick 2005: 327).

Importantly, the act of narration that structures and projects our sense of selfhood and identity over time, along with the tellability of personal stories, is an embodied process. Thus, Becker (1999: 93) states, 'Bodily experience and bodily concerns are deeply embedded in various elements of narrative'. Likewise, Eakin (1999) notes how selves can be heavily invested in people's bodies, and how the body shapes the stories that come out it. This position is supported by Frank (1991) who draws attention to the corporeal character of bodies as an obdurate fact, providing people with the means of acting, and also placing constraints on their actions. For him, in making sense of our experiences, we not only tell stories *about* our bodies, but we also tell stories *out of* and *through* our bodies. Therefore, the body is simultaneously cause, topic, and instrument of whatever story is told. In this sense, the kind of body that one *has* and *is* becomes crucial to the kind of story told. As Hughes and Paterson stress with regard to disability.

> Disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning...Most importantly, the (impaired) body is not just experienced: It is also the very basis of experience...Disability is, therefore, experienced from the perspective of impairment. Ones body is ones window on the world (1997: 334-335).

In relation to disabled bodies, Thomas (2002) argues that the lived experience of disability involves struggling not only with socio-structural barriers, but also with the psycho-emotional dimensions of life, the material body, and the effects of impairment. For her, any attempt to understand the experiences of people with impairments and the ways in which disability is a form of social oppression must start from, and engage with, people's bodies as lived, social, and biological entities [1].

[Disabled] bodies need to be theorised as, at the same time, bio-socially produced and culturally constructed entities...Significant impairments need to be seen as real differences from the 'usual' body whilst simultaneously understood to be invested with meanings or representations that construct these differences in the socio-medical language of 'impairment', 'disfigurement', and so forth. In addition, we need to work on an understanding of the way in which the biological reality of bodies is shaped by, and impacts back upon, social and environmental processes and practices; that is, on the ways in which bodies are the effects of bio-social interaction (Thomas 2002: 76).

Set against the conceptual backdrop we have provided, questions emerge about the connections between certain kinds of narrative and their tellability by certain kinds of bodies in specific sets of circumstance. Linked to these are questions regarding the conditions for, and the consequences of, tellability or non- tellability in relation to individual experiences of different forms of embodiment over time. Therefore, in what follows we seek to explore these connections by focusing upon the life story of one individual called Jamie (a pseudonym) who experienced a spinal cord injury (SCI) and became disabled though playing the sport of rugby football union.

Particular attention is given to Jamie's experiences post SCI because they illuminate the ways in which, as he moves from one form of embodiment to another, he connects to a dominant cultural narrative regarding recovery from SCI that is both tellable and acceptable in terms of plot and structure to himself and those associated with him. Over time, however, the obdurate facts of Jamie's impaired and disabled body lead him to reject this dominant narrative and move into a story line that is located on Norrick's (2005) upper-bounding side of tellability making it transgressive, unwelcome, frightening, and difficult to hear. Importantly, in making such a move, Jamie experiences the twin processes of deprivation of opportunity and infiltrated consciousness as described by Nelson (2001). These are seen to have direct consequences for the tellability of his embodied experiences along with his identity construction and narrative repair over time. There are also direct consequences that go with the biological 'reality' of impairment along with its effects, and due consideration is given to these. Finally, having explored Jamie's experiences we

reflect, without giving the last word, on how the conditions that negate the telling of his story might be challenged so that the chances of narrative repair are enhanced.

Methods

Following ethical approval from the University Ethics Committee, initial contact was made with participants involved in the project via the English Rugby Football Union's support network for injured players. To ensure confidentiality, and following negotiations with the sports injuries administrator for this organisation, it was agreed that an open letter from ourselves explaining the project, along with a brief questionnaire seeking demographic details, would be distributed in one of the newsletters circulated by the network. The questionnaire ended by asking each respondent to indicate if they would agree to be interviewed, and if so, to provide his or her name and address in a stamped addressed envelope that was also supplied. Jamie was one who agreed.

Jamie was involved in confidential, thematic, informal, life history interviews conducted by the primary investigator [Brett Smith]. At the start of the first interview the nature of the project was explained to him and any questions were answered. It was made clear that he was free to terminate an interview or withdraw from the project at any time without having to provide any reason for doing so. Further, it was agreed that pseudonyms would be used in all future publications to assist anonymity.

During each interview, the primary investigator acted as an 'active listener' in an attempt to assist the participant to tell his life story in his own way and in his own words. Jamie was interviewed three times in his own home, over a period of a year, with each interview lasting from two to five hours. All interviews were tape-recorded, transcribed, and subjected to a holistic-content mode of narrative analysis and a structural analysis (see Lieblich, Tuval-Mashiach, and Zilber, 1998, Smith and Sparkes in press, Sparkes 2005). The former uses the complete life story of an individual and focuses on the content presented by it. A structural mode of narrative analysis focuses on the formal plot and organisation of the story to tease out the distinct structures that hold it together with a view to identifying it as a particular narrative type.

Having considered the methods that informed this article, we now turn our attention to the results of the analysis. We begin by providing some biographical

details of Jamie in order to locate him within the story that we have constructed about his life.

Jamie: Context and background

Jamie, who is white and in his mid-forties, was raised in a working class family in a small city in Southern England. He has one elder brother and one younger one. As a young child, relations with his family were generally detached. That said, moments of closeness and emotional bonding were formed through the social practices of sport. Jamie states that as a child and adolescent, like his brothers and father, he was very physically active and devoted a great deal of his time to playing rugby football union and association football.

> I had this quite remarkable body … Back before the accident, the body was always able and strong. My life was sport. I lived for it. I was, even as a young boy, always bigger, stronger, had a little more in the tank than the other kids. My brothers were the same. We were very competitive. Tough and rough, but never nasty, dirty. Always tough and fair. My father instilled that into us: "Always give 110% at whatever you do, and work hard," he would tell us.

His reflections on life pre-SCI suggested that from an early age, physical size, strength, sporting prowess, and bodily regimentation through training regimes were defining features of Jamie's sense of self. During this period his body, in Frank's (1991, 1995) terms, was both disciplined and dominating [2]. These characteristics and their associated emotional investments were reinforced by the kinds of work that Jamie became involved in as an able bodied man. For example, on leaving school with minimal qualifications, he gained employment in various warehouses packing goods before becoming a crane driver in a dockyard. This was a physically demanding job, with long-hours. Here, as in sport, his body-self relationships were shaped by the dynamics of the labour process. Thus, his body was isolated in its own 'performance' in the sense that even though it performed among others it was not with them. As Jamie stated, "I did physically hard jobs. That was always me. Always dirt under my nails, in my skin. No scrubbing gets it out. Working the crane was tough

work. Good work. No one bothered me. I worked along side some good guys, but I was in the crane and you got on with the job."

Despite working long hours in the dockyard, Jamie continued to be heavily involved in rugby union. He trained several times during the week, and his weekends revolved around playing rugby or other sports, and drinking with his team mates and other friends afterward. This general body-self story that he lived in, and through, continued for a number of years until he married at the age of twenty-five. For the first few years of his marriage, rugby and work were still central to his life. However, when he and his wife had their first son, rugby took a backseat. This continued for several years as a daughter and another son were born.

> That was a very good time, with the usual ups and downs in life and marriage. But overall, a good life … Back then, at first, marriage and children took priority. Rugby was sacrificed. My children always came first, always will [five second silence]. But, I felt the need to get back playing. I missed it. And after a few years of marriage and after endless rows with my wife over playing or wanting to play more, I made the decision, and went back. You'd think after not playing too much for a few years, I'd have lost a little. But I didn't. Maybe, I was always fit and strong, with work and everything. Back then, it [the body] only needed a little fine-tuning. I was soon back charging down the rugby pitch.

In 1994, however, his life suddenly changed. On a cold winter's day, aged thirty-five, whilst rushing to tackle an opposing player during a game, Jamie's head collided with the opponents' shoulder. As a result, his spinal cord was damaged at the level C2-complete[3]. Jamie recalls the incident as follows:

> In the second half [of the rugby match], we turned up the pressure. It must have been about five or 10 minutes to go until the end of the match … I remember they [the other team] were coming at us, they were in their own half, there was I on the wing and he [the centre] was outside…Then, then, [silence—five seconds], then as he [the centre] got closer and closer, in a very split second I changed my mind, sort of changed my position, just fractionally. This was in a split second, he dipped his shoulder at the same time as I

lowered my position and his shoulder hit me straight on the top of my head. It was like a bang against a brick wall really…And the next minute I was lying on the floor saying: "Can you put my arms and legs down on the floor".…It just never dawned on me that maybe I was paralysed….The body I had was lost. Now what?

SCI, the body-self, and restitution

Shortly after the incident of SCI, and following the stabilisation of the fracture and the ensured maintenance of essential bodily functions (e.g. respiration and urination), Jamie entered formal spinal injury rehabilitation for a period of nine months. Here, he was told that the severity of his spinal injury was such that he would require artificial life support and breathe using a ventilator for the rest of his life. He was also informed that he would probably live for his entire life with a lack of sensation and movement below the neck. Thus, the fateful moment Jamie suffered SCI whilst playing rugby is immortalised in time (Sparkes and Smith 2003). As Seymour (2002: 138) points out, spinal injuries are 'injuries embedded in time. The body becomes a perpetual memorial to the split second of time in which the spinal cord was severed'.

However, this is not to suggest that Jamie's body became a timeless monument to accidental damage. As Seymour (2002) reminds us, bodies are active agents that help shape and produce culture. Thus, for her, while the inscription of injury in, and on, the body is a product of corporeal practices that by the very nature of spinal injury have become locked in time, 'the relationship between the objective body and the subjective living body is ongoing and survives neural disruption' (Seymour 2002: 138). As part of this process of survival, the body tells stories. Furthermore, not only is the body a 'talking body', but, as Eakin (1999), and Frank (1995) suggest, it also gives its stories their particular shape and direction. That is, bodies have an attraction to specific narratives and are constructed in them. They are drawn toward and propelled by stories of a particular kind.

According to Jamie, one story his body was drawn towards, and propelled by, early on in the process of surviving and living with SCI was the restitution narrative. According to Frank (1995: 77), its plot has the basic storyline: 'Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again'. For Jamie, this translates to: 'Yesterday I was able-bodied, today I'm disabled, but tomorrow or at some point

in the future I'll be able-bodied again'. We would also suggest this narrative has an affinity for the *restored* self as described by Charmaz (1987).

> Interviewer: What can you recall about your life after the accident?
>
> Jamie: The accident happened. My life was over then. It stopped the day it happened. I do remember that I wanted my old life back though. I wanted to get off the ventilator. Thought I would walk again. Inside rehabilitation I had those thoughts sometimes…I said to my wife and children that I would walk again. I believed it too.

In addition to drawing upon a restitution narrative at various times *within* rehabilitation, there were also times *outside* the context of this institution when his body displayed a strong cultural and personal preference for this kind of story. This preference was reinforced by those around him who wanted to generate and sustain a sense of *concrete* hope orientated to a desirable outcome for both Jamie and themselves by offering restitution stories to him and hearing the same story from him (Smith and Sparkes 2005).

> Interviewer: How did other people deal with you after the injury?
>
> Jamie: Most people I knew … soon stopped visiting. The people that still visited, after leaving [name of spinal cord injury rehabilitation centre], the friends and family, my children, I don't think they knew what to do. Maybe they did. I don't know. They told me a cure would happen. I sometimes believed them. I even convinced myself that I would turn things around, and someday get some movement back and breathe like I once did, without the machine … I would imagine playing rugby again, working, having a drink with friends after work, holding my children. I sometimes told myself those things. I can't believe I did say those things to people. I forgot about that. There were times when I even believed in what I said…I believed I would get better.

Clearly, for Jamie, there were times when his body was drawn to and propelled by others toward the restitution narrative. In terms of the *where's* of storytelling (Holstein and Gubrium 2004), this occurred both *within* and *outside* the

context of rehabilitation for a period of years after SCI. However, the power of this narrative, with its belief in a return to the desired, able bodied, state of being, gradually lost its power and began to slip into the background of Jamie's life. This was partly due to the obdurate reality of Jamie's body and what it could and could not do given the level of his SCI, despite his best efforts and those of health professionals. In short, it gradually became apparent to him, and those around him, that the restitution narrative was not working. In such circumstances, as Frank (1995) points out, there is often no other story to fall back on and narrative wreckage ensues as new and undesirable body-self relationships are realised. For Jamie, this meant a rapid descent into chaos.

SCI, the body-self and chaos

According to Frank (1995), the inverse of restitution is the *chaos* narrative because its plot imagines life never getting better. These stories are chaotic in their absence of narrative order. They are told as the storyteller experiences life: without sequence or discernable causality. Further, when living in chaos the present is experienced as empty and static, and the future appears desolate, especially when compared with a past that had promised so much until SCI intervened (Sparkes and Smith 2003, 2005). This story often results in despair and the loss of any kind of hope (Smith and Sparkes 2004, 2005). As Jamie commented halfway through a dialogue with the interviewer about how he feels about his life now.

> Jamie: I feel nothing. Feel, it's shattering, shattering [ten second silence]. The whole thing, just completely shattering. Life has been, its been beaten, life's been beaten out of me [eight second silence].
> Interviewer: I'm, I'm not sure what to say.
> Jamie: What is there to say? My life is a mess now. I can't remember when I was happy last. I feel, I feel, dead now. Since the accident, it's like this all the time. Life was good before it. I was happy. Then, then, I, I don't know. My life is over. It is over. Over. I've gone [five second silence].
> Interviewer: You've gone?
> Jamie: Yes. I am no one now. I may as well be dead. The accident has left me with nothing. No one. Life is a mess. The neck is broke, and, and, and it was

awful. Last night I couldn't sleep. I can't sleep at the moment. I lie there. My
life has ended [five second silence]. My life ended when, when. I don't know
how to say it. It's difficult. I sit here. What do I have? Nothing. It's, it's, it's
over. Nothing to live for. I don't know how else to say it. What can I say? I'm
gone. The accident took everything from me. Now what? And then, then, then,
I don't know. I don't know why I live. Nothing has changed since the
accident. The body has had it. Life has, has, stopped. I have no life left in me
now. Just darkness. Darkness. I'm worthless. And then, then, life has ended.
No cure. Life ended the day I broke this neck.

As these comments suggest, initiated by the actual SCI itself, coupled with an
awareness of the failed restitution narrative, Jamie has moved into chaos. In this
movement, Jamie's previous narrative dissolves and his psycho-emotional well-being
is battered. His world is unmade, reduced to nothing. Thus, not surprisingly, his self
and identities are fragmented as their narrative structures break apart to the point
where life is deemed to be meaningless and devoid of purpose and hope.

Jamie's movement into chaos in relation to SCI is also associated with the
emergence of a different kind of body. This is, a chaotic body. According to Frank
(1995), the body telling the chaos story defines itself as being swept along, without
control, by life's fundamental *contingency*. For sure, efforts have been made to
reassert the predictability of the former body-self but these efforts have failed, and
each failure has had its costs. Therefore, while contingency is not exactly accepted, it
is taken as *inevitable*. Furthermore, when living in chaos, the body on occasions is
monadic in terms of relating to other bodies, including those of loved ones and
friends. In other words, the individual body is closed in upon itself and isolated rather
than connected and existing in relations of mutual constitution with others. The
inability to receive consolation or empathy also echoes and reinforces the body's *lack*
of desire. Finally, in chaos, in solitude, the body is so degraded by the
overdetermination of SCI that survival often depends on the self's *dissociation* from
the body. All this is evident in the following comments:

Interviewer: I have no idea what it's like to live in your body. But, can I ask,
what's it like to live in your body?

Jamie: I've never been asked that before. I'm not sure. It is horrible. That's all I can say. I don't have the words. I sit here. Life is over now. The body keeps me alive. That's all it does. It's not me. I gave up on it along time ago. It just does what it wants. Then, who I am has gone. Now blackness. Sometimes I don't know why I still live. There is no point. On occasions I've got my finger in my mouth, and I've touched my teeth. I can see it's a finger, but I could break it off and I wouldn't feel a thing. I bite down on it. I think I can feel the pressure in my jaw and I think, 'this is weird.' You're biting on it, the finger, but you can't feel it. It's not my finger. It is not my body….I hope you never know what it's like to have this body. It isn't the body I expected to have or ever wanted. It's a mess, not a part of me. And then, I don't know. I can't do a lot of things. It's a strange feeling living in this. I don't know how to say it. It's, it's living in darkness like this …The body has choked the life out of me. That is how it feels I suppose. It is not a reliable body. It's gone from me. And I have no one. No friends. No one to socialise or speak with. I have my children but I can't do anything with them. I don't see them much. They are my children. But I don't see them much. I can't be a dad to them. [five second silence]

Interviewer: That must be tough.

Jamie: Yes. But what can I do. It's sad. Sad. But I can't do anything. I'm alone now. It's over now. I don't let anyone inside my mind. I've pushed my friends away, my wife left, wouldn't let her get close. You are the first person I've spoken to like this for a long time, maybe the first. I'm not good at accepting help. I haven't had proper human contact for a long while. I stay clear of people now. But that is how it is when you are in my situation. Nothing I can do. I can't say what it's like. I feel like nothing and I have no control over it either. That's how it is. Darkness. No control over the pain, the legs, arms, even my breathing I have no control over. There is nothing that I can do.… My condition won't improve. No point anymore. I'm no one now. It's a matter of sitting here alone until I die. Life ended for me the day I broke the neck. Who I am has gone. I can't see any way back or out. This is how it will be until I die. My life ended the day I broke my neck. I've been a wreck since then….Nothing has changed. Then, I can't. I was not living, a mess, when I stayed in the rehabilitation unit after I broke the neck. I'm still like that. Some days are even worse now. I can't see a way out. There is no way out … It's not changed since the accident.

Things have not changed. Rehabilitation was the same. I was a mess. I feel I still am. I can't see any difference. Maybe I've got worse. It, the injury, ended my life.

The dialogue above offers a vision of the disembodiment of chaos and draws attention to the power, and limits, of storytelling to communicate how Jamie's body feels after becoming disabled through sport. It also highlights the absence of dialogical relations in his life following SCI (Frank 2004). Furthermore, the memories of Jamie suggest that, shipwrecked by the storm of SCI and the disasters that attend it, chaos seems to crystallise and identities become damaged during the nine months he spent inside the spinal injury rehabilitation unit. None of this, though, is restoried or repaired once he leaves this institution. Rather, for Jamie, with no imagined end to chaos, outside the context of rehabilitation this state of being remains in the foreground of his story and becomes a cyclical experience. In part, this is due to the twin processes of what Nelson (2001) terms *deprivation of opportunity* and *infiltrated consciousness*.

Disability and deprivation of opportunity

Clearly, the factors that can damage identities and propel a person into chaotic body-self are many and varied. In Jamie's case, the SCI itself is one reason for this. Further, a cycle of chaos and damage to identities may be produced, sustained, and exacerbated when a person experiences what Nelson (2001) terms deprivation of opportunity.

> A person's identity is damaged when powerful institutions or individuals, seeing people like her as morally sub- or abnormal, unjustly prevent her and her kind from occupying roles or impose restrictions on activity and prevent them from occupying roles or entering into relationships that are identity-constituting … Harm to an oppressed person's identity that takes this form may be called *deprivation of opportunity* (2001: 20-21).

One way in which Jamie is deprived of opportunities is intimately connected to socio-structural barriers. The following comment illustrates this issue:

Interviewer: How do you spend your days now?

Jamie: I sit here. I don't do a lot. It's an empty existence. It's a hopeless situation. If I could, if I could summon up the energy, then, then, then, I would spend more time with my children. Work would be good...Then, if I worked, I would have people to speak to. Feel human again maybe. Money. I'd have money. Make friends. Something to fill my days. Make me feel like I was worth something again. But my life is horrible. It won't improve. I'm tired a lot as well. And then, being disabled, people don't want you. I can't blame them. I can't get into most buildings. I can't see people employing me when I need lots of space and good access. I'd like to see my children more. I can't visit them though. Even if I wanted to see them, and could, there are too many obstacles. No transport…The pavements are not made for what has happened to me. I can't move in the same places as my children. Their home is not designed for this body and my needs. It makes me feel sad. But that is how it is. Nothing changes. I'm not a father to them really now. That's gone. Maybe if I could spend more time with them. But I can't. I can't think about it because it hurts too much. I'm alone now. I accept that because I can't do anything else. Life is over for me.

Disability, as these comments suggest, is a form of social oppression involving the deprivation of opportunities connected to socially imposed structural barriers (Thomas, 2004a, b). It becomes a particular type of 'unequal social relationship which manifests itself through exclusionary and oppressive practices – *disablism* – at the interpersonal, organisational, cultural and socio-structural levels' (Thomas, 1999a: 40). Indeed, for Jamie, visiting his children is restricted due to inaccessible environments. Consequently, sustaining valued relationships with them is made more difficult and his ability to maintain and develop an identity as a father is constrained, eroded, and damaged. Likewise, inaccessible buildings and the unwillingness or inability of employers to understand his needs as a wheelchair user can deprive him of the opportunity to gain meaningful work. As a result, the possibility of developing meaningful social relationships with co-workers is prevented and his gendered identity as an economically self-sufficient man is lost [4]. In these conditions, Jamie's body is again separate, isolated, and alone in relation to other bodies (monadic),

thereby alienating him from others, contributing to the inability to find consolation or recognition for the body's suffering, and limiting dialogic relationships (Frank 2004). All of which help produce, sustain, and exacerbate social oppression, damaged identities, and a cycle chaos.

Furthermore, being deprived of such opportunities positions Jamie in ways that help undermine his emotional, expressive lived body, thus helping maintain the cycle of chaos and adding to the damage to his identities and psycho-emotional well-being (Thomas 1999a 2004a, Reeve 2002):

> Interviewer: How have things changed since the accident?
> Jamie: I can't describe it. It's too overwhelming. It's a different world now. The accident has changed everything. I'm a stranger. It's horrible living like this. What can I do? What can I do anywhere? I was in the town centre not so long ago. That is a rarity. I struggle. I feel even worse after going there. I feel useless because I can't get into places. Not accessible. So I mostly stay inside. And people often stare when I do, or have to, leave the house…They have since the accident…They look at me as if I'm an alien. I suppose in some ways I am. Some people have offered me money in the street. I see pity in their eyes. I don't feel good when this happens. I'm reminded of what I live in. I feel worse than usual. I can't scream at them. I really am worth nothing now…What can I do now? Nothing. I withdraw even more. Withdraw. I sit here in the lounge. I'm really alone. Just stare. I don't think much then. Moments like that I don't think about what I live in. This broken body. But it is not me. Me has gone. I can't be anyone again. And now I try not to go out. I don't socialise. It is too painful. Reminds me how useless I am…How alone I am in this world. Sometimes I don't think I can go on. I do. But life won't improve. It can only get worse.

With respect to deprivation of opportunities, the passage above calls attention to the socially engendered undermining of Jamie's psycho-emotional well-being. Specifically, it points out that when faced with socio-structural barriers, he is sometimes made to feel devalued, alienated, and worthless. These emotions are additionally roused through social interactions between people in general, and, in particular, by the gaze that disabled people can be subjected to (Paterson and Hughes 1999). For example, in certain contexts, and on different occasions, Jamie's body

fades and disappears from consciousness (Leder 1990). That said, his comments also suggest that, at other times, and under specific social conditions, the body moves from an absent presence to reappearing as a thematic and sensory focus of experience. Indeed, Jamie's experiences of moving through and within certain socio-spatial environments can produce a vivid but unwanted awareness of his impaired body whereby it *dys*-appears, and is left feeling useless, hopeless, and alone (Leder 1990, Hughes and Paterson 1997, Smith and Sparkes 2002, Sparkes and Smith 2002).

Disability and infiltrated consciousness

In addition to the process of deprivation of opportunity, Jamie's psycho-social and emotional well-being is also damaged, and the cycle of being and having a chaotic body-self is produced, maintained, and exacerbated by *infiltrated consciousness*. According to Nelson (2001), this kind of damage to a person's body, identity, and emotions, is created when a person internalises, as part of their self-understanding, other people's oppressive, dismissive or exploitive understandings of them, and then lose or fail to acquire a sense of themselves as worthy of full moral and self-respect. With regard to this process, Jamie internalises the powerful medicalised story line that is used to frame the experiences of many with impairments in Western cultures (Thomas 1999b). Here, this involves a tragedy narrative that portrays life as over and not worth living:

> Jamie: Before the accident, I could never understand how disabled people carried on with their lives. Now I know they don't. At least I don't. Life is not worth living now. Everyday is another day of emptiness. Life feels jumbled. I can't find the words … My life is empty … Darkness is consuming me. And I can't even move my fingers. What can I do?
> Interviewer: I'm not sure how to answer that…
> Jamie: I don't either. I haven't said this to anyone, but sometimes I think what it would be like if I could kill myself. I don't know if I actually could. I can't do much. Life has been sucked out of me. My children wouldn't understand. I sit here instead and stare. I wouldn't actually do it now. I may as well be dead. I just exist. I have done since the accident. It's lonely existing like this. But that is how it is for disabled people. I can't think of it any other way. Life is not worth

living like this. I can't be a good father. You can't when you are like me, when you have a severe disability…No one would employ me. Why would anyone employ a disabled person with all my problems? They wouldn't. And then, I don't see or speak to people. I've not contacted friends for a long time. I suppose I could, but it's difficult. And my wife isn't here now. And, talking to you now, I forgot that I could speak. It's, looking at me, what have I got to offer. No one wants to speak with me. It's difficult like this, existing. With everything that has happened, and, my life and situation couldn't get any worse. It couldn't get any better either. It's ended. Life is over.

With respect to infiltrated consciousness, the comments by Jamie reveal that when hope is lost, or absent, and when deprived of certain opportunities (e.g. dialogue and relations with others, including his children) the socially framed belief emerges that one's life is in effect over. This is important because, according to Freeman (2003), in situations where certain outcomes are anticipated as inevitable, where things cannot be otherwise, individuals may experience what he calls *narrative identity foreclosure*. This involves the premature conviction that one's life story is effectively over. In such instances, Freeman suggests, if one already knows, or *believe*s one knows what lies ahead, then one may become convinced that there is little value in lasting to the very end. Consequently, one's life may seem a foregone conclusion and, therefore, devoid of hope. The individual in this circumstance might feel that he or she can no longer move creatively into the future. As a result, suicide may well become an option, or at least a thought (see Moore 2004).

Having described how the social processes of infiltrated consciousness and deprivation of opportunity help produce, perpetuate, and exacerbate social oppression and the experience and cycle of chaos, in order to understand the complex nature of life after SCI, impairment and its effects also need to be acknowledged. This is particularly so since the 'reality' of impairment and the materiality of the body, contra to some poststructuralist, constuctionist, and postmodern stances, *does* matter and can play an important part in restricting activities and the process of creating, perpetuating, and exacerbating chaos.

Impairment and impairment effects

According to Thomas (2004a), disability and impairment are inextricably linked and interactive. As she argues, 'while impairment is not the cause of disability, it is the raw material upon which disability works. It is the embodied socio-biological substance – socially marked as unacceptable bodily deviation – that mediates the social relationships in question' (2004a: 25). Thus, impairment, and its effects, are profoundly bio-social, and experienced partly in relation to the personal and cultural narratives that help to constitute its meaning:

> Jamie: The body, it's simply there to keep me alive. It breathes and without the ventilator I would die.
> Interviewer: How do you feel about that?
> Jamie: I don't know. There is nothing to feel. That's how it is. I have other things that take over. I feel pain quite often. It [the body] is in pain. I have tremendous pain in this left leg. Tremendous. It often stops me from doing things. I don't do a lot, but if I did, then I wouldn't be able to stick to things or do much. The pain, you see, just takes over. Even with all the aids available or no obstructions in my path, none of that would make a difference. The pain stops everything. And then, I do feel tired as well. It's tiring being like this. It can take an hour, sometimes more, to get me out of bed, washed, clothed, bowels emptied, which I can't control as you know. All this is very tiring. It's horrible like this, but what else can I do? Nothing. I don't have anything in my life now. If I could have anything, I suppose I would like to cuddle and hold my children. Show them I'm there for them. Take their pain away when they fall. But I can't. They can sit on my lap, but I can't hold them or hug them when they cry, if they have fallen over. This body won't do that. Which is hard for them and me. It's awful. With a body like this, I can't do some things. That's simply a fact … Living like this is unavoidable.

This passage draws attention to the immediacy and obdurate reality of the biological body. In doing this, it suggests that, for Jamie, not *all* restrictions of activity, experiences of chaos, and damages to psycho-emotional well-being are framed and shaped simply by the social deprivation of opportunities or infiltrated consciousness. They can, on *some* occasions, be directly associated with having a physical impairment and being a material body that is unable to do certain things.

Hence, the deprivation of opportunities or infiltrated consciousness will not disappear simply by the removal of all disablist and disabling socio-structural barriers. Jamie also faces difficulties by the fact that he has, and is, a 'real' biological body. Accordingly, after SCI, the presence of pain and tiredness, Jamie's inability to physically cuddle his children, the inevitable lack of control over his bowels and bladder, and the incapacity to breathe without a ventilator, are what Thomas (1999a, 2002, 2004a) describes as effects of impairment - the restrictions of activity which are directly associated with being impaired but which do *not* constitute disability and are thus *not* a form of *social* oppression.

Therefore, the materiality of Jamie's individual fleshy body *does* matter, and the effects that impairment may have cannot easily be ignored. Indeed, whilst not necessarily socially oppressive, some restrictions of activity are caused by impairment. The effects of impairment may also help sustain the cycle of chaos that Jamie lives and breathes. That said, it should also be noted that the 'real' physical features of impairment do not take place in a social vacuum. They *may*, as Thomas (1999a, 2002, 2004a) emphasises, become the medium for the *social* enactment of oppressive practices. Evoking this bio-social nature of impairment and its effects in relation to his experiences of phantom pain, Jamie commented [5]:

> I do feel a lot of pain, then, more pain. Pain…Horrendous pain. And then, what do I do? What do I do? I sit there. It's horrendous. Sometimes though I doubt I can feel it. It is there, I think? No one really believes me. See, I don't know. I don't know. No one believes I'm in pain … I've no control over pain, the body, the legs, arms, eyelids. Even my breathing I have no control over. There is nothing that I can do. See, then the carers don't really believe me. But I can feel the leg, feel pain, hammering me away. And, like I've been sat down for 6 months and that can be really painful. Sometimes if I'm lying in bed, lying on my side, my left side. My right arm is on my side, by my side down my body. Sometimes my arm is on the side of my body but to me it's not. Sometimes it feels as if my hand is opening and closing but I'm looking at my hand and it's not moving. And I have pain in the left … It makes no sense to people. I've given up on the doctors, had lots of opinions, and they say 'no' to the pain and phantom limb pain, or give me more painkillers. I tell them I want something more, but what can I do? No one believes me … My life

ended the day I had my accident. It can't get any better. And the pain is, I don't know. Is it real? I think it is. Maybe it isn't. Maybe the doctors are right and there is nothing there. I still feel destroyed by it.

Jamie, as these comments testify, feels phantom limb pain after SCI in a specific area of his body. According to Siddall, Taylor, and Cousins (1997), this is a neuropathic below level spinal cord trauma pain that has a neurophysiological basis. It may cause some non-socially imposed restrictions of activity and contribute to the cycle of chaos. Yet, this biological dimension of pain associated with having an impairment can also interact and intersect with society and processes of socio-cultural naming. For instance, there is the subjective nature of living 'in' pain and the dilemmas of expressing and sharing it with others via language (Coles, 2004, Scarry, 1985). Furthermore, when and where physical pain can find a voice and begin to tell a story, it may get listened to, believed, and acted upon by people, including health care professionals. This act of naming, as part of the storying process, might, however, be treated with suspicion and disbelieved. As Scarry recognises:

> So, for the person in pain, so incontestably and unnegotiably present is it that 'having pain' may come to be thought of as the most vibrant example of what it is to 'have certainty,' while for the other person it is so elusive that 'hearing about pain' may exist as the primary model of what it is 'to have doubt.' Thus pain comes unsharably into our midst as at once that which cannot be denied and that which cannot be confirmed (1985: 4).

Indeed, as Jamie's comments suggest, even if medicine recognises that there is something physically 'wrong', that recognition by no means guarantees that a person will not be subjected to socially oppressive practices, including what Wendell calls *epistemic invalidation*:

> The cognitive and social authority of medicine includes the power to confirm or deny the reality of everyone's bodily experience. Thus medicine can undermine our belief in ourselves as knowers, since it can cast authoritative doubt on some of our most powerful, immediate experiences, unless they are confirmed by authorised medical descriptions, usually based on scientific

laboratory results. Moreover, this power of medicine subjects us to possible private and public invalidation by others—invalidation as knowers and as truth-tellers (1996: 126).

With regard to his phantom limb pain and impairment, Jamie's stories are open to invalidation by people in society, such as doctors and carers, who often define him as an 'unreliable narrator', and do not believe he can feel pain in a paralysed limb. This not only results in the undermining of the person's belief in him or her self as a knower and truth-teller, but can also contribute, Wendell (1996) argues, to the social oppression, stigmatisation and marginalisation of people with impairments who experience phenomenon such as a phantom limb. Furthermore, by invalidating people's stories and not recognising them, the processes of reconstructing identities and developing differently valued body-self relationships become even more difficult. As Taylor describes:

> Our identity is partly shaped by recognition, or its absence, often by *mis*recognition of others, so that a person or group of people can suffer real damage, real distortion, if the people or society around them mirror back to them a confining or demeaning or contemptible picture of themselves. Nonrecognition or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted, and reduced mode of being (1994: 25).

Reflections

In describing Jamie's life post SCI and interpreting his story through specific analytical lenses, we have tried to illustrate how, as he moved from one form of embodiment to another, he connected to the dominant cultural narrative of restitution regarding recovery from SCI. For Jamie and those around him, this narrative was both tellable and acceptable in terms of plot and structure. Over time, however, the obdurate fact of Jamie's impaired and disabled body led him to reject notions of restitution and propelled him towards the chaos narrative that currently frames his daily experience. As indicated, this narrative is located on Norrick's (2005) upper-bounding side of tellability. Due to its transgressive, unwelcome, and frightening

nature this is a narrative that people prefer not to hear and find it very difficult to listen to on those occasions when it confronts them. Further, Jamie experiences the twin processes of deprivation of opportunity and infiltrated consciousness as described by Nelson (2001), as well as the various consequences of being and having both a biological and social body. In combination, these have direct consequences for the tellability of Jamie's experiences, his identity (re)construction and narrative repair over time, and his psycho-emotional well-being. Thus, this article illuminates the psycho-social impact of SCI in, of, and through the body as a storied, lived, biological, and emotionally expressive phenomenon.

Set against all this, we would like to offer some reflections, but not prescriptions or finalised conclusions, regarding Jamie's situation. In the first instance, we would suggest that Jamie's story highlights the need to extend the upper boundaries of tellability regarding stories of impairment and disability in Western cultures. This involves a collective challenge to those who are connected to Jamie's life to relocate the chaos narratives towards the lower boundary of tellability so that his story can be both told and listened to. This is an important challenge to meet because as Frank (1995, 2004) reminds us, storytelling can play an important role in repairing narrative wreckage as the self is gradually reclaimed in the act of telling.

As a wounded storyteller, Jamie might need the opportunity and the support to recover and reclaim the voices that SCI has taken away from him. In effect, he needs to be granted narratibility. This means his life, voices, and experience of events must be affirmed as being worth telling, and thus worth living, and reclaiming. In part, this involves an enhanced tolerance for chaos as a part of his life story by all those connected to Jamie. As Frank (1995) emphasises, if the chaos story is not honoured, the world in all its possibilities is denied. For him, to deny the chaos story is to deny the person telling this story which means that they cannot be cared for. Furthermore, if the person in chaos and those around him or her wish to change the situation, then as Frank (1995: 110) points out, 'people can only be helped out when those who care are willing to become witnesses to the story. Chaos is never transcended but must be accepted before new lives can be built and new stories told'.

In making the suggestion that the upper boundaries of tellability need to be extended in relation to chaos narratives we recognise that this is no easy task. As Frank (1995) acknowledges, this kind of narrative is anxiety provoking, threatening, and difficult to hear. In part, this is because it lacks any coherent sequence or plot. As

such, the teller is not understood as telling a 'proper story'. Another reason why hearing it is difficult, Frank (1995: 101) suggests, is because the 'chaos narrative is probably the most embodied form of story. If chaos stories are told on the edges of a wound, they are also told on the edges of speech. Ultimately, chaos is told in the silences that speech cannot penetrate or illuminate'.

Furthermore, given that the disabled are one minority group that anyone can join at any time, and given the indistinctiveness and permeability of the boundaries between the able-bodied and the disabled, the chaos narrative can be fear provoking for the able-bodied. As Couser (1997: 178) notes, 'the border is patrolled vigilantly by 'normals' more out of fear that they might stray over it than out of fear of transgression by those on the other side'. Part of this patrolling involves defining and legitimising what acceptable stories of hope are from the perspective of the able-bodied. Thus, the kind of hope offered by the restitution narrative is preferred to the lack of hope and despair that goes with the chaos narrative (Smith and Sparkes 2005).

For Mattingly (1998), the unacceptability of the chaos narrative to listeners is closely linked to the central issue of desire that draws both the hero of the story and the listener to elevate certain story outcomes over others. In this regard, as Frank (2004) suggests, the words 'able-bodied' and 'disabled' can draw people away from the present into some future that is desired or feared. Often 'fear is the dark side of desire: much of what we desire is to avoid what we fear' (2004: 138). Magnifying this is an immense social machinery that includes negative representations of disabled people on television, the reporting of medical breakthroughs to 'cure' disability, and the metaphors associated with disability that circulate in public narratives. In combination, these serve to make the term 'disabled' synonymous with fear and the term 'able-bodied' with desire.

Therefore, confronting the implications of the chaos narrative can instigate in the listener, both able-bodied and disabled, what Marcus and Nurius (1986) term a *feared self*. This is a type of possible or imagined self that one does not desire to become. For Marcus and Nurius, it can serve as a motivator, so that the individual takes action to avoid the possible body-self they fear and are afraid to be. Thus, certain narratives are foregrounded and celebrated while others are marginalised and silenced. As Nelson (2001) observes, this is the dark underside of dialogue in which dialogical relations become distorted due to the unequal social distribution of resources each person has available to tell his or her story. These resources include

listeners, and witnesses, who are willing to recognise the story, speak with the other, and act generously with the teller. Yet what dialogue enables, so the refusal to engage in dialogue can deny. As Nelson suggests, the process of reconstructing selves that dialogue helps make possible can be impeded when some people refuse to accept others as partners in dialogue. As such, telling, hearing, and honouring chaos stories can be an extremely difficult, risky, complex, delicate, and precarious process for all involved. But, if they are not honoured, then the spectre of deprivation of opportunity and infiltrated consciousness looms large and there is a real danger that these become normalised as a way of dealing with people in chaos.

If conditions can be created that honour and respect the telling of a chaos narrative then spaces may be opened up over time for other narratives to move into Jamie's life that shape his experiences in different ways. Again, this is no easy task given that Western societies provide limited narrative resources on which to build alternative identities, notions of self, and forms of embodiment on becoming disabled. That said, there *are* counter-narratives that provide alternative maps and different emplotments regarding disability and impairment that enable different body-self relationships to emerge.

According to Nelson (2001: xiii), counter-narratives 'are tools designed to repair the damage inflicted on identities by abusive power systems'. They are purposive acts of moral definition that set out to resist and challenge, to varying degrees, the stories that 'identify certain groups of people as targets for ill treatment. Their aim is to re-identify such people as competent members of the moral community and in doing so to enable their moral agency' (2001: xiii). One important counter-narrative to the chaos narrative that people might gain access to, and are willing to engage with is the *quest* narrative as defined by Frank (1995). This narrative meets suffering head on, accepts impairment and disability, and seeks to *use* it in the belief that something is to be gained from the experience. It is also closely linked to another counter-narrative potentially available to disabled people. This involves an *affirmative model of disability*.

According to Swain and French (2000), the affirmative model is a non-tragic narrative of disability and impairment that encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits and life experiences of being disabled and having an impairment. This counter-narrative may be liberating *for some* people and help in the process of reconstructing identities by

providing a sense of communal consciousness and expanding the cultural repertoire of stories on which to draw when re-plotting a life. It can also enable the reconstruction of selves by resisting and deviating from standard plots and dominant assumptions about disabled people (e.g., disability is a tragedy that results in life being perceived as effectively over). In so doing, it displaces the tragedy storyline that restricts opportunities to tell new stories and engages with a range of future possible identities that are a necessary part of becoming a developing self (Charmaz 1987). Therefore, as a counter-narrative, the affirmative model can have revelatory, liberatory, therapeutic, and transformative possibilities for some individuals and communities by making available and legitimising different ways of living as a disabled person. It may also compliment the social model (Oliver 1996) that, whilst not without problems (see, e.g., Shakespeare 2006), can help transform and liberate the lives of *some* disabled people. For example, promoting and actually removing the material barriers that restrict people's access to social spaces might, *in certain cases*, can help assist in the process of telling different stories and connecting to different counter-narratives. Making available and multiplying counter-narratives, and moving to a new narrative in which life with impairment is imagined as worth living, *might* further be enhanced through engaging with various types of narrative therapy (see Angus and McLeod 2004).

Of course, none of this is to infer that Jamie would, or should, embrace any counter-narrative that is made available to him. Our point is that for this to even become a possibility, he needs to be afforded the right to challenge the deprivation of opportunities, and the infiltrated consciousness that shape his life. This requires care and support from those around him to enable him to tell his chaos story and be listened to. In effect, Jamie requires consolation and generosity. According to Frank (2004), consolation is a gift.

> Consolation comforts when loss occurs or is inevitable. This comfort may be one person's promise not to abandon another. Consolation may render loss more bearable by inviting some shift in belief about the point of living a life that includes suffering. Thus consolation implies a period of transition: a preparation for a time when the present suffering will have turned. Consolation promises that turning (2004: 2).

To offer consolation, Frank (2004) emphasises, is an act of generosity, a generosity toward others and toward oneself. Generosity may lie in the grace to welcome those like Jamie who have suffered SCI and live in chaos [6]. It begins in, and is renewed through 'dialogue: speaking with someone, not about them; entering a space between I and you, in which we remain other, *alter*, but in which we each offer ourselves to be changed by the other' (2004: 126). It also includes speaking *to* them and thinking *with* their stories rather than just *about* them.

> Thinking with stories means joining with them, allowing one's own thoughts to adopt the story's immanent logic of causality, its temporality, and its narrative tensions. Narrative ethics seeks to remain with the story, even when it can no longer remain inside the story. The goal is empathy, not as internalising the feelings of the other, but as what Halpern calls "resonance" with the other. The other's self-story does not become my own, but I develop sufficient resonance with that story so that I can feel its nuances and anticipate changes in the plot…The first lesson of thinking with stories is not to move on once the story has been heard, but to continue to live in the story, *becoming* in it, reflecting on who one is becoming, and gradually modifying the story. The problem is truly to *listen* to one's own story, just as the problem is truly to listen to others' stories (Frank 1995: 158-159).

Notwithstanding such problems, it would seem that, over time and stimulated by different circumstances, Jamie may well have to tell a range of body stories, need people to listen with them, be offered consolation by others, and sometimes, be left alone to be himself and get his thoughts straight in order to help alter the trajectory of his life and infuse his history with new meaning, complexity, and generosity. All this might enable Jamie to enhance and enrich not only his experiences, but also the experiences of others, as they inhabit, develop, construct, and share different body-selves throughout their lives. Indeed, chaos stories have much to teach us, if only we listen, look long enough, and stay with them.

<u>Notes</u>

[1] Thomas (1999a, b, 2002, 2004a, b) draws attention to the immediacy of the physical, material body, and the importance of narrative, difference, and personal experience, without subscribing to biologically or socially deterministic views.

[2] According to Frank (1991, 1995) the disciplined body defines itself primarily in actions of self-regimentation that makes itself predictable. The most important action problems are about control and so this body experiences its most serious crisis in loss of control. In its relationship with others it tends to be monadic. In terms of self-relatedness this body is also dissociated from itself. The dominating body defines itself in force. Therefore, even though in its other-relatedness it is dyadic, it is against rather than for others. In terms of self-relatedness it tends to be dissociated from itself.

[3] Here, 'C' denotes thoracic vertebrae, and the '2' indicates the neurological level of damage.

[4] This is not to suggest that a barrier free utopia in which all disabled people can gain employment is viable. Nor is it to deny that there will always be people who, because of their impairment, cannot work or do certain jobs. Like Shakespeare and Watson (2002), however, we see no reason why we cannot accept that not everyone will desire or be able to achieve inclusion into the economy and argue instead that a mature society supports everyone on the basis, not on the work they have done, but of the needs they have to lead a meaningful life.

[5] Other examples of how impairment may become the marker for other restrictions of activity can be related to fatherhood and employment. For example, people in positions of power may decide that because Jamie cannot perform certain physical actions, that he is unfit to be a paid worker, or a parent, and should, therefore, be denied employment, or the privilege of being a father.

[6] Consolation need not always be generous. It can, for instance, be divisive, and not healing (see Frank 2004).

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