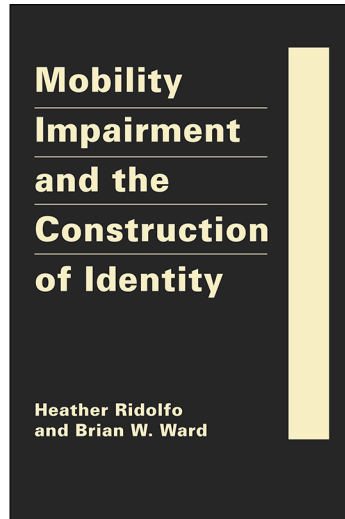


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# Mobility Impairment and the Construction of Identity

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and Brian W. Ward

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ISBN: 978-1-935049-57-9 hc



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Boulder, CO 80301  
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# 1

## Embracing Disability?

Oscar Pistorius is a 26-year-old bilateral amputee. Born with no fibula in either leg, he was only 11 months old when doctors performed a bilateral amputation on him. Pistorius learned to walk on prosthetic legs at the age of seventeen months. In most contexts around the world and in the view of many observers, this amputation would qualify Pistorius to be identified as a disabled person, and his story would be one of personal tragedy. However, his story is not just the tale of a man who endured a bilateral amputation, but one of a world-class athlete who has competed with the best disabled and able-bodied sprinters around the globe. With the use of Össur Flex-Foot Cheetah carbon-fiber artificial limbs, Pistorius has been given the nickname “Blade Runner” (Pistorius 2009) and has been called the “fastest man on no legs.”<sup>1</sup>

At the 2007 South African National Championships, Pistorius ran a 400-meter sprint in 46.56 seconds, earning him second place. That time was, at the time, a personal best, and it encouraged Pistorius to set his sights on the 2008 Summer Olympic Games in Beijing. With his dreams of racing in the Olympics within reach, however, Pistorius was delivered a harsh blow. In March 2007, the International Association of Athletics Federations (IAAF), the international governing body for track and field, issued a new rule banning the use of technical devices containing elements that provide a user with advantages over other athletes. This ruling quickly prompted speculation that the IAAF intended to bar Pistorius from competing against able-bodied athletes at the international level. In response to this controversy, the IAAF sanctioned a series of tests in November 2007 by a team headed by Professor Gert-Peter Brüeggemann to determine if Pistorius’ prostheses provided him any unfair advantage. Based on these tests it was determined that Pistorius did in fact have an unfair advantage over other able-bodied athletes, as he was able to run at the same speed as other able-bodied runners using less energy. As a result of this ruling, Pistorius was

banned from participating in the 2008 Olympic Games. In almost every other situation or context, the use of such artificial limbs would qualify someone as “disadvantaged.” Yet in Pistorius’ case, the same devices were determined to have the opposite effect - they had made him super-able.

Following the IAAF ruling, Pistorius filed an appeal in the Court of Arbitration for Sport and submitted to a second series of tests at Rice University in Houston, Texas. This reassessment found that there was in fact no scientific evidence that the use of Össur Flex-Foot Cheetah limbs provided any advantage to Pistorius over other runners. In May 2008, the Court of Arbitration for Sport ruled in Pistorius’ favor, leading the IAAF formally to grant him the right to compete in the 2012 Olympic Games in London, should he qualify. Following this reversal of the IAAF’s initial ruling, on July 19, 2011, in Lignano, Italy, Pistorius ran the 400-meter sprint in 45.07 seconds, a new personal best time. Pistorius became the first amputee to qualify for the World Championships (held in Daegu, South Korea, in 2011). There he helped his teammates win a silver medal in the 4x400-meter relay. His 400-meter time of 45.07 seconds not only qualified him for the World Championships, but was also 0.18 seconds faster than the 45.25-second qualifying time needed to compete in the 2012 Summer Olympic Games. In August 2012, Oscar realized his dream of competing in the Olympic Games, where he reached the semifinal round in the individual 400 meter sprint, and assisted his teammates in placing eighth in final round of the 4x400-meter relay. In honor of his remarkable journey and great sportsmanship, Oscar was chosen by his teammates to carry the South African flag in the closing ceremonies of the 2012 London Olympic Games.

Like the stories of many other people, Pistorius’ is one that challenges the conception of disability—and as such it is not without controversy. His dream of participating in the Olympics has been scrutinized not just formally by the IAAF, but also by many others. It has fueled and reignited discussions of what makes a person disabled. This discussion is not new—for decades, scholars, disability activists, and policy makers have all debated this very question. Like many others, Pistorius does not view of himself as disabled, despite the many others that reflexively label him as such:

People often ask me how it is that with my artificial legs I can be qualified as anything but disabled? My answer is that, being far more able than they are in more than 90 percent of sports, why should I be qualified as a disabled sportsman? It has been said that using

prostheses is proof of disability, but I fail to see why this aspect of my persona should overshadow all my sporting ability. (Pistorius 2009, p. 100)

Oscar Pistorius is not alone in disidentifying from a disabled identity. Research on such identification has often shown that not all individuals with physical impairment(s) identify as disabled (Watson 1998, 2002; Priestley 1999; Iezzoni et al. 2000; Taub et al. 2004; LoBianco and Sheppard-Jones 2007). This is not at all surprising given the stigmatization of disability. However, claiming an identity as disabled may have important implications for impaired individuals' interpersonal interactions and their overall well-being. Claiming one's identity as disabled can empower impaired individuals to advocate for their needs, such as accommodations in the built environment and equality in social interactions (Wendell 1996; Reeve 2002; Taub et al. 2004). Claiming this identity may also allow individuals to identify personally with other people who have disabilities and lead to a collective identity through which political action can be fostered (Wendell 1996). Claiming an identity as disabled also validates and legitimizes experiences of physical pain, fatigue, and decreased functionality (Wendell 1996). Thus, while such identity claims may be important on a personal level in the everyday lives of individuals, these claims also have broader implications that can affect families, communities, and policies. The goal of our book is to develop an understanding as to why some impaired individuals claim a disabled identity, why others reject it, and the implications of these choices.

In order to reach this understanding, we recognize that it is necessary to identify what it means to be disabled. Historically, such identification has occurred through two predominant models—the medical model and the social model. The medical model of disability defines disability as an outcome of mobility limitations or psychological losses, and therefore locates the issue of disablement within the individual. In contrast to the medical model, the social model of disability defines disability as a socially constructed phenomenon that is imposed on impaired individuals. That is, the social model locates the source of disablement in physical barriers within the built environment and in social barriers (such as stigma) that hamper impaired individuals from fully participating in society. These models present important implications for the study of the acceptance or rejection of a disabled identity; however, we argue that the disablement process is much more complex than either of these two models suggest. Drawing on sociological social psychology theories of identity development, we

believe that impaired individuals engage in self-processes to make meaning out of their experiences of embodiment and barriers in their physical and social worlds, and ultimately these processes influence whether an individual either claims or rejects an identity as disabled. Additionally, an individual's social statuses also play a role in identity construction, and the ability to claim or reject one's disabled identity is also influenced by the context that social statuses such as age, race, gender, and social class create.

To achieve an understanding of why some impaired individuals claim a disabled identity, we used a mixed methods approach that uses both quantitative data that are nationally representative for the United States and qualitative data from in-depth interviews to address three specific research questions. Our first question asks how do physical barriers (that is, barriers in the built environment), social barriers, and physical impairments influence the acceptance or rejection of a disabled identity. Second, we ask how do self-processes inform the acceptance or rejection of a disabled identity. And, finally, our last question asks how is the process of constructing an identity as disabled influenced by social statuses such as age, race, gender, and social class. The use of this mixed methods approach can enable us to reach a richer understanding of the process by which identities are constructed and allow us to better answer these three questions. The nationally representative data allow for the direct and quantifiable measurement of the relationship between physical and social barriers, physical impairment, self-processes, social statuses, and claiming an identity as disabled. In contrast, the qualitative data provide rich insight into the lived experiences of mobility-impaired people and the further elaboration of experiences that are not readily captured in the quantitative data. These data collectively allow for broad generalizations to be made without sacrificing the subtle detail that provides a more complete picture of such identity formation.

### **Description of the Research**

The data used to answer our research questions were drawn from a nationally representative U.S. sample and 30 in-depth interviews with people with varying degrees of mobility limitations. Mobility limitations were defined as: the inability to walk; having difficulty walking for one-quarter of a mile; walking up ten steps without resting; being on their feet for about two hours; sitting for about two hours; stooping, crouching, kneeling, or being unable to kneel by themselves without the use of aids; OR reliance on assistive devices—such as a walker, scooter, wheelchair, cane, or crutches—to get around. The data used in the

**Table 1.1. Descriptive Characteristics of Demographic and Level of Impairment Measures among Mobility-Impaired Adults in the Quantitative Sample (unweighted n=3,637)**

	Range	Mean	SE
<b>Demographic</b>			
Black	0-1	0.14	0.01
Age (in years)	18-64	46.46	0.23
Female	0-1	0.67	0.01
Married	0-1	0.48	0.01
Employed	0-1	0.44	0.01
Education	1-5	2.34	0.02
Income	0-26	17.22	0.14
<b>Level of Impairment</b>			
Severity of movement difficulty	0-5	2.62	0.03
ADL limitations	0-5	0.75	0.03
IADL limitations	0-6	1.02	0.03
Use mobility aid	0-1	0.24	0.01

*Data source: NHIS-D 1994-1995*

*Notes: Estimates are weighted. SE = standard error; ADL = activity of daily living; IADL = instrumental activity of daily living.*

quantitative analyses came from the 1994 and 1995 National Health Interview Survey on Disability (NHIS-D). The NHIS-D sample was limited to African American and Caucasian respondents with mobility impairments, all aged between 18 and 64 years, who participated as self-respondents in Phase I and Phase II of the NHIS-D survey (n=3,637). The majority of the respondents in the NHIS-D sample were white and female (Table 1.1). In terms of education, 24.7% had less than a high school education, 38.9% had a high school degree, 22% had some college, 7.5% had a baccalaureate, and 6.8% had a professional degree

beyond college. The average income was \$17,000-17,999. The mean age of respondents was 46 years old.

The same criteria noted above that were used to establish the quantitative dataset were also used to determine which respondents were eligible for participation in the interviews and inclusion in the qualitative sample. For the qualitative analyses, in-depth interviews were conducted with thirty adults, all aged between 18 and 67 years, who had varying mobility limitations (Table 1.2).

**Table 1.2. Level of Impairment Among Interview Respondents in the Qualitative Sample (n=30)**

	Range	Mean
<b>Mobility Aid</b>		
Use mobility aid	0-1	0.83
<b>Movement Difficulty</b>		
Difficulty...		
Walking ¼ mile	0-3	2.13
Walking 10 steps	0-3	1.73
Reaching	0-3	0.79
Lifting 10 lbs.	0-3	1.53
<b>ADL/IADL Limitation</b>		
Difficulty...		
Performing housework	0-3	1.47
Preparing meals	0-3	0.93
Bathing	0-3	0.69
Dressing	0-3	0.67

*Notes: ADL = activity of daily living; IADL = instrumental activity of daily living.*

In terms of demographic characteristics, the sample consisted of an almost equal number of women and men; however, the sample predominately self-identified as black (Table 1.3). The qualitative interviews lasted one hour, and respondents were remunerated for their



**Table 1.3. Demographic Characteristics of Interview Respondents in the Qualitative Sample (n=30)**

	<b>n</b>	<b>%</b>
<b>Race</b>		
Black	25	83.3
White	3	10.0
Multi-racial	2	6.7
<b>Age (in years)</b>		
26-39	5	16.7
40-49	9	30.0
50-67	16	53.3
<b>Gender</b>		
Female	16	53.3
Male	14	46.7
<b>Marital Status</b>		
Married	2	6.7
Not married	28	93.3
<b>Work Status</b>		
Employed	9	30.0
Unemployed	21	70.0
<b>Education</b>		
Less than high school	2	6.7
High school	13	43.3
Some college	11	36.7
Baccalaureate degree	3	10.0
Graduate degree	1	3.3
<b>Income</b>		
\$20,000 or less	25	83.3
\$20,001-\$30,000	3	10.0
Over \$30,000	2	6.7

time. These interviews were conducted in 2009 as part of a larger cognitive-testing project conducted by staff at the National Center for Health Statistics. Respondents were first administered a questionnaire that asked about their experiences with physical barriers and needs for accommodation in the home, community, transportation, and the workplace; their experiences of discrimination and social inclusion; whether they themselves identify as disabled; and whether they perceive that others view them as disabled. This questionnaire served as a guide for interviewers for the remaining interview time, during which respondents were asked to discuss in-depth their experiences of physical and social barriers and their subjective experiences of their impairment and identity construction. Additional information on both the quantitative and qualitative samples and data-collection procedures can be found in the Appendix.

### **Outline of the Book**

Throughout this book, theoretical and empirical evidence is used to develop an understanding of why impaired individuals either claim or reject an identity as disabled, and what the implications for these disabled-identity claims are. This process begins in Chapter 2, where we draw on the theoretical literature and outline existing models of disability and the theories of self-concept that together are fundamental to understanding the complex relationship among barriers, impairment, and self-processes that result in a disabled-identity construction. We first compare existing models of disability and then follow with a discussion of the need for a more complex model of disablement that simultaneously accounts for both bodily and social experiences. Following this, we present a background of the sociological social psychology approach to identity construction. Drawing on a symbolic interactionist framework, we outline three mechanisms of identity construction that in our case are used to understand a disabled identity: social comparisons, self-presentations, and reflected appraisals. We finish Chapter 2 by providing a model of how these concepts are related to one another and can ultimately influence the creation of a disabled identity.

In Chapter 3, using the conceptual model as a guide, we analyze data from the qualitative interviews to describe the everyday experiences of living with impairment, using the words of those impaired individuals themselves. This paints a picture of the reality of the difficulties these individuals face, often with daily tasks that able-bodied people take for granted. In this chapter, we detail mobility-impaired individuals'

experiences with navigating physical and social barriers and their bodily experiences of physical impairment. Despite the advances made with the 1990 Americans with Disabilities Act (ADA), the respondents we interviewed continued to experience numerous physical and social barriers in their homes and communities almost twenty years after the passage of the ADA. Along with the descriptions of these experiences, we provide insight into the impaired individuals' everyday experiences with pain, fatigue, and other symptoms that are related to their impairment.

In Chapter 4, we explore two specific questions. First, how do environmental barriers and level of impairment influence the acceptance or rejection of a disabled identity? And second, how do self-processes inform the acceptance or rejection of a disabled identity? Empirical evidence used to answer these questions was amassed through a quantitative and qualitative mixed methods approach. Regarding the quantitative analyses, we demonstrate that experiences of environmental barriers, social engagement, and impairment are mediated through self-processes (specifically, reflected appraisals) to shape identity claims. For the second component of our analyses, we again use qualitative data and examine in-depth how mobility-impaired people make meaning out of their experiences of physical and social barriers and bodily experiences of impairment, as well as the role of self-processes, by integrating these experiences into their understanding of self, and we consider how ultimately these experiences shape the identity claims of these individuals. In our analysis of the interviews, we are able to explore two other self-processes that were not captured in the NHIS-D survey data: social comparisons and self-presentations. The result is a discussion of three identity groups: those who identify as disabled, those who reject this identity, and those who are currently in the process of negotiating this identity. The discovery of a third identity group is unexpected, yet in examining the narratives of impaired persons we are able to shed light on the unique experiences of specific individuals who are in the process of negotiating a disabled identity.

We turn our attention in Chapter 5 to the question of how the construction (or rejection) of an identity as disabled is influenced by gender. With our data from the 1994-1995 NHIS-D, we examine how the relationship between claiming a disabled identity, and environmental barriers, social engagement, and impairment differs among men and women. Furthermore, we explore gender differences in reflected appraisals and claiming one's identity and the indirect effects of gender. We then analyze the qualitative interview data and explore the relationship between gender and claiming a disabled identity, noting two

important findings. First, how male and female gender roles affected identity claims; and second, how disability influenced the enactment of gender for both men and women.

We conclude in Chapter 6 by using the findings to answer the three research questions we posed above. The results of these overall research findings are then used to discuss the larger implications of this work, both for the mobility-impaired individuals themselves and for persons involved in policy and practice.

**Note**

1. More information on Oscar Pistorius can be found at his official website (<http://www.oscarpistorius.com/>).