

# Re-Claiming Disability: Identity, Procedural Justice, and the Disability Determination Process

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*This research highlights the crucial role of an intimate link between a disabled person's self-identity and the perceived fairness of legal procedures. In doing so, it brings to the foreground a wholly ignored aspect of procedural justice. Earlier researchers have failed to delve into the role identity politics plays in the relationship between the institutions and the beneficiaries of their services, and the way different members of a group understand and define themselves. This research explores the way people with disabilities in the United States, with different kinds of disability identities, experience and evaluate the procedure of claiming Social Security benefits. The findings suggest that disabled people who identified with the social model of disability (as opposed to the medical-individual models) hold a critical view of the procedure for retaining benefits. They felt they had no control over it, could not voice their opinions, were mistreated by representatives, and had to present an image that was not necessarily true of their disability. They also saw the procedure as discouraging them from participating fully in the labor market, and consequently integrating better in society, an idea that was not present among disabled people who identify with medical-individual models. Exposing this relationship between the way people perceive themselves and the way they experience and evaluate legal procedures can contribute to the creation of better policies, while improving communication between the state and members of the disability community, along with other marginalized groups.*

## I. INTRODUCTION

At twenty-eight years old, Lisa moved to Berkeley. It was the late 1970s and the height of the disability rights movement. Since a car accident injured her spinal cord at the age of sixteen, Lisa has been paraplegic and a wheelchair user. Growing

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The title of this article is a tribute to Simi Linton's book *Claiming Disability: Knowledge and Identity* (1998), which foregrounded the concept of claiming one's disability.

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up in the Midwest, where there were only a few people with significant visible disabilities, Lisa remembers clearly the message she received from everyone except her parents—that her life was pretty much over: “That I probably wouldn’t be able to live independently. Going to college would be very limited, if at all . . . That I was unattractive, you know probably would not have a mate. All the stereotypes were just full-blown. And I sensed it immediately from the way [other people], even the medical world, were relating to me.”

In Berkeley, Lisa felt that everything was accessible and everyone was friendly. She began learning about the concepts underlying the new social movement, her community, and her claimed, empowered disability identity.

Lisa, like more than 18 million other Americans with disabilities, has an ongoing, long-term relationship with the Social Security Administration (SSA) (Disability Statistics and Demographics Rehabilitation and Research Training Center 2014, 76).<sup>1</sup> She has been receiving disability benefits since the age of eighteen.

Lisa says obtaining her benefits was a “horrible experience.” She felt at the time that the SSA representatives constantly suspected her of “gaming the system,” treated her with disrespect, and brought her to tears more than once. She felt unable to voice her opinion or tell her story to the representatives, who, she believed, cared nothing about her needs. All in all, Lisa felt that she had no control over the process. She believes the procedure of obtaining benefits was unfair because it made her present an image of herself as someone different from who she really was, as someone completely dependent, helpless, and even “pathetic”—an image she believes complies with the common social perception of a person with disabilities.

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This exploratory research uses the qualitative methodology of narrative analysis of in-depth interviews to investigate how the perception of self influences subjects’ experiences with the SSA’s disability determination process (DDP). The DDP is a quasijudicial procedure, which allows people with disabilities to claim benefits (whether SSI or SSDI). Perhaps even more intriguing than the claim for benefits, however, is the question of how the state’s procedure assesses subjects’ identities in a formal way by establishing a binary category of disabled versus nondisabled, foregrounding how the state and society perceive them.

No research currently focuses on how subjects perceive the DDP.<sup>2</sup> I focus here on those perceptions, and couple social identity theory with a grounded study of procedure by distinguishing between different characters and identities within a specific group and studying how each subgroup experiences such processes.

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1. According to a recent report (published in 2014), in December 2012, 8,262,877 individuals were receiving SSI and 9,850,966 were receiving SSDI benefits (Disability Statistics and Demographics Rehabilitation and Research Training Center 2014, 76).

2. In 2000, political scientist Joe Soss published his research “Unwanted Claims: The Politics of Participation in the U.S. Welfare System.” That research did not focus on the DDP or people with disabilities, but it used a similar method of qualitative interviews conducted in 1994 with benefits claimants who received SSDI or Aid to Families with Dependent Children (AFDC). Despite the differences in the focus of the two research studies, I found some similar patterns of findings, as indicated in this article.

This research is significant because of the potential impact disability benefits have on a large portion of the US population. A report by the US Census Bureau has shown that one in every five Americans is living with some kind of disability (US Census Bureau 2012).<sup>3</sup> Since the 1990s, disability benefits claims have steadily increased. About 46 million Americans with disabilities currently receive some kind of governmental assistance, and have thus gone through the DDP (Boursiquot and Brault 2013, 2–3).

It is important, moreover, to pay greater attention not only to the material needs of this significant population, but also to how the complexity of life with disabilities manifests in processes affecting these people. This research could therefore also inform the state about how to communicate better with people with disabilities and to contribute to the creation of better procedures that would enhance the state's legitimacy in their eyes. This project thus focuses on procedural aspects, which are just as important in creating a sense of inclusion and value for members of a minority group as substantive rights.

This project combines two theoretical frameworks: models of disability and procedural justice theory. The social model of disability emerged in the 1970s as a response to medical-individual models of disability, the then prevailing approach, and today serves as an alternative paradigm for the appropriate social approach toward people with disabilities. The social model views disability as a social rather than a purely medical or tragic phenomenon. This model has evolved over the years, and focuses on social construction and the complex processes by which people with disabilities are stigmatized as the reason for their discrimination and exclusion. Ideas derived from the social model established disability studies, a new interdisciplinary academic field that examines disability as a social, cultural, and political phenomenon. My research builds on the new field of disability legal studies, which seeks to apply the theory behind disability studies to the law and examines the role legal institutions play in the social construction of disability.

The social model has also moved beyond the borders of the academic realm, penetrating the “real world.” It has helped empower people with disabilities, by changing the ways they think about themselves and their place in society, allowing them to form a common identity, to establish a sense of community, and to overcome obstacles and hardship in their lives. Nevertheless, some people living with disabilities have never heard about the social model or concepts derived from it and still view themselves in terms of older (and some would argue more common) conceptions of disability as a tragic and unfortunate state that is completely intrinsic to the individual. These older concepts comprise the medical-individual models of disability.

This project also utilizes procedural justice theory, which emphasizes the process that rights claimants experience during adjudication. The group engagement model of procedural justice predicts that willingness to cooperate with a group flows from the “identity information” the individual receives from that group. This information arises from the individual's perception of the fairness of the process she

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3. According to research done by the US Census Bureau in 2010, about 56.7 million people—19 percent of the US population—had a disability.

experiences. A relationship therefore exists between fair process and group engagement: how people identify themselves is directly connected to how they experience procedures made by the group of which they would like to be a part (Tyler and Blader 2003, 358). I argue that the sense of fairness experienced by the DDP's subjects, in this context, is grounded in how they perceive themselves. In other words, people with different types of disability identities perceive the DDP differently, and that perception influences their relationships with state authorities and their feelings about their position in society.

My findings suggest that people who identified with the social model (as opposed to the medical-individual models) were more critical of the DDP. They felt they had no control over it, could not voice their opinions, were mistreated by representatives, and had to present an image that was not necessarily true of their disability. Those who embraced the social model also felt that the procedure itself actually discourages disabled people from participating fully in the labor market, and consequently integrating better in society, an idea that was not present among those identifying with the medical-individual models. The findings regarding the experiences of the interviewees with the DDP and their relationship with the SSA could further serve as a basis for policy recommendations regarding this procedure, the way it is communicated to its subjects, and how the subjects perceive their place in society as a consequence.

I conducted interviews with people with a range of disabilities and different backgrounds in California's Bay Area, the symbolic birthplace of the independent living and disability rights movements (Shapiro 1994, 41–58; Bagenstos 2009, 18). Each interview comprised two sets of questions: the first was about the interviewee's experience of living with disabilities and about her perception of self; the second focused on the interviewee's experience of the DDP, her relationship with the SSA, and how those experiences affected the way the interviewee perceived her place in American society.

I later coded and analyzed the interviews in two parts. First, I analyzed each interviewee's disability identity and categorized her into an identity category within two larger groups based on concepts tied to either the social or the medical-individual models. Second, I analyzed the interviewees' procedural justice perceptions and interactions with the SSA and their resulting feelings about their position in society. I examined each identity group separately in order to see if I could find a relationship between self-identification and procedural justice perception.

Section II introduces the models of disability and the concept of disability identity. It also provides an overview of the Social Security benefits system and the DDP as well as the theory of procedural justice. In the third section, I provide an overview of the methodology behind this research and its limitations, before mapping out and dividing the interviewees into two large groups of disability identity: the medical-individual models group and the social model group (Section IV). In the fifth section, I analyze the procedural justice perceptions of both identity groups. Finally, in Section VI, I explore how interviewees in both groups felt about the procedure in terms of the group engagement model of procedural justice, meaning its effect on their consequential feelings about their position in society and their relationship with the SSA.

## II. THEORETICAL FRAMEWORK: DISABILITY IDENTITY, THE US WELFARE SYSTEM, AND PROCEDURAL JUSTICE

### A. From Disability Models to Disability Identities

Disability research explores how Western societies have mostly regarded disability as grotesque and a deviation from the norm (tenBroek and Matson 1966, 812; Michalko 2002, 38–39; Davis 2010, 4). Disability is viewed socially as a personal tragedy or misfortune that requires charitable giving, pity, and paternalism from society (Wendell 1996, 27). Such a social perception has found its way into policies concerning people with disabilities, and contributed to (if not caused) their marginalization (Stein and Waterston 2006, 869, 895–97; Schweik 2009, 7–9).<sup>4</sup> Disability has thus been historically perceived as inherent to the individual as well as a tragedy or misfortune that a person has to overcome, notions known as the individual model of disability (Oliver 1986, 6; Minow 1990, 111; Michalko 2002, 6–7, 51).<sup>5</sup>

As Elizabeth Emens has observed, there is a tension between how the law and its institutions, as well as society as a whole, perceive disability (an “outside view”) and the way people living with disabilities and their close ones view it (an “inside view”). While those on the outside look at disability as an “unhappy place,” the inside view simply looks at it as “a mundane feature of a no-less-happy life, rendered inconvenient or disabling largely by interactions with the surrounding environment, which legal accommodations alter in ways that sometimes provide benefits to many” (Emens 2012, 1386; Rovner 2001, 250, 269–75).<sup>6</sup>

Because disability has historically been seen as a purely medical-clinical phenomenon, people with disabilities have been kept apart from the rest of society by hospitalization in medical institutions under the cover of treatment, but really out of what seems to be fear, disgust, and misunderstanding (Stone 1984, 107–17). People with disabilities have also largely been excluded from the labor market and the mainstream education system (Smith 2003, 21). In other words, the medical profession has traditionally been considered the authority on determining abilities, conditions, and “body knowledge” (LoBianco and Sheppard-Jones 2007, 1; Wendell 2010, 349), and consequently has made basic, everyday decisions for disabled persons. The sociolegal treatment and definition of disability is known as the medical model of disability, which was dominant until the 1970s, and influenced myriad laws and policies (Drum 2009, 28; Heyer 2015, 25–26).

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4. A clear example of laws that absorbed the negative societal associations of disability are the so-called Ugly Laws that were first enacted in the late 1860s and were valid until the 1970s in some cities in the United States. These laws made it illegal for people with “unsightly or disgusting” disabilities to appear in public.

5. In her influential book *Making All the Difference: Inclusion, Exclusion, and American Law* (1990), which is often considered in relation to laws and policies regarding people with disabilities, Martha Minow discusses how difference is not inherently embedded in the individual but is only meaningful in comparison.

6. Laura Rovner has pointed to the fact that even laws that are enacted in order to protect people with disabilities have stereotypes about this group embedded in them and that the beneficiaries of those laws need to pay the price of adopting those very stereotypes in order to gain protection.

Since the mid-1970s, people with disabilities and their allies have brought attention to their legal rights, reorienting social norms while challenging conventional notions about the phenomenon of disability (Shapiro 1994, 49–58). They build their arguments using the social model of disability, which stands in contrast to the medical and individual models presented above (Areheart 2008, 188; Weber 2009, 592–94; Heyer 2015, 23).

The social model focuses on society's attitudes toward and stereotypes about people with disabilities as the root of their discrimination and exclusion. This model illuminates the psychology of social constructivism, where a hierarchy of physical and mental attributes, grounded in difference, stigmatizes disabled people as inferior (Oliver 1990, 11). This process is often referred to as *ableism*, a term that embodies a rating of a person's abilities, attractiveness, and productivity based on her sensory, physical, or mental abilities, which are determined by nondisabled people (Linton 1998, 9; Campbell 2008, 153; Wolbring 2008, 253; Thomas 2014, 10). Michael Oliver has made an important distinction between impairment and disability. Impairment, he argues, represents the organic-biological aspect of the disability phenomenon, whereas disability represents the degradation caused to people with impairments by society (Oliver 1996, 37–38; Wendell 1996, 5).<sup>7</sup>

Nevertheless, disability is a much more complex phenomenon and the distinction between impairment and disability is perhaps not so simple. The slogan-like nature that helped to popularize the social model has been criticized for occluding the variety of personal experiences of disabled people, and for preventing a full understanding of the complexity of disability (Shakespeare 2010, 269–93; 2012, 131, Thomas 2014, 12–14). Later scholars have therefore revised the social model. A contemporary concept of disability that draws on the classic social model views the term as complex and fluid rather than a dichotomous process of presence or absence, which is multidimensional, dynamic, bio-psycho-social, and interactive in nature (Zola 1993, 18; World Health Organization 2002, 9). Disability is formulated through a complex interaction between the health condition (the pathology) and the social environment (Nagi 1991, 326).

Such thinking has inspired a new academic field, disability studies, which examines disability as a social, cultural, and political phenomenon (Linton 2005, 518; Goodley 2011, 1; Kanter 2011, 416–19; Barnes 2014, 17–24), and transcends multiple disciplines, including legal studies and practice. My research is another building block in the relatively new field of disability legal studies, which seeks to apply disability studies perspectives to law while examining the role legal institutions play in the social construction of disability (Mor 2006, 64; Heyer 2007, 267–68; Kanter 2011, 426–28).<sup>8</sup> The social model has exceeded the borders of the academic realm, penetrating into the real world to help empower people with disabilities by changing the way they think about themselves and their place in society (Michalko 2002, 6).

As a result, this research has important implications for and ties to disability identity. According to the model of the looking-glass self, the concept of self arises

7. This distinction resembles that made between sex and gender in feminist studies.

8. Although a disability rights critique of the law can be traced to the mid-1960s in the writings of Jacobus tenBroek, an official proclamation of disability legal studies as a new field in legal scholarship was only made in the mid-2000s.

from a process of seeing ourselves as others see us. Pioneered by the sociologist Charles Horton Cooley, the looking-glass self theorizes self-identity as a reflexive understanding of a person's biography (Cooley [1909] 2005, 52); that is, it focuses on an individual's understanding of how society and culture perceive one's social status, functions, family tree, and other traits (Taylor 1989, 35; Giddens 1991, 53).

According to social identity theory, because persons with disabilities are prone to encounter stigma, they must find ways to protect themselves from negative treatment and characterization (Olney and Brockelman 2003, 47). The demedicalization of disability through ideas derived from the social model has played a part in liberating large numbers of people with disabilities and helped them create an empowered disability identity and, in terms of social identity theory, to choose a collective coping strategy (Darling and Heckert 2010a, 205–06; Nario-Redmond, Noel, and Fern 2013, 470). Those who embrace this model, at least in part, can see themselves as victims of prejudice and discrimination or as survivors of oppressive treatment as opposed to flawed and worthless individuals (Shakespeare 2012, 129; Malhotra and Rowe 2013, 4). They might take pride in their life experiences and their bodies and claim disability as a life-enriching experience, a part of a positive cultural heritage, or at least a salient and defining aspect of identity (Olney and Brockelman 2003, 40–41; Hughes 2014, 56). Empirical studies have shown that those who identify closely with the disability community often engage in direct political action aimed at bringing social change and improving the conditions and lives of group members (Nario-Redmond, Noel, and Fern 2013, 470).

However, some disabled people still view themselves through the more traditional medical model. According to empirical research, those people will choose an individualistic coping strategy and view persons with disabilities as weak and disempowered, and therefore try to distance themselves from that group in what have been referred to as acts of normalization (Watson 2002, 521; Darling 2003, 884). Such people will usually try to conceal or minimize their disability, and might even take measures to “fix” themselves (Nario-Redmond, Noel, and Fern 2013, 470).

Although an individual's awareness of and relation to a social movement or progressive social concepts certainly help shape identity, that awareness is largely affected by social, cultural, and economic circumstances. Frank Munger and David Engel use the term *resources* to describe life circumstances that are entrenched in both the individual and the environment and contribute greatly to the creation of self-identity for people with disabilities. Such resources include “upbringing, education, wealth, and social relationships, as well as personal attributes such as imagination, character, congeniality, and perseverance” (Engel and Munger 2003, 177, 215–20, 189, 202–03), alongside such factors as gender, race, age (Darling and Heckert 2010b, 131–43), proportion of life disabled, religious belief (Engel and Munger 2003, 159–60), and sexual orientation (Olney and Brockelman 2003, 42).

The idea of mapping out and categorizing types of disability identities is helpful in creating a basis for empirical research that tries to assess impacts, correlations, and effects of those categories on various policies and social realities (Darling and Heckert 2010a, 203). Because the idea of labeling and pigeonholing people can stigmatize and have other negative implications, even with good intentions, it should be done with great care, as I try to do here (Minow 1990, 347).

In 2003, Rosalyn Benjamin Darling developed a new typology of disability identities (Darling 2003, 884–85). In 2010, Darling and Heckert empirically tested this typology using quantitative and qualitative methods. The results generally supported this system of categorization (Darling and Heckert 2010a, 214, 216, 223).

This typology suggests that there are two primary groups of disability perceptions among the population of people with disabilities: one that embraces the social model and another that identifies with the medical-individual models.<sup>9</sup>

## B. Disability, Social Insurance, and Welfare

For hundreds of years, people with disabilities were deemed unemployable and excluded from the labor market and the rest of society (tenBroek and Matson 1966, 810; Stone 1984, 55). It is no wonder that poverty and disability are so closely connected (Smith 2003, 29; Wing 2005, 657; Schweik 2009, 16; Mor 2011, 184). Research indicates that there is a stereotypical expectation of people with disabilities to “just sit home, out of society’s sight, and collect the check” given to them as a paternalistic gesture of governmental assistance (Little 2010, 193). This notion of welfare mentality goes along with the *sick role* people with disabilities are expected to play in order to receive the help and accommodations they need (Winter 2003, 40; Parsons 2013, 294).

There is a strong connection between the presumed inability to work and the medical model. Governmental agencies rely almost exclusively on medical certifications to assess a person’s ability to work. As Debora Stone puts it, “for all practical purposes, the concept of impairment stands as the proxy for disability or inability to work” (Stone 1984, 113).

Social insurance is the government’s mandatory monetary protection against risks and social hazards, not covered in the private market, associated with living in an industrial and postindustrial society in which income is derived from paid labor. It is thus a dedicated tax on workers’ earnings, which employers match with their own contributions, and is collected into funds. To be deemed insured, a person must therefore work a substantial amount of time to be able to save sufficient sums of money (Weber 2009, 578–80; Barnes and Burke 2015, 52).

In contrast, a welfare program (formally known as public assistance) is a means-tested program, meaning its eligibility is measured by the applicant’s income and assets, and is not connected to participation in the workforce (Weber 2009, 584).

The social insurance program aimed at the population of people with disabilities in the United States is the Social Security Disability Insurance (SSDI), and the welfare program aimed at this group is the Supplemental Security Income (SSI). Both programs are operated under the authority of the Social Security Administration (SSA), an independent federal statutory authority (Social Security Act 1935).

These two programs are governed by the same authority and use the same standards and criteria to determine a person’s disability (Weber 2009, 584). To receive

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9. Darling refers to the group identifying with the social model as “the minority or subculture orientation” and the group identifying with the medical-individual models as “the cultural majority orientation.”



either SSDI or SSI, a person must “be unable to engage in any Substantial Gainful Activity (SGA), by a reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months” (Social Security Act 2000, § 423(d)(1)(A)). This definition of disability clearly divides those who have work potential (and thus are not eligible for benefits) and those who have no work potential (and are therefore eligible) (Social Security Advisory Board 2003, 3).<sup>10</sup>

The difference between these two programs, which is inherently connected to their nature and rationales, is the populations they serve: SSDI serves former workers who cannot continue to work because of a disability that appeared during their lifetime (usually, but not always, people in their fifties or sixties) (Berkowitz and Wolff 1986, 81),<sup>11</sup> while SSI serves a disadvantaged and low-income group of individuals regardless of their employment history, as well as children under the age of eighteen with disabilities (Bloch 2003, 42).<sup>12</sup>

Especially in the period before the Affordable Care Act, which seeks to guarantee health care coverage for the United States population, many disabled people were forced to turn to SSDI or SSI in order to obtain health care (Little 2010, 192). Thus, SSDI and SSI also served the purpose of covering some medical costs for their recipients through such complementary programs as Medicare and Medicaid (or Medi-Cal in the State of California) (Weber 2009, 581; Huberfeld and Roberts forthcoming).

The number of people receiving SSDI has steadily increased since the 1990s: from 2.2 percent of adults aged 25 to 64 in 1985 to 4.1 percent in 2005 (Anderson, Turner, and Burkhauser 2013, 2; National Bureau of Economic Research n.d.). As of December 2012, 8,262,877 individuals were receiving SSI and 9,850,966 were receiving SSDI benefits (Disability Statistics and Demographics Rehabilitation and Research Training Center 2014, 76). In 2011, 1.47 million people with disabilities received some kind of governmental assistance (SSDI or SSI) in the State of California (Boursiquot and Brault 2013, 2–3).

### C. The Disability Determination Process as a Formal Identity-Defining Procedure

The disability determination process (DDP) is a five-step procedure to determine a person’s disability and thus eligibility for SSDI or SSI (Brandt et al. 2011, 118; Barnes and Burke 2015, 89). Although the SSA is a federal authority, this

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10. Drum views the SSA’s definition of disability as representing a new kind of theoretical model called the functional model of disability, which focuses on the inability of an individual to engage in some functional activities.

11. Interestingly, one of the initial requirements for receiving SSDI was that the recipient be at least fifty years old. Congress removed this requirement in 1960 only after the system had been proven and emerged from the controversy that characterized its early days.

12. It is possible for a claimant to be eligible for both SSDI and SSI. When a claimant applies for Social Security benefits, the DDS will check her eligibility for both programs. Claimants who receive both are people who have worked for a short period of time and therefore are able to collect a small amount of SSDI money in their funds, but this amount does not reach the SSI rate. Therefore, the SSA will complement the SSDI coverage with SSI benefits.

procedure is performed by state agencies, known as Disability Determination Services (DDS), which are partnerships between the states and the federal government (Barnes and Burke 2015, 64).<sup>13</sup> Perhaps even more intriguing than the claim for benefits, however, is the question of how the DDP, representing the state, validates a subject's identity in a formal way. It does so by establishing binary categories of disabled versus nondisabled (Broyer 2011, 51).

A wide conceptual gap exists between the SSA's approach and definition of disability and contemporary social models of disability (Barnes and Burke 2015, 77–78, 95). The SSA strongly emphasizes the link between impairment and disability and the medical-individual aspects of the disability, with little focus on a person's actual functioning; important attributes like the environment's accessibility and the person's strengths, character, and actual needs are not taken into account (Brandt et al. 2011, 118).<sup>14</sup>

My research probes the relationship between how a person perceives herself (her disability identity) and how she believes the DDP procedure perceives her. This research investigates how the tools, criteria, and definitions utilized by the SSA (through the DDS agencies) in this procedure and throughout the SSA's relationship with its subjects may differ from an individual's personal assessment criteria (Brown 1993, 391–93, 398).<sup>15</sup> The research therefore examines concepts of fairness and justice at both the administrative and individual levels to reveal core disjunctions. Because everyone who receives SSDI or SSI belongs to a stigmatized and marginalized group, this research asks whether this otherwise well-intended administrative procedure might potentially harm its subjects' sense of self-worth, and whether this procedure itself may not in fact distance its subjects further from mainstream activities.

#### D. Procedural Justice Concepts and Overview

The rising number of disability benefits claims (SSDI and SSI) creates pressure on the SSA to achieve a more uniform, fair, and efficient decision-making procedure (Verkuil and Lubbers 2003, 734). But how might one measure such concepts as justice or fairness when examining procedural arrangements for claiming substantive rights (rather than the study of substantive rights themselves)? This question underlies the field of procedural justice.

Unlike distributive justice, which deals with how people perceive the justice of outcomes, procedural justice focuses on how subjects experience the procedure through which decisions regarding substantive rights are made, rather than its

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13. Therefore, the experiences of claimants going through the DDP might vary from state to state. That is why this research focuses only on the experiences of benefits claimants in northern California and specifically in the San Francisco Bay Area.

14. Samuels refers to such processes engaged in by medical and bureaucratic authorities in order to "authenticate a [disabled] person's social identity through biology" as biocertification (Samuels 2014, 122).

15. Brown explores the way the liberal state forms a universal identity of "we" that clashes with the particularistic "I" created by a political process.

outcomes (Tyler and Lind 2000, 65; Welsh 2001, 817; Deutsch 2006, 47–48). Research done in this area has shown that laypeople “pay a great deal of attention to the way things are done [i.e., the way an authority or decision maker comes to a decision] and the nuances of their treatment by others” (Lind and Tyler 1988, 242). Procedural justice accordingly also emphasizes the interaction between the individual and the authority. This field of research suggests that subjects who are not repeat players (Galanter 1974, 124) may use their intuitions about the fairness of a procedure as a proxy for assessing its outcomes (Hensler 2003, 426–27). Sometimes, subjects who consider a procedure fair maintain that view even if they disagree with or are not pleased by its outcomes (Lind and Tyler 1988, 71).

A strong connection seemingly exists between notions about procedural justice and the perceived legitimacy of and deference given to legal and governmental institutions. Subjects who believe that they have been treated in a procedurally fair manner are more likely to think highly of the institutions they have dealt with in terms of respect, loyalty, and obedience (Tyler and Lind 2000, 66–68).

Research on procedural justice has produced several characteristics that can serve as criteria for assessing the fairness of procedures.

- *Having a Voice*—the opportunity for a subject to recount her side of the story freely and to voice her views, opinions, and concerns is an important indicator of the perceived fairness of a procedure (Relis 2002, 182–83).
- *Consideration*—the flipside of the voice criteria is the subject’s notion that she has been heard. Having a voice reassures the subject that she has some way of exercising influence on the decision maker and that what she said matters (Lind, Kanfer, and Earley 1990, 957; Welsh 2001, 823).
- *Dignity and Ethical Treatment*—interpersonal interaction between the subject and the authority is also important. Subjects assess the degree to which the decision maker, or its representatives, treated them in a dignified and polite manner (Lind et al. 1990, 958). Dignified and respectful treatment demonstrates to subjects that authorities recognize their role as public servants who give services to entitled citizens (Welsh 2001, 824). The subject also expects that the authority will try to treat her in a fair and even-handed manner (Relis 2002, 183–84). The idea of being treated fairly and equally can be reduced to three important components: *consistency* of decision making, *impartiality* (bias-free decision making), and *corruptibility* (the right to appeal the decision) (Blader and Tyler 2003, 748, 753). Jerry Mashaw emphasizes this point even further by saying that openness and comprehensibility in the decision-making process will lead to a better sense of self-respect for the subject, who will consequently stop viewing herself as an “object susceptible to infinite manipulation by ‘the system’” (Mashaw 1984, 90–91).
- *Control Over the Procedure and Decisions*—Allan Lind and Tom Tyler stress that “virtually all of the studies of procedural fairness in dispute resolution” have shown an independent effect of process control even “in conditions where subjects received negative outcomes” (Lind and Tyler 1988, 97, 99). It seems that subjects appreciate the opportunity to feel as though they control, even to some extent, both the procedure and the final decision.

### E. The Group Engagement Model of Procedural Justice

The focus of procedural justice research on interpersonal relations and the equality of treatment inspired theoretical models that help us understand how and why procedures shape cooperation in groups, organizations, and societies (Tyler and Blader 2003, 351–52). The group engagement model is one of the newer models. It is connected to social identity theory, and focuses on the manner in which members of minority and stigmatized groups experience governmental and state procedures.

The group engagement model predicts that willingness to cooperate with a group flows from identity information the individual receives from the group, which arises from the individual's perception of the fairness of the procedure. In other words, there is a relationship between fair process and group engagement: how people identify themselves is directly connected to how they experience procedures made by the group of which they would like to be a part (Tyler and Blader 2003, 358).

Powerful institutions and authorities sometimes stigmatize members of a certain group, even unintentionally. This is something that the DDP has done through its public policies concerning people with disabilities, which are governed by notions associated with medical-individual models of disability. In such situations of stigmatization, the individual might feel the need to withdraw from community life and citizenship. The individual does so in order to avoid social rejection by the formal bodies or, in more extreme cases, because she feels that she is not capable or worthy of social opportunities (Watson and Angell 2013, 32). This same individual is also more alert and sensitive to cues from the authorities regarding her acceptance (Okimoto and Wrzesniewski 2012, 628).

Fair procedures help members of stigmatized and minority groups gain confidence in their association with the larger group (in this case, mainstream American society). This is because the two aspects of a procedure—the quality of its decision making and its interpersonal treatment—contribute to a person's assessment that it is safe for her to be part of the group/society. An unfair procedure might signal to the person that there are stigmas and biases against her, and she will decide not to cooperate with the group and distance herself from it (Watson and Angell 2007, 689; Okimoto and Wrzesniewski 2012, 628).

In sum, fair and respectful treatment and procedures should increase feelings of inclusion and value for people with disabilities in society at large. This is especially valuable in light of the current discussion of how the DDP can be seen as a formal identity-defining procedure.

## III. RESEARCH METHODOLOGY

### A. Research Questions and Hypothesis

This research unravels the relationship between a subject's self-perceived identity as a person living with disabilities, her perception of the justice and fairness of the DDP procedure, and her interaction with the DDS agencies in claiming Social Security benefits. That is, how does a person's exposure to the field of disability

studies, the social model and/or the strategies for coping with stigma (individualistic or collective) relate to the way she perceives the DDP and the interaction with the SSA in the process of claiming benefits? Further, drawing on the group engagement model of procedural justice, this research also analyzes how an individual's perception of the fairness of the DDP procedure informs her perception of herself as a welcomed and included member of society.

My hypothesis is that disabled people who embrace the social model (as opposed to their counterparts who use only individualistic coping strategies and identify with the medical-individual models) are likely to be critical of the DDP and their interaction with the SSA (and specifically the DDS agencies) in claiming benefits. They are more prone to see the agency's misalignment with their own perceptions of themselves as disabled persons and with what they perceive to be contemporary concepts of disability. As a result, they are likely to view the procedure as another tool that authority figures and societal leaders use to marginalize and mistreat people with disabilities.

## **B. Data Collection and Methodological Limitations**

This research comprised fourteen extensive interviews with people living with a wide array of disabilities in California's Bay Area, conducted between November 2013 and February 2014. Since this research is exploratory, and because of time and budgetary constraints, I was unable to interview a large number of people or use a focus group or any other kind of sampling technique when choosing my interviewees. My volunteer sample therefore consists of people who have self-selected to participate in this research.

It is important to note that this research design resulted in a somewhat biased research population. The design mostly allowed access to interviewees who are active in the disability community and have a specific kind of disability identity that goes hand-in-hand with the collective coping strategy and the acceptance of the social model. Keeping this concern in mind during data collection, I tried to reach as diverse a population as possible within my constraints. Since disability studies scholars were criticized for not taking account of aspects of oppression that are derived from other intersecting identities such as gender, race, class, and sexual orientation (Asch 2001, 418; Bell 2010, 377; Little 2010, 187; Ribet 2010, 219), I kept those identities and the idea of intersectionality in mind while trying to recruit participants for the research and assess its subjects' disability identities. I managed to interview people representing different demographics, backgrounds, socioeconomic statuses, and legal consciousness so as to offer a broad description of the phenomena (see the Appendix for the summary table describing the research population).

Another limitation of the research methodology has to do with the effect of memory on procedural perceptions. The amount of time elapsed since the interviewees have gone through the DDP will differ and could be large. The interviewees will also have gone through the DDP during differing periods of their lives. To deal with this issue, I took into consideration the way memory connects to the construction of identity, narrative, and perceptions (Scheman 1997, 125–26).

#### IV. WHO'S WHO?—IDENTITY MAPPING OF THE RESEARCH POPULATION

This section maps the interviewees into two large groups: “identities under the medical and individual models of disability” (the medical-individual models group) and “identities under the social model of disability” (the social model group). These two large groups are, in the next section, investigated in terms of how their members perceive the DDP procedure. My analysis shows that a much higher number of interviewees (nine of fourteen) were categorized under identities that accept the social model. As previously mentioned, this finding has two possible explanations.

First, the specific sociocultural context of the geographic location of the research seems to influence the nature of the research population. The independent living and disability rights movements were both initiated in the Bay Area (Shapiro 1994, 67). This perhaps explains why a larger portion of my interviewees were very involved with activism on behalf of the disability community and therefore identify with the social model, a cornerstone for this movement (Albrecht 2010, 197).

Second, the way I recruited interviewees for this research also played a part in how the research population took shape. I recruited interviewees through listservs, groups, and events that are connected to disability studies and the disability rights movement. The people who participate in those events, or subscribe to such listservs, were thus more likely to self-select to participate in this research and to hold views that align with the social model.

Although the research population does not represent the whole population of people with disabilities in the United States or even in California, it provides a snapshot depicting some of the results and consequences of the springtime of the independent living and disability rights movements in the Bay Area, in the late 1960s and mid-1970s.

##### A. Analysis of the Identities in the Medical-Individual Models Group

###### 1. *Unawareness or Rejection of Contemporary Concepts of Disability*

Interestingly, almost all the interviewees (except Ben) were unaware of the concepts of disability pride, the social model, and disability studies. When asked if she sees herself as part of the disability community, Dayna responded: “I didn’t know there was one, so I guess not.” She later observed that it never occurred to her that she belonged to a community of disabled people, possibly because she is generally not involved with large groups or communities: “I don’t see myself as part of a community of disabled people. That never even occurred to me. It’s just me and my life. But I haven’t taken it on as an issue or tried to fit it [the disability] in [my personality]. I’ve always felt comfortable being a little bit different in different ways and so that wouldn’t be a natural thing for me to try to find that place within [the disability community].”

Ben, a sixty-four-year-old blind man, who was the only one familiar with newer concepts of disability, went even further and dismissed the concept of

disability pride: “To be honest, I think it’s stupid because I don’t think being disabled is anything to be proud of; I think it’s a card to be dealt [with]. In other words, it’s nothing we chose. It happened to us and we do the best we can, but to be proud? ‘Hey, I’m proud I’m blind, you know, I wouldn’t want my sight back if they offered it to me’—no, I don’t agree with that.”

This lack of awareness, or even rejection, of newer concepts of disability as a product of one’s environment, and the social movement for disability rights based on those ideas, demonstrates that the people in this category chose the individualistic coping strategy to deal with their disabilities.

## ***2. Normalization and Identification with the Individual Model of Disability***

The idea of overcoming disability—seeing it as something inherent to the individual (the individual model of disability)—was also a recurring theme with the interviewees in this category. Ben, for example, said: “I’m kind of proud of what I accomplished [professionally]. You know, I did work and I think I’ve done a pretty good job of trying to overcome, you know, my difficulties.” Because all of them perceived their disability as a limiting and negative trait, they felt the need to push beyond and normalize it, again disregarding concepts about the role of the environment in creating the disability.

One example of normalizing the disability while attempting to pass as normal was Dayna’s early efforts to conceal the fact that she was losing her vision while in her fifties. The result of her attempts led to greater environmental alienation: “For a long time I tried to hide that, cover it up, because I was afraid. . . . Well, I used to pretend to see something that I couldn’t [pause] and then people would be impatient with me because they thought I was just not paying attention or, you know, stupid.” Those experiences, Dayna said, made her identify with and feel compassion toward adults who are illiterate, something she never thought about before. It took Dayna a few years before she started using a cane—a classic example of a “stigma symbol” that people who try to achieve normalization tend to reject: “I was very hesitant [about using a cane], I waited a long time. . . . I could have used it probably a couple of years before. . . . Sometimes you don’t want to face things [disability] and because I could get by [without the cane].”

## **B. Analysis of the Identities in the Social Model Group**

### ***1. Deep Awareness of Stigma and the Social Construction of Disability***

The awareness of stigma and the social construction of disability was featured prominently in my interview with Gayle, a twenty-one-year-old student who lives with facioscapulohumeral muscular dystrophy, which is a progressive (a term she finds ironic) neuromuscular disability. Gayle feels different from others, like she is a “member of a minority.” It takes her a little bit of time to get used to a new environment and for people to get used to her. She might even feel more comfortable with other people with disabilities because she thinks they understand her better.

Gayle says that those feelings can be generalized to people who belong to other minorities. Nevertheless, there are some issues she sees as specific to the disability community:

One example is stigma. . . . I think there is . . . a different kind of stigma associated with disability compared to race, ethnicity, gender, sexual orientation, and socioeconomic status, all of those things. Disability is unique in that it takes away ability in some ways. It takes away my ability to walk, it takes away my ability to smile at you too, right? . . . and so it's quite easy for me to look at myself and say, "That is something that I cannot do" and it's easy to think of the problem of being inside me. However, I'm realizing more and more that, I'm sure you know of the social model of disability . . . I think . . . it is in the responsibility of society and technology to let me do those things [that my body cannot do] and let me achieve everything that I am trying to achieve. . . . So, I often feel frustrated . . . not only because I cannot do something, but because the world is not set up so I could do it . . . and another thing that is frustrating to me is that, where we are right now, some people might hear me say that and say: "That's very selfish of you to say." . . . It's just part of ethics and justice.

Trevor, a thirty-five-year-old quadriplegic who also has respiratory failure and uses a breathing machine, said that he defies stigmas about people with disabilities, such as being incompetent, childlike, dependent, asexual, shy, and not charismatic. Trevor said he enjoys "confusing" other people and "disarm[ing] those prejudices just by quickly say[ing] a few words that will challenge all of their assumptions [by telling them a few things about myself], such as 'I speak six languages and I traveled to 50 countries and I'm married and have a full life and children.'"

## ***2. Disability as a Life-Enriching Experience***

The interviewees in this group view their disability as a life-enriching experience, and they all talked about experiences, opportunities, and relationships they gained because of it. Rebecca, a forty-year-old African American blind woman who resides in San Francisco, said she feels blind, disabled, or different because other people make her feel that way. She said she perceives her disability as a blessing, a gift, and that she would not change or cure it:

Because prior to my vision loss, I was such a . . . I had so much inside that I wanted to just let run free, I was so isolated and an introvert and afraid of the world and just lived in fear and I was afraid of trying and taking risks, trying new things because of the fear of failure or the fear of rejection, whatever. But now, it's like, I see every opportunity as a step closer to where I am destined to be, and the fact that I don't see people's faces when I say things to them, or the fact that I might not necessarily know if I'm talking to someone of prominence or [a homeless person] . . . the outer appearance, the externals, are never a factor to me anymore.



Like Rebecca, most of the interviewees (except Gayle, Jenny, and Lisa) would not wish to cure their impairment because it plays such a big part in who they are, and does not limit them to a great extent. Lisa and Jenny, who belong to the “old generation of disability advocates,” and are now in their sixties, are seemingly more likely than younger interviewees to acknowledge their desire to accept a cure as their health conditions worsen.<sup>16</sup> Gayle, who is twenty-one, did not actually express a desire for someone to cure her impairment, but said it *would* make life easier for her if someone did. As a person who truly embraces and identifies with the social model, she explained that the only reason for her to wish to cure her impairment is the societal limitation and disablement caused by a lack of accessibility and unfair treatment. Gayle said that curing her impairment would make life easier for her “but this should not be the case. It should be [that] in the future, I hope that we’ll get there sooner than maybe later . . . that there are enough systems in place that my disability would not limit me or prevent me from having a fulfilling life.”

Noah, twenty-seven, was born deaf and was diagnosed with Asperger’s syndrome while in college. When asked how his disability affects the way he thinks of himself and the way others may think of him, he answered: “I think of myself as having a unique personality and [as] an overall brilliant and logical [person]. Other people think I’m different, eccentric, special, and bright.” Noah belongs to two groups within the disability community that view themselves as having a cultural identity that is distinct from the one developed by the larger disability rights and independent living movements: the deaf community and the neurodiverse community (comprising people who are on the autistic spectrum).

Some people in the deaf community have been known to view themselves as a linguistic minority and a separate cultural subgroup and not as disabled (Shapiro 1994, 74–105; Wendell 1996, 28–29; Wrigley 1996, 75–76; Jankowski 1997, 31–35; Lawson, 2001, 215–16; Brueggemann 2009, 12; Lane 2010, 78; Solomon 2012, 62). Similarly, a global movement of people who are on the autistic spectrum constructed the term neurodiversity to avoid existing negative associations with autism. They claim to have a cultural identity of their own and object to the use of a vaccine aimed to prevent autism (Armstrong 2010, 5–8; Straus 2010, 535–59; Shakespeare 2012, 129; Solomon 2012, 263, 265). It is therefore not surprising that Noah sees his disabilities as positive traits that contribute to his own unique self-perception.

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16. Lisa said that at an earlier point in her life she identified with the social model to a great extent. Today, however, she is older, and she might not hold those same strong beliefs and might act in a different way than she used to: she is a bit more tired of advocating for the rights of people with disabilities and has become more aware of the impact of the impairment and pathology on their lives. In her own words: “I thought it was worth it to be disabled [and thus] to have those experiences. . . . That feeling did fade . . . and it continues to fade really as I get older and the physical part of it [the disability] really takes its toll . . . and for someone my age . . . I have a lot of health issues that I would not have if I weren’t disabled, and I think, for sure it’s going to shorten my life, and I think I kind of come back around to really appreciating the life I’ve had, but now it’s such a drag on my life experience. . . . I don’t know, I feel a little bit like it [the disability] enriched [my life]. It gave me perspective that is unique for my community, and it’s not entirely gone but I do remember times when I felt very differently about it [my disability].”

### 3. *Quasi-Normalization*

In his well-known 2002 study, Nick Watson found that, on the one hand, some people acknowledge the complex processes of social constructionism and stigmatization of people with disabilities and refuse to define themselves by those terms. On the other hand, those same people do not take pride in their disability and do not fully identify with concepts associated with the social model. Those individuals claim that their disability does not play a salient part in their self-identity and therefore see themselves as “normal people” who “happen to have” a disability (Watson 2002, 521–22).

Three interviewees were categorized in this subidentity-category: Tami, Steve, and Nicole. Steve, sixty-one, has been blind since birth. He has worked for twenty-five years at a center for the blind. He not only teaches visually impaired persons how to be more independent, but also constantly tries to educate others and show them that he can do anything that they can. When I asked for an example during our interview, Steve simply took out his smartphone and demonstrated how he uses a voice navigation system to control it and use it just like any other person. “So being visually impaired really means you just do things differently, that’s what it’s all about.” Sometimes he might ask someone for assistance, when, for instance, crossing the street, “even though I don’t need it. I do it for a different reason—want to educate them . . . and find out more about them and let them know what I do, so I’m making a win-win situation.”

When asked how her disability affects the way she thinks of herself, Nicole, who became an incomplete quadriplegic later in her life as a result of a car accident, said that although she is very active and enjoys a lot of outdoor activities and sports, she came to understand that she is not defined by her physicality. However, she sometimes wakes up in the morning and is surprised that she cannot simply stand or walk. In her mind, Nicole is not disabled, though her accident occurred almost ten years ago.

When discussing the role disability plays in her life, Tami gave the analogy of a recipe, and said that her disability adds a little bit of flavor to the dish that is her whole identity: “You have certain ingredients that you really like to put in a certain recipe . . . like garlic and pepper. Garlic and pepper would always be with me—and that’s what I see about my disability. It will always be with me but anything else I add on to it and take away from, it’s still part of my whole personality.” The bottom line: No matter what her disability is, she believes she is just the same person as she was before but with a little bit of spice—the drive is the same.

## V. PROCEDURAL JUSTICE PERCEPTIONS OF THE DDP AND THE INTERACTION WITH THE DDS AND SSA

This section analyzes the experiences that interviewees have had going through the DDP procedure.

## A. The Effect of the Visibility of the Disability on the Procedure

One issue that came to influence the findings is the visibility of disability of the DDP's subject. When assessing a person's eligibility for Social Security benefits, the DDS checks whether her medical condition fits within one or more of the impairments found on the official listings, and whether it is "considered severe enough to prevent an individual from doing any gainful activity" (Social Security Administration 2014). People with more prominent/visible disabilities who can easily prove their impairments therefore have an easier time obtaining benefits than others whose disability either is less apparent or does not correspond with the official definitions.

The disability rights movement is a unique entity among other civil rights movements since it is incredibly diverse in nature, declaring a "cross-disability" approach (Scotch 1989, 385; Shapiro 1994, 5, 24–25; Longmore 2003, 111; Bagenstos 2009, 3). Many disabilities are less apparent, ranging from chronic diseases to mental disabilities, and can be harder to prove. Moreover, nondisabled members of society sometimes doubt their existence or their effects on many aspects of life, which can lead to further difficulties in proving and obtaining disability benefits.

Some of the interviewees have moved from having an invisible or less apparent disability to a more visible or obvious one, and provided valuable insight. Sheila, for example, was living with a few invisible disabilities<sup>17</sup> before becoming an amputee about a year ago. Sheila says that before she became an amputee and began using a wheelchair regularly, she had a hard time proving to other people her condition, especially because she is such a positive person who "presents well." Sheila said even her husband did not believe that she had a disability and that she was in pain and that her daughters "still don't."

Sheila feels she does not receive much support from her daughters and this has been hard on her. She and her husband suggested that their daughters are in denial because they are afraid they might become disabled themselves since they carry the same genes. The notion that many people, at some point in their lives, will become disabled has been addressed in the disability studies literature in the form of the term *temporarily able bodied*. This notion is sometimes used in order to make a broader crowd interested in disability-related issues or to promote related policies (Goodley 2011, 1).

Sheila was categorized under the medical-individual models group and admitted to having hard time accepting the fact that she has a disability. As a result, it took her years to obtain a disability parking permit before becoming an amputee and having a visible disability. When she finally got the permit, she had to face the experience of proving her disability to others. Sheila said: "The thing that I feared most actually happened. First day that I used it [the permit] I parked . . . I was going shopping and I parked and it was raining and this lady comes up to me with an umbrella and starts hitting me," because that woman thought Sheila was not really

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17. Sheila has spinal stenosis (a narrowing of the spinal canal that causes some motoric limitation, pain, and numbness), is diabetic, and also has a visual impairment.

disabled and was abusing the system by using a disabled parking permit she did not deserve. “And I just looked at her and said: ‘You know, I’m not a really vengeful person but I wish you would have one hour of the pain that I have to live with before you make those kind of assumptions.’”

Hilary, who has lost most of her ability and sense in her left side (hemiparaplegia) as a result of a brain tumor and who now uses a Segway as a walking aid most of the time, told a similar story. Once, before using a Segway, she and her mother left their car in a disabled parking spot when a stranger said to her, “Why are you even using that, you don’t need that.” Hillary said that her mother asked her to pull up her pants and show that man her brace so he would believe that she was really disabled. Those experiences fit with the description of “policing of disabled parking placards” that was addressed in the literature (Moorhead 2003, 23; Samuels 2014, 132–33).<sup>18</sup> Such stories demonstrate the need to prove a less apparent disability over and over again when exercising a right designated to people with disabilities. It shows how disabled people sometimes need to expose themselves before others and prove the private experiences and pain that go along with their impairments.

This idea is translated in a very clear way into the DDP procedure. Rebecca, for example, who used to be diabetic and had a kidney dysfunction before losing her vision, had twice been rejected for disability benefits. Rebecca, who was not aware of her right to appeal, luckily met someone from within the system “who helped push through” her application and get her on benefits.

It is therefore not coincidental that only two other interviewees, both of whom had been rejected by the DDS and had gone through an appeal before an administrative law judge, had less apparent disabilities: Jenny, who has severe adult onset asthma, and Dayna, who gradually lost her vision in old age and did not use a cane or any aid for years. Both lacked “clear cut” cases and had to prove that they were disabled before a judge.

## B. Having a Voice

All the interviewees (regardless of their identity group) felt they lacked the opportunity to voice their opinions and tell their stories during the DDP. Those with visible disabilities mentioned that they did not have significant encounters with a DDS representative. Because they could easily prove their disability by submitting their medical records, the opportunity to tell their stories never materialized.

Nevertheless, attitudes toward the idea of voice differed between the members of the two large identity groups: members of the medical-individual models group

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18. Moorhead wrote about her life with multiple sclerosis, describing very similar experiences from the time her disability was still invisible: “In the year that followed my dx [the multiple sclerosis diagnosis], my car was keyed, its antenna broken, and I got accusing looks and comments—from other disabled people. I became afraid to use the handicap parking spot and other privileges that I was completely entitled to. All because I looked ‘so good.’”

seemingly cared less about this aspect and did not want to share their stories, while people in the social model group saw value in it. From the medical-individual models group, for instance, Ben said, "To tell you the truth, I am a little bit paranoid. So as long as I get my disability [benefits], I kind of would rather be more quiet about it and just leave them alone and they leave me alone." Dayna agreed with Ben and said she does not feel having a voice is important to her. She prefers the process to be "as objective as possible," so there is no need to go into so many details about a person's daily life.

On the other hand, members of the social model group did appreciate having a voice. For example, both Hillary and Tami compared the DDP to another procedure done by the California Department of Rehabilitation, a state agency that offers professional and financial support to college students with disabilities and helps them find their way in the labor market. They said that the DDP process is far less personal, and does not take into account the needs of the claimant. They longed for a representative who understood them and to whom they could raise their concerns about their current needs and expectations. Rebecca addressed this issue more directly by saying she lacked the opportunity to voice her opinion because of the manner in which the representatives presented themselves: "I didn't feel like I could [voice my opinions] because some of them project themselves [to be] like so big and bad and mean and you better not say anything or do anything. I was [laughs] 'yes, whatever you say.' No, I didn't feel comfortable because then if you start to speak up for yourself, then they think you're getting an attitude and they start [pause] they really start coming at you." Similar descriptions of reticence of welfare claimants because of the fear of alienating or making representatives angry were found in previous research (Soss 2000, 136–37).

This view of the DDS representatives and the nature of interaction with them could be derived from the intersectional identities Rebecca possesses being a low-income African American woman (Crenshaw 1991, 1251–52, 1262; Ribet 2010, 222). Rebecca, who needed the SSI money so badly, did not want to do anything that would somehow cause her to be rejected and so gave up on the idea of conveying her story.

Although Rebecca argues that she herself did not talk back to the DDS representatives, one could argue that not all benefits claimants take the same approach. Some of them might project disrespect for the DDS representatives, causing the latter to treat them in the same way, evoking feelings of unethical treatment. None of the interviewees in this research observed this situation in their cases, but this "it takes two to tango" mode might suggest a source for the negative feelings toward the procedure. This idea of increased frustration, sensitivity, or even oppositional approaches taken by members of politicized identity groups, such as the social model group, seems to derive from the social model's origins and the view that it began as a protest against historical notions of exclusion. As pointed out by Wendy Brown, those inherent frustrations can stand in the way of achieving full integration into society in the future (Brown 1993, 406).

Rebecca's answer naturally leads to the next aspect of procedural justice examined: the ethical and respectful treatment by DDS representatives.

### C. Dignity, Ethical Treatment, and Impartiality

Another difference was found in the way interviewees from the two groups perceived the treatment they received from DDS representatives. Generally speaking, the interviewees in the social model group were more critical of the attitudes and “quality of treatment,” unlike the interviewees in the medical-individual models group, who all found the representatives to be respectful and professional.

A neutral approach to this aspect of the DDP came across clearly in my interview with Ally, who was accompanied by her mother. Both found the treatment they received from the DDS representative to be very impersonal (“cut and dry”), but respectful and professional (“they are mostly friendly and definitely not nasty”). They did not meet anyone who was mean or unfriendly, and actually recalled meeting someone who was very nice.

On the other hand, people in the social model category encountered at least some disrespect from DDS representatives. They argued that they lacked a “customer service attitude” and were mean and intimidating. However, it seems that their view of their experience was not only affected by their identity perception, but also by the nature of the benefits they received. All these interviewees had received SSI at least once in their lives. Lisa, who received SSI for many years but now receives SSDI, expressed the difference in treatment between the two programs:

SSI is welfare, so they always treated us like we were suspicious. They were mean to us and rude and talked down to us. I remember once I complained about something: they were not following their rules in relation to me and I pointed that out to them, and I remember the person saying: “You don’t have any rights, you know, you’re on welfare,” and that’s the way it was. . . . When I went on to SSDI it was like I entered a whole another world and I could see how the other half lived. . . . It’s just like night and day. I felt like I went from the pits, being thought of as “a welfare queen” or “welfare cheat”; this is how I experienced it, like I’ve entered a world where the sun was shining and butterflies were flying and the birds were singing and people were nice to me. That is how dramatic the difference is.

This difference between the two Social Security programs is that SSDI is social security and SSI is a welfare system, which in liberal welfare regimes like the United States is aimed at those who are most disadvantaged, such as the unemployed and the disabled (Arikan and Ben-Num Bloom 2015, 432).

According to the interviewees, negative social attitudes toward welfare had found their way into the policy itself and its implementation, thereby affecting the treatment of DDP subjects. The representatives did not appear impartial, as one might expect from state officials, but possessed biases against and stigmatized those who applied for benefits. Similar differences between SSDI and welfare claimants regarding views of dignified and ethical treatment by SSA representatives were found in previous research (Soss 2000, 93, 110, 120–22, 151). Joe Soss hypothesized that those differences in views were related to the different demographics and

personal backgrounds of the members of the two groups of claimants, although such a connection could not be substantiated by his evidence (Soss 2000, 116–19). This awareness of bias among DDS representatives was observed only by interviewees in the social model group, and not the medical-individual models group. This is not surprising because people in the first group are often aware of the ways in which disability is socially constructed, and were thus more attuned to stigma.

#### **D. The Idea of Incorporating People with Disabilities in the SSA**

The interviewees were asked whether they think it is important for people with disabilities to work within the SSA (including the DDS agencies) and help to assess claimants for benefits. The interviewees' answers were distributed in a clear way: while all of the members of the social model group said that it is important for disabled people to be part of the SSA system, the people in the medical-individual models group said they do not see any benefit to this idea.

This clear separation was seemingly connected to the fact that the people in the social model group believe in a common social identity built on the experience of living with disabilities. Unlike the people in the medical-individual models group, they see disability as an essential and positive influence on a person's character. Hence they believe that those who experience firsthand the complexity of living with disabilities (an "inside view") could likely positively change the system from within. This belief also resonates with the theme of "nothing about us without us," which is prominent in disability studies, and calls for the inclusion of disabled people in the design and execution of policies that affect them (Charlton 2000, 16–17; Heyer 2015, 24, 37). Such successful implementations of voices of people with disabilities into social policies and specifically into the Social Security systems were made recently in Australia and Canada (Parliamentary Committee on Palliative and Compassionate Care 2015, 20; Thrill 2015, 20–25). When translating this idea into policy, it is important for the SSA and the DDS to hire a diverse group of people with disabilities who represent the different views on disability.

#### **E. Accessibility of the Procedure and the Role of the Community**

When asked how the DDS communicated the procedure to them, whether they understood the process or felt they had any control, most of the interviewees—regardless of their identity group—found it difficult to understand how the system worked. Nevertheless, there was one clear difference between the two groups. Interviewees from the social model group received at least some support from the disability community through the process.

Hillary, from the social model group, said: "It's like learning to play a game. There's a steep learning curve to dealing with SSI. . . . You either going to get your benefits or lose your benefits, and since nobody is explaining things to you, you have to learn how to play the game: you have to know people who have been on the system and know a lot about it. I was just fortunate to be involved in the

disability community and have the resources, but the everyday average person [may not have that].” Lisa and Jenny, who are long-time activists, also spoke about how the disability community in the Bay Area has helped its members go through the procedure. Embracing a common social identity and belonging to a community has seemingly allowed people to understand the procedure better—or at least go through it more easily—and has thus also affected their experiences with the DDP (Soss 2000, 66, 77–84; Soss and Keiser 2006, 138, 144).

## F. “Your Worst Day” Approach

During the interviews, an important suspicion arose repeatedly among most of the interviewees from the social model group: that the SSA intentionally makes the DDP procedure difficult. Steve, for example, said that the SSA writes letters to claimants “that are mean-spirited” because they know that “95 percent of the people are not going to fight it.” Jenny went even further, speculating that the SSA has a quota of people they can approve to receive benefits. This notion, which rarely if ever came up with members of the medical-individual models group, exposes a deep mistrust between members of the social model group and the SSA.

Another recurring pattern, which can be seen as the response to or the way the claimants dealt with what they perceive as intentional disqualification, surfaced among members of the social model group. They argued that the DDS asks claimants counterintuitive questions that are designed to create grounds for disqualification. Those questions target everyday tasks done by the claimants and are used to assess the nature of their disability.

Such questions are counterintuitive because of the entrenched need for a person with a disability to prove her worth and “put on her best face.” The catch in the specific context of the DDP is that in order for a person to be eligible for benefits, she actually needs to prove the exact opposite—that she is unable, weak, and in need of major assistance. Because getting into this mind-set is so hard to do, the approach recommended by interviewees is to answer the questions presented in the DDP as if it were the claimant’s worst day. Lisa makes this point very clearly, stating: “There is this saying that advocates for Social Security use . . . that you have to think about your worst day. You have to talk to them about how hard it is to live with a disability, how much it limits you, how much trouble it is, how bad you feel, how often you’re sick. You have to talk that way. Because you have to impress [pause] you have to present an image of being pathetic and helpless.” Lisa points out how, in order to get benefits, a person must channel the “outside view of disability as a sad place,” or “play the sick role”—two notions routinely presented in research into disability (Winter 2003, 40; Emens 2012, 1389–93).

Lisa went on to explain the paradox presented to claimants:

As you go about the rest of your life with a disability, you know, there’s times when you have to prove yourself or prove you can do things. Like,



if you want to get into college, you know you're always "putting your best foot forward," or [when] you're trying to get a job, you're talking about how confident you are, right? How strong you are, how skilled you are, how positive thinking you are, you know, how much you can do, OK? People don't realize, if they don't have advocates helping them, that if they'll go to Social Security with that attitude, they will not be eligible. . . . But, instead so many people stay on top of themselves because that's how they're used to presenting themselves in the positive way. . . . It's hard enough being disabled, people think you're helpless and pathetic, you know, so they're always trying to overcome that. . . . But when you go trying to get benefits . . . you have to talk about how bad it is and that's not easy because your mind doesn't necessarily wants to go there. You don't want to like immerse yourself in how bad it is being disabled. . . . How often do I really hurt and have pain and can't do what I want to do and you know have to go to the doctor . . . so that's why they [the advocates] say "think about your worst days," that's how you have to present yourself. That's how you have to talk about how disabled you are when you talk to Social Security and they're evaluating your eligibility.

When I asked Lisa for a specific example, she said that, in a review not long ago, she was asked about her daily activities: "What do you do with your spare time?" . . . So I write in the box . . . 'I read,' I don't say I go out to the movies, I go shopping . . . I don't say that. . . . So I would respond to all those questions, 'Yes, I had a lot of laundry. I spend my time doing laundry because I'm incontinent.' . . . I had to prove them that I was disabled enough, pathetic enough . . . yeah, that's how the system is set up."

Tami believes that if people with disabilities were part of the assessment team within the SSA or DDS, they would know how to ask those questions correctly, possibly because they would see disability from an inside perspective and understand its complexity: "[The questions] would be more realistic instead of decisions that are based on formulas. Because if I say, 'Yeah I can take the trash down the street,' you know, then they say, 'Well you can get up and walk.' Well what if that person says, 'Every step I take is painful' then there is reality." Life with a disability is complex for a lot of reasons, but the need for interviewees to downplay their abilities and emphasize their weaknesses by using the worst-day approach is a problematic aspect of the DDP procedure.

As Michael Asimow points out, the DDP procedure "is much closer to the inquisitorial end of the scale than the adversarial end" (Asimow 2013, 99). The main characteristic of an inquisitorial system is the never-ending quest for the truth. In inquisitorial systems, only a few procedural rules are applied in order to fulfill the goal of allowing the truth to surface naturally (Jolowicz 2003, 283–84). The current situation, where claimants are seemingly required to present an exaggerated version of their life experiences and abilities in order to be deemed eligible, conflicts with the search for the truth—the underlying purpose behind this inquisitorial procedure.

The DDP itself is designed in a way that requires claimants to construct their disabilities socially using the outside view (Broyer 2011, 53).<sup>19</sup> In his 1991 article about widows' disability benefits, Anthony Alfieri argues that "[t]he practice of silencing permeates the disability determination process, enforcing the ideals of benevolence and discipline and excluding the alternative ideals of autonomy and community" (Alfieri 1991, 797–98). In Tami's words:

This is kind of funny and sad at the same time; when I wake up in the morning, I look at myself in the mirror, not every day but I do, and I go, "Who am I today?" Am I the female? Of course. Is it my ethnicity? Am I disabled? Who am I going to be today in front of. And if you look at all government assessment evaluation papers, you know, the census at the very last page ... you check all of that and then "the other."... I'm always the other, cause I don't identify with all the boxes they, Social Security, wants me to be. ... And it can get very confusing for me because if I was going to be that day "the disabled," then I would have to play the disabled. You know that takes away so much of where I also see disability as an enrichment. I don't get to play the goodness of it. I have to play the identity of it.

## VI. PROCEDURAL IMPLICATIONS—THE EFFECTS OF THE DDP ON ITS SUBJECTS' FEELINGS OF INCLUSION

This section presents the ramifications the DDP has on the way its subjects view their relationship with the SSA and the state in general, and how they view their place as people with disabilities in society. It offers a glimpse of the bigger picture, and points out how procedures performed by the state socially affect members of a minority group, in accordance with the group engagement model of procedural justice.

### A. Discouraging Full Participation in the Labor Market

Throughout the interviews, the question of how much a person can actually work and still be eligible for benefits came up often. Lisa, from the social model group and who used to work for nonprofit organizations, said that she always ensured that she did not make too much at her job so that she could still be eligible for SSI. If she had allowed herself to earn even a little over the limit and have her benefits cut, she would not have enough money to support herself—it was a catch-22. Members of both groups were also highly motivated to work and contribute to society as full members. Jenny and Ben (who belong to different identity groups) both said they wanted to feel the sense of pride that comes with being considered productive "because of ego."

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19. Judith Butler's famous concept of "performativity" comes to mind in the situation promoted by the DDP, where claimants feel obligated to act according to the social concept (the outside view) of how a disabled person should look or act in order to receive benefits.

A recurring theme among interviewees from the social model group (which was not present among the medical-individual models group) was the critical perception that the DDP discourages disabled people from participating fully in the job market, and that it pushes them into the margins of society (Stone 1984, 20). According to Trevor:

So, for the longest time because I needed to keep my health insurance and because I needed mostly to keep my Medical which is linked to in-home support services . . . I had to avoid working, because under Social Security law, disability is defined as an inability to work, so in order to qualify for disability-related benefits you have to be disabled, which means you must not be able to work. . . . So I in a sense had to continue a career in academia, postponing my entry to the labor market until my human capital was sufficiently high to generate the income that would allow me to cover the costs of my disability.

Therefore, Trevor is not surprised that the DDS representatives never asked him about his longtime career goals, nor did they offer him help in achieving them: “So if they would have asked you [what is your career goal] and I would say: ‘My goal is to be a professor,’ then your goal is to work, which means your goal is to have no benefits. What I’m saying is that it’s a perverted system.”

Nicole made the same point, though more diplomatically than Trevor. She said she is grateful for having the system in the first place and that it plays an important role in her income. However, she said, “I find that the way that it’s set up though . . . one of the things that you get out of SSDI is you get health benefits through Medicare<sup>20</sup> and where it’s ‘touchy’ is that if I produce income over a certain amount a month then all of that goes away. So there is a certain negative aspect to being employed fully.”

The system puts benefits claimants in a quandary: on the one hand, they would love to work and contribute to society, but on the other, they feel that without the benefits and the medical insurance, it would be hard to support themselves and cover the expenses that go along with living with disabilities.<sup>21</sup> This situation came across in interviews with members from both identity groups; however, members of the social model group blamed the SSA for creating this situation in the first place. In other words, and as we saw in the last section, the interviewees who embrace the social model were more critical about the procedure and the intention of the SSA toward them.

Tami had an idea of how to resolve this dilemma, and observed that society could actually benefit from people with disabilities while still allowing them to receive their benefits: “What would be nice is if [pause] cause we are a work force that has not been tapped . . . it would be wonderful if we can be credited to the volunteer work that we do. [To have] some sort of exchange within the community. For example, if I volunteer at a school district in an afterschool program for . . . five

20. This interview was conducted before the Affordable Care Act was enacted and enforced.

21. Research by Asghar Zaidi and Tania Burchardt quantified the extra costs of living with disabilities in the UK. It demonstrated that disability generates significant additional costs of living that should be taken into account when comparing incomes across the population.

hours a week, it would . . . [be] nice if I could have a choice of using those volunteer hours and turn them into an income . . . any kind of income.” Although preliminary, this idea could potentially serve as a basis for policy change around the benefit system. The DDS agencies could collaborate with municipalities or other local authorities, perhaps even independent living centers, to establish a program that would offer some extra monetary compensation to benefits claimants who do work in the community based on its needs as well as the strengths of the claimants.

The benefits of this type of program are threefold: first, it would allow better integration of people with disabilities into society by fostering stronger relationships with their communities as well as boosting their sense of self-worth; second, it would help benefits claimants live more independently and would lessen their financial burdens; third, this program would be tapped to the actual needs of communities and would benefit those as well. This suggested program also fits well with the notion of interdependence, that is, embracing the idea of mutual dependency in the human experience and stressing the need for communal support for disabled and nondisabled persons alike, which is prominent in disability studies scholarship (Condeluci 1995, 90).

## B. Trying to Fight Stigma

Another issue that was discussed by interviewees from both identity groups was the social stigma associated with claiming disability benefits—with not working and collecting checks. The findings from the interviews validate existing notions in the literature about stigma (Soss 2000, 38, 48, 57–59; Little 2010, 193). Ben, from the medical-individual model group, said, “I think they [the SSA] should take into consideration that most people apply to disability [benefits] because they really don’t feel like they have a choice. Things weren’t working well on my job and I just couldn’t stand to do it anymore. It wasn’t something that I said, ‘Oh wow, I’m going to get disability [benefits] this is so cool.’” Steve told a story about how he met a stranger on his way to work who, after noticing Steve was blind, said: “‘You don’t work, right?’ [laughs] and he goes, ‘You just get a check each month,’ I said, ‘Excuse me?’ I said I work, I told him what I do. I said, ‘What kind of job do you do?’ he said, ‘I’m a lawyer,’ I educated him all the way [downtown on the train].”

Interestingly, though not surprisingly, only people from the social model group felt that the DDP procedure actually perpetuates that social stigma. According to Jenny, “I think it’s [the SSA] the place where I most rub up personally with these kinds of attitudes because I don’t put myself in a position where I have to be around unpleasant people. But when I go to these hearings or when they call me in for whatever reviews, I have to rub up against this kind of thing [stigmatizing attitudes] and it’s painful.”

## C. Implications Regarding the Place in Society and Relationship with the SSA

The conclusion drawn from the interviews with members of the social model group is that the stigma did find its way into the DDP and that they felt it during the procedure. However, interviewees from the medical-individual group felt

differently about the DDP. Although he acknowledged its existence, Ben did not connect social stigma and the DDP, saying, “I was just happy to get it and I kind of wish that it would be more money, but it didn’t affect my [view of my place in society]. I didn’t think much into ‘oh this means that . . . the United States doesn’t think I can do anything’ no, no, I didn’t feel that.”

Dayna also felt that the DDP has no effect on the way she perceives her place in society: “I’m not sure it really changed my belief about where I fit in the scheme of society or within the country [pause]. I don’t think I got something that I didn’t deserve ‘cause I worked hard [to save for SSDI]. It was one of the things the judge said [in the appeal Dayna had to go through], it was clear to her that I wasn’t trying to just avoid working.” When asked if the DDP made her think about the way people with disabilities are treated in American society, she said, “I don’t know. I never thought of it in a larger sense. I don’t see myself as part of a community of disabled people, it never even occurred to me.”

Dayna’s answer also speaks directly to the hypothesis of this research. Dayna had undertaken a two-and-a-half-year-long procedure for receiving SSDI because she was not considered disabled or blind enough. She is not, however, as critical as others who embraced the social model, even though, for the most part, they have been through a much less cumbersome and much less difficult procedure for receiving benefits. This demonstrates the extent to which an identity perception that accompanies a more critical view of how society disables others can influence one’s view of procedures.

Some of the interviewees from the social model group articulated very hard feelings regarding the DDP. Trevor was especially critical and direct about the emotions the DDP evoked in him. When asked how the DDP made him feel about his place in American society, Trevor said he felt like a “non-citizen. I felt like I was unvalued, I mean there was no expectation that I would contribute to society. . . . In some ways it felt like a right without a responsibility. In some way it felt like no rights no responsibility—‘just take this and shut up,’ you know what I mean? Sometimes it felt like [long pause] you’re never going to be part of American society so [the] American society is so generous that they’ll allow you to sort of exist in the margins. And in a way it was like ‘we’ll help you but only just enough.’” Trevor therefore directly connected the idea of citizenship, which we might consider the ultimate expression of inclusion in a certain society, with the feelings derived from the DDP. This connection aligns well with the notions underlying the group engagement model.

Rebecca shared some of Trevor’s feelings. She felt that society treats people with disabilities who claim benefits

disdainfully. Like, we’re doing you a favor. Like, I just kind of felt like a burden. . . . We’re looked at as a drain on society and that’s how I felt. And I still sometimes feel like that and that’s why I want to free myself from Social Security disability [benefits], SSI and SSDI, because it’s really demoralizing: you can’t afford rent, I mean you can barely afford food. . . . But I’m going to make it work for me because I’m not staying on Social Security! . . . People don’t understand how much of a struggle it is and they think, ‘Oh, you got a check, you should be happy.’ Yeah, I’m grateful

for it and I'm grateful that I have somewhere to sleep every night but this is not the way I want to live the rest of my life for sure.

The conclusion derived from the findings presented in this section, and summarized by Rebecca and Trevor, is that the interviewees who belong to the social model group absorb a subtle message about the social and institutional perception of people with disabilities and their place in society from the DDP and the Social Security disability benefit system. They believe that society gives them some assistance in the form of benefits, which is appreciated but insufficient to support themselves due to the high cost of living with disabilities that has been set by society. This valued assistance, however, comes at the high price of marginalization and stigmatization. They feel that the system's current design prohibits them from fully participating in society by engaging substantively in the labor market because that would automatically disqualify them from receiving the benefits they desperately need. They see themselves as being blamed for taking advantage of the system when what they really want, at the end of the day, is to be integrated within the labor market (and therefore society) and to live a dignified life.

From the subjects' point of view, a system that was designed for people with disabilities, but based on an outside view of disability, resulted in a disparate policy that actually works against them. These kinds of policies and practices are seemingly neutral, but in fact have a disproportionately negative effect on certain groups (Stein and Waterston 2006, 861, 911). Such disparate policies emerge from deeply embedded stigmatizing notions and norms in society about persons with disabilities that are derived from the outside view. Those stigmatizing notions and norms might unintentionally impact policies that were developed with little attention to, or understanding of, the nature of a group or the potential effects of such policies on it (Stein and Waterston 2006, 868–69). A possible solution to this disconnect might be involving people with disabilities (and their allies), who have first-hand knowledge and an inside view of disability, in the decision-making processes around policies that affect them (Charlton 2000, 16).

## VII. CONCLUSION

The conclusions we can draw align with the preliminary hypothesis: people from the social model group, who embrace ideas stemming from prominent social movements, were more critical about how the DDP is designed and implemented. In addition, they discerned a subtle message from the procedure regarding the place of disabled people in society and their relationship with the SSA and the state, a notion that correlates with the group engagement model of procedural justice. On the other hand, members of the medical-individual models group did not seem to have the same notions about the procedure, and they tended to adopt the outside view of disability when it came to the SSA policies and the DDP itself.

Since this research is exploratory in nature, it does not represent the disability community as a whole, and it has other limitations; it can only call attention to patterns indicating a possible relationship between self-perception and procedural

justice. Further research that relies on more elaborate sampling techniques is needed in order to prove such a relationship does exist, both in the disability community context and with regard to other minority groups.

## REFERENCES

- Albrecht, Gary L. 2010. The Sociology of Disability: Historical Foundations and Future Directions. In *Handbook of Medical Sociology*, 6th ed., ed. Chloe E. Bird, Peter Conrad, Allen M. Fermont, and Stephen Timmermans, 192–209. Nashville, TN: Vanderbilt University Press.
- Alfieri, Anthony V. 1991. Disabled Clients, Disabling Lawyers. *Hastings Law Journal* 43:769–851.
- Anderson, Eloise, Jason Turner, and Richard Burkhauser. 2013. Reforming Disability. Paper presented at Social Security Disability: Time for Reform—A Social Security Board Forum, March 8, in Washington, DC. <http://nebula.wsimg.com/67d550972ab8cfada1df70e71f6136de?AccessKeyId=EEB98E648E3097DCA50D&disposition=0&alloworigin=1> (accessed February 7, 2016).
- Areheart, Bradley A. 2008. When Disability Isn't Just Right: The Entrenchment of the Medical Model of Disability and the Goldilocks Dilemma. *Indiana Law Journal* 83:181–232.
- Arikan, Gizem, and Pazit Ben-Num Bloom. 2015. Social Values and Cross-National Differences in Attitudes Towards Welfare. *Political Studies* 63:431–48.
- Armstrong, Thomas. 2010. *Neurodiversity: Discovering the Extraordinary Gifts of Autism, ADHD, Dyslexia, and Other Brain Differences*. Cambridge, MA: Da Capo Lifelong Books.
- Asch, Adrienne. 2001. Critical Race Theory, Feminism, and Disability: Reflections on Social Justice and Personal Identity. *Ohio State Law Journal* 62:391–423.
- Asimow, Michael. 2013. Inquisitorial Adjudication and Mass Justice in American Administrative Law. In *The Nature of Inquisitorial Processes in Administrative Regimes: Global Perspectives*, ed. Laverne Jacobs and Sasha Baglay, 93–112. Farnham, UK: Ashgate.
- Bagenstos, Samuel R. 2009. *Law and the Contradictions of the Disability Rights Movement*. New Haven, CT: Yale University Press.
- Barnes, Colin. 2014. Disability, Disability Studies and the Academy. In *Disabling Barriers—Enabling Environments*, 3rd ed., ed. John Swain, Sally French, Colin Barnes, and Carol Thomas, 17–24. London: Sage.
- Barnes, Jeb, and Thomas F. Burke. 2015. *How Policy Shapes Politics: Rights, Courts, Litigation, and the Struggle Over Injury Compensation*. New York: Oxford University Press.
- Bell, Chris. 2010. Is Disability Studies Actually White Disability Studies? In *The Disability Studies Reader*, 3rd ed., ed. Lennard J. Davis, 374–82. London: Routledge.
- Berkowitz, Edward D., and Wendy Wolff. 1986. Disability Insurance and the Limits of American History. *Public Historian* 8:65–82.
- Blader, Steven L., and Tom R. Tyler. 2003. A Four-Component Model of Procedural Justice: Defining the Meaning of a “Fair” Process. *Personality and Social Psychology Bulletin* 29:747–58.
- Bloch, Frank S. 2003. Three Steps and You're Out: The Misuse of the Sequential Evaluation Process in Child SSI Disability Determination. *University of Michigan Journal of Law Reform* 37:39–94.
- Boursiquot, Bernice, and Matthew Brault. 2013. *Disability Characteristics of Income-Based Government Assistance Recipients in the United States: 2011*. Washington, DC: US Census Bureau. <http://www.census.gov/prod/2013pubs/acsbr11-12.pdf> (accessed January 3, 2016).
- Brandt, Dian E., Andrew J. Houtenville, Minh T. Huynh, Leighton Chan, and Elizabeth K. Rasch. 2011. Connecting Contemporary Paradigms to the Social Security Administration's Disability Evaluation Process. *Journal of Disability Policy Studies* 20:1–13.
- Brown, Wendy. 1993. Wounded Attachments. *Political Theory* 21:390–410.
- Broyer, Nili. 2011. Becoming Disabled: Knowledge and Truth. *Postscript: Journal of Graduate Criticism and Theory* 8:34–62. <http://journals.library.mun.ca/ojs/index.php/postscript/article/view/287/169> (accessed January 3, 2016).
- Brueggemann, Brenda Jo. 2009. *Deaf Subjects: Between Identities and Places*. New York: New York University Press.

- Campbell, Fiona A. Kumari. 2008. Exploring Internalized Ableism Using Critical Race Theory. *Disability & Society* 23 (2): 151–62.
- Charlton, James I. 2000. *Nothing About Us Without Us—Disability Oppression and Empowerment*. Oakland, CA: University of California Press.
- Condeluci, Al. 1995. *Interdependence: The Route to Community*, 2nd ed. Boca Raton, FL: CRC Press.
- Cooley, Charles Horton. [1909] 2005. *Social Organization: A Study of a Larger Mind*, 4th ed. Piscataway, NJ: Transaction.
- Crenshaw, Kimberlé. 1991. Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color. *Stanford Law Review* 43:1241–99.
- Darling, Rosalyn Benjamin. 2003. Toward a Model of Changing Disability Identity: A Proposed Typology and Research Agenda. *Disability & Society* 18:881–95.
- Darling, Rosalyn Benjamin, and D. Alex Heckert. 2010a. Activism, Models, Identities and Opportunities: A Preliminary Test of a Typology of Disability Orientations. In *Disability as a Fluid State*, ed. Sharon Barnartt, 203–29. Bingley, UK: Emerald Group.
- . 2010b. Orientations Towards Disability: Differences Over the Lifecourse. *International Journal of Disability, Development and Education* 57:131–43.
- Davis, Lennard J. 2010. Constructing Normalcy. In *The Disability Studies Reader*, 3rd ed., ed. Lennard J. Davis, 3–19. London: Routledge.
- Deutsch, Morton. 2006. Justice and Conflict. In *The Handbook of Conflict Resolution: Theory and Practice*, 2nd ed., ed. Morton Deutsch and Peter T. Coleman, 43–68. San Francisco, CA: Jossey-Bass.
- Disability Statistics and Demographics Rehabilitation and Research Training Center. 2014. *Annual Disability Statistics Compendium*. Durham, NH: University of New Hampshire, Institute on Disability. [http://www.disabilitycompendium.org/docs/default-source/2014-compendium/2014\\_compendium.pdf](http://www.disabilitycompendium.org/docs/default-source/2014-compendium/2014_compendium.pdf) (accessed July 4, 2015).
- Drum, Charles E. 2009. Models and Approaches to Disability. In *Disability and Public Health*, ed. Charles E. Drum, Gloria L. Krahn, and Hank Bersani, Jr., 27–45. Washington, DC: American Public Health Association.
- Emens, Elizabeth F. 2012. Framing Disability. *University of Illinois Law Review* 2012:1383–1442.
- Engel, David M., and Frank W. Munger. 2003. *Rights of Inclusion: Law and Identity in the Life Story of Americans with Disabilities*. Chicago, IL: University of Chicago Press.
- Galanter, Marc. 1974. Why the “Haves” Come Out Ahead: Speculations on the Limits of Legal Change. *Law & Society Review* 9:95–160.
- Giddens, Anthony. 1991. *Modernity and Self Identity: Self and Society in the Late Modern Age*. Stanford, CA: Stanford University Press.
- Goodley, Dan. 2011. *Disability Studies—An Interdisciplinary Introduction*. London: Sage.
- Hensler, Deborah R. 2003. Money Talks: Searching for Justice Through Compensation for Personal Injury and Death. *DePaul Law Review* 53:417–55.
- Heyer, Katharina. 2007. A Disability Lens on Sociolegal Research: Reading Rights of Inclusion from a Disability Studies Perspective. *Law & Social Inquiry* 32:261–93.
- . 2015. *Rights Enabled: The Disability Revolution, from the US, to Germany and Japan, to the United Nations*. Ann Arbor, MI: University of Michigan Press.
- Huberfeld, Nicole, and Jessica L. Roberts. Forthcoming. An Empirical Perspective on Medicaid as Social Insurance. *University of Toledo Law Review*. [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=2532495](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2532495) (accessed January 3, 2016).
- Hughes, Bill. 2014. Disability and the Body. In *Disabling Barriers—Enabling Environments*, 3rd ed., ed. John Swain, Sally French, Colin Barnes, and Carol Thomas, 55–62. London: Sage.
- Jankowski, Katherine A. 1997. *Deaf Empowerment: Emergence, Struggle and Rhetoric*. Washington, DC: Gallaudet University Press.
- Jolowicz, J. A. 2003. Adversarial and Inquisitorial Models of Civil Procedure. *International and Comparative Law Quarterly* 52 (2): 281–95.
- Kanter, Arlene S. 2011. The Law: What’s Disability Studies Got to Do with It or an Introduction to Disability Legal Studies. *Columbia Human Rights Law Review* 42:403–79.
- Lane, Harlan. 2010. Construction of Deafness. In *The Disability Studies Reader*, 3rd ed., ed. Lennard J. Davis, 77–93. London: Routledge.



- Lawson, John. 2001. Disability as a Cultural Identity. *International Studies in Sociology of Education* 11 (2): 203–22.
- Lind, E. Allan, and Tom R. Tyler. 1988. *The Social Psychology of Procedural Justice*. New York: Springer.
- Lind, E. Allan, Ruth Kanfer, and Christopher P. Earley. 1990. Voice, Control, and Procedural Justice: Instrumental and Noninstrumental Concerns in Fairness Judgments. *Journal of Personality & Social Psychology* 59:952–59.
- Lind, E. Allan, Robert J. MacCoun, Patricia Ebener, William L. F. Felstiner, Deborah R. Hensler, Judith Resnick, and Tom R. Tyler. 1990. In *the Eye of the Beholder: Tort Litigants' Evaluations of Their Experiences in the Civil Justice System*. *Law & Society Review* 24:953–96.
- Linton, Simi. 1998. *Claiming Disability: Knowledge and Identity*. New York: New York University Press.
- . 2005. What Is Disability Studies? *PMLA* 120:518–22.
- Little, Deborah L. 2010. “Sit Home and Collect the Check”: Race, Class and the Social Construction of Disability Identity. In *Disability as a Fluid State*, ed. Sharon Barnartt, 183–202. Bingley, UK: Emerald Group.
- LoBianco, Anthony F., and Kathy Sheppard-Jones. 2007. Perceptions of Disability as Related to Medical and Social Factors, *Journal of Applied Social Psychology* 37:1–13.
- Longmore, Paul K. 2003. *Why I Burned My Book and Other Essays on Disability*. Philadelphia, PA: Temple University Press.
- Malhotra, Ravi, and Morgan Rowe. 2013. *Exploring Disability and Disability Rights Through Narratives: Finding a Voice of Their Own*. London: Routledge.
- Mashaw, Jerry L. 1984. *Bureaucratic Justice: Managing Social Security Disability Claims*. New Haven, CT: Yale University Press.
- Michalko, Rod. 2002. *The Difference that Disability Makes*. Philadelphia, PA: Temple University Press.
- Minow, Martha. 1990. *Making All the Difference: Inclusion, Exclusion, and American Law*. Ithaca, NY: Cornell University Press.
- Moorhead, Lorena. 2003. *Coffee in the Cereal: The First Year with Multiple Sclerosis*. Tucson, AZ: Pathfinder.
- Mor, Sagit. 2006. Between Charity, Welfare, and Warfare: A Disability Legal Studies Analysis of Privilege and Neglect in Israeli Disability Policy. *Yale Journal of Law & the Humanities* 18 (2): 63–138.
- . 2011. Disability and the Persistence of Poverty: Reconstructing Disability Allowances. *Northwestern Journal of Law & Social Policy* 6 (1): 178–214.
- Nagi, Saad Z. 1991. Disability Concepts Revisited: Implications for Prevention. In *Disability in America: Toward a National Agenda for Prevention*, ed. Andrew M. Pope and Alvin R. Tarlov, 309–27. Washington, DC: National Academies Press.
- Nario-Redmond, Michelle R., Jeffery G. Noel, and Emily Fern. 2013. Redefining Disability, Re-Imagining the Self: Disability Identification Predicts Self-Esteem and Strategic Responses to Stigma. *Self & Identity* 12 (5): 468–88.
- National Bureau of Economic Research. n.d. *The Growth in the Social Security Disability Insurance Rolls*. <http://www.nber.org/bah/fall06/w12436.html> (accessed July 4, 2015).
- Okimoto, Tyler G., and Amy Wrzesniewski. 2012. Effort in the Face of Difference: Feeling Like a Non-Prototypical Group Member Motivates Effort. *European Journal of Social Psychology* 42 (5): 628–39.
- Oliver, Michael. 1986. Social Policy and Disability: Some Theoretical Issues. *Disability, Handicap & Society* 1:5–17.
- . 1990. *The Politics of Disablement: A Sociological Approach*. New York: St. Martin's Press.
- . 1996. *Understanding Disability: From Theory to Practice*. New York: Macmillan.
- Olney, Marjorie F., and Karin F. Brockelman. 2003. Out of the Disability Closet: Strategic Use of Perception Management by Select University Students with Disabilities. *Disability & Society* 18:35–50.
- Parliamentary Committee on Palliative and Compassionate Care. 2015. NOT TO BE FORGOTTEN: Re-Writing the Disability Chapter in Canada: A Functional, Forward-Looking Approach. Report of the Parliamentary Committee, Ottawa, ON. <http://pcpcc-cpspsc.com/wp-content/uploads/2015/03/FinalDisability.March20.2015.pdf> (accessed January 21, 2016).
- Parsons, Talcott. 2013. *The Social System*, 2nd ed., ed. Turner S. Bryan. London: Routledge.

- Relis, Tamara. 2002. Civil Litigation from Litigants' Perspectives: What We Know and What We Don't Know About the Litigation Experience of Individual Litigants. In *Studies in Law, Politics and Society* 25, ed. Austin Sarat and Patricia Ewick, 151–212. Bingley, UK: Emerald Group Publishing.
- Ribet, Beth. 2010. Surfacing Disability Through a Critical Race Theoretical Paradigm. *Georgetown Journal of Law & Modern Critical Race Perspectives* 2:209–56.
- Rovner, Laura L. 2001. Perpetuating Stigma: Client Identity in Disability Rights Litigation. *Utah Law Review* 2001 (2): 247–318.
- Samuels, Ellen. 2014. *Fantasies of Identification: Disability, Gender, Race*. New York: New York University Press.
- Scheman, Naomi. 1997. Queering the Center by Centering the Queer: Reflections on Transsexuals and Secular Jews. In *Feminists Rethink the Self*, ed. Diana Tietjens Meyers, 124–62. Boulder, CO: Westview Press.
- Schweik, Susan M. 2009. *The Ugly Laws: Disability in Public*. New York: New York University Press.
- Scotch, Richard K. 1989. Politics and Policy in the History of the Disability Rights Movement. *Milbank Quarterly* 67:380–400.
- Shakespeare, Tom. 2010. The Social Model of Disability. In *The Disability Studies Reader*, 3rd ed., ed. Lennard J. Davis, 266–73. London: Routledge.
- . 2012. Still a Health Issue. *Disability & Health Journal* 5:129–31.
- Shapiro, Joseph P. 1994. *No Pity: People with Disabilities Forging a New Civil Rights Movement*. Portland, OR: Broadway Books.
- Smith, Armantine M. 2003. Persons with Disabilities as a Social and Economic Underclass. *Kansas Journal of Law & Public Policy* 12:13–68.
- Social Security Administration. 2014. *Listing of Impairments*. <http://www.ssa.gov/disability/professionals/bluebook/listing-impairments.htm> (accessed July 4, 2015).
- Social Security Advisory Board. 2003. *The Social Security Definition of Disability*. <http://www.ssab.gov/portals/0/DisabilityForum/Social%20Security%20Definition%20Of%20Disability.pdf> (accessed January 3, 2016).
- Solomon, Andrew. 2012. *Far from the Tree: Parents, Children, and the Search of Identity*. Southern Pines, NC: Scribner.
- Soss, Joe. 2000. *Unwanted Claims: The Politics of Participation in the U.S. Welfare System*. Ann Arbor: University of Michigan Press.
- Soss, Joe, and Lael R. Keiser. 2006. The Political Roots of Disability Claims: How State Environments and Policies Shape Citizen Demands. *Political Research Quarterly* 59:133–48.
- Stein, Michael Ashley, and Michael E. Waterston. 2006. Disability, Disparate Impact and Class Actions. *Duke Law Journal* 56:861–922.
- Stone, Deborah A. 1984. *The Disabled State*. Philadelphia, PA: Temple University Press.
- Straus, Joseph N. 2010. Autism as Culture. In *The Disability Studies Reader*, 3rd ed., ed. Lennard J. Davis, 535–62. London: Routledge.
- Taylor, Charles. 1989. *Sources of the Self: The Making of the Modern Identity*. Cambridge, MA: Harvard University Press.
- tenBroek, Jacobus, and Floyd W. Matson. 1966. The Disabled and the Law of Welfare. *California Law Review* 54:809–40.
- Thomas, Carol. 2014. Disability and Impairment. In *Disabling Barriers—Enabling Environments*, 3rd ed., ed. John Swain, Sally French, Colin Barnes, and Carol Thomas, 9–16. London: Sage.
- Thrill, Cate. 2015. Listening for Policy Change: How the Voices of Disabled People Shaped Australia's National Disability Insurance Scheme. *Disability & Society* 30 (1): 15–28.
- Tyler, Tom R., and Steven L. Blader. 2003. The Group Engagement Model: Procedural Justice, Social Identity, and Cooperative Behavior. *Personality & Social Psychology Review* 7:349–61.
- Tyler, Tom R., and E. Allan Lind. 2000. Procedural Justice. In *Handbook of Justice Research in Law*, ed. Joseph Sanders and V. Lee Hamilton, 65–92. New York: Springer.
- US Census Bureau. 2012. Nearly 1 in 5 People Have a Disability in the US. Census Bureau Reports, news release, July 25. <https://www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html> (accessed July 4, 2015).

- Verkuil, Paul, and Jeffrey Lubbers. 2003. Alternative Approaches to Judicial Review of Social Security Disability Cases. *Administrative Law Review* 55:731–85.
- Watson, Amy C., and Beth Angell. 2007. Applying Procedural Justice Theory to Law Enforcement's Response to Persons with Mental Illness. *Psychiatric Services* 58:787–93.
- . 2013. The Role of Stigma and Uncertainty in Moderating the Effect of Procedural Justice on Cooperation and Resistance in Police Encounters with Persons with Mental Illness. *Psychology, Public Policy & Law* 19:30–39.
- Watson, Nick. 2002. Well, I Know This Is Going to Sound Very Strange to You, But I Don't See Myself as a Disabled Person: Identity and Disability. *Disability & Society* 17:509–27.
- Weber, Mark C. 2009. Disability Rights, Disability Discrimination, and Social Insurance. *Georgia State University Law Review* 25:575–606.
- Welsh, Nancy A. 2001. Making Deals in Court-Connected Mediation: What's Justice Got to Do with It? *Washington University Law Quarterly* 79:787–862.
- Wendell, Susan. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability*. London: Routledge.
- . 2010. Toward a Feminist Theory of Disability. In *The Disability Studies Reader*, 3rd ed., ed. Lennard J. Davis, 336–52. London: Routledge.
- Wing, Adrienne Katherine. 2005. Examining the Correlation Between Disability and Poverty: A Comment from a Critical Race Feminist Perspective—Helping the Joneses to Keep Up! *Journal of Gender, Race & Justice* 8:655–66.
- Winter, Jerry Alan. 2003. The Development of the Disability Rights Movement as a Social Problem Solver. *Disability Studies Quarterly* 23:33–61.
- Wolbring, George. 2008. The Politics of Ableism. *Development* 51:252–58. <http://www.palgrave-journals.com/development/journal/v51/n2/pdf/dev200817a.pdf> (accessed January 3, 2016).
- World Health Organization. 2002. *Towards a Common Language for Functioning, Disability and Health: ICF*. <http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf> (accessed January 3, 2016).
- Wrigley Owen. 1996. *The Politics of Deafness*. Washington, DC: Gallaudet University Press.
- Zaidi, Asghar and Tania Burchardt. 2005. Comparing Incomes When Needs Differ: Equalization for the Extra Costs of Disability in the UK. *Review of Income and Wealth* 51:89–114.
- Zola, Irving Kenneth. 1993. Disability Statistics, What We Count and What It Tells Us—A Personal and Political Analysis. *Journal of Disability Policy Studies* 4:9–39.

## STATUTES CITED

- Social Security Act, 42 U.S.C. § 901 (1935).  
 Social Security Act, 42 U.S.C. § 423 (2000).

APPENDIX: SUMMARY TABLE DESCRIBING THE RESEARCH POPULATION

TABLE A1.

Name (Alias)	Age	Disabilities	Proportion of Life Disabled	Intersectionality (Race/Sexual Orientation)	Class (Determined by Self-Identification)	SSI/SSDI	Identity Group
Ally	29	Epilepsy + learning disability	Since teen years (since the age of 15)	Caucasian, straight	Upper-middle class	SSI	Medical-individual models
Rebecca	40	Blind + neuropathy (former diabetic)	Later in life	African American, straight	Working class	SSI + SSDI	Social model
Ben	64	Blind	Since birth	Caucasian, gay	Middle class	SSDI	Medical-individual models
Tami	57	Incomplete quadriplegic	Later in life	Asian American (Philippines), straight	Lower-middle class	SSDI	Social model
Noah	27	Deaf + Asperger	Since birth	Asian American (Philippines), straight	Upper class	SSI + SSDI	Social model
Steve	61	Blind	Since birth	Caucasian, straight	Lower-middle class	Former SSI, current SSDI	Social model
Jenny	64	Adult onset asthma (severe respiratory impairment)	Later in life	Caucasian, lesbian	Working class	SSI	Social model
Trevor	35	Spinal muscular atrophy	Since childhood	Latin American (Colombia), straight	Lower-middle class	SSI	Social model
Gayle	21	Neuromuscular dystrophy + hearing impairment	Since childhood	Asian American (China), straight	Upper-middle class	Denied SSI and SSDI	Social model

Table A1. Continued

Name (Alias)	Age	Disabilities	Proportion of Life Disabled	Intersectionality (Race/Sexual Orientation)	Class (Determined by Self-Identification)	SSI/SSDI	Identity Group
Sheila	68	Spinal stenosis + amputee + visual impairment + diabetic	Later in life	Caucasian, straight	Upper-middle class	Denied SSDI	Medical-individual models
Dayna	67	Severe visual impairment (macular degeneration)	Later in life	Caucasian, straight	Middle class	SSDI	Medical-individual models
Lisa	62	Paraplegic	Since teen years (since the age of 16)	Caucasian, bisexual	Working class	Former SSI, current SSDI	Social model
Hillary	22	Mild quadriplegia + visual impairment + learning disabilities (cancer survivor)	Since childhood	Latin American (El Salvador), straight	Middle class	SSI	Social model
Nicole	65	Incomplete quadriplegic	Later in life	Caucasian, straight	Upper-middle class	SSDI	Social model

All names are pseudonyms to protect the anonymity of the interviewees.