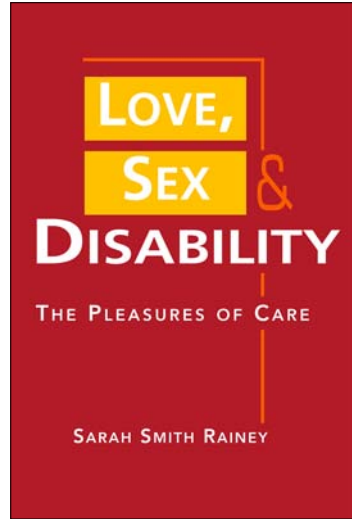


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Love, Sex, and Disability: The Pleasures of Care

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1

Introduction: Love, Sex, and Disability

My late partner, Max, had secondary progressive multiple sclerosis (MS). We met in an online dating forum during the summer of 2003. When he contacted me, I read his profile and was struck by the many things that we had in common personally, socially, and politically. We obviously were a good match and he was very handsome. I definitely was interested in chatting, but he had been upfront about his disability and I felt that I had to consider what that meant for a relationship before pursuing it any further. I did not want to begin chatting online, then on the phone, and maybe meeting in person only to back out because the disability was too much for me to handle. For several days, I read everything I could get my hands on about multiple sclerosis. I learned that Max's form of MS was not the worst (e.g., primary progressive), but not the best either (relapsing remitting). Max had gone downhill quickly, remitted, and was now in a slow, but supposedly continual decline. There were medications that could help slow the progress of the disease, but there was no cure. The medications usually worked so well that it was no longer common to die from MS. Before these medications became widely available, people with MS died when the disease began attacking their respiratory system. Nevertheless, a number of physical symptoms could come and go: poor vision, cognitive problems, inability to walk or stand or move any part of the body, depression, erectile dysfunction, low sex drive, pain, numbness, and poor coordination. Did I want to start dating such a person? What if we fell in love? Would caring for Max on a daily basis make me resentful, tired, or depressed? Could I handle it when he got worse? How would my friends and family react?

Obviously, I decided to jump in. I spent five wonderful years with Max before his death in April 2008. I am recounting this story because the questions that I initially asked myself reflect popular culture's assumptions about care, disability, and the nature of relationships. I think it is telling that my first questions were not: How will Max love me and take care of me? What kind of fun

will we experience? How could taking physical care of Max be part of our intimacy? I did not ask such questions because they were not available to me. The cultural script for relationships in which one person is physically disabled and the other is nondisabled is one of despair and pity.

This script is enforced by portrayals of care burden on television, in film, and by the questions and comments of friends, family members, health care professionals, and strangers. For example, it was common for strangers at the grocery store to assume that I was Max's personal care assistant. Checkout clerks would ask if I "enjoy my job." It was inconceivable to them that Max and I could be a couple. Once while flying to Chicago for a family vacation, the airline bumped Max up to first class without asking if he was traveling with anyone else. When confronted, the airline attendants said they assumed he was traveling alone. Both of these examples illustrate that people with disabilities are imagined as single, sexless, and pitiable—definitely not intimate partners, fathers, or mothers. Conversely, the partners of people with disabilities are either viewed suspiciously or as martyrs. When I was filing travel grant paperwork after presenting a portion of the research that I describe in this book, the student assistant who was helping me asked if I was "in such a relationship." When I responded affirmatively, he said, "Wow, you must be a really great person. That has to be really hard on you." I said that I was just as much work for Max as he was for me, but I could tell that my correction was not heard—the image of burden was too strong. In writing about women with disabilities, Adrienne Asch and Michelle Fine relay a similar story:

Disabled women who have partners, especially if they are non-disabled men, are likely to discover that they and their partners are subjected to curiosity, scrutiny, and public misunderstanding. Ubiquitously perceived as a social burden, the disabled woman evokes pity that spreads to her partner. "Whenever my husband and I are shopping and he is pushing my wheelchair, people stop us and say [to him], 'You must be a saint.' What about me? Do you think it's easy to live with him?" The public assumption is that this woman is a burden and her husband is either saintly or a loser himself.¹

Even if the disabled/nondisabled couple does not experience physical care as a burden, it is impossible to escape the prevailing beliefs about care burden and dependency. Strangers usually exhibit an amazing level of audacity when confronted publicly with disability, revealing their beliefs about disability, care, and relationships.

Family members and friends also may freely express doubt and concern over disabled/nondisabled intimate relationships. In Rose Galvin's qualitative study on disabled identity, disabled people described numerous examples of discriminatory attitudes about their sexuality and ability to be in a relationship. For example, one of Galvin's research participants, Craig, says that friends and family members "advised his wife against marrying him, saying 'He's a nice

man, but he's disabled."² Similarly, in Dikaïos Sakellariou's study of men with spinal cord injury, family members' disapproval of intimate relationships between disabled and nondisabled people is a frequent theme. "Alexandros shared a story, where the brother-in-law of a man with spinal cord injury suggested that his sister should find a lover, since she wouldn't be possibly getting any sexual satisfaction from her spinal cord injured husband."³ Another participant in Sakellariou's study, John, says that his girlfriend left him because she could not present him to her family.⁴

Some disability theorists argue that the cultural taboo against disabled/nondisabled intimate relationships is a form of "erotic segregation," similar to the social taboos placed on interracial relationships.⁵ Writing about the discriminatory treatment and sexual shame that people with disabilities receive on a daily basis, Barbara Faye Waxman notes, "I believe this is done tacitly to keep us from doing the thing that poses an overwhelming threat to our disability-phobic society: taking their sons and daughters as sexual and life partners, bearing their grandchildren."⁶ Fearful that a disabled person will partner with a nondisabled person, burdening nondisabled family members and potentially creating more disability, people with disabilities are erotically segregated—socially through taboo and institutionally by way of separate education for people with disabilities, institutionalization in nursing homes, and isolation due to inaccessible physical environments and economic strain. I find the concept of erotic segregation helpful in thinking through the construction of disabled/nondisabled intimate relationships, but it does not explain all the forms of discrimination that such couples experience. In particular, it does not approach the particular constructions of care and dependence/independence that seem to root many of the biased statements outlined above.

As a feminist scholar, I turned to feminist research for further understandings of the causes and consequences of stereotyped constructions of care in disabled/nondisabled intimate relationships. I found that feminist scholars are more likely to critique the meaning of independence woven into many disability stereotypes; however, caring between intimate partners is largely absent in the formidable body of work that examines the gendered nature of care. Instead, feminists more commonly address issues of caregiving in terms of caring for dependent children or elderly parents.⁷ Ellen K. Feder and Eva Feder Kittay describe care as "interactions of unequals . . . between the caregiver and the dependent to be cared for."⁸ In *Love's Labor: Essays on Women, Equality, and Dependency*, Eva Feder Kittay goes even further and calls the cared-for a "charge" to indicate that self-direction and care are "outside the ability or entitlement of the charge."⁹ Within this scheme, dependents or charges are rarely also intimate partners and producers of care in relationships. Furthermore, the vast majority of contemporary feminist research constructs nondisabled partners as victims of a system that refuses to help caregivers, who are statistically female.¹⁰ For example, the National Organization for

Women conducts campaigns for both disability rights and mothers' and caregivers' economic rights; however, these platforms are not linked. In fact, disabled people are not addressed in the mothers' and caregivers' economic rights statement of policy and program goals.¹¹ Suggested solutions involve respite care, paying informal caregivers, and job protection for caregivers. These reforms are all aimed at helping the (nondisabled) caregiver. Reforms aimed at disabled people—including direct funds to the disabled so that they can hire and manage their own personal care assistants—are not listed. It is true that family caregivers need help, but it is symptomatic of the beliefs about disability in intimate relationships that the disabled partners are erased in much feminist care research and policy.

Thus, much of the feminist research on care and disability supports the pre-dominate image of the burdened and asexual disabled/nondisabled couple. I find this ideological hegemony remarkable. Of course, the hegemony is never complete—there are individuals who approve of disabled/nondisabled intimate relationships, and there certainly are plenty of couples who resist attempts to construct their relationship as burdensome and asexual. In this book, I begin the necessary process of understanding and countering the dominant representations of disabled/nondisabled intimate relationships. I examine two key discursive sites that contribute to the ideological hegemony—popular culture (e.g., mainstream film, television, and magazines) and the applied fields (e.g., rehabilitation sciences, medicine, and psychology). To provide alternative understandings of care and sexuality in disabled/nondisabled relationships, I turn to the words and images of people involved in such relationships. Their experiences help construct new scripts about care, love, and sexuality.

Such a holistic approach to the topic is a radical departure from most studies on the relationship between disabled/nondisabled partners. As Chapter 2 details, this topic is common in the applied fields; however, such relationships are typically viewed as burdensome for the nondisabled partner and the couple's sexuality is consistently absent in the research. Importantly, the couple's "problems" are rarely framed within the social world. In other words, how films, media, social movements, and the people around them shape (and are shaped by) the couple is seldom part of the framework in scientific studies on disabled/nondisabled relationships. To date, there have been only a handful of studies that adopt a social view, incorporating questions about the couple's treatment and how stereotypes about sexual and care relationships involving disability affect people with disabilities and their partners.¹² Most notably is Gillian Parker's book-length study of couples in England during the late 1980s and early 1990s, which is called *With This Body: Caring and Disability in Marriage*. Parker interviewed twenty-one couples (using both couple and individual interviews) in which one partner had become physically disabled since marriage. She was particularly interested in how the couple negotiated inde-

pendence and dependence, and how the preexisting relationship shaped the roles adopted in the presence of disability. However, Parker weaves in information about the influence of public policy on the relationship, and positive and negative effects of prejudice and support from friends, neighbors, and extended family members. Thus, Parker understands that the couple exists in a social and political matrix that influences the experience of disability and care in marriage. Similarly, Celia Shultz's more recent study of collaboration within intimate relationships situates the people with disabilities and their partners within a social world.¹³ Shultz examined four physically impaired people, three of whom were married to other people with disabilities. Shultz's participants were all physically impaired at the time of their marriage. Like Parker, Shultz found high levels of collaboration, problem solving, and reciprocity between partners. Caregiving and receiving were blended into the couples' daily interactions.

Parker, Shultz, and other researchers are beginning to simultaneously investigate the social, political, and experiential dimensions of care in intimate relationships involving disability.¹⁴ However, the sexual aspects of these relationships are typically left out or downplayed in the little research that does exist. Thus, this study is unique in that I look at care and sexuality/intimacy in disabled/nondisabled intimate relationships. Additionally, the study includes both pre- and postdisability couples. In other words, some of the examples involve couples in which the disabled partner was impaired after they became a couple and some before they became a couple.

This project is also unique because I was interested in both (1) understanding how dominant narratives of care and intimacy are circulated and enforced in contemporary society; and (2) how disabled/nondisabled couples work with and against dominant narratives of care and intimacy. To adequately carry out such an extensive, holistic study, I had to draw on a wide range of disciplines and employ several different kinds of research methods. With respect to the circulation of norms, I focused on popular culture and the applied fields because these two arenas are particularly powerful for people with disabilities. I used feminist, textual analysis to analyze popular culture representations, and content analysis to examine research from the applied fields. While I acknowledge that these sites help shape the experiences of disabled/nondisabled couples, they do not determine their lives. In other words, popular culture and the applied fields research influence, but do not dictate realities. Couples adopt, alter, and resist dominant narratives about their lives. Thus, I also systematically examined alternative renderings of disabled/nondisabled relationships by turning to a variety of self-representations. I used three sources of self-representations in this study: autobiographies written by people in disabled/nondisabled relationships, filmic self-representations, and both oral and written statements of participants in the four focus groups that I conducted as part of this research project.

Key Voices and Concepts

The voices of the focus group participants, along with the authors of the written and filmic self-representations, ground the analysis in this book. In other words, I used their understandings of care, intimacy, and love to analyze the dominant representations of disabled/nondisabled relationships and to help make sense of their complicated self-representations. Thus, before outlining the chapters of this book, I will introduce my “coauthors” and explain how their specific deployment of key concepts helped guide the subsequent analysis.

I start by introducing the authors of the autobiographies because use of autobiographies as a data source is atypical. And at least from the perspective of disability rights activism, it is a somewhat controversial move because disability autobiography often features individuals overcoming impairment and downplays interdependence (the way each of us is dependent on others for survival) and disability pride.¹⁵ However, the six autobiographies that I reference throughout this book do not reify popular understandings of the self as separate and independent of others, nor do they tell tales celebrating the return to disability-free bodies.¹⁶ The autobiographies that I selected put forth new paradigms about interdependency, the relationship between self and others, by highlighting the relationality of the body. Four of the authors—Nancy Mairs, Bonnie Sherr Klein, Robert Francis Murphy, and John Hockenberry—write from the perspective of the disabled partner.¹⁷ The other two—Marion Deutsche Cohen and Morton Kondracke—write from the perspective of the nondisabled partner.¹⁸ All of these authors narrate what Paul John Eakin calls the “relational life,” stories that describe a “relational model of identity, developed collaboratively with others, often family members.”¹⁹ The relational life makes connection very obvious. The lives of others figure prominently in the autobiographies of relational selves, so much so that the text becomes partially a biography of the proximate other.²⁰ Physical impairment can facilitate the saliency of relationality because the disabled person needs the other in atypical ways. Indeed, the disability rights movement puts forth the concept of interdependency²¹ to emphasize how the disabled and nondisabled alike are dependent on others for daily survival. The authors of the autobiographies that I analyzed are aware of the way in which caregiving and receiving can help them see their connection to others, and they mark this connection using a variety of strategies.

One way that interdependency is marked in the texts is through what Susanna Egan calls “mirror talk”: the dialogue between two characters, the dialogue between reader and author, and the internal dialogue of the narrator in autobiographical texts.²² Mirror talk includes all of the dialogic moments that create the relational self. Egan argues that this mirror talk exemplifies intersubjectivity because it stresses the need for a subject to be recognized by another subject. The dialogic moments in the autobiographical texts enact

intersubjectivity, producing a self in relation to another, producing a narrator always in the process of subject formation. In other words, through dialogue with the writer, with the reader, and between characters, the narrator emerges into subjectivity.

I selected these six authors because they speak to—and speak back to—the dominant representations of care and sexuality in disabled/nondisabled. In different ways, each author shows that care is not necessarily a binary relationship and that their disabled body can be a site of pleasure. The autobiographies are case studies of self-representations that bring alternative constructions of care and sexuality into relief.

In addition to written autobiographies, I used three autobiographical documentary films made by or with people with disabilities—*Shameless: The ART of Disability* (2006), *Want* (2007), and *Sick: The Life and Death of Bob Flanagan Supermasochist* (1997).²³ These filmic self-representations also offer new understandings of disability and intimacy, and all three films engage in filmic practices that blur the boundaries between self and other, highlighting interdependence. Each film also features intimate, sexual relationships between people with disabilities and those that help care for them. In doing so, these films emphasize reciprocity between partners, suggesting that care can increase (not hinder) intimacy.

As self-representations, the autobiographies and films offer viewers a rich portrait of life with physical impairment, but they also were typically produced by people with certain levels of social and economic privilege.²⁴ Disabled authors and performers/filmmakers have the means and experience to create and produce their representations. The relative privilege of disabled authors and performers/filmmakers may impact their experience of care and sexuality, limiting the applicability of the research findings. In order to diversify the self-representations that I analyzed in this study, I also conducted focus groups with couples in disabled/nondisabled relationships (for a more detailed discussion of my focus group methodology, including recruitment and data analysis, please see Appendix A). I recruited twelve couples into four focus groups in four different areas of Ohio. The demographics of all the participants who framed this study are displayed in Table 1.1, but I will now introduce each couple.

The makeup of each of the focus groups was somewhat determined by the organizations that helped me recruit participants. For example, I recruited three of the four couples in Focus Group 1 through a multiple sclerosis group. Although they did not know each other, these three white couples share the experience of dealing with MS, an unpredictable and progressive disease. Tracy and Jeff are a thirty-something couple who married about a year after Tracy's diagnosis with MS. She works part-time and cares for their toddler daughter while he works full-time. Sabrina and Adam are also a thirty-something couple who married after Sabrina's diagnosis with MS. However, they are a blended family with four children between them. These two couples are newlyweds

Table 1.1 Participants

Demographics	Sex	Age	Race/ Ethnicity	Marital Status	Disabled/ Nondisabled	When Disabled	Time Lived Together (years)	Length of Relationship (years)
Focus Group 1								
Tracy	F	31	White	Married	Disabled (MS)	Before	4	4.5
Jeff	M	31	White	Married	Nondisabled	Before	4	4.5
Sabrina	F	34	White	Married	Disabled (MS)	Before	1	1.5
Adam	M	33	White	Married	Nondisabled ^a	Before	1	1.5
Kevin	M	44	White	Married	Nondisabled	After	16	25.0
Ellen	F	43	White	Married	Disabled (MS)	After	16	25.0
Rachel	F	32	White	Not married	Disabled (spinal muscular atrophy type 2)	Before	2	5.0
Jack	M	33	White	Not married	Nondisabled	Before	2	5.0
Focus Group 2								
Richard	M	64	White	Married	Nondisabled	Before	7	7.0
Emma	F	48	White	Married	Disabled (CP)	Before	7	7.0
Olivia	F	30	White	Married	Nondisabled	Before	7	7.0
Randall	M	36	Black	Married	Disabled (CP)	Before	7	7.0

continues

Table 1.1 Continued

Demographics	Sex	Age	Race/ Ethnicity	Marital Status	Disabled/ Nondisabled	When Disabled	Time Lived Together (years)	Length of Relationship (years)
Focus Group 3								
Victoria	F	37	White	Not married	Disabled (muscular dystrophy)	Before	11	12.0
Gene	M	52	White	Not married	Nondisabled	Before	11	12.0
Ted	M	35	White	Not married	Nondisabled	Before	5	7.0
Sofia	F	37	White	Not married	Disabled (SCI)	Before	5	7.0
Kay	F	40	White	Married	Nondisabled	Before	14	19.0
Dan	M	46	White	Married	Disabled (SCI)	Before	14	19.0
Focus Group 4								
Allison	F	23	White	Not married	Disabled (vision impairment)	Before	3	6.0
Jason	M	23	White	Not married	Nondisabled	Before	3	6.0
Bob	M	55	White	Married	Nondisabled	After	14	15.0
Connie	F	55	White	Married	Disabled (MS)	After	14	15.0
Frank	M	Not disclosed	White	Not married	Nondisabled	Before	1	1.5
Jennifer	F	44	White	Not married	Disabled (SCI)	Before	1	1.5

Notes: All couples self-identified as heterosexual. Abbreviations: CP, cerebral palsy; MS, multiple sclerosis; SCI, spinal cord injury. a. Adam also has MS but was considered the nondisabled partner in my study because he was largely not symptomatic.

compared to Kevin and Ellen, who have been married sixteen years. Now in their forties, Kevin and Ellen were married well before Ellen's diagnosis of MS. Although Ellen can no longer work outside the home, both remain active in their church and keep busy with their two teenaged daughters. The fourth couple in Focus Group 1 is Rachel and Jack. Rachel was born with spinal muscular atrophy type 2. She and Jack met online and dated three years before moving in together. Both Rachel and Jack work full-time and they are the only pair in the first group without children.

I recruited both of the couples in Focus Group 2 through a disability rights organization and they knew each other quite well. Richard and Emma are a middle-aged white couple and have been married for seven years. Although they do not have children together, they are close to Richard's adult daughters from a previous marriage. Emma was born with cerebral palsy and does not work full-time and Richard is now retired (he is about fifteen years older than Emma). Olivia and Randall are an interracial couple and, like their friends Richard and Emma, have been married for seven years. Randall is a black man who was born with cerebral palsy and Olivia is a nondisabled white woman. Together they raise Randall's teenaged son from a previous marriage and they have recently adopted a daughter together. Ironically, both couples met through online dating websites.

I also recruited the three couples in Focus Group 3 through a disability rights organization and they too knew each other well from working closely on activist and educational projects. Kay and Dan are the only couple in this group with children. They have been married fourteen years and have two small children. Dan is disabled from a spinal cord injury and they both work full-time. Gene and Victoria are a middle-aged white couple. Victoria was born with muscular dystrophy and requires the care of a paid nurse. Both Gene and Victoria work full-time. Ted and Sofia have been married five years. Sofia is disabled from a spinal cord injury and uses a wheelchair. Ted works full-time.

Focus Group 4 was diverse in the sense that I recruited all three couples from different sources, they had different disabilities, and they did not know each other prior to the group. Connie and Bob are a middle-aged couple with adult children. They have been married fourteen years. Although they both used to work full-time, Connie had to leave her job after her diagnosis of MS. Jennifer and Frank are both in their forties and have lived together for only about one year. Jennifer is disabled from a spinal cord injury. Jennifer and Frank do not have any children, and neither do Allison and Jason, the youngest couple (both twenty-three years old). Allison was diagnosed with macular degeneration as a child and is blind.

Although all of the recruitment announcements indicated that I was interested in talking with both same-sex and opposite-sex couples, only opposite-sex couples contacted me. In addition, only one participant was African American. All other participants, including his wife, identified as white or Caucasian.

The sample was more diverse with respect to age. The mean age was thirty-nine years old, ranging from age twenty-three to sixty-four. Based on representations in popular culture and research from the applied fields that indicate it is more likely for disabled women to be divorced or abandoned by male partners than disabled men by female partners,²⁵ I expected the sample to be heavy with disabled men. However, the woman was the disabled partner in ten of the twelve couples in the focus groups. As expected, only two couples experienced the onset of the disability after the start of their relationship: for the vast majority of the sample, the disability was present when the pair met.

The self-representations included in this book—autobiographies, films, and focus groups—are obviously not a representative sample, nor were they intended to be. My intention was to focus on couples outside of a clinical, therapeutic setting. As Chapter 3 shows, so much of what we know about disabled/nondisabled couples has come from scientific studies on couples in distress. Although “relationship satisfaction” was not a qualification for the focus groups, it is likely that the couples whom I recruited into the focus groups are not distressed because they were willing to talk in a group setting about their experiences. The couples had experienced some problems, but they were not on the brink of divorce or caregiver burnout. Likewise, the autobiographies and films I selected feature couples that are still in love. My goal was to make visible disabled/nondisabled couples that “make it work”; therefore, the fact that the data I drew on were all from couples that are happy and in love is important. Nevertheless, these couples do not erase the hardships. Instead, these self-representations paint a complex picture of life with disability.

Almost all of the focus group participants and authors of the written and filmic self-representations included in this book are connected to the disability rights movement, in which disability is figured as a normal aspect of life. Following the lead of Nancy Mairs, one of the key autobiographical voices, and Simi Linton, a disability studies theorist and activist, my use of the term “nondisabled,” instead of “ability” or “able-bodied,” signals a centering of disability.²⁶ Mairs says that she calls people who lack disabilities “the nondisabled” because “in relation to me, they are the deficient ones.”²⁷ By using the terms “disabled” and “nondisabled” to describe group membership and identity, disability becomes the privileged perspective and the typically unexamined position of the nondisabled is moved to the margins. Naming the nondisabled, like naming and analyzing whiteness, also reveals the way in which the able body is set as the standard in society, the way it is positioned as supposedly natural or neutral, and the starting point on which impairment is layered. Reversing this and centering disability suggest that the impaired body may be the natural state, the neutral perspective. In this book, then, nondisabled is situated as the negative position, as not having disability.

With disability firmly at the center of this analysis, I am critical of any force that impedes or discourages the disability point of view and life. I use

the term “ableism” to describe the many ways in which the participants and authors whom I discuss in this book experienced explicit and implicit acts of discrimination, marginalization, and violence because they deviated from the nondisabled norm. For many of the participants, ableist attitudes surround them, punctuating their daily lives. The pervasiveness of ableism should not be too surprising considering society’s long history of eugenic policies that actively sought the elimination of people with disabilities as well as a dominant medical model of disability that seeks to fix, cure, or otherwise “normalize” the impaired body. As I show in detail in Part 1 of this book, the medical model informs almost all of the medical and social science research on disability, and curing or overcoming disability is a common narrative in popular culture. The medical model is ableist in the sense that it views the disabled person as a problem that needs to be solved.

For the focus group participants and self-representation authors and performers/filmmakers in this study, their love relationship is a vital component to combating the negative effects of ableism. All of them understand that in our culture, care is typically associated with physical and emotional stress, even burnout. They know that outsiders see the physical caregiving required in their love relationship as a problem, an indicator that their love is bound to fail. However, their concept of care deviates from dominant representations. For them, care is sometimes physical (dressing, bathing, and so on), but it is also emotional, mental, and instrumental. Randall, who has cerebral palsy and requires the help of his wife Olivia for bathing and dressing, says that “caring is more than just the physical. Caring is mental, caring is—I define caring as something that you do or say to help that other spouse.” Because physical needs are so immediate and pressing, the couples in this study place care at the foundation of a love relationship. Care is not something performed intermittently, as needed; for disabled/nondisabled couples care is a regular, integral part of their lives, and it is how they learn about each other, express love and devotion, and become intimate.

This perspective on care is actually quite radical. As I mentioned at the beginning of this chapter, when I began to investigate care, I first came across what I call “feminist care research,” feminist studies from the social science fields that position women as victims of informal care. From this standpoint, care is a burden and drain on women. Bound to feminine gender roles, women disproportionately serve as caregivers to children, parents, partners, relatives, and friends. Thus, according to this research, caregiving isolates women, prevents them from engaging in wage work or other activities outside the home, and exposes them to harmful physical and emotional toil.²⁸

Although aspects of this research rang true for me—physical care was sometimes physically and emotionally draining, and there were times when my activities outside of the home were foiled because of Max’s needs—I felt that, overall, the research failed to capture the complexity of our care relation-

ship and the way care was defined and experienced by the focus group participants. Most significantly, this research erased the disabled partner's subjectivity and caregiving. Max's subjectivity and the ways that Max cared for me were ignored. Disabled feminists, like Jenny Morris, have also critiqued the way in which feminist research on care has erased disabled people. Morris argues that the feminist critique of community care, which grew from the socialist analysis of women's role in the family, creates an us-and-them dichotomy between female caregivers and "dependents."²⁹ Concerned with women's roles as caregivers, most feminist care research has failed to recognize that most recipients of care are also women. Thus, as Margaret Lloyd argues, "polarized constructions of the disabled person as a burden and the informal carer as an oppressed woman do an injustice to the real issues for many women."³⁰ Furthermore, treating the disabled as "passive recipients of that care" fails to adequately capture the experience of caregivers.³¹ And it ignores the "reciprocity involved in caring relationships."³²

Jan Walmsley and other disabled feminists have pointed out that many women, including disabled women themselves, want to care for others and that this desire should be supported by feminist activism. Walmsley finds that "for some women who are denied the opportunity to be carers [because they are themselves disabled] caring becomes a valued activity to be sought, rather than an oppressive burden to be shifted. For others, caring is burdensome and exploitative."³³ Thus, Walmsley argues that "it is not that caring in itself is valuable, but that the dignity of choice is important to all adults."³⁴ Obscuring the subjectivity of the disabled person therefore produces a biased and problematic picture of family care. In addition, *I enjoyed* caring for Max. I refused to believe that my pleasure was some kind of false consciousness because, as a feminist, I was highly aware that the government benefited from my unpaid labor in the home, that Max and I deserved formal assistance, and that I had been socialized to assume caregiving responsibilities as a woman. Despite this knowledge, I gained concrete physical and emotional pleasure from caregiving. Feminist care research, however, portrays care as physically, socially, and emotionally harmful to women.

Eventually, I picked up the work of Nel Noddings and other feminist philosophers who focus on the moral and interpersonal dimensions of care.³⁵ It is through their work that I began to see Max's and my experiences reflected, and found a language from which to frame the voices of the focus group participants. Noddings focuses on "the caring relation" because, as she puts it, "relations, not individuals, are ontologically basic."³⁶ She is concerned with the role of both the caregiver and the cared-for, how both contribute to the care relation. According to Noddings, when caring is working, the pair is locked into a mutually reinforcing connection: "Clearly, the cared-for depends upon the one caring. But the one caring is also oddly dependent upon the cared-for."³⁷ The cared-for reciprocates in a variety of ways, including direct

response (“thank you”), personal delight (“Oh, that feels so much better”), and growth (care allows the cared-for’s pursuit of happiness).³⁸

This reciprocity sustains the caregiver, provides purpose, and helps define his or her sense of self. Reciprocity, then, blurs the roles of caregiving and care receiving. As Noddings puts it, “I could as easily say ‘I am giving’ as ‘I am receiving.’”³⁹ This was so true for me. Max was a brilliant man and I bounced all of my ideas off him. Many nights we discussed feminist theory until the morning’s first rays of light peeked through our bedroom window. Even while I performed various care activities, we talked. While I helped with toileting, we talked about the boundaries of the body, privacy, and body image. Dressing could generate a conversation about the role of touch in moral agency; shaving could lead to a discussion of gender performativity. Such constant discourse was immensely useful to me as an academic. But Max did other things for me as well, including editing all of my papers, giving me neck and foot rubs, holding me when I was sad, and making fantastic, healthy meals for us. Max also qualified for Social Security Disability Insurance and received money from disability insurance paid by his former employer. So, even though Max could not work, he had a reliable source of income that was his and that he could use to contribute to the overall financial health of our household. I may have helped with activities of daily living that he could not complete alone, but I certainly never felt that our relationship was one-way. We both gave and we both received.

Noddings’s formulation of the care relation made both of our contributions visible. In an effort to focus on reciprocity and to honor the care work that both the disabled and nondisabled partners perform in the relationship, I therefore avoid making the distinction between caregiver and care receiver unless I am talking about a specific example of someone giving and someone receiving care. Instead, I conceptualize the couple as disabled/nondisabled. Using the terms “disabled partner” and “nondisabled partner” allows for the possibility that both partners give and receive care, that the roles of caregiver and cared-for are not fixed or defined by the presence or absence of physical impairment. In this book, I assume that the disabled and nondisabled both provide and receive care. I suggest that this dynamic is fundamental to the spark of the intimate relationship. In other words, the care relation contributes to the sustainability of the couple and the individuals.

To help theorize care’s role in the subjectivity of both partners, I also draw on the work of Jessica Benjamin, a feminist psychoanalyst who is most famous for her work on “intersubjectivity” in *The Bonds of Love: Psychoanalysis, Feminism, and the Problem of Domination*. Benjamin suggests that the provider/dependent or caregiver/cared-for dynamic is essential to selfhood. As an alternative to ego psychology in which the self is formed through differentiation, “the intersubjective view maintains that the individual grows in and through the relationship to other subjects.”⁴⁰ Paramount to intersubjec-

tivity is the recognition that, although connected and in fact dependent on each other, the self and the other are separate entities. Significantly, these entities do not need to be social equals to enact intersubjectivity. To emphasize the freestanding nature of the other, Benjamin draws on D. W. Winnicott's work on the use of objects. According to Winnicott, a child can only "use" the object when he perceives it 'as an external phenomenon, not as a projective entity,' when he recognizes it '*as an entity in its own right*.'"41 The other's separate, but connected, subjectivity is affirmed by the other's survival: "When I act upon the other it is vital that he be affected, so that I know that I exist—but not completely destroyed, so that I know he also exists."<42 Later, in *Like Subjects, Love Objects: Essays on Recognition and Sexual Difference*, Benjamin elaborates and suggests that "'like subjects' refers to the possibility of both recognition and identification."<43 In other words, intersubjectivity allows us to see both the other's difference and sameness from the self. Like subjects are both like and dislike our selves; like enough to see an equivalent subjectivity in the other, and dislike enough to not see the other simply as an extension of one's self.<44

This is a particularly relevant point for sustainable care relationships because care is primarily viewed as a burdensome activity that often leads to burnout and dissolution of the care relationship. To keep the care relation viable, the disabled and nondisabled partners must recognize each other's separateness. More than this, the other must recognize the subjectivity of the other, and how his or her own subjectivity is dependent on that subjectivity. As Benjamin eloquently puts it, "the need for recognition entails this fundamental paradox: at the very moment of realizing our own independence, we are dependent upon another to recognize it."<45 Further, Benjamin suggests the term "mutual recognition" to describe this fundamental need, "the necessity of recognizing as well as being recognized by the other."<46 Reaching mutual recognition is a psychologically ideal state in which the self and the other attain emotional attunement and distinction; "in the ideal balance, a person is able to be fully self-absorbed or fully receptive to the other, he is able to be alone or together."<47 Maintaining this "constant tension" between the self and the other is the ideal resolution to the paradoxes of recognition and is precisely how intersubjectivity can facilitate an appreciation for difference while confirming one's sense of self.<48 Benjamin later adds that "mutual recognition is meaningful as an ideal only when it is understood as the basis for struggle and negotiation of conflict . . . , when its impossibility and the striving to attain it are adequately included in the concept."<49 Thus, mutual recognition describes the process in which the relationship between the self and the other is maintained.

It is particularly important for this study that physical bodies remain visible when thinking about mutual recognition and intersubjectivity. Ironically, bodies have occupied a precarious position in disability activism. For decades, disability scholars and activists have offered the social model of disability as

an alternative to the historically predominant medical model as mentioned above. The social model, however, views the physical and social environment as the problem. Inaccessible buildings and transportation, prejudice, and fear of people with disabilities cause poverty, isolation, and depression—not the impairment itself. The solution, then, is to change the built environment and to shift attitudes. The social model has led to many significant improvements for people with disabilities, including passage of the historic Americans with Disabilities Act in 1990. However, it has also obscured the realities of the disabled body. In fact, some scholars and activists purposively discourage attention on the disabled body⁵⁰ because, they believe, such attention individualizes and sentimentalizes the problem, distracts from the real problem of disabling social conditions, and is a poor political organizing platform.⁵¹ In other words, the disabled body is strategically ignored for the political good.

Disabled women and people whose disabilities are not fixed with physical and social accommodations are increasingly critiquing the social model for its inability to account for the body and its refusal to think critically and openly about impairment.⁵² Cheryl Marie Wade argues that the social model of disability creates people who are the “able-disabled” by focusing on those people with disabilities who live “normal” lives once physical accommodations are in place.⁵³ This marginalizes the vast majority of people with disabilities whose bodies continue to impede and shape their existence, even when their environments are barrier free. To rectify this situation, Wade advocates airing the realities of the disabled body, especially those aspects that “ain’t exactly sexy”: “To put it bluntly—because this need is as blunt as it gets—we must have our asses cleaned after we shit and pee. Or we have others’ fingers inserted in our rectums to assist shitting. Or we have tubes of plastic inserted inside us to assist peeing or we have re-routed anuses and pissers so we do it all into bags attached to our bodies.”⁵⁴ Disabled bodies break the boundaries of privacy and politeness around bodily functions associated with adult control. Wade argues: “If we are ever to be really at home in the world and in ourselves, then we must say these things out loud. And we must say them with real language. So they are understood as the everyday necessity and struggle they are. How can we assert a right (for personal care) if we are too ashamed of the need to state it openly?”⁵⁵ The right to care depends on drawing attention to the body. Likewise, Julia Twigg argues that making visible the body in care work is important for disabled people and the people that provide their care.⁵⁶ Attention on the body and “personal care” (e.g., shitting and peeing) can improve social policy.⁵⁷ “Enabling policy to look at bodily issues” does imply different political strategies than the equal rights and inclusion model offered with the social model of disability, but it will likely lead to better policy.⁵⁸ In addition, bringing the body back into the discourse allows disability scholars to acknowledge physical pain (and pleasure).⁵⁹ And it allows them to consider the medical

response to impairment, including issues of prevention, quality of life, and “cure.”⁶⁰

Attention to the body does not, however, have to be reductionist, focusing only on the physical/biological. On the contrary, the new scholarship views “the materiality of the body [as a] dynamic interrelationship with the social and cultural context in which it is lived.”⁶¹ The new body scholars eschew the nature/nurture, social/biological, and impairment/disability binaries. The social can influence the body and vice versa. As Kelly Oliver puts it:

All human relationships are the result of the flow and circulation of energy, thermal energy, chemical energy, electrical energy, and social energy. Social energy includes affective energy, which can move between people. . . . Just as thermal energy from our bodies can warm the bodies of others, affective energy from our psyches can affect the psyches of others. In important ways, the psyche is a material biological phenomenon, a biosocial phenomenon.⁶²

Thus, there is no easy distinction between impairment (biological) and disability (social) because they are mutually influential. Tobin Siebers calls this the “new realism of the body.” He states that “the body is alive, which means that it is capable of influencing and transforming social languages as they are capable of influencing and transforming it.”⁶³ Similarly, Janet Price and Margrit Shildrick put forth a model of “embodied subjectivity” that accounts for the ways in which we are “actively and continuously produced through social interactions with other body-subjects.”⁶⁴ Both new realism and embodied subjectivity privilege the dialectic between physical body and social experience and thus seek to expose how “impairment is social and disability embodied.”⁶⁵

I am invested in this new disability politics that embraces corporeality and acknowledges interdependency; therefore, I pay special attention to the role of the physicality in care activities. The physical care in disabled/nondisabled relationships requires touching and contact between bodies. As Margrit Shildrick notes, “to touch another . . . is in some sense always to compromise control, to feel my sense of wholeness and self-sufficiency dissolve, for even where the intent is outward and aggressive, I am also touched in return. An undecidable moment of exchange occurs, a crossing of corporeal boundaries, which unsettles the dimensions of the embodied self.”⁶⁶ Touch emphasizes the connection between bodies, and I argue touch is also a necessary component to the fundamental paradox of dependence. In other words, witnessing and recognition are not enough. Subjectivity is also dependent on touch, specifically a caring touch, thus bodies are central to my analysis of care in disabled/nondisabled relationships. Gail Weiss’s concept of intercorporeality is particularly useful because it emphasizes the role of the physical body and subjectivity. As Weiss notes, “the experience of being embodied is never a private affair”;⁶⁷ it is an unconscious, “ongoing exchange between

bodies and body images.”⁶⁸ By “body image,” Weiss is referring to proprioception or the sense of one’s body in space, how it looks, feels, and is bounded. Individuals have many different body images (although relative stability is needed for reliable movement and response) and these body images adjust in response to physical changes within the body, the physical environment, and other bodies one encounters. Intercorporeality “implies that body images are in continual interaction with one another, participating in a mutually constitutive corporeal dialogue that defies solipsistic analysis.”⁶⁹

Sometimes the caring touch is also clearly an erotic touch. Yet in contemporary Western societies, care touching is explicitly associated with mothering. And although from a psychoanalytic perspective, this touching initiates sexuality in the infant, care and erotics are unambiguously disconnected for mature adults. To be turned on by someone helping you dress, bathe, or toilet is certainly not normative and maybe even taboo. Nevertheless, as the self-representations in this research show, the line between care touch and erotic touch is frequently blurred for disabled/nondisabled couples. In those parts of the book, I draw from the theoretical tradition of queer theory, which challenges the dominance of heteronormativity. As Diane Richardson notes, queer “displace[s] the categories of ‘lesbian’ and ‘gay’ and heterosexual.”⁷⁰ Furthermore, Richardson explains:

Ideas about what is “normal” and “acceptable” sexual behaviour, indeed what is regarded as sexual practice, also reflect dominant constructions of sexuality as heterosexual (vaginal) intercourse. . . . Not only does this affect how forms of sexual activity are evaluated as sexually satisfying or arousing or even as counting as “sex” at all, it also serves to “discipline” the body . . . , marking out the boundaries which represent our private and public zones, and distinguishing the potentially sexual from the non-sexual bodily surfaces action.⁷¹

Even though most of the people represented in this book self-identify as heterosexual, almost all of them had expansive, nonheteronormative definitions of what counted as sexually intimate. Thus, I read the sexuality that they describe as “queer.” Describing the many ways he has gotten to know his wife’s body while dealing with her MS, Kevin says, “as far as intimacy goes, intercourse isn’t [the] only intimacy.” For Kevin and many other people involved in disabled/nondisabled relationships, intimacy can include not only sexual acts, but also acts that exemplify a high level of connection between two bodies, including massage, touching, dressing, and even toileting and feeding. Intimacy is used, purposely, as an umbrella term and includes feelings of love and devotion as well as sexual desire and attraction.

Another useful concept related to queer and queer theory is Tobin Siebers’s “sexual culture.”⁷² Siebers uses sexual culture to define the way in which intimacy is figured differently for people with disabilities, including people in disabled/nondisabled relationships. It refers to the expansive, non-

genital focus that an erotics based on care expresses. The need for care opens up a diffuse sexuality in which touch and connection are ongoing intimate expressions. In addition, it exposes the ways in which disabled/nondisabled sexual intimacy violates the notion that there are proper erotic zones, and that sexuality (and personal care) are private matters. For people with disabilities, a sex life is not a discreet, personal matter. Sex is not limited to the bedroom behind closed doors; it happens in the shower while being bathed, in the bathroom while being dressed, and in the kitchen while being fed. It may also involve additional assistance beyond the normative dyad. Thus, sexual culture refers to the way of being sexual that the care opens up.

Limitations and Overview of the Book

The analysis in this book is limited to couples experiencing physical disability; however, I do not focus on any one particular disability. Paralleling the move away from sexual identity to sexual behavior in sex research, I am more interested in care needs and activities than in the medical identity of people with disabilities. In other words, this book examines people who need help with one or more activities of daily living (bathing, dressing, toileting, eating) regardless of what caused or continues to cause that impairment. Of course, I also recognize that diseases have social histories that influence how the disabled person and his or her partner experience life,⁷³ and there are places in which I mention the person's specific disability because it is contextually significant. However, my decision to include all physical impairments that created a need for daily care reflects the disability rights movement's goal to foster a common group identity among people with disabilities.⁷⁴ Although the exact type of care may vary with each disability or illness, all of the people with disabilities highlighted in the book need help with at least one activity of daily living and their partners provide most or all of this care. That is their commonality. I limited this study to physical impairment, however, because cognitive and emotional disabilities raise additional questions and concerns around consent (both sexual consent in their relationships and consent to research) and self-direction, and highlight completely different kinds of care.

Although the project did not start this way, it has become, for a variety of reasons, a project about heterosexual disabled/nondisabled relationships. There are few representations of same-sex disabled/nondisabled relationships. In fact at the time of this writing, I could find no mainstream, popular culture examples. I found a few studies on disabled/nondisabled same-sex intimate relationships, as well as a few self-representations (documentary film examples), but the rest of the studies, autobiographies, and documentaries analyzed are straight. In addition, despite attempts to recruit same-sex couples, the focus group research that I conducted is composed entirely of couples that identify

as heterosexual. Regardless of the straightness of the couples, what I discovered was sexual expression that did not fit normative understandings of sex and intimacy. Thus, while future work should investigate the specificities of same-sex disabled/nondisabled relationships, the data that I present in this book also should not be read as fully straight.

The book is divided into two parts. In Part 1 I focus on dominant representations and beliefs about disabled/nondisabled intimate relationships. Chapter 2 examines popular culture representations—films, television shows, and magazine and newspaper articles—featuring disabled/nondisabled intimate relationships. Popular culture typically represents disability as a tragedy that dooms sexual relationships and strains love. In addition, love—as an institution and expression—is something available only to those who can perform in certain nondisabled physical and emotional ways. Love itself is apparently able-bodied. Significantly, the message is highly gendered. Disabled women are more frequently represented as “doomed” than disabled men. I argue that this disparity stems from heteronormative beliefs about gender roles in intimate relationships. Disability impedes a woman’s ability to care for her husband and is therefore more disruptive than disability in men.

In Chapter 3, I conduct a content analysis of literature from the applied fields, including rehabilitation, medicine, and nursing. Much of this literature focuses on caregiver burden and barriers to sexuality for people with disabilities. I argue that the dissemination of these study results—on the evening news, on the Internet, and in the newspapers—contributes to the negative perception of disabled/nondisabled relationships. The self-representations that I analyze in Part 2 of the book are full of stories of discrimination. Parents, friends, family members, health care professionals, and even strangers make biased and damaging comments about disabled/nondisabled relationships based on the popularization of research from the applied fields.

Part 2 of the book speaks back to dominant representations as I present the self-representations—autobiographies, documentaries, and data from focus groups with disabled/nondisabled couples. Looking at the self-representations together, it is clear that “successful” disabled/nondisabled couples were able to (1) move beyond traditional gender roles, (2) find strength and pride in disability identity and culture, (3) focus on reciprocity and mutuality in their love relationship, and (4) redefine sex and eroticize care intimacy. Thus, Part 2 is divided into these four major themes: gender, disability pride, love, and sex.

Chapter 4 suggests that one reason the disabled/nondisabled couples whom I study are so successful is their gender role flexibility. Sometimes this meant that as individuals and as a couple, they would flat out ignore gender norms. Other times it meant creatively appropriating gender norms to fit physical difference. Regardless, most of the couples viewed gender flexibly and were able to forge gendered positions that worked for them: rarely did the couples get hung up on gender stereotypes.

When their ability to be flexible with gender and to endure adversity were tested, disabled/nondisabled couples weathered this prejudice through disability pride and humor as well as the strength of their love for one another. Thus, Chapter 5 focuses on pride and humor in disabled/nondisabled intimate relationships, arguing that these tools are used as effective survival mechanisms, countering the prejudicial views reflected in the popular culture and opinion.

Chapter 6 moves more fully into a discussion of what love means in these relationships, especially how disabled/nondisabled couples stay in love in spite of the outside forces that discourage their love and the internal stress of physical impairment. The expression of love in the self-representations emphasizes the role of care, reciprocity, and commitment.

Finally, Chapter 7 focuses on intimacy and sexuality in disabled/nondisabled relationships. Because disabled/nondisabled couples are dealing with bodies that deviate from the norm, their sexual expression often also is non-normative. The chapter explores how these relationships are different from other love relationships, especially how disability may queer sexuality for people in disabled/nondisabled relationships. Thus, Chapters 4–7 focus on four different ways in which people in disabled/nondisabled relationships manage, even flourish, through gender role flexibility, the ability to find humor and pride in the face of prejudice, paying careful attention to reciprocity and creating new forms of sexual intimacy.

What emerges from this comparison of dominant representations and self-representations is a complicated, nuanced picture of care and intimacy in disabled/nondisabled relationships. Self-representations contradict the binary and asexual relationship between disabled and nondisabled partners popularized in academic research and the mainstream media. Disabled/nondisabled couples emphasize reciprocity, mutuality, and eroticized daily care in their relationships. These findings help correct popular stereotypes and suggest that reciprocal relationships and alternative forms of sexuality should be considered in future research on care and disability. Thus, on a practical level, understanding the ways in which disabled/nondisabled relationships are characterized by reciprocity, and the ways that couples are intimate and sexual, may improve the treatment of people in disabled/nondisabled relationships. Instead of assuming burden and asexuality, professionals, friends, and family may be able to see love and mutuality.

These findings are also significant on a theoretical level. As Robert McRuer argues in his groundbreaking book *Crip Theory: Cultural Signs of Queerness and Disability*, queer theory and disability studies have much to learn from each other. Both are dedicated to the intellectual project of “working the weakness in the norm” by exposing compulsory heterosexuality and compulsory able-bodiedness, respectively.⁷⁵ McRuer puts forth “crip theory” as a way to understand how the “severely disabled/critically queer body . . . remaps the public sphere and reimagines and reshapes the limited forms of

embodiment and desire proffered by the systems that would contain us.”⁷⁶ Disabled/nondisabled couples expose how limited the dominant understandings of care really are—how care has become synonymous with burden, and how care can be otherwise. By expanding care to include sexual intimacy, and by focusing on the ways in which disabled partners reciprocate in the care relationship, disabled/nondisabled couples crip or queer the meaning and nature of care, disability, and intimacy.

Notes

1. Asch and Fine, “Nurturance, Sexuality, and Women,” p. 245.
 2. Galvin, “Researching the Disabled Identity,” p. 407.
 3. Sakellariou, “If Not Disability,” pp. 104–105.
 4. *Ibid.*, p. 104.
 5. Wilkerson, “Disability, Sex Radicalism,” p. 42.
 6. Waxman, “It’s Time,” p. 86.
 7. For example, Meyer, *Care Work*.
 8. Feder and Kittay, “Introduction,” p. 2.
 9. Kittay, *Love’s Labor*, p. 31.
 10. See, for example, Bubeck, “Justice”; Folbre, “Reforming Care”; Schutte, “Dependency Work”; and Suthers, “Women Still Shouldering.”
 11. National Organization for Women, “NOW and Disability Rights”; NOW, “Mothers and Caregivers Economic Rights”; NOW, “A Feminist Future.”
 12. See Crawford and Ostrove, “Representations of Disability”; Parker, *With This Body*; Schulz, “Collaboration in the Marriage”; and Shuttleworth, “The Search for Sexual Intimacy.”
 13. Schultz, “Collaboration in the Marriage Relationship.”
 14. For example, see Asch and Fine, “Nurturance”; Fine and Glendinning, “Dependence”; and Walmsley, “Contradictions in Caring.”
 15. Disability scholars and activists, however, have mixed reactions to this boon in disability autobiography. David Mitchell, for example, is suspicious of the current celebration of disability autobiography because “even the most renowned disability autobiographers often fall prey to an ethos of rugged individualism that can further reify the longstanding association of disability with social isolation” (“Body Solitaire,” p. 312). Because disabled people’s “lives are so inextricably tethered to the lives of others,” Mitchell believes that disability autobiography could promote a new model of interdependency, undermining notions of independence and autonomy that are so valued in contemporary society (p. 314). However, Mitchell argues that disability autobiography is just as likely—perhaps even more likely—to express a singular self (p. 312). In an effort to convince the nondisabled that “we are just like you,” people with disabilities may downplay the interdependence that characterizes their lives.
- In addition, the most popular disability autobiographies are “overcoming stories” or what Arthur Frank calls “restitution narratives.” Such a narrative “affirms that breakdowns can be fixed,” easing the anxiety that the nondisabled may have about illness and disability (*The Wounded Storyteller*, p. 90). Because restitution narratives are about the body overcoming the illness or disability, characteristic of the medical model of disability, they are not politically viable tools. Following the social model of disability, in which attention is drawn to the social and physical barriers in the environment that dis-

able the impaired, it would be best to have narratives that critique ableism and celebrate the disabled body instead of healing it. These narratives are out there; indeed, the autobiographies that I analyzed in this chapter are prime examples, but they do not yet outnumber the more popular story of overcoming.

16. See Appendix B.

17. Hockenberry, *Moving Violations*; Klein, *Slow Dance*; Mairs, *Waist-High*; Murphy, *The Body Silent*.

18. Cohen, *Dirty Details*; Kondracke, *Saving Milly*.

19. Eakin, *How Our Lives*, p. 57.

20. *Ibid.*, p. 86.

21. Although I will use both interdependence and intersubjective to signify this fundamental connectivity, I prefer intersubjective because it foregrounds subjectivity.

22. Egan, *Mirror Talk*.

23. *Want*, directed by Loree Erickson, 2007 (Toronto, Ontario: Femmegimp Productions), DVD; *Shameless: The ART of Disability*, directed by Bonnie Sherr Klein, 2006 (Montreal, Quebec: National Film Board of Canada), DVD; *Sick*, directed by Kirby Dick, 1997 (Santa Monica, CA: Lions Gate Home Entertainment), DVD.

24. Couser, *Recovering Bodies*, p. 4.

25. Singh and Sharma, "Sexuality and Women," p. 29.

26. See Linton, *Claiming Disability*, especially chapter 2, for a thorough discussion of the term *nondisabled*.

27. Mairs, *Waist-High*, p. 14.

28. See, for example, Bubeck, "Justice"; Feder and Kittay, "Introduction"; Folbre, "Reforming Care"; Meyer, "Care Work"; Schutte, "Dependency Work"; Suthers, "Women Still Shouldering."

29. Morris, "'Us' and 'Them?'" pp. 28–29.

30. Lloyd, "The Politics of Disability," p. 721.

31. Morris, "'Us' and 'Them?'" p. 34.

32. *Ibid.*, p. 35.

33. Walmsley, "Contradictions in Caring," p. 131.

34. *Ibid.*, p. 139.

35. I make a distinction between feminist care research and feminist care philosophy. Feminist care research focuses on the negative health outcomes of a system that makes informal care the sole responsibility of women. Feminist care philosophy focuses on the moral, ethical, and social dimensions of giving and receiving care. However, I believe that it is time for the care research to incorporate the disabled point of view and to more carefully consider how feminist care research portrays care. In other words, research on care activities and care policy should begin with the insights about care relations formulated in feminist care philosophy. Recognizing care as a valued activity for disabled and nondisabled women alike does not abandon the feminist project of removing care burdens.

36. Noddings, *Caring*, p. xiii.

37. *Ibid.*, p. 48.

38. *Ibid.*, p. 74.

39. *Ibid.*, p. 52.

40. Benjamin, *The Bonds*, pp. 19–20.

41. *Ibid.*, p. 37, emphasis added.

42. *Ibid.*, p. 38.

43. Benjamin, *Like Subjects*, p. 7.

44. *Ibid.*, p. 7.

45. Benjamin, *The Bonds*, p. 33.

46. *Ibid.*, p. 23.
47. *Ibid.*, p. 28.
48. *Ibid.*, p. 36.
49. Benjamin, *Like Subjects*, p. 23.
50. See, for example, Finkelstein, "The Social Model"; and Michael Oliver, *Understanding Disability*.
51. Thomas, *Sociologies*, p. 122.
52. See, for example, Hughes, "Disability and the Body"; Morris, "'Us' and 'Them'?"; Wade, "It Ain't"; and Wendell, *The Rejected Body*.
53. Wade, "It Ain't," p. 89.
54. *Ibid.*, p. 88.
55. *Ibid.*, p. 89.
56. Twigg, "The Body," pp. 428–430.
57. *Ibid.*, p. 430.
58. *Ibid.*, p. 431.
59. *Ibid.*
60. Shakespeare, *Disability Rights and Wrongs*, p. 40.
61. Thomas, *Sociologies*, p. 137.
62. Kelly Oliver, "Subjectivity as Responsivity," p. 329.
63. Siebers, "Disability in Theory," p. 749.
64. Price and Shildrick, "Bodies Together," p. 63.
65. Hughes, "Disability and the Body," p. 66.
66. Shildrick, "Unreformed Bodies," p. 329.
67. Gail Weiss, *Body Images*, p. 5.
68. *Ibid.*, p. 3.
69. *Ibid.*, p. 33.
70. Richardson, "Heterosexuality," p. 5.
71. *Ibid.*, p. 6.
72. Siebers, *Disability Theory*, pp. 137–139.
73. For examples of cultural histories of disease, see Finger, *Elegy for a Disease* (on polio); Sontag, *Illness as Metaphor* (on cancer); Sontag, *AIDS and Its Metaphors*; and Irvine, "Regulated Passions" (on sexual addiction).
74. See, for example, Shapiro, *No Pity*.
75. Judith Butler, quoted in McRuer, *Crip Theory*, p. 30.
76. *Ibid.*, p. 31.