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Living with Brain Injury

Narrative, Community, and Women's Renegotiation of Identity

J. Eric Stewart



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Living with Brain Injury: Narrative, Community, and Women's Renegotiation of Identity

J. Eric Stewart

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Introduction

NANCY: And this is so funny, constantly doctors were asking me, "Tell me what this means: People who live in glass houses shouldn't throw stones." Constantly! They were giving me these little phrases and asking me what they mean: "Tell me what this means. Tell me what this means." You know? Those are hard. Those are hard to deal with.

When Nancy was in her late twenties she began having blinding headaches, tunnel vision, and dizziness, which led to a diagnosis of a congenital arterial malformation on her brain stem. Surgery was scheduled and she wrapped projects at her job as a financial consultant, assuming she would be back at work in three weeks. The first surgery was unsuccessful, and complications during a second surgery caused serious damage to the right side of her brain, resulting in partial paralysis of the left side of her body and memory and cognitive problems: "I woke up and there were all these deficits and I was really blown away by it. I was pretty severely depressed about it." Although she was constantly evaluated in various ways, Nancy's own questions and her distress got little attention in the hospital; it took a suicide threat to obtain acknowledgment and help for her depression. Her cognitive impairments remitted

significantly during rehab and she returned to work—six months later—but only after having to threaten a lawsuit under the Americans with Disabilities Act (ADA). Despite excellent job performance, her physical impairments were regarded as an “embarrassment” to the “perfect” and “beautiful” corporate image.

Her post-injury experiences completely changed her relationship to the corporate culture, which she now sees as “sick,” and shifted her aspirations and values. Despite a lot of anger and uncertainty about her new future, Nancy’s already strong religious faith was deepened. In fact, she understands the whole incident as a test of her faith. She found her experiences with other people with disabilities, during and after rehabilitation, to be the most “honest, intimate, and amazing” relationships she has ever known; a year after leaving rehab, she remains actively involved with those people and contexts, viewing those engagements and experiences as an extension of her Christian faith, and as a counter to the values of the corporate culture in which she still has to work (primarily for the insurance benefits).

Nancy is still working out “what this all means,” the larger significance and the day-to-day consequences of her injury. Her account, and those of nine other women living with severe brain injury, receives extended and first-person explication in the chapters to follow. This very brief gloss is meant to provide an opening indication of the ways an acquired brain injury is not just a personal crisis for an individual but also entails a major change in social position. Learning how to live with brain injury is a struggle that revolves around the question of *who am I?* This is more than a psychological question, because it involves negotiating the powerful cultural store of narratives and practices relating to disability and to personhood. Identity as a social phenomenon becomes salient in new ways as one is perceived and positioned as *different*. Whatever else it may involve in terms of adjusting to new impairments, working out how to live with brain injury is a struggle with the many representations and abstractions that mystify and divide one in relation to self and others. It involves significant work of personal reconstruction that will be shaped in various ways by competing systems of meaning, representation, and legitimacy (Garland-Thomson, 2005, 2011; Goodley, 2011; Hogan, 1999; Thomàs, 1999). It entails questions about what it is *good* to be, and what are proper relationships to

self and others; living with brain injury is therefore an ethical and inter-subjective negotiation. Furthermore, living with brain injury involves identifying or creating a sense of what it is *pleasing* and enjoyable to be; it therefore entails aesthetic negotiations of being in the world.

This book offers an analysis of extensive interviews conducted with ten women at varying stages of recovery from and living with brain injury. The primary focus is on how the women reauthor identity, meaning, and relationships post-injury. It looks at their strategies for negotiating the complex array of narratives, practices and contexts that support and/or impede that process. The use of terms like “reauthoring” and “negotiation” intentionally emphasizes agency, creativity, and complexity in the women’s experience of negotiating living with brain injury in an “ableist world.” They are also meant to confer value on the accounts, and the ways they might enable a “reimagining” of living with brain injury, and of disability more broadly (Garland-Thomson, 2005). In that regard, it is worth pointing out that the term “negotiation” is used here in the sense of adaptation married to opposition in response to dominant forces (Gramsci, 1971), not in Goffman’s (1963) sense of managing stigma and negotiating a spoiled identity within terms and conditions that stigmatize and spoil (Fine & Asch, 1988a; Hogan, 1999).

Dominant narratives about disability, particularly brain injury, negate complexity, agency, and creativity; people with disabilities are generally represented as broken, abject, lacking, unfit, and incapable, or more sentimentally as suffering and brave. Such narratives subjugate the lives and bodies of people we think of as disabled (Garland-Thomson, 2011). They also limit the imaginations of people who consider themselves nondisabled (Siebers, 2008). The women and their accounts are therefore positioned in this book in terms of human variation, rather than essential inferiority or lack; their voice and their agentive struggles are foregrounded in the interests of “formulating a logic that allows people to claim the identity of disabled without having to conceive of it as a diminishment of self” (Garland-Thomson, 2005, 1567).

Meaning, in relation to brain injury and disability, can be understood in two ways: in terms of *consequences* and in terms of *significance* (Bury, 1991). As consequences, meaning refers to the practical impact of a disability on roles and relationships in day-to-day life, such as adjusting to functional limitations or fatigue and the changes in roles that

these may demand. As significance, meaning references the social or cultural connotations and symbolizations that surround and define disability and being disabled. Literary accounts by people with disabilities consistently testify to the fact that adjusting to an acquired impairment ultimately pales in comparison to adjusting to the stigmatization, disqualification and division that comes from being classified as disabled (Garland-Thomson, 2005). Both ways of understanding meaning make embodied experience central: a shifting spatial, temporal, and culturally mediated relationship to the world and, in that, agentive and epistemologically valuable engagements with that world by people with disabilities (Garland-Thomson, 2011; Siebers, 2008).

Consequences and significance are, of course, interrelated: cultural significations and symbolizations of impairments have practical consequences for people with disabilities in terms of frameworks of meaning, representation, and self-understanding; different impairments lead to different contexts and to different vulnerabilities and availabilities to disabling and disqualifying significations (for example, Hughes, 2009). The consequences/significance distinction, though, helps to highlight the shifting terms and contexts in which meaning and identity must be negotiated following brain injury. This distinction also relates to the one drawn by disability rights and disability studies between *impairment*, referring to functional limitations and bodily conditions taken to be impaired, and *disability*, referring to the heterogeneous social processes that mark and marginalize some bodies and minds as deviant and deficient (Garland-Thomson, 2011, Mintz, 2007; Oliver, 1996; Snyder & Mitchell, 2006). Disability, therefore, indexes a broad array of significations that the women we will meet in this book must contend with and negotiate—through compromise, renunciation, or reimagining—in a reauthoring of identity and relationships post-injury, and in striving to reauthor the oppressive social scripts in place for those identified as disabled (Garland-Thomson, 2005).

In the rehabilitation and psychology literatures, concerns with identity and self have recently come to be recognized as endemic to living with brain injury (for example, Gracey & Ownsworth, 2012; Heller et al., 2006; Klonoff, 2010; Levack, Kayes & Fadyl, 2010; Lorenz, 2010; Nochi, 2000). Identity-related issues that have been identified as important in brain injury recovery include: (1) disconnect with the pre-injury

identity and learning or reconstructing a new, post-injury self; (2) social disconnect and building new relationships and a place in the world; (3) the need for contexts and resources to engage in meaningful activities and roles; and, (4) “loss of self” in the eyes of others, involving negative perceptions and social categorizations of brain-injured persons by themselves, by others, and by culture in general (Ditchman, 2011; Douglas, 2012; Gracey & Ownsworth, 2012; Jones et al., 2012; Klonoff, 2010; Levack, Kayes & Fadyl, 2010; Lorenz, 2010; Nochi, 1998). With the recent development of frameworks like “social neuropsychology” (Haslam et al., 2008; Jones et al., 2011) and “holistic neuropsychology” (Klonoff, 2010), rehabilitation psychologists have taken a “social turn” in a traditionally individual and biocognitive field, giving recognition to social processes that are the material from which personal identities are constituted (Gracey & Ownsworth, 2012).

Attention to identity and identity processes, and how these are bound up with social factors and contexts, represents a catching up to the rhetoric of a biopsychosocial model of disability and the goal of understanding the interactions between individual and environment that determine life experiences, functioning, and outcomes for people with disabilities (Ditchman, 2011; Dunn & Elliott, 2008; Heinemann, 2005; World Health Organization, 2001). This is certainly a welcome advance over the litany of deficits and the objectifying individualization that has traditionally characterized the medical/rehabilitation literature on brain injury (Klonoff, 2010; Lorenz, 2010; Strandberg, 2009). These advances also represent an overdue, if very preliminary, catching up to the decades of progress in disability rights and disability studies, which began with a “social model” of disability (for example, Oliver, 1990).

Aspects of identity reconstruction following brain injury can be meaningfully addressed within the social identity theory approach employed by rehabilitation psychologists, which focuses on stages of categorization, identification, and comparison (Swain & Cameron, 1999). Social identity, in this model, is defined by social roles and group memberships that provide an important means through which a sense of self is formed and maintained (for example, Jetten, Haslam & Haslam, 2012). Attention may be given to experiences of personal and social discrepancy, or the tendency to view oneself negatively in

comparison to both the pre-injury self and to other people (Gracey & Ownsworth, 2012). Attention may also be directed to the loss of identity (the pre-injury self) and disdain for the new, post-injury self (Klonoff, 2010; Nochi, 1998). Moreover, drawing on social psychological research on stigma and identity processes more generally, attention has begun to be directed to the loss of self in the eyes of others due to the negative perceptions and social categorizations of brain-injured persons by others in society (Jones et al., 2012; Klonoff, 2010; Nochi, 1998; St. Claire & Clucas, 2012). For instance, Gracey and Ownsworth (2012) propose that for “many who struggle with the adjustment process, it is the actual or feared negative experience of self in social contexts, and the resulting attempts to manage ‘threats to self’ that result in a long-term maladjustment process. This is marked by increased self-discrepancy and failure to develop an updated and adaptive post-injury identity” (291).

If social identity theory holds some relevance, the last quote also indicates how the approach is nevertheless limited by its psychological perspective. There is little opportunity there for people with brain injury to work through contested identities and multiple encounters with the subjectifying effects of marginalization, let alone their experiences of multiple selves (for example, Heller et al., 2006; Hogan, 1999). Nor does social psychological identity theory offer an accounting of the toll taken by the emotional labor involved in the assault on the self in response to demands to fit the expectations of others (Hochschild, 1983). People with disabilities, in one way or another, learn to respond to expectations of nondisabled culture and the policing of self-presentation; they are expected to fit the categorizations and fantasies of others, along with social prescriptions and proscriptions of affect and emotion (Goodley, 2011; Marks, 1999; Olkin, 2009; Shildrick, 2007).

From the viewpoint of disabled people, then, their personal and social identities have been preformed within a framework from which they have been excluded, which makes the goal of adjustment somewhat treacherous. In defining parameters that state emphatically what brain injured people are *not* (normal, competent, qualified), dominant cultural narratives and practices determine what their self-reference is measured against (Swain & Cameron, 1999). Because disability is regarded as both a personal attribute and an undesirable quality—one to be managed—there is sparse incentive to view, let alone take up, brain

injury as a positive part of one's social identity, except perhaps to appear well adjusted in the eyes of psychologists and rehabilitation professionals. There are, however, innumerable opportunities to become caught up in various forms of self-oppression (Swain & Cameron, 1999). A priori, the process of reauthoring identity and meaning following brain injury is overpopulated with the varied and conflicting intentions of others. Indeed, the terrain is especially constrained and overpopulated for people with brain injury because the institutional constraints are so great and overdetermined. The negotiation of identity, needs, and relationships—and the construal of the meaning of brain injury itself—involves medical and rehabilitation professionals, legislators and policy makers, the media, clergy, employers, academic theorists, support organizations, advocates, friends and family, and others classified as disabled. In addition, people recovering from an acquired brain injury also have to contend with themselves—their prior, “premorbid” selves—and the narratives of self and the world (and of disability) they had held pre-injury. They must take up the ethical and aesthetic negotiations of self-in-the-world while being unable to rely on a lifetime of prior cognitive practices and resources. In addition, they have the daunting task of distinguishing which of the problems they confront—problems of meaning, of access, of separation—are symptoms of impairment and which are the symptoms of culture.

There is little scope within rehabilitation psychology to account for a redefinition of disability or to challenge existing relations, roles, identifications, and categorizations—and even less scope for challenging the dominant ideologies that hold these in place (for example, Corker & French, 1999; Fine & Asch, 1988a; Goodley, 2011; Goodley & Lawthom, 2006). Thus, as Swain and Cameron (1999) point out, the social comparison of importance for disabled people is not a comparison of the attributes of one group (disabled) against another (nondisabled), but rather an analysis of the social structures that favor some people over others. The reauthoring of identity, meaning, and relationships post-injury, then, involves confronting the variety of practices and narratives of exclusion and disqualification that adhere to acquired brain injury. These are the narratives and practices that force invidious comparisons, define and naturalize social categorizations, and spoil identities and identifications. These narratives have legitimacy because they have

been authorized by those whose able-bodiedness and able-mindedness legitimize their cultural capital, authority and power (Garland-Thomson, 1997; Tremain, 2005). The very language of adjustment and integration configures disabled people *as* the problem, because it structures an understanding that the disabled person should become more like nondisabled people, rather than offering possibilities for accepting, even affirming, the disabled person for who she is (Garland-Thomson, 2011; Siebers, 2008; Snyder & Mitchell, 2006; Swain & Cameron, 1999).

This is not to say that psychology is unimportant—or inherently dangerous—in making sense of living with brain injury, particularly if it allows us to conceptualize a situated, embodied, feeling, and agentive person engaged with a world of practices and ideologies that variously enable or disable their efforts to construct meaning and identity (for example, Goodley & Lawthom, 2005, 2006; Kelly, 2006; Nochi, 2000; Olkin, 2009; Rappaport, 2000; Thomas, 1999; White & Epston, 1990). While disability studies has helped articulate a counternarrative to the medical model of disability by pointing out the many ways that culture disables certain people, until recently it allowed little ideological room for considerations of personal identity or embodiment; the social model's aversion to individualizing disability and to anything that suggested a psychological determinism rendered individual psychology difficult to address (Shakespeare, 1996). In recent years, however, that field has recognized the need to complement sociocultural approaches with approaches that can make sense of the psychoemotional aspects of life that people with disability experience (Goodley, 2011; Olkin, 2009; Siebers, 2008; Thomas, 1999). The goal is to make sense of these aspects of life in terms of disability rather than in terms of impairment, and to account for the personally or intersubjectively felt effects of the social forces and processes which operate in shaping the subjectivities of people with disabilities (Thomas, 1999; see also Goodley & Lawthom, 2006; Mintz, 2007; Olkin, 2009). That shift has been accompanied by concern about preserving the possibility for understanding and recognizing personal agency (however entangled it may be), variation, embodiment, and situatedness (Corker, 1999; Garland-Thomson, 2011; Scully, 2008; Siebers, 2008).

Confronting the ways that they have been objectified, divided against themselves and from others, and recruited into particular subjectivities

engages women with brain injury in struggles that involve and question their status as individuals. These are struggles of identity, and they involve a kind of positive identity politics that if nascent for women with physical disabilities has so far been nonexistent for those with cognitive impairments (Garland-Thomson, 2011; Sherry, 2006; Siebers, 2008). These struggles of identity are complex and paradoxical: on one side they assert the right to be different and to affirm everything that makes the women truly individual. Yet, on the other side, they involve a refusal of everything that separates or divides them, every practice, narrative or positioning that breaks their links with others and splits up community life—everything, that is, that forces them back on themselves and ties them to a constrained and constraining identity (Foucault, 1983). Thus, struggles for a positive disability identity involve an affirmative recognition and valuation of difference *and* a resistance to division from oneself and from others, and to constraining, flattening and isolating forms of subjectification.

Furthermore, and perhaps particularly for brain injury, reauthoring identity also entails struggles in opposition to the effects of power linked with knowledge, competence, and qualification: struggles against the privileges and authority of scientific, economic, political, and social knowledge that operate to define and control people through objectification (Foucault, 1983; Tremain, 2005). This has been true for the struggles against the various authoritative and moral configurations of race, sex/gender, and sexuality; these configurations historically share with disability similar and intersecting forms and practices of exclusion, colonization, medicalization, invalidation, infantilization, and rehabilitation (Campbell, 2009; Connor, 2008; Ghai, 2006; Goodley, 2011; K. Q. Hall, 2011; Leonardo & Broderick, 2011; McRuer, 2006; Michalko, 2002; Sherry, 2004, 2006; Venn, 2000). But the linking of power to competence and qualification may be especially pronounced (though not unique) in the context of brain injury due to the casting of impairments as medical crises in need of cure through technology, the “entry” into an acquired brain injury and sometimes totalizing sequestration in treatment settings, the division from family and self, and the fact that it is one’s *brain* in question (Sherry, 2004, 2006; Siebers, 2008; Tremain, 2005).

Finally, the struggle over identity and against attitudinal and physical barriers also involves resistance to the shame imposed on people