

Introduction

Ronald J. Berger

Disability is a social enigma. Throughout history, people have felt compelled both to stare at the disabled in their midst and then turn their heads in discomfort. Franklin Roosevelt is considered by many to be one of the greatest presidents in the history of the United States, but he had to hide his polio-induced paralysis and use of a wheelchair lest the public think him too weak to lead the free world.¹ The Bible teaches that “Thou shalt not curse the deaf nor put a stumbling block before the blind” (*Leviticus*), but also that “If you do not carefully follow His commands and decrees . . . the Lord will afflict you with madness, blindness and confusion of mind” (*Deuteronomy*).²

The institution of the “freak show,” which reached its heyday in the nineteenth century but lasted in the United States until the 1940s, featured the disabled as public spectacle. People with physical disabilities and bodily deformities, as well as tribal nonwhite “cannibals” and “savages,” were displayed for public amusement and entertainment along with sword swallowers, snake charmers, bearded women, full-bodied tattooed people, and the like.³

The rise of the “medical model” of disability helped change this state of affairs. People with disabilities were now deemed worthy of medical diagnosis and treatment and viewed more benevolently.⁴ But benevolence breeds pity, and the pitied are still stigmatized as less than full human beings. Thus, Jerry Lewis’s annual muscular dystrophy telethon features pitiable “poster children” who help raise money for a preventive cure, but it does little to help improve the lives of those who are already disabled. Some may wonder why one would even want to live in such a state. The storyline of Clint Eastwood’s 2004 Academy Award–winning *Million Dollar Baby* went so far as to suggest that euthanasia may be the most humane response to quadriplegia.⁵

In 2005, a film about disability of a radically different sort appeared on the cultural scene. Nominated for an Academy Award for best documentary, *Murderball* portrayed a group of wheelchair rugby players who challenged conventional views of disability. The highly competitive, outgoing, self-confident, and sexually active protagonists revealed an empowering side of the disability experience that relatively few people had seen. For readers of *Wheelchair Warrior*, it is our hope that the life story of Melvin Juetter—the story of a gang member who was shot and paralyzed and became a world-class wheelchair basketball player—will do the same.

I first met Melvin when he was enrolled in my criminology course at the University of Wisconsin–Whitewater in the spring of 1990. He seemed a quiet youth at the time, unlike the vivacious man I later came to know. But, of course, like many students, he did not reveal much of himself to me. He would not have stood out among his classmates had he not been one of the relatively few black students at my university and one of even fewer black students in wheelchairs.

I became reacquainted with Melvin a few years later. Amy Bleile, another student who uses a wheelchair, was taking my criminology course. I had assigned the class an autobiography of a Los Angeles

gang member to read.⁶ Amy said she knew Melvin and told me that he had been a Chicago gang member who was shot and paralyzed in a gang dispute when he was sixteen years old. She suggested that I invite Melvin to speak to the class.

Melvin graciously agreed to be a guest speaker. It was then that I learned of his involvement in, indeed his passion for, wheelchair basketball. Later, he told me that he had always wanted to write a book about his life and the sport that he loved so much. Coincidence would have it that I also had an emerging interest in disability issues. My daughter had just been diagnosed with cerebral palsy, and I was seeking the counsel of those who had experience living with a disability. Thus, the personal and the professional merged for me as the project that led to this book began to unfold.

Melvin is a remarkable young man. His paralysis from the shooting, he often says, was “both the worst and best thing that happened” to him. If he had not been shot, he would have “probably ended up in prison or been killed, like so many of [his] former gang associates,” friends and enemies alike. It was the reason he had gone on to college, made the U.S. national wheelchair basketball team, traveled throughout the world, and visited the White House for a photo op with the President of the United States.

Melvin had decided early on, when he was still recuperating in the hospital, that he was not “going to give in to self pity or despair.” He remembered how he and his friends had reacted to James, a neighborhood youth with muscular dystrophy. “Although James used a power chair,” Melvin recalls, “we all tried to include him in everything we did. We even changed the rules for touch football to accommodate him; if the passer hit James with the ball, it was counted as a catch. But James would at times feel sorry for himself, and some of the kids began to tire of his negative attitude” and stopped inviting him to play. Melvin didn’t want “to end up like James.” People told him he was in denial about his newly acquired disability, but he was determined to make the best of his situation.

People who write about disability often complain about the media's (and by inference my own) preoccupation with the so-called supercrips, those individuals whose inspirational stories of courage, dedication, and hard work prove that it can be done, that one can defy the odds and accomplish the impossible.⁷ The concern is that these stories of success will foster unrealistic expectations about what people with disabilities can achieve, what they *should* be able to achieve, if only they tried hard enough. This myth of the “self-made man” implies that society does not need to change to accommodate the needs of people with disabilities.

I do not view Melvin as a supercrip, however. His story and the stories of others like him indicate that these individuals did not “make it” on their own.⁸ These athletes—and indeed they are *athletes*—deserve credit for their perseverance and accomplishments in the face of adversity, but their lives must be understood in social context. Herein lies the crux of the sociological framework that informs this book: the dynamic interplay between *social structure* and *personal agency*, the two fundamental categories of general sociological discourse.⁹

Melvin's Life Story in Sociological Perspective

Sociologists use the concept of social structure to refer to patterns of social interaction and relationships that endure over time and that enable and/or constrain people's choices and opportunities. Social structure is, in a sense, external to individuals insofar as it is not of their own making and exists prior to their engagement with the world. Importantly, social structures are situated in time and place, in specific historical epochs and geographical environments.

Melvin grew up in Chicago in the 1970s and 1980s, on the city's south side, where the majority of residents are African American and many are poor. The South Side of Chicago is the city's largest section, covering over half of the metropolitan area. It includes commercial

districts and spacious parks, as well as pleasant residential neighborhoods and poverty-stricken communities. For four decades, it was the location of Chicago's largest housing project, the infamous Robert Taylor Homes, where about 20,000 (mostly black) residents lived in twenty-eight crowded apartment complexes that spanned about fifteen city blocks. Before city officials decided to demolish the project in the early 2000s, it was infested with gangs, drugs, and crime.¹⁰

Melvin's parents were from an entirely different social milieu since they grew up in rural Mississippi. Although they were from stable and economically secure families, they sought greater opportunities in the North. They were part of a historic wave of rural-to-urban migration known as the Great Migration that increased the size of Chicago's African American population from 10 percent in 1910 to 40 percent by 1980.

The residential destination of African American migrants differed from those of whites who came from either the South or abroad. Local white residents resorted to a variety of exclusionary practices to segregate blacks—discriminatory neighborhood covenants and bank lending policies, vigilante violence, and white flight. Consequently, black newcomers tended to settle in racially homogeneous neighborhoods, and regardless of class status—the Juettes could be considered working or middle class—they were more likely than their white counterparts to live in or on the fringes of poor areas marked by high rates of crime and gang violence.¹¹

Elijah Anderson, in his book *Code of the Street*, an ethnography of street life in Philadelphia, identified two residential value orientations, “decent” and “street,” which African American residents used to describe their own neighbors. The so-called decent families, like the Juettes, are relatively better off financially than their street-oriented neighbors. They socialize their children to accept conventional values of hard work, self-reliance, respect for authority, religious faith, and self-improvement through education. They tend toward strict child-rearing practices and encourage their children to be on guard against troublesome peers.¹²

On the other hand, parents from so-called street families—who are more likely to be unmarried with children and lead lives complicated by drug or alcohol abuse or other self-destructive behaviors—socialize their children to accept the code of the street. In that code, receiving respect—being treated with proper deference—is highly regarded. Even a fleeting or awkward glance or eye contact that lingers too long can be taken as a sign of disrespect, or “dissing.” Children witnessing interpersonal disputes learn, as Melvin did, that “might makes right.” In almost every encounter, the victor is the one who physically wins the altercation, and this person enjoys the esteem and respect of onlookers. Humility or “turning the other cheek” is no virtue and can in fact be dangerous. Failure to respond to intimidation by others only encourages further violation.

Anderson observes that since youths from decent families go to school and hang out with kids from the street, the distinction between the two social types is not always clear. Thus, decent youths often adopt a street posture and learn to “code switch,” that is, to behave according to different sets of rules in different situations. How far they will go in the direction of the street depends on how fully they have already been socialized by their parents, their degree of involvement in constructive social institutions, and their own decision making in the face of obstacles and opportunities that come their way.

Gangs are, of course, a prominent feature of the social environment confronted by urban youths. In large cities like Chicago, gangs have been around for decades. During the first half of the twentieth century, Chicago gang members were largely the children of economically disadvantaged European immigrants. By the time Melvin came of age, African American gangs, the history of which is described later in the book, had emerged as a dominant force on the streets. Regardless of historical era, youths have generally joined gangs for similar reasons: physical protection, fun and profit, and a sense of belonging to a close-knit group. Often, children have had older relatives, even parents and grandparents, who were involved in gangs. Moreover, gang members are not social

outsiders in their communities; they are sons and daughters, grandchildren, nephews and nieces, and neighbors' kids. The majority of their time is not spent in law-violating activities, and they behave appropriately in most social situations.¹³ Once Melvin got involved in gangs, for example, he still did well in school, attended church regularly, and even brought gang friends with him to Sunday services.

The core membership of a gang is generally tied to a particular neighborhood, or "hood." The city of Chicago, which expands over 228 square miles, has more than thirty identifiable neighborhoods. However, the notion of a neighborhood is somewhat of a misnomer since borders are permeable and disputed, and youths' networks of social relationships traverse these boundaries.¹⁴ In Melvin's case, he joined a gang whose core membership was tied to a neighborhood outside of his area, which made him vulnerable to rival gangs within his own community.

The social-structural conditions that I have been describing do not, of course, exist independently of personal agency. They are ongoing accomplishments of people whose actions reproduce them in specific situational contexts. Nevertheless, people are not mere dupes or passive recipients of social structures; they are thinking, self-reflexive beings who are capable of assessing their circumstances, choosing among alternative courses of action, and consequently shaping their own behavior.¹⁵ Through this capacity for personal agency, they exercise a degree of control over their lives and at times even manage to transform or reconfigure the social relationships in which they are enmeshed. Social psychologists often describe this as a matter of self-efficacy, that is, the ability to experience oneself as a causal agent capable of *acting on* rather than merely *reacting to* the external environment.¹⁶ If this were not possible for people to do, personal and social change could not occur.

According to Mustaf Emirbayer and Ann Mische, personal agency consists of three interrelated yet analytically distinct components: the

habitual, projective, and practical-evaluative.¹⁷ The *habitual* component entails social action that reproduces social structure; it is generally unreflective and taken for granted, although it is nonetheless agentive since it entails attention, intention, and effort. Melvin, for example, did not create the socially structured gang milieu in which he found himself as a youth, but through his actions, he helped to recreate or reproduce the conditions previously laid out for him.¹⁸

The *projective* component of agency entails the imaginative dimension of human consciousness, the ability to achieve cognitive distance from the routine and envision future possibilities. Conflic-tual or problematic situations are often the driving impetus for such imaginative projection since they disrupt the taken-for-granted and present themselves as challenges not easily resolved through habitual modes of action. Norman Denzin calls these situations “epiphanies,” moments of crisis or transformational experience that indelibly mark people’s lives.¹⁹ Epiphanies have the power to “alter the fundamental meaning structures” of life²⁰ and, as Arthur Frank observes, are therefore “privileged in their possibility” for personal growth and change.²¹ They can, on the other hand, also be potentially debilitating, occasions of impotence and despair. In Melvin’s case, his gunshot injury was the epiphanic experience that compelled him to reflect on his life and seek an alternative future. But in the initial phase of his recovery, it was not clear to him what that future would entail. He found himself in what Robert Murphy describes as a condition of “liminality,” being betwixt and between his life as an able-bodied and disabled-bodied person, on the threshold of something new but not yet of it.²²

Melvin’s resolution of this dilemma relied on the third component of agency highlighted in the scheme of Emirbayer and Mische—the *practical-evaluative*, which consists of people’s capacity to appraise their options, mobilize personal and social resources, and engage in adaptive, problem-solving actions. Practical-evaluative action draws on past experience but applies or transposes it to new circumstances in innovative ways. Until the shooting, for instance, Melvin had been

an accomplished member of the Chicago gang scene, someone who knew how to negotiate the streets. He was tough and agile, a capable fighter, a leader among peers, someone who commanded respect. Gang life had been a resource for constructing Melvin's sense of self-efficacy²³ as well as his masculine competence.²⁴ As a disabled man, however, Melvin now faced a world that often devalues men who lose control of their bodies, who appear vulnerable and weak, incomplete and inefficacious. For Melvin, wheelchair basketball was an alternative, practical resource for resolving his potentially debilitating and liminal status, retaining his sense of self-efficacy and manhood, and moving forward with his new life. The survival strategies he had learned on the streets of Chicago could be transposed to the basketball court. He could still be athletic, tough and competitive, resourceful and resolute, still experience his body as a masculine "presence," that is, as "an active power . . . which [could] be exercised on and over others."²⁵ At the same time, Melvin's new body opened the door to new ways of accomplishing masculine self-efficacy, as he became more empathetic, more considerate of others, a positive role model for youths in need.

Sociologists have long noted, to paraphrase Karl Marx, that people make their own history, but they do not do so under conditions of their choosing. As such, the possibilities for agentive or self-efficacious action in the face of disability are not entirely of one's own making. Successful life outcomes under such circumstances also require social-structural resources and opportunities. Thus, Melvin's successful adaptation to his spinal-cord injury must be understood in terms of the broader context of changing claims about disability that have been advanced by proponents of the contemporary disability rights movement. It is this movement that has been the progenitor of a powerful cultural shift in our understanding of disability, one that has provided Melvin and others like him with a narrative or "rhetoric of self-change," as Frank would put it, that has helped them move beyond stigma and pity.²⁶

Building on the accomplishments of other “oppositional consciousness” movements of the 1960s and early 1970s,²⁷ the contemporary disability rights movement viewed disability as an institutionalized source of oppression comparable to inequalities based on race, gender, and sexual orientation. Critiquing the “medical model” of disability, which emphasized people’s personal adjustment to impairment and their adaptation to a medical-rehabilitative regimen of treatment, disability rights activists advanced a “social model” of disability, claiming that it is not an individual’s impairment but the socially imposed barriers—the inaccessible buildings, the limited modes of transportation and communication, the prejudicial attitudes—that constructed disability as a subordinate social status and devalued life experience.²⁸

Advocates of disability rights also rejected conventional assumptions of the disabled as abnormal, inferior, or dependent people who at best should be pitied or treated as objects of charitable goodwill. While disability may never be wished for and is often a great source of suffering, people with disabilities differ quite dramatically in the nature of their impairment, and their condition is not always as “wholly disastrous” as some might imagine.²⁹ People with disabilities commonly learn to appreciate and enhance their remaining abilities and strive for goals and qualities of human worth that are still within their grasp.³⁰ Adapting the discourse of identity politics and multiculturalism that had been integral to other oppositional movements, people who shared a common experience of stigmatization and discrimination challenged societal ideals of normality and promoted disability as an acceptable, even celebrated, form of social difference.³¹

Identity politics as applied to disability has had its limitations, however. Many people who are disabled, Melvin included, do not identify themselves as such. They do not dismiss their impairment as irrelevant, but neither do they internalize its significance.³² Moreover, “people with disabilities” is not a homogeneous category; it consists of individuals with varying needs and interests who “may have little

in common except the stigma society imposes on them.”³³ The divide between people with physical and cognitive impairments is but one example of the divisions. After Melvin was released from the hospital, for instance, school officials assigned him to a special high school that segregated students with disabilities. He was placed in classes with those who had severe cognitive disabilities, and he did not like being treated like someone who was mentally impaired. The “supercrip” complaint is another manifestation of the divisions within the disability community. It stems from a discord between those who want to play sports recreationally (or not at all) and those, like Melvin, who want to play competitively at the elite levels of the sport.

Disability, Sports, and Basketball

Sociologists view sports as a social institution through which cultural conceptions of “desirable and normalized” bodies are constructed.³⁴ At first it might seem obvious that the “disabled” body stands (or sits) in contradistinction to the “athletic” body. To some, the notion of a disabled athlete in a wheelchair may even seem to be an oxymoron, as people with mobility impairments are, for the most part, unable to participate in sports that have “historically been oriented to the able-bodied.”³⁵ On the other hand, the experience of dedicated wheelchair athletes, like Melvin and the protagonists in *Murderball*, suggests another side of the story. These are individuals who have resisted stigmatized views of their physical capabilities by devoting themselves to athletic activities that allow them to embrace rather than reject their impairments. They are, in the terms of Michael Schwalbe and Douglas Mason-Schrock, engaged in a process of “oppositional identity work,” transforming a potentially discrediting identity (i.e., disability) into a crediting one (i.e., athleticism) so that they may be seen as representing a “noble rather than flawed character.”³⁶

Sports for people with mobility impairments are a mid-twentieth century phenomenon, a by-product of World War II, when improved

battlefield evacuation methods and medical technologies dramatically increased the survival rate of the wounded. These soldiers, including those with spinal-cord injuries, would have died in previous wars. Now they survived, warehoused in veterans hospitals throughout the United States. Many of these individuals previously enjoyed participation in competitive sports and would not tolerate inactivity. They started playing pool, table tennis, and catch, and then progressed to swimming and bowling, and eventually to water polo, softball, touch football, and basketball. Today, people with disabilities participate in the full gamut of sports, including bicycling, skiing, tennis, track and field, rugby, volleyball, and horseback riding.³⁷

Among all the sports currently available for people with disabilities, wheelchair basketball is arguably the most popular. In the United States, the National Wheelchair Basketball Association (NWBA), organized in 1949, boasts a membership of more than 2,000 athletes. It organizes men's, women's, and youth divisions and sponsors more than 200 teams. Although the NWBA is an amateur organization, a number of its teams receive financial support from, and bear the names of, professional National Basketball Association teams. In addition, a United States national team competes every four years in the international Paralympics, which is held in the same venue as the regular Olympic Games, and in the Wheelchair Basketball World Championship, or Gold Cup, which is held every four years in the off years between the Paralympics.

Jay Coakley notes that the "performance ethic" of competitive sports entails several elements of what it means to be an "athlete": sacrificing other interests for "the game," striving for distinction, accepting the risk of defeat, playing through pain, and refusing to accept limits on the pursuit of excellence.³⁸ Sociologists of sports are often critical of this ethic because it sometimes devolves into a hyper-masculinity of sorts whereby athletes take performance-enhancing drugs and develop an attitude of hubris and a desire to humiliate or even physically harm an opponent during a game.³⁹ Indeed, some

viewers of *Murderball* were critical of the masculinist ethic exuded by some of the players, who took great joy in a game that allowed them to “hit” and smash into their opponents. Thus, as competitive opportunities for playing wheelchair sports have expanded, critics have questioned whether people with disabilities actually benefit from emulating the athletic model.⁴⁰

At the same time, it is also true that a person can derive much inner strength from a commitment to work hard to excel, to push oneself to the limit, to be as good as one can be. When someone is faced with the challenge of living with a disability, sports can be a resource that helps him or her move forward with a sense of determination. In fact, a large body of research indicates that participation in sports entails substantial benefits for people with disabilities.⁴¹ For many, the primary benefit is the intrinsic satisfaction, the reward felt for playing the game, accomplishing the task itself. Others enjoy the camaraderie and affirmation that they get from teammates and peers. Participants gain improved physical conditioning and a sense of bodily mastery, along with a heightened sense of self-efficacy that spills over into other social pursuits. They learn to view “challenges as possibilities rather than as obstacles,” to deal with defeat not as failure but as incentive to do better.⁴² These enhancements are not simply “rehabilitative” or “therapeutic,” for they are the same ones often enjoyed by the nondisabled who participate in athletics.

Even those who enjoy basketball may not appreciate the special skills involved in this sport if they have never seen a wheelchair game, especially a game played by elite athletes like Melvin. During my informal observations and conversations with spectators at games, I found people to be truly in awe of what they see. They are amazed that players can accurately shoot at a ten-foot-high basket from the three-point line, the free-throw line, or even closer, *while sitting in a chair*. They are enamored with how effortlessly the players maneuver their chairs with such speed and agility, maintaining their stamina for the duration of a forty- or forty-eight-minute game. And they

are impressed with the players' durability as they witness the physical contact, chairs banging against chairs, chairs tipping over as players fall to the ground and then pull themselves up without assistance from others. During the course of a game, onlookers tend to forget that these are people with disabilities. Instead, they see incredible *athletes* doing things that an untrained, able-bodied person simply could not do. The players' bodies communicate a different meaning, tell a different story, that disrupts conventional assumptions about people with disabilities.

Methodology: Constructing the Life Story

Before beginning Melvin's story, a few observations about research method are in order so that we may situate our approach in "methodological context." *Wheelchair Warrior* participates in a time-honored tradition of social research that has "vacillated in acceptance and popularity over the years."⁴³ Various called interpretive biography, life-history research, or life-story research, among other terms,⁴⁴ this qualitative genre aims to advance what C. Wright Mills famously called the "sociological imagination," a sociology that grapples with the intersection of biography and history in society and the ways in which personal troubles are related to public issues.⁴⁵ By documenting stories that reflect the interplay between personal agency and social structure, this method strives to recreate the "experiential integrity of human existence" as seen from the vantage point of those whose lives are being revealed.⁴⁶ By linking personal stories to collective narratives (e.g., the gang or disability experience), biographical accounts give voice to muted memories and allow society to "speak itself" through the lives of individuals.⁴⁷

Some sociologists are concerned, however, that by acknowledging that every person has *his or her own story* to tell, biographical inquiry risks substituting commonsense accounts for sociological analyses. According to this view, it generally takes a trained observer to make

sociological sense of the story. As Jaber Gubrium and James Holstein note, it is fine to allow “indigenous voices [to] have their own say,” but researchers should not abandon their authorial obligation to “complement and contextualize the explication of [subjects’] accounts, or nonaccounts, as the case may be.”⁴⁸ The challenge, of course, is to decide how to balance the *analytic* and *storied* components of the biography, to decide whether one or the other should be given privileged status in the narrative that is told, and to choose which should be foreground and which should be background.⁴⁹

Carol Gill observes that much disability research has privileged analysis over story, whereby researchers’ theoretical and methodological constructs have taken precedence over the conveyance of subjects’ experiences.⁵⁰ In doing so, Gill argues, the individual and collective voices of the disabled have been silenced and marginalized. More generally, Ann Goetting views the biographical method as a remedy to this marginalization and is leery of researchers whose primary goal is to dissect or deconstruct life stories for the sake of the analytical enterprise.⁵¹ Rather, sociologists should collect and tell stories to make connections with readers—to generate empathy, build social bonds, make it more difficult to dismiss others as irrelevant or inferior.⁵² Although analytical understanding remains important, the stories that we tell should help readers locate and make sense of their own lives in light of the experience of others, to “aid each of us in our own transformation of unique experience into sociological text.”⁵³

Melvin and I gathered the data for the book as I guided him through several informal interview sessions that yielded more than twenty hours of tape-recorded material, which I transcribed verbatim. Melvin began by chronologically reconstructing his life through the best of his recollection and according to his own relevancies, animating his story with conversational exchanges and details of thought and action that imbued it with verisimilitude.⁵⁴ I occasionally intervened to ask Melvin questions and encourage him to elaborate with more detail, and in subsequent sessions, we focused on particular

topics, such as family and friends, gang culture, hospital rehabilitation, and wheelchair basketball.

In the writing of the book, Melvin and I made a conscious decision to keep his story intact, to write the main part of the book as an autobiography, and to bracket the sociological analysis in the Introduction and Conclusion. Although I helped edit and fashion Melvin's account into a coherent written narrative, I took great pains to do so in a way that allowed Melvin to retain ownership of the story as we continually exchanged multiple drafts through various stages of revision until we arrived at the final manuscript. On the other hand, we did take some minor license with the life-story method in the strictest sense, as we decided to include brief historical accounts of Chicago gangs and the game of wheelchair basketball to give readers greater appreciation of the social context in which Melvin's life was embedded. (We felt this was especially important for those readers who might choose to bypass the Introduction and Conclusion, as we noted in the Preface.) I assisted Melvin in researching these sections by sharing material from published sources that added a little detail to the knowledge he had acquired through personal experience. We also culled back issues of *Sports 'N Spokes* magazine for details regarding games he played in, and we talked to several individuals from the University of Wisconsin–Whitewater basketball community—John Truesdale, Mike Frogley, Eric Barber, and Jeremy Lade—who contributed some details that enhanced their part in Melvin's story.

Storytelling is, of course, an ancient human endeavor, and the telling of a life story necessarily involves appropriation of general narrative formats and archetypical experiences that structure how people tell and write about their lives.⁵⁵ Thus, our story about Melvin's life relies (implicitly and explicitly) on conventional plot-making devices: It has a beginning, middle, and end and is marked by key turning points or epiphanies in which the protagonist (Melvin) exercises agency in the face of adversity, falters and progresses,

and ultimately triumphs. It also adopts what Frank refers to as the archetypal “quest” narrative. According to Frank, the quest narrative reframes adversity—and in the case of an illness or acquired disability, an “interruption” of a life—as a challenge that hinges on the question of how one rises to the occasion. The quest narrative reminds us that obstacles may be overcome. It exhibits an “ethic of inspiration . . . rooted in woundedness” but that refuses to give into despair. It entails a belief that something can be gained through the experience of “traveling the distance” to realize an imagined possibility, that a person can turn fate and contingency into “confidence in what is waiting to emerge.”⁵⁶

Our use of this narrative archetype raises the question of narrative “truth.” Are there not other storylines that we could have employed to tell Melvin’s life? In the “chaos” narrative, for example, the protagonist’s dilemma is never resolved; there is no happy ending. The plot “doesn’t progress by meaningful steps, but winds upon itself, digresses, retreats” and ultimately collapses.⁵⁷ The reader will see, however, that while chaos presented itself as a possibility, Melvin held it at bay, although his ability to do so was not simply a matter of individual effort. There were significant others along the way, and enabling institutional resources at his disposal, that gave him the opportunity to imagine and realize a new way of living in the world. Melvin should not be viewed as a supercrip, because his actions were enabled by the social circumstances around him.

Goetting argues that biography is “not simply a ‘true’ representation of an objective ‘reality’” but an incomplete reconstruction of a remembered past that is inevitably marked by a degree of distortion due to the fallibility of memory and the subjectivity of perception.⁵⁸ Just as “two people telling a story about the same event may tell it differently,” any one person may tell his or her story differently at different points in his or her life.⁵⁹ If a story of one’s life is told honestly, it may be the closest approximation to the truth that he or she can muster, but it is not the invariant “truth” of what transpired. At the same

time, when one tells his or her story from the perspective of hindsight rather than the immediacy of the events, it is no less authentic for having been seasoned by conscious reflection, as *how one remembers* the past may be the most essential part of *the story* that he or she has to tell.⁶⁰

I do not believe that those who tell their life stories should be expected to disclose every intimate detail of their lives. Storytellers, Melvin included, are entitled to some privacy. Indeed, Denzin reminds us that our primary obligation in life-story research is always to the people whose lives we study, “not to our project . . . or discipline. [Their] lives and stories . . . are given to us under a promise . . . that we protect those who have shared with us.”⁶¹ Ethical considerations require that we allow the people who tell us their stories to be the final arbiters of what gets told and not told. Besides, as Robert Atkinson observes, a “person’s story is essentially an expression of his or her self-understanding. . . . What may be of greatest interest . . . is how [they] see themselves and . . . want others to see them.”⁶²

Melvin may be a wounded warrior, but he is a warrior nonetheless. He resists those who read his life as a tragedy, and his account does not conform to some preordained therapeutic scheme of grieving over loss, such as Elisabeth Kübler-Ross’s stages of denial, anger, bargaining, depression, and acceptance.⁶³ This narrative of disability—a policing “technology of the self,” to borrow a term from Michel Foucault⁶⁴—is one that is imposed on Melvin’s life *from without* and does not comport with how he experienced his circumstance *from within*. Like John Hockenberry, who was paralyzed in a car accident during his teenage years, disability taught Melvin “that life could be reinvented. In fact, such an outlook was required. . . . Formulae for change and grief efface the possibility that we might each discover our own way through difficulty, and by doing so reclaim our lives.”⁶⁵