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; Thomas, 1999). It entails questions about what it is good to be, and what are proper relationships to
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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 agentic 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
with brain injuries that divides them from themselves and from others. It involves resistance to the distortions imposed on them by disqualifying narratives and constraining environments. It also entails resistance to the variety of mystifying representations imposed on them, directly and indirectly, by persons and by culture (Foucault, 1983; Snyder & Mitchell, 2006; Tremain, 2005). Recovery from and living with brain injury involves a refusal of the various forms of economic and social violence that ignore who one is individually, as well as a refusal of the scientific and administrative inquisitions that determine and constrain who one is (Foucault, 1983; see also Goodley, 2011; Ghai, 2006; Snyder & Mitchell, 2006; Tremain, 2005, 2006). Rather than a rehabilitative/therapeutic inquisition into brain injury recovery, this book seeks to recuperate the narratives of these women with acquired brain injury and their strategies for reauthoring a meaningful response to the question of “who am I?”

Identity and Narrative Reimaginings

Cindy: I’ll give you this article that I wrote, for a women’s journal. I think you’ll like it because you’re a community person, because it actually starts off talking about the inability to, I mean the dissociation I experienced from my body, and the dissociation I experienced communally, in the women’s community. And I kind of like used the parallel, and then how I reclaimed, you know, a sense of community and a sense of personal body and wholeness through my work in disabled women’s issues.

Cindy and her fiancé were victims of a violent random attack while they were camping in a state park in Hawaii. Her fiancé was killed; Cindy barely survived, with extensive injuries to her face and the right side of her head. She was partially paralyzed on her left side, with some loss of vision and hearing on the left side. Twenty years after the injury, she has some relatively mild cognitive difficulties and a constant but manageable posttraumatic anxiety. A “gigantic turning point” in Cindy’s recovery process was coming to identify with the disability rights community, an identification—in fact, something of a conversion experience—that was initially “very scary, very hard,” which she resisted quite
a bit as not being her personality. She has gone on to become a nationally recognized advocate for people (particularly women) with disabilities, and has cocreated a very supportive and proactive community in which she feels safe and can work collectively for change. Her membership in a community of disabled women helped her identify and overcome a loneliness and sense of isolation she had been feeling but not quite recognizing since her injury.

Cindy’s account illustrates how it might be possible to author an affirmative identity post-injury, an identity that incorporates disability but is not flattened to a medicalized condition or a singular way of knowing oneself and others. A key point is that if dominant narratives and practices surround and animate brain injury and disability in disqualifying and divisive ways, then counternarratives that challenge social norms and configurations can prevent individuals from being isolated, from being “trapped within story-lines of the prevailing narratives” (Thomas, 1999, 55; see also Rappaport, 1998, 2000). In the reauthoring of identities, people with (and without) disabilities can strengthen counternarratives so that oppressive social narratives begin to unravel (Cole et al., 2011; Finger, 2004; Linton, 1998, 2007; Thomas, 1999; Torrell, 2011).

Narrative and an authoring metaphor are useful here for several interrelated reasons. Most obviously, much of the material presented in the chapters that follow takes the form of life histories, which are narrative in nature and structure. Identity is taken here to refer to “an entity that considers itself to remain the same being in spite of changes over time” (Venn, 2000, 98). Identity-as-narrative knits the past of a life (the “having-been”) to the “making-present” and to the future (the “coming-towards”), according to culturally stored emplotments of being and doing that enable (or not) the figuration of each “self” (Venn, 2000, 21; see also Ricoeur, 1984, 1991). Identity, then, is not the self-identicalness of a permanent and continuous entity, but a “mode of relating to being that can be characterized as selfhood . . . it is not reducible to the facticity of things-in-themselves” (Venn, 2000, 98–99; see also Ricoeur, 1996). Self is constituted as an identity by the stories a person tells about herself and those that are told about her by others. Every identity is “mingled with that of others in such a way as to engender second order stories which are in themselves intersections between numerous stories. . . . We are literally ‘entangled in stories’” (Ricoeur, 1996, 6).
Identity-as-narrative, then, is fundamentally temporal and intersubjective, and therefore also cultural and ethical.

Identities are a means of inserting persons into a social world; they are narrative responses to and creations of social reality (Siebers, 2008). All of us come to be who we are through being located or locating ourselves, consciously and unconsciously, in social narratives that are rarely of our own making (Alcoff, 2006; Somers, 1994). The authoring metaphor in relation to identity emphasizes temporal and social processes, ongoing practices, strategies, interactions, assertions and refusals, rather than a once and for all or “true” resolution, and so provides a way of presenting and understanding living with brain injury as a developing, iterative, inter-subjective and “always-already cultural” complex of negotiations (Ricoeur, 1988; Venn, 2000).

Narrative also provides a conceptual framework that crosses disciplinary boundaries, for example between psychology, the humanities, and critical/political theory. Narrative is quite useful for spanning levels of analysis, between the personal, the interpersonal, and the structural/discursive, elucidating their relationships without reducing any one to the other (for example, Holstein & Gubrium, 2005; Mankowski & Rappaport, 1995; Polletta et al., 2011; Rappaport, 1998). Narrative as metaphor and as practice offers the means to handle the private/public, body/culture, and individual/social dichotomies that have been problematic for the conception and study of disability, and of persons and culture more generally (Corker, 1998; Garland-Thomson, 2011; Meekosha, 1998; Shakespeare, 1996; Wendell, 1997; see also Rose, 1992; Venn, 2000). In fact, there is particular usefulness in the possibilities narrative offers for an accounting of the many instances of both/and that define identity and disability: the importance both of agency and of social structure, of both the what and the how of accounting for oneself and the world, both the materiality of body and impairment and the socially mediated nature of our relationships to them, and of both personal and cultural historicity (the “little” narratives of lives and the grand narratives of culture). Narrative offers insights into the powerful role that time and spatial arrangements play in shaping people’s lives and embodiment in socially enabling and/or constraining ways (Freund, 2001; Sparkes & Smith, 2003; Venn, 2000). Like experience, body as lived and social is never knowable in unmediated ways, as truth-as-correspondence;
narratives are important because bodily experience is deeply embedded in narrative, and narratives emanate from embodied experience (Garland-Thomson, 2011; Smith & Sparkes 2002, 2005; Sparkes & Smith, 2003, 2005).

When personal and cultural (and scientific) narratives are understood not as transparent representations of reality or interiority but as ideologically mediated and culturally bound (and bound up) interpretive accounts, they can be understood to represent forms of social action (Atkinson & Delamont, 2006; Rappaport, 1998; Smith & Sparkes, 2008). Personal accounts of experience and identity are not private, virtuoso achievements but derive from—and therefore enable—social relationships (Gamson, 2002; Mankowski & Rappaport, 1995; Torrell, 2011). They are—at least potentially—a shared resource that can help guide action and give substance, creativity, and texture to people's lives (Finger, 2004; Gamson 2002; Garland-Thomson, 2011; Smith & Sparkes, 2008). A variety of social narratives, products of particular times and spaces, interact to constitute the ontological narratives of those who live in those times and spaces (Thomas, 1999). Counternarratives can provide alternative emplotments regarding disability and impairment that refuse and displace the tragic abjection story, that resist social oppression and allow different body-self and self-other relationships to emerge (Garland-Thomson, 2005; Smith & Sparkes, 2008; Rappaport, 2000; Wendell, 1996). Finally, narrative inquiry offers promise for engaged scholarship committed to varied and situated possibilities for individual and social transformation, resistance, and living life differently (Smith & Sparkes, 2008).

In relation to social change, disability studies theorist Tobin Siebers (2008) argues for the ways that narrative enables political and practical action by providing a rhetorical form that satisfies the requirements of negotiating a minority or marginalized identity:

Narratives about disability identity are theoretical because they posit a different experience that clashes with how social existence is usually constructed and recorded. They are practical because they often contain solutions to problems experienced by disabled and nondisabled people alike. They are political because they offer a basis for identity politics, allowing people with different disabilities to tell a story about their
common cause. The story of common cause is also the story of an outsider position that reveals what a given society contains. (104)

Critical awareness about disability requires the ability to abstract general rules based on personal experience while also being able to recognize how one's experience differs from that of others. Narratives of identity provide the means for such an abstraction—for the critical negotiations of sameness, difference, and cooperation between people—because they represent “significant theories about the construction of the real,” and provide useful information about how one can make an “appearance in the world” (Siebers, 2008, 105; see also Alcoff, 2006; Moya, 2002).

Fitting Together

Although people with brain injuries may have little power in society—in fact they may be disqualified in many instances from membership in society—their accounts and identities hold theoretical power because they reflect perspectives “capable of illuminating the ideological blueprints used to construct social reality. Disability identities, because of their lack of fit, serve as critical frameworks for identifying and questioning complicated ideologies on which social injustice and oppression depend” (Siebers, 2008, 105). Rosemarie Garland-Thomson (2011) extends this argument by articulating how “misfitting” represents a “spatial and perpetually shifting relationship that confers value and agency on subjects at risk of social devaluation by highlighting adaptability, resourcefulness, and subjugated knowledge as potential effects of misfitting” (592). Experiences of misfitting, if recognized for their political implications, make apparent the relational nature and fragility of fitting: “Any of us can fit here today and misfit there tomorrow” (597).

The discourse of individuality is a form of oppression that “has manufactured the community of disabled people as a community of ‘unrelated strangers,’ largely without the benefit of a relationship based on collective co-operation and trust” (Corker, 1998, 223). To the extent that this changed, the change is due to increased population density, along with diversifying and increasing forms of communication that have made it possible for individuals to form recognizably distinct groups
based on different and increasingly diverse relationships. The development of communities, often small enough to allow everyone voice—and a fit—has been important for allowing disabled people to challenge oppression and division (Corker, 1998; see also Cole et al., 2011; Torrell, 2011). Such settings, and the meaning-giving interactions they facilitate, provide people with disabilities places in the world, experiences of fitting (Williams, 1998). Importantly for people with disabilities, the construction of divisions between supportive, nurturing interpersonal relationships or networks on one side, and organized, critical social action opposed to structural and discursive oppression on the other serves to enable social control and various forms of division (Corker, 1998); that is to say that for people with brain injuries, it may be important for “fitting” to be linked to intentional and orchestrated “misfitting.” Social contexts in which to develop and be supported in personal and collective identities are critical, in both senses of the term.

Community reintegration and community outcomes have come to be recognized as important in the field of rehabilitation, most recently for brain injury recovery (for example, Douglas, 2012; Heinemann, 2005; Jetten, Haslam & Haslam, 2012; Ylvisaker & Feeney, 2000; Ylvisaker, Feeney & Capo, 2007; Ylvisaker et al., 2008; Ylvisaker, Turkstra & Coelho, 2005). Research has identified strong links between social activity, self-identity, and post-injury adjustment, and some work is underway to focus on these constructs in rehabilitation (Douglas, 2012). But rehabilitation research and practice related to community integration are limited on a number of fronts, including the same limitations that characterized the work on social identity discussed above: a lack of critical attention to aversive physical and social characteristics of community contexts for people with disabilities, and the demands made on them to do the costly emotional labor of adjusting to the disabling expectations of others. That is, the adjustment is all on one side, with no allowance or valuation for “creative maladjustment” (King, 1968) to the oppressive or objectifying experiences and expectations that structure community functioning and restrict the meaning of access (Garland-Thomson, 2011; James, 2011; Sherry, 2006; Swain & Cameron, 1999). While experiences of misfitting can and often do lead to segregation and alienation from community and exclusion from full participation as citizens, they might also produce positive oppositional
consciousness, an awareness of social injustice, and the formation of a “community of misfits” that can collaborate not only for a liberatory politics but also for new ways of relating to self and others—including for the able-bodied (Garland-Thomson, 2011, 597). But that is only if the misfits can be allowed to escape the tyranny of adjustment.

Another limitation in the rehabilitation literature is in how “community” and “integration” are understood and measured. “Community” is typically conceptualized broadly and generically, rather than referring to a specific (or meaningful) context (Ditchman, 2011; Kelly, 2006). Integration typically focuses on individuals’ access to and frequency within community settings, and to activities like shopping or spending time with friends, with little attention to the influence a person feels she has in communities, her sense of belonging or mattering in community contexts, or an experience of reciprocity in relationships (Ditchman, 2011; Chronister, Johnson & Berven, 2006). These are central aspects of sense of community, or SOC (Fisher, Sonn & Bishop, 2002; McMillan & Chavis, 1986; Sarason, 1974). One of the orienting concepts of community psychology, SOC is an interactionist perspective that aims to link extra-individual phenomena with psychology, with a focus on individuals’ experience—rather than simply their physical presence—in specific community contexts. Though SOC promises particular value in relation to disability, very little work has been done in this area (Ditchman, 2011). While offering a significant practical and theoretical advance over the traditional rehabilitation literature on community, the sense of community literature has tended to focus on geographical community (that is, neighborhood), with little attention to other forms of community, such as those based on shared experiences or identities (but see Aber, Maton & Seidman, 2011; Mankowski & Rappaport, 1995; Rappaport, 1995, 2000). Nor has it attended to virtual and “textual” communities, which may be of particular relevance to people with certain kinds of disabilities or people living in rural or otherwise isolated locations (for example, Cole et al., 2011; Finger, 2004; Miller et al., 1993; Torrell, 2011).

The kinds of oppression, marginalization, and invisibility—“attitudinal barriers”—that brain-injured people experience in communities have also received little attention in the SOC literature, which is surprising given its conceptual focus on the experience of community
(see Townley & Kloos, 2009, for a notable exception). In fact, it seems fair to say that the SOC literature has so far given little critical attention to how difference in general relates to sense of community. It also offers little by way of assistance in understanding the complexities of people’s membership in multiple communities, or the challenges of navigating within and between these identifications.

All of the women in this book referenced community—more accurately communities—as important in various ways and forms: for providing material, social, emotional, spiritual, and/or political support; for performing and audiencing meaningful, competent, and affirmative identities; for providing and receiving information and expertise; and for work. None of the women identified solely as disabled, and they all identified different communities and identifications as important or central: a variety of religious communities; the Black community, both politically and in terms of a specific place and set of relationships; queer women; the women’s community; a town or neighborhood; high school or college; professional colleagues; and, family. There was also significant variation and complexity in how they talked about what their disabilities meant for fitting or misfitting those communities. Two of the women, both fairly early in the recovery process, had no relationship at all to what could be called a disability community; the other eight women did, but each held differing, sometimes fluid, degrees and forms of relationship or identification with it and with a disability identity. Those women who identified connection to other disabled people as important discussed those relationships and identifications in varied and complicated ways.

The complex fluidity of community identification gets specific attention in the chapters that follow, but it bears preliminary mention because it is relevant to framing the women’s reauthoring of identity, particularly their strategies for negotiating the variety of narratives, practices, and contexts that enable or disable that process. All of the women were members of multiple communities and relationships, and they discuss varying experiences of fitting and misfitting across and within those social locations. That is, misfitting was a common, if variously interpreted experience, both inside and outside “disability community.” In some cases, it was what these women brought of their experiences with disability to their other, “able-bodied dominated”
relationships and settings that generated critical consciousness both in themselves and in those others. And vice versa: some of the women brought experience with the women’s movement, queer politics, Black consciousness, or spirituality to bear in constructing a positive, critical consciousness about disability. All of which is to say that people are generally part of multiple communities and negotiate multiple and complexly interrelated identities, and they do so in situated, affective, and embodied—rather than just theoretical—ways.

The field of rehabilitation has given little attention to the relevance of developing an affirmative disability identity, or to the need to confront—not adjust to—the ubiquity of disabling practices and narratives. Conversely, disability rights has made identification with and participation in disability community central to positive personal and social change, but the emphasis has largely been on disability community and identity. Feminist disability studies have done considerable work on illuminating the intersection of woman and disability, in both critical/theoretical and experiential ways. That is, the field has explicated the ways that sex/gender ideology intersects—overlaps and is reciprocally structured by—ableist ideologies, while also examining the life experiences and strategies of women negotiating that intersect (a list of citations would be long and surely incomplete, but points of entry will be found in Fine & Asch, 1988b; Fries, 1997; Garland-Thomson, 2002, 2005; Ghai, 2006; Gonzalez, 2008; K. Q. Hall, 2011; Klein, 1992; Linton, 2007; Meekosha, 1998; Mintz, 2007; Morris, 1996; Schriempf, 2001; Wendell, 1996, 1997). Recent work has begun to articulate the intersection of queer theory and disability (for example, Brownworth & Raffo, 1999; Clare, 1999; McRuer, 2002, 2003, 2006; Sherry, 2004, 2006; Shildrick, 2007), though with a heavier emphasis on theory and as yet little life writing or accounts of experience. There is a burgeoning of work on the intersection of race and ableist ideologies, particularly in the context of colonialism and postcolonial studies (for example, Connor, 2008; Ghai, 2006; Leonardo & Broderick, 2011; Meekosha, 2012; Michalko, 2002), but as yet there is little critical work on personal or situated experiences of navigating lived identities as, say, Black and disabled (James, 2011; see also Balcazar et al., 2010). All of this work (and others that are not cited here) is important in illuminating the ways that ideologies of race, sex/gender, sexuality, and the political economy
intersect in mutually supportive and informing ways, thereby exposing the similarities between different and differently marginalized identities and their relation to oppression. It also helps lay bare the complicated workings of ideologies that split up community life and divide us from ourselves and others while also denying everything that makes us truly individual.

Because this work is largely highly theoretical and complex it is not just difficult to navigate but also raises critical concerns for representing and theorizing the experience of people with disabilities (Corker, 1999; Davis, 2001; Hughes, 2009; Mitchell & Snyder, 1997; Sherry, 2006). If the literature and questions of representation and theorization are difficult to navigate, the lived experience of people whose lives involve negotiating these intersections are particularly complex, sometimes treacherous, in the context of brain injury and disability, as will be clear from all of the complex permutations of identities and social positions that just the ten women in this volume represent. Work on intersecting and multiple identities does, however, underscore the complexity and power-laden nature of identity and community (and their representation), which needs to serve as contextualization of the women's difficulties (and solutions) in navigating them. The experience of multiple selves can provide a critical point of analysis for understanding how the taken-for-grantedness of everyday interactions and the stability of social practices are actually not at all granted or stable (D. E. Hall, 2004; Hogan, 1999). Also, and germane to the interests of this book, multiple identities and intersecting forms of oppression point to the theoretical and practical power to be gained from sharing and representing the experiences of oppression and struggle—of misfitting—lived by minority or marginalized people, both separately as individuals or groups and in relation to others differently marginalized (K. Q. Hall, 2011; Scully, 2008; Siebers, 2008). That is because, as the accounts in this book demonstrate, attention to the similarities between different and differently marginalized identities exposes their relation to oppression while also increasing the chances for common cause (Alcoff, 2006; Collins, 2000; K. Q. Hall, 2011; Johnson & Henderson, 2005; Kelley, 1997; Moya, 2002; Moya & Hames-Garcia, 2000).

A final theoretical point needs to be made because it is closely related to the aims, methodology, and reading of this book. What
follows are accounts of reauthoring identity. There is a risk that in presenting these authorial processes that the singular nature of the autobiographical voice might reinforce a pejorative assumption about disability: that the experience of disability is an isolated one and that the issues addressed are personal problems that do not require social and political action (Mitchell, 2002; Stewart, 2011; Torrell, 2011). In the employment of the narrative and authoring metaphors here, and in a focus on identity and experience, there is the risk of reinforcing a singularity of disability, of severing the connection between the personal and the political dimensions of both disability and the authoring of identity. That is, there is a risk of reinscribing the individualizing and isolating practices of medical/rehabilitation discourses and practices in relation to disability. As Lennard Davis argued, “by narrativizing an impairment, one tends to sentimentalize it and link it to the bourgeois sensibility of individualism and the drama of an individual story” (1997, 3–4). However, the goal in the presentation of these accounts is not to elucidate the struggle against impairments or a singular and heroic overcoming of deficits but to foreground the highly social negotiations of ableist and individualistic ideologies. The intention is to employ autobiography and voice—specifically the voices of brain-injured women that have been absent in the literatures of rehabilitation, psychology, and disability studies—toward a conception of individual lives in the service of creating positive, even liberatory, resources for living and identity for disabled people, on both a personal and a socio-political level (Finger, 2004). In other words, the narratives of individuals can affirm the potential of “singular” voices for constructing community—in a variety of forms and combinations—and contributing to personal and social change (Crossley, 2003; Frank, 2004; Linton, 2007; Smith & Sparkes, 2008; Torrell, 2011). And, because brain injury and disability are so seldom presented as an integral part of one’s embodiment, character, life, and way of relating to the world, and even less often as part of the spectrum of human variation, the women’s accounts might enable a “re-imagining” or “resymbolization” of disability and disabled people (Garland-Thomson, 2005). They may also enable a reimagining for (currently) nondisabled people.
What Follows

This book gives priority to the voice and experiences of women living with brain injury. When women (or men) with brain injury are spoken of, it is almost invariably by and in the terms of others—doctors, researchers, family members—and so often become stories about others. The person with the brain injury is typically framed as a problem, something about which something must be done. Therefore, it is a central aim here to present the women as artful, if entangled, agents, strategists, and epistemologists. The accounts present the women’s work and art—and difficulties—in creating and refashioning selves and identities in multiple ways and forms and in different contexts. To that end, the interview material is presented to preserve the length and form of the women’s narratives.

A second aim, however, is to attend to the dominant cultural narratives and practices that the women struggle against—with varying forms and degrees of critical consciousness—and to how they do it—successfully, unsuccessfully, or figuring that out. There is, then, a dialogical back-and-forth between story telling and story analysis, attention to what the women say and critical attention to constitutive, entangling and dividing effects of cultural discourses and practices (Smith & Sparkes, 2008). This means there is a self-conscious attention to interpretive practices—the women’s, both singly and in relation to one another’s accounts, and my own, which also extends to subjecting theory to the women’s accounts, not just the more usual other way around. But, the commitment is to always being on the women’s side in that analysis, as well as a theoretical and methodological desire to clearly distinguish between the women’s interpretive resources and aims and my own (Holstein & Gubrium, 2005).

Examining data from different viewpoints is intended to value the complexity and diversity of the women’s accounts of disability and impairment, but it does also construct that complexity (Coffey & Atkinson, 1996). The goal is an evocative, empathetic, multivoiced presentation in which the construction of meanings remains open and unfinalized, and the reader will not just know the facts but can also keep in mind the complexities of culture, society, and concrete moments
of lived experience (Ezzy, 2002; Frank, 2004; Richardson & St. Pierre, 2005). The third aim—one that should be accomplished in effectively documenting how identity, meaning, and social reality are constructed, sustained, and altered, and not once and for all or all at once—is to link these political and aesthetic accomplishments of meaning to social action, and to the development of resources and perspectives for personal and social change.

Organization of the Book

Chapter 1 (“People and Methodology”) introduces the ten women who are the focus of this book along with two medical professionals, a physiatrist and clinical neuropsychologist, who had first hand knowledge of the women’s “cases” over a significant period of time. The women are introduced in brief biographical sketches that also provide information about the nature and severity of their injuries, number of years since those injuries, and other biographical information drawn from their accounts. I position myself, as participant and researcher, in terms of my relationship to the women and in terms of methodological and analytical approaches. The chapter describes the procedural methods for interviewing, transcription, analysis and presentation of data. It concludes with some words about words, and some of the challenges of vocabulary and connotation related to researching, writing and talking in the context of disability.

Chapter 2 (“Meeting Post-Injury”) takes up the influences and experiences of early recovery and rehabilitation settings, practices, and communications. Drawing on interviews with rehabilitation professionals, the chapter begins with some perspective on rehabilitation practices and contexts, including their changing climate under managed care. The major portion of the chapter draws on the women’s discussion of their experience and the effects of early recovery in inpatient and outpatient rehabilitation settings.

Chapter 3 (“Oneself as Another”) discusses coming to terms with the disconnect or division between the pre-injury and post-injury selves. It serves as bridge between consideration of rehab in chapter 3 and of the “outside world” experiences of the subsequent chapters, and shifting the site of fighting from one’s body and brain to the disabling narratives.
and arrangements of the ableist world—as well as decisions about when to fight and when to let it go—a theme picked up in chapter four.

Chapter 4 (“Fighting”) addresses challenging or resisting cultural barriers in place for people with brain injury: at work, at school, and in the range of contexts in which the women did or wanted to participate. This involved specific fights to gain access, agency, or legitimacy, for example against transit systems, employers, or universities. The women’s accounts also attend to more diffuse and pervasive fights, including the fight to identify and name forms and instances of oppression or exclusion, as well as struggling with identifying as disabled and/or with other disabled people.

Chapter 5—“Sense (and Sensibility) of Community”—considers the importance and value of finding a fit, creating or locating place and company within community. Again following the women’s accounts, this often meant finding a place and identification in a disability community, including the benefits and discontents of heterogeneity within and intersecting that community. Finding a place within or in relation to a disability community involves differences in types and severity of disability: “invisible” versus visible disabilities; primarily cognitive versus primarily (otherwise) physical impairments; and so on. But finding “place” also involves intersections and tensions with other identifications or positions, and finding a location or fit within the disability community also entails marking distance and differences within it. However, as mentioned earlier, two of the women had no connection to or identification with a disability community or identity, and those who did also pointed to central importance of other identities and communities. Thus, this chapter also considers finding or re-creating a place in other communities and the intersections of several identities.

Chapter 6 (“Wrestling with an Angel”) addresses the metaphysics of brain injury and disability. Metaphysical questions and commitments cut across most of the themes, relationships, and dilemmas discussed throughout the book, this chapter brings them—and their varied forms and functions—forward for direct attention. Chapter 6 focuses on the variety of spiritual and religious narratives and affiliations the women discuss, from the resolutely materialist to the most mystical, the positive or complicating roles those have played in their authoring processes, as providing the grounds for refusing forms of division
and subjectification, and as a “place aside” for asserting the immanent (thereby returning to and consolidating some themes and arguments of preceding chapters).

The brief concluding chapter (“Coda”) revisits and links the main themes of the book and its goals and considers some practical, theoretical, and ethical implications for research, practice, representation, and/or social action.