Love, Sex, and Disability: The Ethics and Politics of Care in Intimate Relationships

Dissertation

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By

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ABSTRACT

“Care” in relationships between disabled and nondisabled partners is typically constructed as a binary between care-givers and care-receivers. In other words, the disabled partner is represented as only a care-receiver and the nondisabled partner as only a care-giver. This dependency dynamic desexualizes nondisabled/disabled relationships because the care burden is expected to interfere with sexual intimacy. This image of care and sexuality between disabled/nondisabled partners can be found in a variety of fields and discourses that touch the lives of people with disabilities and their partners. For example, in the applied fields (e.g., rehabilitation, medicine, counseling) the assumption that nondisabled partners experience only burden is frequently built into research designs and it is rare for such studies to even measure sexual and marital satisfaction or positive aspects of caregiving. Similarly, contemporary feminist research constructs nondisabled partners as victims of a system that refuses to help caregivers, statistically female. It is true that family caregivers need help, but it is symptomatic of our beliefs about disability in intimate relationships that the disabled partners are erased in much feminist care research. Even in the disability rights movement, care is often downplayed because, in a culture that views care so negatively, it is only a liability to draw attention to personal care needs. Disability rights advocates prefer to emphasize the similarities between disabled and nondisabled people. Thus, contemporary feminist research, the applied
fields, popular culture and the disability rights movement—all relatively disparate
discourses—engage in a surprisingly coherent, negative image of care in intimate
relationships.

The voices of people involved in disabled/nondisabled intimate relationships are
missing from this picture. This project turns to self-representations of people in
disabled/nondisabled intimate relationships to illuminate alternative understandings of
care and sexuality. It combines data from focus groups, autobiographies, and
documentaries made by people with disabilities and/or their partners. Contrary to
dominant representations of care in disabled/nondisabled relationships, this research
suggests that the boundary between caregiver and care-receiver is often blurred. That is,
the disabled partner gives care and the nondisabled partner received care and vise versa.
In addition, physical care is often part of sexual intimacy.
DEDICATION

For Max
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“My Way In”

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 all the things we had in common personally, socially, and politically. We were obviously a good match and he was very handsome. I was definitely interested in chatting, but he was upfront about his disability and I felt I had to consider what that meant for a relationship before pursuing it any further. I didn’t want to begin chatting online, then on the phone and maybe meeting in person only to back out because the disability was “too much” to handle. For several days I read everything I could get my hands on about MS. I learned that Max’s form of MS was not the worse (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 medicines that could help slow the progress of the disease, but there was no cure. The medicines usually worked so well, however, that it was no longer common to “die from MS” (before these medications people with MS would eventually die when the disease began attacking the 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 him on a daily basis make be 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 him before his death in April 2008. I relate this story because the questions I asked myself reflect the 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, take care of me? What kind of fun will we experience? How could taking physical care of Max be part of our intimacy? I didn’t 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 I was Max’s personal care attendant. Checkout clerks would ask if I “enjoy my job.” It is inconceivable that Max and I may 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 other people. When confronted the airline attendants said they assumed he was traveling alone. Both 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 martyred. When
I was filing my travel grant paperwork after presenting a portion of this dissertation the student worker and I were discussing my research and then he 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 made just as much work for Max as he did for me, but I could tell my correction was not being heard—the image of burden was too strong. Adrienne Asch and Michelle Fine, writing about women with disabilities 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. (245)

Even if the disabled/non-disabled couple does not experience physical care as a burden, it is impossible to escape the prevailing beliefs about care burden and dependency.

Strangers exhibit an amazing level of audacity when confronted publicly with disability, revealing their beliefs about disability, care and relationships.

Family members and friends may also freely express doubt and concern over disabled/non-disabled 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, Craig says that friends and family members “advised his wife against marrying him, saying ‘He’s a nice man, but he’s disabled.’” (407). Similarly, in Dikaios Sakellariou’s study with 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” (Sakellariou 104-5) Another participant, John, says that his girlfriend left him because she could not present him to her family (ibid. 104).

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 (Wilkerson 42). Writing about the discriminatory treatment and sexual shame 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” (86). Fearful that a disabled person will partner with nondisabled people, 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 doesn’t explain all the forms of discrimination 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 and/or elderly parents (e.g., Meyer). Feder & Kittay describe care as an “interactions of unequals…between the caregiver and the dependent to be cared for” (2). In Love’s Labor, 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” (31). 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, statistically female (c.f. Bubeck; Folbre; Schutte, Suthers). For example, the National Organization for Women has 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. Suggested solutions involve respite care, paying informal caregivers, job protection for caregivers—all reforms 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 attendants—are not listed. It is true that family caregivers need help, but it
is symptomatic of our 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 predominating 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 are certainly plenty of couples who resist attempts to construct their relationship as burdensome and asexual. This dissertation begins the necessary process of understanding the ideological hegemony on disabled/nondisabled intimate relationships and gives voice to those that resist. The first part examines several key discursive sites that contribute to the ideological hegemony, including popular culture (e.g., mainstream film, television, magazines, etc.), the applied fields (e.g., rehabilitation sciences, medicine, psychology, etc.) and even some parts of the disability rights movement. Part two highlights the experiences of people involved in disabled/nondisabled intimate relationships.

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, the 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 social science studies on disabled/nondisabled relationships. To date, there have only been 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/or their partners (c.f. Crawford & Ostrove; Parker; Schulz; Shuttleworth). Most notably is Gillian Parker’s book length study of couples in England during the late 1980s and early 1990s called With This Body: Caring and Disability in Marriage. Parker interviews 21 couples (using both couple and individual interviews) in which one partner has become physically disabled since marriage. She is particularly interested in how the couple negotiates independence and dependence, and how the pre-existing relationship shapes 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 affects of prejudice and/or support from friends, neighbors, and extended family members. Thus, Parker’s study 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. Shultz’s examines 4 physically impaired people, 3 of which are married to other people with disabilities. Shultz’s participants were all physically impaired at the time of their marriage. Like Parker, Shultz finds high levels of collaboration, problem-solving and reciprocity between partners. Caregiving and receiving is 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. However, the sexual aspects of these relationships are typically left-out or downplayed in the little research that does exist. Thus, my study is unique in that it looks at care and sexuality/intimacy in disabled/nondisabled intimate relationships. Additionally, my study includes both pre- and post-disability 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.

**Theoretical Underpinnings**

There are several key philosophers/theorists and theories that influence my readings of both dominant and resistant narratives of disabled/nondisabled intimate relationships. First, I draw heavily on feminist care philosophy, especially the work of Nel Noddings. As I mentioned above, when I began to investigate care, I first came across what I will call “feminist care research,” feminist studies from the social science fields that position women as victims of informal care. 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 (c.f. Bubeck; Feder and Kittay; Folbre; Meyer; Schutte, Suthers).

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 the home were foiled because of Max’s needs—I felt that, overall, the research failed to capture the complexity of our care relationship. Most significantly, this research erased
Max’s subjectivity and the ways Max cared for me. 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 carers and “dependents” (28-29). Concerned with women’s role as carers, most feminist care research has failed to recognize that most recipients of care are also women. Thus, as 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” (“The Politics” 721). Furthermore, treating the “cared for” as “passive recipients of that care” “fail to fully address the experience of carers” (Morris 34), including the “reciprocity involved in caring relationships” (ibid. 35). 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 I—and Max—deserved formal assistance, and that I had been socialized to assume caregiving responsibilities as a woman. Despite this knowledge, I gained very 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, Maurice Hamington, and other philosophers who focus on the moral and interpersonal dimensions of care. It is through their work that I began to see my and Max’s experience reflected. Noddings focuses on
“the caring relation” because, as she puts it, “relations, not individuals, are ontologically basic” (xiii). She is concerned with the role of both the one caring and the cared-for, how both contribute to the care relation. According to Noddings, when caring is working, the pair are 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” (48). 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) (74).

This reciprocity sustains the one caring, provides purpose, and helps define his/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’” (52). This rang so true for me. Max was a brilliant man and I bounced all of my ideas off of 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 would talk. While helping with toileting, we would talk about the boundaries of the body, privacy, and body-image. Dressing may generate a conversation about the role of touch in moral agency; shaving could lead to a discussion of gender performativity. As an academic, such constant discourse was immensely useful, but Max did other things for me as well, including editing all my papers, giving neck and foot rubs, holding me when I was sad, and making fantastic, healthy meals. Max also qualified for Social Security Disability Income and he 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 received. Noddings’ formulation of the care relation made both of our contributions visible. Likewise, other philosophers like Joan Tronto, Hamington, and Kelly Oliver, paid attention to the supposed “care-receiver.” Even Eva Kittay, whose work I disagree with because it doesn’t go far enough in acknowledging the subjectivity of people with cognitive impairments, theorizes care as a relationship. Nevertheless, the feminist research on care and care policy seemed to only ever address the caregiver.

Thus, I differentiate between feminist care research and feminist care philosophy. However, I believe, as Margaret Lloyd does, that it is far 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 start with the insights about care relations formulated in feminist care philosophy. Lloyd believes that the feminist analysis of informal care can be enhanced with the disability perspective by 1) recognizing that “caring is something that women might want to do” (722), 2) demonstrating that “the caring role is not synonymous with the caring function” (723), and 3) re-establishing that “informal caring takes place within a relationship” (725). 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” (131). Thus, Walmsley argues that “it is not that caring in itself is valuable, but that the dignity of choice is important to all adults” (139). On a similar note, Traci Levy argues that “caregiving should be protected and facilitated as a right” (547). Drawing on feminist care philosophy, Levy views caregiving as a potentially positive experience, noting that “it is not caregiving itself, but caregiving experienced as strain, that triggers the accelerated mortality rate” and other physical, social, and emotional problems for caregivers (556). Care is ontologically essential to humans, therefore, Levy argues that care must be a “positive” right—“something meant to enable and facilitate instead of merely to protect from external interference” (568).

Thus, recognizing care as a valued activity for disabled and nondisabled women alike does not abandon the feminist project of removing care burdens. As Morris argues, ignoring the perspectives of disabled women sets up the false dichotomy of community/family care versus institutional care. Care in the community can be carried out in a non-sexist, non-ablist way. Lloyd says, “in arguing for their rights to the practical support which they may need in order to accomplish the tasks associated with caring, disabled women are clarifying the point that the successful fulfillment of caring responsibilities is not reliant on the isolated, unsupported carrying out of caring tasks” (724). That is, disabled women want the option to take responsibility for caregiving and in arguing for this right they are helping make the realities of caregiving better for all people. Assistance with caregiving tasks—whether it is physical assistance in the form of
government sponsored personal care assistants, access to better care equipment, or financial relief—make care in the home a viable choice, not a sexist and ablist duty. Thus, disabled feminists and feminist care philosophers emphasize the value of caregiving and seek reform that makes care in the community feasible.

Lloyd’s call to re-establish care as a relationship is quite obviously drawing on Nel Nodding’s early care philosophy, but also on work by disabled feminists such as Walmsey and Morris that insist feminist care research should examine the ways in which the roles of “carer” and “cared-for” shift in care relationships. In what follows, 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 theorists such as Jessica Benjamin, Albert Memmi, and Kelly Oliver that examine dependence/independence.

Albert Memmi’s work on dependence offers several significant ways to build on Noddings’ formulation of the care relationship. Similar to Noddings’ cared-for and carer, Memmi argues that the “provider” and “dependent” create a “duet” in which each shapes the other (20), and that “It is reciprocity that explains the tenacity, continuity, and stability of the human duet” (66). The dependent may reciprocate emotionally, socially, economically, or physically, and it is this give and take that sustains dependent/provider relations. Thus, for Memmi, dependence is not inherently a negative part of the human condition. Mirroring Noddings’ ethical care-receiving, Memmi says that “we should ask
ourselves not how to avoid being dependent, but how to be dependent” (emphasis added, 149). In other words, learning how to reciprocate is essential for it allows the provider to continue to care. Memmi’s work suggests that even when the dependent is unable to reciprocate, the provider may receive recognition, pleasure and satisfaction that sustains the relationship. He writes: “attending to a need is a pleasure in itself: we satisfy needs. When we prevent suffering, or make it go away, we get a certain satisfaction—relief” (158). By emphasizing what the provider receives and what the dependent gives, Memmi’s work helps establish care as a mutually reinforcing relationship.

The work of Jessica Benjamin, a feminist psychoanalyst who is most famous for her work on “intersubjectivity” in The Bonds of Love, extends this analysis by suggesting that the provider/dependent or carer/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” (19-20). Paramount to intersubjectivity is the recognition that, although connected and, in fact, dependent on each other, the self and 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 Winnicot’s work on the use of objects. According to Winnicot, 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.’ (italics added)” (37). 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” (38). Later, in Like Subjects, Love Objects, Benjamin elaborates and suggests that “‘like subjects’ refers to the possibility of both recognition and identification” (7). 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 (7).

This is a particularly relevant point for sustainable care relationships because (as chapter 2 elaborates), care is primarily viewed as a burdensome activity that often leads to burn-out 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 one’s 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” (33). Further, Benjamin suggests the term “mutual recognition” to describe this fundamental need, “the necessity of recognizing as well as being recognized by the other” (23). Reaching mutual recognition is a psychologically ideal state in which the self and 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” (28).

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 (36). She adds later 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” (Like Subjects 23). Thus, mutual recognition describes the process in which the Hegelian dialectic between self and other is maintained.

Kelly Oliver, a feminist philosopher, extends this Hegelian articulation of the fundamental paradox and argues that the “dependent foundation of subjectivity brings with it an ethical obligation to the world and others” (325). Oliver uses the term “witnessing” to identify this ethical obligation. She writes:

I use witnessing to describe the subject’s absolute dependence on another or others for its very sense of itself as a subject and an agent. Acknowledging the witnessing structure of subjectivity means acknowledging that dependence…the ethical subject as witnessing subjectivity acknowledges her dependence upon her addressee and interlocutor whom she cannot possess but upon whom she is absolutely dependent for her very subjectivity. This acknowledgement is the moment of ethical self-consciousness for the witnessing subject. It is the moment in which the subject realizes that an ethical obligation to others is built into the conditions of possibility for subjectivity (325).

Witnessing attests to the need for mutual recognition and understands this need as part of an ethical obligation to care for the other’s continued subjectivity. One must care in order to maintain self subjectivity, to remain an agent. For Oliver, subjectivity includes both “addressability” (“the ability to address others and be addressed by them”) and “response-ability” (“the ability to respond to others and oneself”) (326). This “ability to respond and to be responded to” is essential to witnesses in care relationships (327). The disabled partner must be seen as a meaningful subject, someone who can address the nondisabled partner (and others) and whose response affects the other(s). Likewise, the
nondisabled partner’s response-ability and addressability must be sustained. As demonstrated in Chapters 4 and 5, couples that maintain a care relationship often explicitly give “witness.” That is, they articulate (through words and actions) their dependence on each other, the way in which they come into being through their partner’s recognition.

It is particularly important for this study that physical bodies remain visible when thinking about witnessing, mutual recognition and intersubjectivity. Ironically, bodies have occupied precarious position in disability activism. For decades, disability scholars and activist have offered the “social model” of disability as an alternative to the historically predominant “medical model,” in which the problem of disability is located in the body of the impaired person, and the “solution” is to cure, minimize, or rehabilitate—to “normalize” the impaired body. 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 lead 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 activist (c.f. Finkelstein, M. Oliver) purposively discourage attention on the disabled body because, they believe, such attention individualizes and sentimentalizes the problem, distracts from the real problem of
disabling social conditions, and, finally, is a poor political organizing platform (Thomas 122). 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, its refusal to think critically and openly about impairment (c.f. Hughes, Morris, Wade, Wendell). Cheryl Marie Wade argues that the social model of disability creates the “able-disabled” by focusing on those people with disabilities who live “normal” lives once physical accommodations are in place (89). 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 anus and pissers so we do it all into bags attached to our bodies. (88)

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. (89).

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 (428–430). Attention on the body and “personal care” (e.g.
shitting, peeing) can improve social policy (Twigg 430). “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 (ibid. 431). In addition, bringing the body back into the discourse allows disability scholars to acknowledge physical pain (and pleasure) (Twigg 431), and to consider the medical response to impairment, including issues of prevention, quality of life, and “cure” (Shakespeare, *Disability Rights and Wrongs* 40).

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” (Thomas 137). The new body scholars eschew the nature/nurture, social/biological, impairment/disability binaries. The social can influence the body and vise 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 (329).

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, “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” (749). Similarly, Janet Price and Margrit Shildrick put forth a model of “embodied subjectivity” which accounts for the ways in which we are “actively and continuously
produced through social interactions with other body-subjects” (63). 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” (Hughes 66).

I am invested in this the 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, 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. (“Unreformed” 329).

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 body images—how one internalizes/feels a physical sense of self—in intersubjectivity. Weiss argues: “To describe embodiment as intercorporeality is to emphasize that the experience of being embodied is never a private affair, but is always already mediated by our continual interactions with other human and nonhuman bodies” (5). Indeed, people involved in disabled/nondisabled intimate relationships know that bodies are not private and that body exchange is necessary for
survival. Although all people experience intercorporeality, those that experience physical impairment are often more conscious of corporeal exchange.

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,” maybe even taboo. Nevertheless, as the self-representations in Part 2 of the dissertation show, the line between care touch and erotic touch is frequently blurred for disabled/nondisabled couples. In these parts of the text, I draw from the theoretical tradition of Queer Theory which challenges the dominance of heteronormativity. As Diane Richardson notes, queer “displace the categories of ‘lesbian’ and ‘gay’ and heterosexual” (5). 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” (6).

Even though most of the people represented in this text self-identify as heterosexual, I read the sexuality they describe as “queer” because it is an erotics based on care touch. In addition, disabled/nondisabled sexual intimacy violates the notion that there are proper erotic zones, and that sexuality (and personal care) are private matters. Queer and Queer
Theory are therefore useful concepts to re-think care and intimacy in disabled/nondisabled relationships.

**Study Questions & Overview of Dissertation**

The concepts of “care” and “intimacy” are the key targets of investigation throughout the dissertation because, as noted above, I argue that it is specifically the dominant constructions of these two concepts that create the image of the burdened, sexless disabled/nondisabled relationship. In our culture, care is typically associated with physical and emotional stress, even burn-out. And, since care is primarily understood as something given to babies and the elderly, it doesn’t mix well with intimacy in most people’s minds. Intimacy, particularly genital intimacy, is associated with heteronormative, able-bodies. In this study, however, I try to divorce care and intimacy from these negative and limiting connotations in order to capture how they are deployed in a variety of domains (e.g. popular culture) and by a variety of people (e.g. those people involved in disabled/nondisabled intimate relationships). I define care as physical, emotional or intellectual support given to one partner by another. Intimacy is used, purposely, as an umbrella term and includes feelings of love and devotion, as well as sexual desire and attraction. Thus, intimacy can include sexual acts, but also acts that exemplify a high level of connection between two bodies, including massage, touching, dressing, etc.

Throughout, I will also avoid making the distinction between caregiver and care-receiver unless I am talking about a very specific example of someone giving and someone receiving care. Instead, I conceptualize the couple as disabled/nondisabled.
Using “disabled partner” and “nondisabled partner” allows for the possibility that both partners give and receive care; that the role of carer and cared-for are not fixed or defined by the presence or absence of physical impairment.

The analysis 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 project 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/her partner experience life (c.f. Anne Finger on Polio, Susan Sontag on Cancer and AIDS, Janice Irvine on Sexual Addiction), and there are places in which the person’s specific disability is mentioned 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 (c.f. Shapiro). Although the exact type of care may vary with each disability/illness, all of the people with disabilities highlighted in this dissertation 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 highlights 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 very few
representations of same-sex disabled/nondisabled relationships. In fact, 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 I conducted is composed entirely of couples that identify as heterosexual.

The dissertation is divided into two parts, reflecting the two main goals of this
research: 1) To achieve a better understanding of how the binary construction of care is
maintained in dominant discourses; analyzing how such disparate literatures work
together to create a coherent and negative image of care within intimate relationships, and
2) Compare these constructions to self-representations by people involved in
relationships in which one person has a physical disability and the other is physically
nondisabled.
As the Figure 1 shows, in each domain I selected three areas to investigate. These, of course, are not exhaustive; however, selecting three represents a triangulated research methodology that allows for multiple and even contradictory understandings to emerge. Part 1 examines what I call “dominant constructions.” Chapter 1 examines popular culture representations—films, television shows, magazine and newspaper articles--featuring disabled/nondisabled intimate relationships. In Chapter 2, I conduct a content analysis of literature from the applied fields, including rehabilitation, medicine, and nursing. Finally, Chapter 3 analyzes the disability rights movement, closely examining how intimate relationships are, or are not, connected to care in the movement’s political discourse. I selected these three areas because it is not unreasonable to assume that each has a very strong influence on the lives of people with disabilities and their partners.
In Part 2 I turn to self-representations. Chapter 4 analyzes several autobiographies and documentary films by people with disabilities and/or their partners. As self-representations, autobiographies and documentaries offer viewers a rich portrait of life with physical impairment, but they are also typically produced by people with certain levels of social and economic privilege (Couer 4). 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. Thus, Chapter 5 provides data from focus groups composed of disabled/nondisabled couples. I conducted these groups to allow for greater diversity by seeking the opinions of people that have not had the means to produce self-representations. In addition, previous research suggests that couples that deal with disability report social isolation (Parker 114-115). Focus groups can, potentially, facilitate community building among couples experiencing similar forms of disability discrimination and isolation (Madriz 842). In all, I conducted four focus groups in Ohio with 2-4 couples in each group.

What emerges from this comparison of dominant representations and self-representations is a very 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 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 recent, 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 (Butler 26, qtd. in McRuer 30). 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” (31). Disabled/nondisabled couples expose how limited 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.
Granted, Kittay’s formulation of what she calls the “dependency relationship” is ultimately concerned with the caregiver’s situation, she does nonetheless acknowledge that care takes place in a relationship. Kittay’s work is problematic from a feminist disability point of view, but that critique is beyond the scope of this book.
Part I
CHAPTER 1: DISABILITY, CARE, AND INTIMACY IN POPULAR CULTURE

Introduction

In a recent Mothers Against Drunk Driving commercial a young man is reading on a park bench and the text reads “your best friend.” An attractive woman walks up and kisses him as the screen reads “your girlfriend.” The camera moves to the inside of an institutional-looking room with a man in a wheelchair gazing upon the pair and the text reads “you.” The screen fades to black and reads “You have a lot to lose.” The intent of the commercial is to deter drunk driving, but the message hinges on understanding disabled people as sexless and isolated. Within this discourse, disabled people are not adequate friends or lovers because they need constant care to maintain their disabled bodies. They are “burdens,” not active participants in relationships, particularly in a sexual sense.

Representations reflect social attitudes, but they also set limits of possibility—they help define what is socially imaginable. As Hilde Zitzelsberger notes, “relationships between cultural representations of bodies and people’s experiences are fundamental to understanding the conditions that shape the lives of people with physical disabilities and differences in western societies” (389). In popular culture, people with disabilities are rarely represented as care-givers or sexual partners. Such images can negatively affect
disabled people and their partners at the psychological level by lowering self-esteem (Crawford & Ostrove). In addition, the stereotype of the dependent, needy disabled person—perpetuated in popular culture— influences social service providers (see chapter 2) and likely factors into public policy. For example, in the U.S., disabled adults often lose most or all of their Social Security and/or Medicare benefits if they marry or cohabitate. Such “marriage penalties” leave people with disabilities who want to live with their partners with three, unappealing choices: live alone and keep their health care and income, cohabitate and lose their financial autonomy, or cohabitate and hide their living arrangement from the government (Crawford and Ostrove; Waxman). Although it is difficult to know conclusively which factors policymakers considered when making such policies, it is clear that the nondisabled spouse, constructed as the care-giver, is expected to provide fully for the disabled partner. In addition, Medicare calls in-home assistance with activities of daily living (e.g., bathing, dressing, toileting) “custodial care.” Such terminology clearly marks the disabled person as a ward whose rights and autonomy are withdrawn for his/her own good. Assumptions about disability, sexuality and care, reflected in representations, factor into the allocation and delivery of services.

This chapter closely examines how care, intimacy and disability are represented in popular culture, focusing on film, theatre, and the news media. Although there are a few notable exceptions, some of which will be reviewed later in this chapter, care in disabled/nondisabled intimate relationships—when represented at all--is primarily viewed as a burden that makes sexual intimacy impossible. I argue that for nondisabled audiences, disability representations evoke the fear of dependency and the loss of

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autonomy. Significantly, these fears operate within normative gender expectations.

Disabled men are much more likely to be shown in intimate relationships than disabled women because it is more acceptable for men to be cared for by their female partners (Asch and Fine). In the heteronormative environment of mainstream film, it is simply unthinkable, and thus unrepresentable, for male partners to care for disabled women. In addition, when disabled/nondisabled representations do appear onscreen or in the news, I argue that there is another strong cultural undertone at work—the fear of pollution. Drawing on Mary Douglas’ understanding of dirt and social pollution, I show how the history of eugenics in the west, but especially in the U.S., shape contemporary disability representations of disabled/nondisabled intimate relationships to evoke fears of “contamination.”

A Little Background on the Analysis of Disability and Popular Culture

In terms of the analysis of films that follows, I am drawing on what Thomas Hoeksema and Christopher Smit call an “integrated approach” and a “disability activist posture.” Hoeksema and Smit advocate the “integrated approach,” which “relies upon the combination/juxtaposition of cinematic consideration and disability consideration” (40). Hoeksema and Smit argue that authors such as Paul Longmore, Martin Norden, and David Mitchell and Sharon Snyder take a “disability activist posture” but fail to consider film as an artistic medium that is negotiated by spectators to create meaning (ibid 34). Longmore, Norden, and Mitchell and Snyder focus on examining stereotypes and stock narratives in film, arguing that these largely negative portrayals of disability negatively effect real people with disabilities. Cinematic techniques, such as framing, close-ups,
panning, and genre conventions, are ignored in the “disability activist” analysis of popular film. In addition, Hoeksema and Smit argue that “disability activist” analyses use outmoded theories of film spectatorship that assume a passive audience, “a non-thinking film consumer” (37). According to Judith Mayne, “institutional models of spectatorship” dominated film studies in the 1970s. Such theories focused on how the cinematic apparatus—the darkened movie theatre, the image onscreen—worked to interpellate particular subjects; the apparatus made viewers see, feel, and believe in certain, expected ways (41). Since the 1970s, scholars have offered various revisionist models focused on reception. These “reception theories” emphasize the viewer’s power to resist the cinematic apparatus, to critique, deconstruct, and otherwise distort the film’s intended message. In other words, reception theories acknowledge spectator resistance. Hoeksema and Smit clearly favor “reception theories” of spectatorship, arguing that “disability activist” analyses favor “institutional models.”

I agree with Hoeksema and Smit’s assertion that a balanced analysis of film must consider cinematic narration, along with plot and character development. Contemporary audiences have been subtly and unconsciously trained in understanding visual conventions and film scholars must pay attention to how these work in the films we analyze. However, I am not as convinced that spectators resist as easily or as frequently as Hoeksema and Smit seem to assume. Cinema is a very powerful cultural institution and few people are trained to question the ideologies mainstream cinema conveys. As Rosemarie Garland-Thompson states, “in our ocularcentric era, images mediate our desires and the ways we imagine ourselves” (Extraordinary 57). Since people with
disabilities are still isolated from the nondisabled world, film is one of the primary ways in which the nondisabled learn about disability. Indeed, Cahill and Norden argue that, “It is not simply a matter of movies reflecting reality; for some people, movies are the reality on which to draw for ideas about disability” (72). There is no reason to think that most audience members would know enough about disability to form a critique. In addition, as Richard Dyer points out, “Audiences cannot make media images mean anything they want to, but they can select from the complexity of the image the meanings and feelings, the variations, inflections and contradictions, that work for them.” (cited in Weiss, 35). When it comes to disability, I believe it is especially unlikely that audiences question or resist representations. Resistance spectatorship is limited by the options offered by the film and the awareness of counter discourses that critique dominant ideologies. Thus, I am more sympathetic to Longmore, Norden, and Mitchell and Snyder, who focus on the power of stereotypes and stock narratives. In this chapter, I am interested in particular disability narratives in film and popular culture, many of which have been previously outlined by Longmore, Norden, and Mitchell and Snyder, thus, I draw heavily from these “disability activist” authors in the following analysis. I will, however, supplement my analysis of these representations with close textual reading of the film, paying particular attention to cinematic conventions such as framing, distance of shot, and so on. I use similar tactics on non-film popular culture texts such as theatre, magazine articles, news stories, and so on. Attention is paid to both content and form, and when appropriate, reader/audience reception. Before I move onto the analyses of popular culture, I will
outline some of the previous work on disability representations as my intent is to push forward scholarship on popular culture in feminist disability studies.

Disability film scholar Paul Longmore argues that films that feature physical disability typically associates the visual aberration with criminality, insanity, moral decay, and monstrosity; however, in the latter part of the 20th century, disability cinema has shifted focus to “portrayals of adjustment.” These stories feature the maladjusted disabled person, who is bitter and depressed about his disability, or the super-hero figure who is able to not only overcome his disability, but excel in some other compensatory arena. In either case “disability is primarily a problem of emotional coping, of personal acceptance. It is not a problem of social stigma and discrimination. It is a matter of individuals overcoming not only the physical impairments of their own bodies, but more importantly, the emotional consequences of such impairments” (Longmore 9). From a Disability Studies perspective, such portrayals are inherently problematic as they obscure the ways in which social stigma and environmental barriers create disability. He goes on criticize the belief that “nothing can defeat us; only we can defeat ourselves,” noting:

This belief in the power of a positive mental outlook, so widely and successfully marketed in popular psychology, not only currently but throughout American history, suggests a primarily reason for the popularity of stories about disabled people adjusting and overcoming. It points to one of the social and cultural functions of that image and to one of the primary social roles expected of people with disabilities: in a culture that attributes success or failure primarily to individual character, ‘successful’ handicapped people serve as models of personal adjustment, striving, and achievement (9).

Thus, overcoming narratives serve to ease the anxiety of nondisabled audiences and place the responsibility for disability with people with disabilities. In essence, such representations uphold medical models of disability that individualize impairment, and
obscure the social model of disability—developed by disability activists—that places the problem of disability in the social and physical environment, not in the body of the person with an impairment. It is physical barriers (e.g., stairs) and social attitudes (e.g., discrimination, prejudice) that are disabling, not the impairment. Individualizing narratives support the medical model of disability, obscuring social and cultural factors such as racism, sexism, and ablism that complicate American ideals of meritocracy. I add to Longmore’s assessment by arguing that the prevalence of overcoming narratives is also linked to a culture-wide fear of dependency. In fact, drawing from Mitchell and Snyder, physical disability has often functioned as a “narrative prosthesis”—a visual code that works as shorthand for something larger—to signify dependency, helplessness.

Our cultural fear of dependency helps explain disability stereotypes and narrative conventions (e.g., overcoming) that frequent the silver screen; however, even a cursory look at disability and film reveals gendered patterns as well. Madeleine Cahill and Martin Norden argue that Hollywood portrayals of disabled women are constrained by women’s role as object of the male gaze. Thus, there are fewer portrayals of disabled women because physical disabilities disrupt women’s sexual attractiveness (57). As Susan Wendell points out, “Physical ‘imperfection’ is more likely to be thought to ‘spoil’ a woman than a man by rendering her unattractive in a culture where her physical appearance is a large component of a woman’s value” (43). When women with disabilities are represented, they are usually blind, deaf, mute—disabilities that do not adversely affect their attractiveness (Cahill and Norden 58). Cahill and Norden note that “the tradition of Hollywood movies heroines whose disabilities always affect their fates

I agree with Cahill and Norden’s analysis of the gendered nature of disability representation in Hollywood films; however, I add that the differences between disabled male and female characters is also influenced by gendered understandings of dependency. In our culture, it is socially acceptable for a nondisabled man to be intimately cared for by his wife, thus, it is not a very large imaginative leap to see a disabled man taken care of by loving women. The disabled man does not necessarily violate the expectations of heteronormative companionship, and he may be able to continue to fulfill his social role as economic provider and decision maker, despite his physical impairment. A disabled woman, however, is perceived to be incompetent because her value is determined by her ability to provide care, especially to her husband and children (Asch and Fine 244-145; Lloyd, *The Politics of Disability* 722-723). Adrienne Asch and Michelle Fine argue that “if men can accept emotional sustenance only from women who can provide the maximum in physical caretaking, the woman with limitations may be viewed as inadequate to give the warmth, companionship, and shelter men traditionally expect from their mates” (245). Physical dependence is not acceptable for women because nurturance is associated with the ability to “make house” and provide physical care to the family. As a participant in Hanna and Rogovsky’s 1991 study on women and disability aptly puts it:
“There is a big difference between a disabled husband and a disabled wife. A disabled husband needs a wife to nurture him, but a disabled wife is not seen by society as capable of nurturing a husband who is not disabled” (56). Thus, I add to Cahill and Norden’s understanding of the gendered nature of disability representations by noting that a woman’s value in patriarchy remains connected to her ability to care for her husband and children.

In what follows I show how such gendered understandings of care and dependency are played out in popular culture. Although an analysis of the portrayal of disability in all mainstream films, television, stage-productions and plays was beyond the scope of this study, I did review well over 30 visual texts (e.g., films, TV shows) and read plots of countless films logged on websites about disability in film. In addition, I read numerous news articles gathered through database queries on marriage and disability. Based on my own extensive investigation, as well as the research conducted by other disability scholars, I am confident that the specific texts reviewed in detail in this chapter are representative of mainstream popular culture portrayals of care, sexuality and disability. The exceptions to the gendered patterns of representative outlined below are rare, but it is important to note that there are a number of independent and foreign films with more balanced portrayals of disability, such as Saved (2004), Be With Me (2005), and Dance Me to My Song (1998).

Fear of Dependency

Writing about Robert Murphy’s autoethnography, The Body Silent, Rosemarie Garland-Thomson notes,
disabled people are made to signify what the rest of Americans fear they will become. Frightened with anxieties about loss of control and autonomy that the American ideal repudiates, ‘the disabled’ become a threatening presence, seemingly compromised by the particularities and limitations of their bodies….Cast as one of society’s ultimate ‘not me’ figures, the disabled author absorbs disavowed elements of this cultural self, becoming an icon of all human vulnerability and enabling the ‘American Ideal’ to appear as master of both destiny and self. At once familiarly human but definitively other, the disabled figure in cultural discourse assures the rest of the citizenry of who they are not while arousing their suspicions about who they could become (Extraordinary 41).

Disability signifies dependency in popular culture, and in the West, dependency is a state to be feared. This fear is also gendered. It is much more common to find examples of men with physical disabilities in popular culture. Disabled men’s “failure”—their dependency—is often recuperated in film and popular culture through demonstrations of how closely they embody what R.W. Connell has called “hegemonic masculinity” in other aspects of their lives. According to Connell, “Hegemonic masculinity can be defined as the configuration of gender practice which embodies the currently accepted answer to the problem of the legitimacy of patriarchy, which guarantees (or is taken to guarantee) the dominant position of men and the subordination of women” (77). In other words, hegemonic masculinity is our culture’s normative ideal of masculinity. It is not necessarily the most prevalent form of masculinity; rather, it is the most socially endorsed. Men are supposed to be cunning, strong, aggressive, potent (connote their phallic authority), and decisive. Making these qualities salient in representations of disabled men can work to shore up their need for physical care. For example, in the Bone Collector (1999), Detective Lincoln Rhyme (Denzel Washington) is quadriplegic and dependent on the help of his assistant (Queen Latifah) for all his personal care; however, he is also a potent and cunning detective who not only solves the crimes and finds the
serial killer, but wins the love of Amelia Donaghy (Angelina Jolie). Rhyme’s masculinity is thus shored up by his superior skills as a detective and his ability to “get the girl.” Parallel stories for women simply do not exist because, I argue, a woman’s femininity—her ability to meet societal expectations about womanhood—is entirely dependent on her ability to care for others and her sexual attractiveness. Unable to care for others or satisfy men, women with disabilities are rendered socially useless. Thus, women with physical disabilities who require care from others are killed off or rendered invisible in popular culture. In this section I examine films, a stage play, and various news media that demonstrate such gendered understandings of disability, dependency and care.

**Better off Dead**

The massively successful and controversial film *Million Dollar Baby* (2004) is an excellent litmus test for contemporary attitudes toward disability and gender. Directed by Clint Eastwood, *Million Dollar Baby* is about the relationship between trainer and gym owner Frankie Dunn (Eastwood) and boxer Maggie Fitzgerald (Hilary Swank). The film uses voice-over narration from Eddie “Scraper-Iron” Dupris (Morgan Freeman), an ex-boxer who now ekes out a living by cleaning—and living at—Frankie’s gym. Scraps seems to rely on hand-outs from Frankie (in one scene Frankie wants to give Scraps money to buy new socks), yet he is the film’s “voice of reason,” playing the wise, old black man through which the leading white characters learn something sage about life. In the beginning of the film, Frankie’s star boxer, Big Willie, has just left him for a manager willing to secure Willie a title match. Frankie—who’s motto is “always protect
yourself”—is reluctant to take risks. Through Scraps we learn that Frankie blames himself for Scraps’ last match in which he lost his eye. It is important to note here that this self-blame places Frankie in an omnipotent position because, as Scraps notes, Frankie was not Scraps’ manager and did not have the authority to stop the fight (the manager was off getting drunk). In fact, Frankie pleaded with Scraps to stop, but Scraps did not take his advice. Since then, we are told, Frankie has always taken the safe route, avoiding risks at all costs (even though Frankie never had the authority to prevent Scraps’ impairment in the first place). Thus, when Maggie Fitzgerald comes to the gym begging Frankie to train her, he refuses claiming that he does not train girls. It is, of course, Scraps who facilitates their relationship—giving Maggie tips and encouragement until they are able to wear Frankie down and convince him to train the eager Maggie.

With Frankie’s guidance and hard work, Maggie becomes an extremely talented boxer, winning most fights in the first round. As Frankie and Maggie travel the world, they become each other’s family. Frankie’s wife and daughter left him long ago (although we never know why, it is inferred that his fear of risk may have played a part) and Maggie’s family is characterized as the most stereotypical “white trash;” her mother is fraudulently living off welfare, is overweight and only interested in Maggie’s money. Thus, the two loners learn to trust again through each other. On the road, Frankie even gives Maggie a new name, “Mo Chúisle,” which the film says is Gaelic for “my darling, my blood.” Eventually, Maggie has beaten almost everyone in her class and she is clearly ready for a title fight, and Frankie, reluctantly, decides to take the chance. The title match is against Billie “the Blue Bear” (Lucia Rijker), a former prostitute who is
known for her dirty tricks in the ring. Early in the fight Billie appears to be winning, but after Frankie’s advice to punch her in the kidneys (an illegal punch, indicating Frankie’s willingness to take risks and ignore rules) Maggie pummels Billie. At the bell, Frankie’s assistant slides the chair into the ring for Maggie, who turns away from Billie to walk toward the chair and revel in the cheering crowd. Billie punches the unsuspecting Maggie who falls, breaking her neck on the chair. Maggie has a complete C2 fracture which means that she is unable to move anything below her neck and needs a ventilator to breath. Frankie is devastated but vigilantly stays with his boxer, visiting her in the hospital, assuring she is getting the best possible care. Maggie remains strong until one of her legs has to be removed because of a badly infected bed sore. After the surgery she asks Frankie to kill her, noting that she has achieved everything she has ever wanted and now wants to die before her fame and success become a distant memory. Frankie refuses and Maggie attempts suicide by biting off her tongue (and biting it off again after the doctors sew it back on). Seeking advice Frankie turns to his priest who advises him against fulfilling Maggie’s wish of assisted suicide, but after hearing Scraps’ opinion on the matter, Frankie decides to proceed. He enters her hospital room in the middle of the night, tells her what “Mo Chúisle” means, removes her ventilator and gives her a shot of adrenaline to stop her heart. Frankie leaves the hospital never to be seen again.

In the film’s world, no one would choose to live with a disability like Maggie’s—assisted suicide is the logical response. For most audiences, film critics and reviewers, this logic worked. Million Dollar Baby won four Oscars (best motion picture, best female lead, best supporting male, best director), has won 45 other awards and has been
nominated for 29 more. Roger Ebert calls the film “a masterpiece, pure and simple.”

Clearly, this film was well-received by audiences. For disability audiences, however, *Million Dollar Baby* (*MDB*) served a devastating blow by suggesting that the disabled life was not worth living. Even more upsetting was the way in which the mainstream media downplayed the concerns of disability activists, highlighting instead the concerns voiced by the Christian right. Jay Dolmage and William DeGenaro characterized the ensuing discourse by writing: “The conservative press attacked the film for promoting euthanasia and accused Clint Eastwood of contributing to a culture of death…The political right suggested the film served as another example of elite, liberal Hollywood undermining traditional values. The left, on the other hand, cast euthanasia as a right-to-choice issue, and defended the artistic license of the film and its makers.” Mainstream media outlets failed to address the complex perspectives of people with disabilities.

Although Eastwood insists that *MDB* does not validate euthanasia (Ertelt; Miner; W. Smith), in many ways *MDB* is a zeitgeist film, tapping into cultural debates and anxieties about assisted suicide for the disabled. In 2004, long time disability activist Christopher Reeves—arguably the most famous quadriplegic ever—died from complications with a bed sore. The Terri Schiavo case had been in the headlines for years, ending with Terri’s death on March 31st, 2005. Jack Kevorkian, imprisoned for helping Thomas Youk end his life in 1998, made headlines with his possible release in 2005 (he was denied parole). Indeed, 2004-2005 witnessed a flurry of assisted suicide headlines, thus, *MDB* hit a raw nerve. At least unconsciously, *MDB* weighed in on this hot topic. Disability activists argued that the movie did more than ask the audience to
decide if Frankie made the right decision. The star power of Eastwood and Swank, combined with the bleak world of disability that the film paints, amounted to an endorsement of euthanizing the disabled. Michael Wilmington of the *Tribune* noted “Because it’s Clint Eastwood, we tend to accept it as the right thing to do” (qtd. in Miner). In addition, the disabled life viewers are shown is horrific. We are told that Maggie’s care at “Serenity Glen” is the best available; however, Maggie quickly develops an enormous bed sore on her leg (she says to the doctor examining the sore, “it don’t smell too pretty, do it?”) and the doctors have to amputate. Although she is in a rehabilitation hospital, we never see Maggie outside of her bare room—she never visits a pool for therapy, there is no one working with her on range of motion, no counselors talking about adapting to life as a quadriplegic—in fact, we see no other people with disabilities at the hospital. There are no balloons, flowers, notes from adoring fans (even though we know that she was world famous and “in magazines”). In fact, Maggie’s room is bare, white, and sterile, strikingly different than her cluttered, lived-in apartment and the homey mise-en-scene of the gym. She is completely isolated, “frozen” in a rotting body—what logical person wouldn’t want to die in this situation?

In reality, Maggie would be surrounded with doctors, nurses, physical and occupational therapists, psychologists, social workers, and other professionals at the rehabilitation center. She would also interact regularly with other quadriplegics, learning adaptive skills from other people with disabilities. In addition, many facilities (especially one as good as Serenity Glen is supposed to be) have special beds that move to shift the person’s weight, relieving pressure and preventing bed sores. At the very least, Maggie’s
bed sore would have been preventable by moving and shifting her weight frequently. Maggie would also have the right to refuse care, including the use of the ventilator. Thus, instead of begging Frankie to put her out of her misery (like her daddy did with their lame dog) or biting off her tongue, she could have simply ordered her respirator turned off. In addition, as Wesley Smith notes, “people suffering the emotional agony that Maggie experienced in the film can be treated for their depression and their suicides prevented—without being force-sedated.” In fact, some studies show that several years post-injury, levels of depression are similar to able-bodied people (W. Smith). Wesley Smith argues that these omissions are the film’s “million dollar missed opportunity.”

Smith writes,

The most important point omitted from the film is that people with quadriplegia, when they are not merely warehouse in a nursing home, live very rich and satisfying lives. That Eastwood never seems to have given this matter any thought is odd, given that Christopher Reeve demonstrated famously that becoming quadriplegic does not mean that meaningful life ends…every day tens of thousands of our disabled brothers and sisters lead meritorious and productive lives, aided by respirators and wheelchairs that come to be seen not as dignity-robbing impediments, but facilitators and tools of independent living.

For some disability activists, *MDB* was more than a missed opportunity—it was symptomatic of Eastwood’s contentious relationship with the disability rights movement. In 1997, Clint Eastwood was sued by Diane zum Brunnen, a woman who used a wheelchair because of muscular dystrophy, because his hotel in Carmen California did not meet accessibility standards. The only accessible restrooms at the Mission Ranch were 234 feet away from the restaurant, across the parking lot. In addition, “accessible rooms in the inn cost $225 a night, while others were as low as $85, and because the main office could only be reached by climbing two stairs” (Dave Reynolds). After losing his
case (he was convicted of minor violations, but was not forced to pay any damages), Eastwood became a vocal opponent to the Americans with Disabilities Act of 1990, testifying before congress in support of HR 3590, “ADA Notification Act” in 2000. The bill would allow businesses 90 days to bring their business into line after a complaint is filed before they could be sued. Although Eastwood’s support of HR 3590 could be read as pro-business, his very public commentary has inaccurately represented the reality of ADA suits. On talk shows such as Hardball and Crossfire, Eastwood has claimed: “What happens is these lawyers, they come along and they end up driving off in a Mercedes and the disabled person ends up driving off in a wheelchair” (qtd. in Colker 171). If fact, ADA Title III (public accommodations) permits only injunctive relief, not punitive damage, and there have been very few lawsuits filed (Colker 170). In addition, under Buckhannon Board and Care Home, Inc. v. West Virginia Dep’t of Health and Human Resources, 532 U.S. 598 (2001), “the defendant is not required to pay attorney’s fees to the plaintiff’s lawyers if there is no court order requiring corrective action. In other words, if the defendant takes corrective action on the eve of litigation, the defendant does not need to pay attorney’s fees” (Colker 171). This ruling has made it even more difficult for people with disabilities to represent them in ADA Title III cases (Colker 171). The ADA Notification Act would give businesses even more leeway, reducing suits—which are the only ADA enforcement mechanism in place—even more. Thus, disability activist organizations like Not Dead Yet read MDB as part of Eastwood’s attack on people with disabilities, his not so subtle disdain for physical difference.
I agree that *MDB* is a deeply negative portrayal of disability, but add that this representation is bound up with contempt for female and lower-class bodies that exceed American ideals of independence and strength. As Dolmage and DeGenaro argue, in *MDB*:

stereotypes of ability and of class rely upon twinned disavowals of dependency….Maggie’s body becomes the marker for her class status, the embodiment of her rags-to-riches life project. She must change her socio-economic status and as a means to that end, she must change her body…She can’t allow herself to become fat like her mother—clearly, the ‘natural’ thing for her body to do. She turns to boxing, an unnatural act, a way to beat the odds, a way to pick herself up by her bootstraps. Her body becomes a site of individuality. Her body is a personal achievement, a project.

Indeed, as Maggie’s body turns into a lean, muscled machine, the distance between herself and her excessive, lazy working class family increases. It also distances Maggie from the softness of femininity, another marker of dependency. But Maggie’s injury permanently halts this rise. With her disability, her body begins to leak, sag, and fall apart like her mother’s classed body. Maggie’s family has “failed as individuals and rely on a larger collective for their well-being—something Maggie never does (pre-injury anyway). Maggie’s spinal injury changes things; now she relies on help, and this is what is most damning for her” (Dolmage and DeGenaro). Thus, disability, femaleness and lower-class status become conflated to signify dependency. For the film, Maggie has become useless and the only logical response is death.

On stage, disdain for dependency can be found in the musical *Wicked*. Based on the novel *Wicked: The Life and Times of the Wicked Witch of the West* by Gregory Maguire, the musical, billed as the “untold story of the witches of Oz,” focuses on the unlikely friendship between Elphaba and Galinda that blossoms while at Shiz University,
explaining how Elphaba becomes the Wicked Witch of the West and Galinda becomes Glinda the Good Witch. Early on we learn that Elphaba has green skin due to a potion called “Green Elixer” that her mother drank when she was conceived. Marginalized by her unusual appearance, she is sent to Shiz primarily to watch over her much favored younger sister Nessarose who is beautiful, but “wheelchair-bound.” At Shiz, Elphaba’s natural talent is discovered and she is given a sorcerer position; however, she eventually turns on the Wizard and others in charge as she learns they are part of the anti-Animal force in Oz that is taking the voices away from Animals, including her beloved Professor Dillimaud. Her disavow is labeled subversive and dangerous by the powers in charge and she is named the Wicked Witch of the West. Thus, the moral of the story is that Elphaba was really just “misunderstood,” and that it is discrimination which is truly wicked.

Green skin and species status serve as metaphors for people oppressed based on race and gender; however, the progressive message of Wicked is not extended to disability. While at school Nessarose falls in love with Boq, a munchkin who is more interested in Galinda. Bitter over her unrequited love, Nessarose becomes governor of Munchkinland (after her father dies) and enslaves Boq. Seeking refuge from her sister, Elphaba attempts to gain her favor by casting a spell on Nessarose’s silver shoes, turning them ruby red and giving them the power to let her walk. Nessarose, however, only becomes more tyrannical, refusing Elphaba, turning Boq into the Tin Man, and becoming the Wicked Witch of the East (who dies when Dorothy’s house falls on her). Nessarose is the embodiment of the bitter cripple—isolated, angry and viewed as an unsuitable
sexual partner in the play’s narrative. Dependent on the help of others, Nessarose’s difference exceeds the play’s embrace of diversity; therefore she is quite literally stamped out (when Dorothy’s house falls on top of her).

In the popular culture, falling in love and caring for someone with a disability—especially a disabled woman—is almost unimaginable…maybe even “heroic.” In the June 2007 “Real Women, Real Courage” spread in *Glamour Magazine*, Maria Corona is featured alongside Jessica Gaulke, a beauty queen fighting in Iraq, Melissa Hawkinson, a woman who saved a young boy from drowning, and Kendra Kern, who started an organization called Safe Passage that has helped more than 600 kids in Guatemala City attend school. What was Maria’s heroism? She re-united with her life partner, Krystina Jackson, when Krystina became paralyzed in a snowboarding accident. “After the accident, Maria moved in. She feeds me, showers me, takes me to the bathroom and goes to class with me and writes my notes; someday I’ll get my business degree. We’re a couple again, and our love is stronger than ever” (233). By juxtaposing Maria and Krystina with women who have saved lives and helped hundreds of needy people across the globe, *Glamour* sends a clear message that being in a relationship with a disabled woman is exceptional.

The representation in *Glamour* is drawing from a well established tradition in Hollywood film, television, and theatre of isolating disabled women, even ending their lives (as in *MDB* and *Wicked*) when they cease to fulfill expected gender roles. *What Ever Happened To Baby Jane?* (1962) is an excellent early example of this trend. Blanche Hudson (Joan Crawford) is a famous young film actress who is paralyzed in a
car accident by her jealous sister, “Baby Jane” Hudson (Bette Davis), a washed up child star. After the accident Baby Jane “cares” for Blanche who, despite her fame and good looks, is apparently left with no other options. Once sought after by men, she is portrayed as socially worthless in a wheelchair. The bulk of the film shows how Baby Jane tortures Blanche (preparing dead rats for dinner, removing the phone from Blanche’s bedroom, starving her, etc.). As Baby Jane falls further into madness her behavior becomes outrageous (matched by the gaudy make-up and ridiculous children’s dresses) and she nearly kills Blanche, who is literally trapped on the second floor of her own home. Overall the film is an over-the-top horror film featuring two aging divas, but the film’s assumption about disabled women is clear—society has no place for them.

Audiences are also frequently warned that such displaced women may become dangerous and manipulative. In a recent *Law and Order: Special Victims Unit* episode called “Manipulated,” we meet Tessa, a paraplegic woman, and her husband, Linus, who explains that he stays with his wife out of guilt because he caused the accident that left her paralyzed. Linus says he is having an affair because “I haven’t been able to have sex with my wife since her accident.” The twist is that Tessa has framed her husband for murder as punishment for the affair because, “I need him, I couldn’t survive without him.” The psychologists evaluating Tessa tell her that “you crave attention so much that you made your husband into a servant,” and you are “too invested in assuming the sick role.” Tessa’s “queer” position as cared-for becomes connected, then, to her depraved and criminal behavior. In an ironic turn, we learn at the end of the episode that Tessa’s paralysis has been cured and she has been playing paralyzed to gain attention, to keep
being cared for. Thus, it is questionable whether Tessa counts as a disabled character; however, I argue that it is the show’s portrayal of pathological female dependence that is important in this case. Tessa plays the manipulative “cripple” who saps those around her for attention and care. Once again, the message is clear: beware of women with disabilities. They can only be cared for, and this drain is eventually, inevitably dangerous.

Disabled women in mainstream popular culture are represented as threatening to heteronormative expectations embedded in intimate relationships and family affairs. Supposedly unable to fulfill their roles as caregivers, their dependency is social excess that must be eliminated (by killing them off) or controlled—lest they become too draining or too manipulative of the system. Psychological research suggests that attitudes towards people with disabilities are gendered, and that ideas about disabled women are generally much more negative. Reporting on Hanna and Rogovsky’s 1986 study with college students, Asch and Fine write:

When asked how women and men using wheelchairs became disabled, non-disabled students attributed male disability to external situations such as war, work injury, or accident. They attributed female disability to internal causes, such as disease. The authors suggest that attributing disability to disease may foster more negative attitudes because disease stimulates primitive fears of contagion or the person’s inherent moral badness. Thus, the disabled woman may be viewed as more dangerous than a similarly disabled male, more morally suspect, or more deserving of her fate. (243).

Thus, attitudes towards women with disability and popular culture representations appear to reinforce each other. Even when disabled through injury (e.g., MDB and Baby Jane), the disabled woman is depicted as pitiable and fully dependent. They are not shown caring for others and/or being in a sexual relationship. There are a couple of films that
suggest the possibility of a romantic relationship for the disabled main character, but, tellingly, the films end with this prospect (e.g., *Passion Fish* (1992), *An Affair to Remember* (1957)). And, the films in which the women are allowed romance on-screen end with their death (e.g., *Frida* (2002), *Theory of Flight* (1998)). The only exception to these rules that this author could find was for supporting characters. For example, in *Notting Hill* (1999), Gina McKee plays Bella, one of William’s (Hugh Grant) friends. Bella is in a wheel-chair and she is married; she is presented as a successful, loving, and funny woman. Such representations, however, are usually marginalized (quite literally, as in the case of supporting characters), when not entirely absent, in mainstream popular culture. Women with disabilities are usually portrayed as socially useless, if not threatening, an excess that must be contained and even eliminated.

**Disabled Men and Heteromasculinity**

In popular culture, especially film, disabled men are treated differently than disabled women. Although their physical difference and the ways in which their dependency foils their masculinity are often highlighted, disabled men in film do have intimate relationships. In addition, their physical dependency is often balanced out by showing how they perform in other aspects of their lives. This differential treatment of disabled men and women is symptomatic of gendered understandings of care in heterosexual relationships. It is acceptable in American culture for women to take personal care of their male partners in a variety of ways: doing laundry, preparing meals, shopping for the family, managing the family accounting, and household cleaning. Although the care a person with a disability may need exceeds these tasks, it is
interpreted as a “natural” extension of a woman’s role. This section examines three films—The Men (1950), Coming Home (1978), and Murderball (2005)—that reflect this cultural belief. In each film, the disabled male character(s) “beats” his disability and “gets the girl,” regaining some level of hegemonic masculinity. By examining these films I will to show how our understandings of care and dependency are gendered.

The Men is a classic “portrayal of adjustment” (Longmore). The film is about Lieutenant Kenneth “Bud” Wilcheck’s (Marlon Brando) struggle to come to terms with his paraplegia, including his reconciliation with his fiancé Ellen Wilosek (Teresa Wright). The film’s opening, on the battlefields of WWII, emphasizes movement, strength, and autonomy, setting up the “fall from masculinity” that becomes the problem to solve in the film’s narrative. As the credits roll on the screen, we see men in uniform marching toward the camera, across the screen, away from the camera. The low angle shots make the men appear larger than life, authoritative. As the credits end, the camera focuses on Lt. Wilcheck just as he is shot in the back by enemy fire. He falls to the ground and Wilcheck’s voice-over begins as the image dissolves to the hero laying in a hospital bed. Wilcheck is clearly depressed and has given up hope, breaking up with Ellen and refusing to see her because he believes himself to be a worthless cripple. It is the task of Doctor Brock (Everett Sloane) and the men in the rehabilitation hospital (most of whom are members of the Paralyzed Veterans of America and oversee hospital governance) to help Wilcheck accept his impairment and move on with his life. Ellen contacts Doctor Brock and convinces him to set up a meeting with Bud against his will. She insists that she wants to marry him, not out of pity, but out of true love. Although
resistant at first, Bud begins to accept Ellen’s love and his disability. However, after they marry Ellen suddenly expresses doubt about their relationship. Shaken by Ellen’s moment of exacerbation, Bud returns to the rehabilitation hospital, taking up the role of the drunken, bitter cripple. Eventually, his peers kick him out so that he will attempt to reconcile with Ellen. The ending shows Bud driving to Ellen’s parents house and asking her on a date, implying that the two will reconcile and that Bud has finally accepted his disability.

Although Bud does live and marries Ellen, and the film indicates that the two will go on to have a happy life together, the film never lets the audience forget about his disability and his need for care. Rehabilitation makes Bud less dependent, more mobile, but he will always need help. Early in the film there is a scene in which Doctor Brock addresses a room of women—presumably the mothers and lovers of the hospitalized men—explaining the nature of spinal cord injury, what to expect in terms of recovery, and so on. The scene functions primarily to inform audiences members and to introduce Ellen, but it also speaks volumes about the expectations of women and care. Doctor Brock is shot from a low angle and the women are shot from high angles, indicating the unequal power relations. He instructs the women that there “will be problems,” but that it is their duty to help their men accept their limitations and move on with their lives. As there are no men in the audience, it is clearly the expected job of these women to help, care, and assist the men. Nevertheless, the film also makes it clear that this level of personal care is horrifying. As Dr. Brock explains that the word “walk” should be forgotten, that some men never regain bladder and bowel function, and that some men
will not be able to father children, the camera cuts to reaction shots of the women. Each
close-up reveals the women’s complete shock and horror, instructing the audience too on
how to react. As the women anxiously ask about surviving as a married couple, Dr.
Brock says that it takes “a special kind of woman,” but that they should try. Later, when
Ellen is telling her parents that she plans to marry Bud, her father says that he fears she
will get married and then realize that she has “signed a contract to be his nurse.” These
moments highlight the film’s anxiety over care of disabled men. In one sense, it is
clearly the proper role of women, natural and unproblematic. In another sense the film
seems to suggest that no or few women could handle such relationships.

During Ellen and Bud’s wedding, Bud decides to stand at the alter with his bride,
but when he goes to hold hands he begins to fall. Foreboding music floods in and there is
a cut to Ellen’s disturbed reaction. After the wedding the two enter their new home.
Ellen appears shaken by the fall at the wedding but proceeds to feign excitement as she
shows Bud the house and gets the champagne. As Bud wheels around the family room
his chair begins to squeak loudly, further troubling Ellen. He spills the champagne and as
she frantically cleans up “her carpet,” he begins to have a leg spasm. The camera zooms
in on his leg and the dark music returns. Ellen’s look has turned to horror. Her groom is
a helpless, grotesque body dependent on her care. She breaks down and he leaves.

Although the ending of The Men suggests Bud and Ellen will reconcile, it is
important to note that we do not see this, nor do we actually see the couple kiss or be
affectionate for the entire film. So, as a disabled man, Bud can have a wife, but he and
Ellen cannot be sexually expressive. This dynamic is typical of Hollywood films
involving disabled men (and, sometimes, disabled women as noted in the previous section). For example, both *My Left Foot* (1989) and *Bone Collector* (1999) end with a budding romance, thwarting cinematic expressions of disabled/nondisabled sexuality. This is also what makes *Coming Home* (1978) so unique—the audience gets to see disabled/nondisabled sex *and* it’s sexy, not tragic.

*Coming Home* is also a rehabilitation film about a wounded war veteran; however, this film is about the Vietnam war and is explicitly anti-war. Politically, the film is about the fallout of the war, but it is also about the love triangle between Luke Martin (Jon Voight), Sally Hyde (Jane Fonda), and Bob Hyde (Bruce Dern). Like *The Men*, the film opens in a Veterans Affairs Hospital, introducing us to Luke, a Sergeant who has become paraplegic from a combat injury. Luke is depressed, alcoholic, and violently resistant to rehabilitation. We are then introduced to Captain Bob Hyde, who is just being sent overseas to fight, and his naïve wife Sally. After seeing Bob and his friend Sgt. Dink Mobley (Robert Ginty) off, Sally befriends Dink’s girlfriend Val Munson (Penelope Milford) and decides to volunteer at the VA hospital (against her husband’s wishes). This “work” experience opens Sally’s eyes to the atrocities of the war and the government’s treatment of veterans and reunites her with Luke, a friend from high school. The sexual tension between Luke and Sally is palpable from the beginning, even though they encounter each other when Luke crashes his mobile hospital bed into Sally, spilling his own urine (from his catheter bag) all over her. The film makes a point to emphasize lingering glances, tense conversation and nervous laughter to draw out the potential intimacy between the two. This meeting seems to encourage Luke to quit
drinking and accept his paralysis. Sally, empowered by her new experiences away from her husband and Luke’s advances, quite literally blossoms—changing her hair, buying a new car (a sporty roadster) and renting an apartment on the beach (none of which she shares with her husband oversees). Confident and invigorated, Sally invites Luke over to her new apartment for dinner. From here the two begin an intense and mutually beneficial affair (both seem to grow from the experience), all the time knowing that it will end upon Bob’s return. At the end of the film, Bob returns in relatively good physical health (he limps because he shot himself in the leg), but emotionally broken. He learns about the affair and, in the final scene, undresses on the beach and walks into the ocean. It is implied that Bob intends to kill himself; however, we do not see this, nor do we see how Luke and Sally go on.

Although typical for its “portrayal of adjustment,” *Coming Home* is unique because so much attention is spent on the sexual and romantic connection between Luke and Sally, and the way in which mutual care functions in their relationship. As the nondisabled partner, Sally helps Luke into bed during the sex scene, over the stairs to her apartment, and into her car. She is also an emotional helpmate, calling him out on his self-centered loathing early in the film. However, Luke also helps Sally. He holds the door open for her and helps her with beds at the VA hospital, and literally rescues her when Bob almost assaults Sally after finding out about the affair. Emotionally, he encourages Sally’s independence and righteous outrage toward the military’s refusal to acknowledge problems at the VA hospital. Luke even gives Sally her first orgasm. This mutuality and reciprocity is emphasized through the film’s narration. Two shots (as
opposed to shot-reverse-shot sequences) of Sally and Luke dominate the film, adding to our sense of equality between the two. In contrast, conversations between Sally and Bob often occur in shot-reverse-shots, literally separating the couple, or the composition of the shot emphasizes Sally’s subservient position to Bob and her disapproval of Bob’s values and behavior. For example, when Sally goes to Hong Kong to visit Bob on his R&R, there is an interesting shot in which Bob is in the foreground, obscuring Sally. This is significant because the dialogue indicates the couple’s growing distance, including Bob’s inability to see Sally as a full partner. The shot emphasizes the pair’s inequality and cements their disconnection. Bob wants Sally to remain naïve and in the private sphere, but Sally has already outgrown such restrictions. The film is critical of heteronormative relations and offers Luke and Sally as an alternative (which is also “alternative” in terms of disability). The relationship between Luke and Sally is a bond that allows both to grow, to be more themselves together. It also undercuts the binary position of caregiver and care-receiver; Sally and Luke are equal partners in the film’s narrative.

I believe that it is this sense of mutuality and equality (as well as the film’s overtly radical nature) that allows for the explicit sexual representation. In other words, the potential for sex and intimacy is not forestalled in this film because the disabled partner is not equated with dependency. The sex scene occurs after Luke has been arrested for protesting the war. Sally bails him out of jail and tells him that she would like to sleep with him (he propositioned her earlier in the film when he came over for dinner). He tells her they can go back to his place. When they enter Luke’s apartment he says he needs to do a few things in the bathroom and that he will only be a few minutes.
We then cut to the bedroom and see Sally waiting on the bed with her long coat on (she is naked underneath). Without cutting, we see Luke roll in to the bedroom (toward the camera and Sally) and up to the bed. He is naked except for a hand towel he has placed across his lap. He asks Sally to position his sheep skin in the center of the bed and then he transfers. She lifts his legs into the bed and then turns off the light. The screen turns to black and then we hear Luke tell Sally to turn the light back on because, “I want to see you.” The next shot lasts almost one full minute (average shot duration in film is only 10 seconds) and is a close, tight shot that pans their bodies, following their hands as they touch each other and kiss. The lighting is soft and warm tones are used, adding to the sense of closeness and heat. In the final part of this scene we see Sally’s face in close-up as she orgasms. She then begins to sob because “that has never happened to me before” and then Luke comforts her. The last shot is of Luke resting his head on Sally’s breasts.

Cinematically, this scene looks and feels much like the typical sex scene in a Hollywood film; however, as the sequence above indicates, female pleasure is foregrounded. In addition, the dialogue addresses viewer anxieties about “how a disabled person has sex.” After Sally turns on the lights, we hear the following exchange while the camera pans over their bodies.

Sally: What do I do?


Sally: Where can I touch you? Where can you feel?

Luke: That’s nice. I’m real sensitive in all the areas that I feel. Real sensitive.

Sally: Can you feel that?
Luke: Can’t feel it but I can see it.

Sally: I wish you could feel me.


The dialogue lets viewers know that people with paralysis are still sexually aroused by touch in the “numb” areas because they can see the touching and feel through body-memory. It also suggests that the rest of the body becomes hyper-sensitive to touch. It is, in fact, possible for some men with paraplegia to “learn” how to orgasm through caresses on their chest, nape of their neck, or other areas. In other words, the dialogue combats the notion that paraplegia deadens sexual feeling and desire.

This sex scene is remarkable for Hollywood film because we watch for over 4 minutes as a disabled/nondisabled couple has physically hot and emotionally intimate sex. Their physical differences are present. The dialogue highlights his paraplegia, we see her help him into bed, and we see a glimpse of the scar on his spine. However, these physical differences do not undercut the scene’s sexiness; instead they are blended seamlessly into the eroticism of the encounter. I know of no other Hollywood film that treats disabled sexuality this way. It is much more typical for sexuality to be suggested than shown. And, as the following discussion of Murderball illuminates, it is common for the anxiety of disabled sexuality to override other elements in the film. Coming Home’s treatment is exceptional in the cinematic landscape.

Released in 2005, Murderball is a documentary about wheelchair rugby. According to the film’s website, filmmakers Dana Adam Shapiro, Jeffrey Mandel, and
Henry Alex Rubin, sought to create a hard-hitting and dramatic film that would defy stereotypical notions about people with disabilities.

From the gyms of middle America to the Olympic arena in Athens, Greece, Murderball tells the story of a group of indomitable, world-class athletes unlike any ever shown on screen. It will smash every stereotype you have ever had about ‘gimps’ and ‘cripples.’ It is a film about family, revenge, honor, and the triumph of love over loss. But most of all, it is a film about standing up, even after your spirit, and your spine, have been crushed. (2005, website).

Thus, the filmmakers place the film within the long history of disability adjustment films, despite their efforts to provide something new and innovative.

Although the film is about the lives of men with spinal cord injuries, it is important to remember that it is made for able-bodied audiences by able-bodied men. As a documentary it is very educational, explaining graphically the process of spinal cord injury and rehabilitation to a general audience that is assumed to be ignorant about physical impairment. The film’s narration also speaks to the nondisabled audiences’ anxieties about disability. It is carefully crafted to invoke and satiate disability anxiety. For example, the first shot of the film is a long shot of Mark Zupan dressing himself, a difficult and long process for a quadriplegic. There is no music, only the diegetic sounds of the creaking wheelchair and Zupan’s struggling grunts. The camera rolls, without cutting, for nearly a minute, zooming in on Zupan’s tattooed, but shriveled legs. These techniques highlight the visual specter of the disabled body and are clearly designed to invite the perverse gaze\textsuperscript{viii} of the spectator. Viewers are encouraged to gaze upon this private moment, and it works because it is designed to play upon the spectator’s anxieties about the fragility of their own body.
The viewer is immediately shown, however, that this film will not focus on fragility. Driving, heavy-metal music begins to flood in as the opening credits—in the shape of white bandage tape—flash on the screen. We hear the clanging of metal and the whir of a drill. Quick cuts of Zupan preparing his gladiator-like rugby chair and bits of talking-head like interviews of other men in the film are followed by an explanation of the sport of wheelchair rugby, complete with computer graphics and special effects. A graphic of the pins and metal inserted into the spine to stabilize spinal cord injuries “fades into a shot of the actual scars that mark one player’s neck” (Barounis 58). Each edit moves with the fast-paced music and compliments the video-game like appearance of this second opening. These techniques signal the adrenaline-rush, muscle-pumping tone of the film and the personalities of the “characters” in the documentary, easing any discomfort the disabled body may have induced in the first opening. The first 20 minutes of the documentary acknowledge the uncomfortable reality of physical impairment, but quickly establish that this film is going to be different: these men may struggle, but they are great athletes who can endure not only the pain of their disability, but the harsh beatings from professional rugby. Drawing from the image of the cyborg, Cynthia Barounis argues that this opening offers viewers an “extraordinarily refashioned machinic masculinity” (59). In other words, they are “more-man” than most. To satiate anxieties around the specter of the invalid body, the film assures viewers that men can indeed survive and adjust to disability.

Interestingly, however, the film does not let us forget that in some ways these men fail the ideal of “hegemonic masculinity,” undermining the otherwise coherent portrait of
strength that the film emphasizes. For example, the vignette about Mark Zupan and his girlfriend Jessie is sweet and sentimental; however, the critical potential is undercut by camera techniques that remind the spectator of Zupan’s inadequate body and dependency. The dialogue tells us that they have a good, mutually satisfying relationship, but the camera is showing us Zupan’s dependency. We watch as she ties Zupan’s shoe; Jessie loads groceries as the camera focuses on Zupan sitting in his chair watching; and as Jessie pumps the gas, the camera pans to Zupan sitting in the car. We do not see any moments in which Zupan helps Jessie. It is likely that Zupan’s girlfriend is highlighted to potentially counter images of the lonely, un-partnered cripple. This is potentially positive; however, the film seems to have difficulty fitting such alternatives into hegemonic masculinity. In other words, his penis works, but he cannot be the same kind of man to his partner; therefore, the film reminds us that there are still failures and inadequacies in the disabled body—hegemonic masculinity can never be complete.

This glimpse of dependency and the need for care, however, is an exception in the film. For the most part the film clearly emphasizes the ways in which men with disabilities can approximate hegemonic masculinity. Murderball vigilantly establishes the phallic authority of each main character. Indeed, one of the central narrative themes of the film centers on the characters’ working penises. For a “sports film,” an inordinate amount of screen time is devoted to the characters’ sexual prowess. “Scene 7: A Jock” is a six minute\textsuperscript{9} section all about the phallic authority of the characters; thus, about 14% of the film is not about “wheelchair rugby” at all. The ability of the penis to work, or get an
erection, becomes a central theme in the film, reifying the focus on the phallus in hegemonic masculinity.

To help emphasize their sexual potency, the women in the character’s lives are repeatedly highlighted, and at the end we are even given status updates on their romantic involvements. Cynthia Barounis argues that it is precisely the persistent presence of the “gender-normative able-bodied woman who reinforces heteromasculine potency” in the film (61).

Thus we see women in various contexts, but they are always feminine, always heterosexual, and always engaging in activities that support and reinforce the heterosexual masculinity of the players. They are featured as friendly nurses, cheering sections at games, concerned mothers and, most important, proof that whatever other effects the injury has had on their bodies, their ability to engage in heterosexual, penetrative sex is not compromised (61).

In *Murderball*, it is the men’s status in disabled/nondisabled intimate relationships that assures their position in hegemonic masculinity. It is important to note here, again, that this is not a self-representation. Zupan’s autobiography, *Gimp*, actually paints a much more complex picture of masculinity, particularly when it comes to his relationships with women. He is still invested in a working penis and details his quest to find medication that help him with erections, he also says, “I realized that I was a different kind of lover now. I used to worry only about pleasing myself. Now I was constantly thinking about my partner. I didn’t rush foreplay. I didn’t want to.” 223). Thus, the heteronormative masculinity that the film is so clearly invested in demonstrating for viewers may more accurately reflect nondisabled anxieties than actual hyper-masculine disabled rugby players.
Other techniques are also employed to distance these men from the image of the impotent invalid body. For example, the film pokes fun of the sex education offered in rehabilitation. Excerpts from the film “Sexuality Reborn”—a how-to sex education video popular with physical rehabilitation centers—are used to mock the medical perspective of sex and disability. The grainy, amateur film features a dead-pan doctor in a white lab coat explaining that normal sex is possible—with slight modifications—for most men with spinal cord injuries. This is potentially a useful critique because, indeed, research suggests that the sex education offered in rehab is dry, paternalistic, and medicalized; however, it falls short because the comedy is based on hegemonic masculinity. In other words, it is funny because these men seem to have no problems with sex and erections. Sure there may be adjustments, but because these men can get an erection, they are able to perform a sexuality that is exemplary of hegemonic masculinity.

Like Coming Home and The Men, Murderball shows that disabled men are permitted female sexual partners in film. Since women already care for men in heterosexual relationships, the care provided to these disabled men does not provoke too much anxiety (or any at all in the case of Coming Home). Nevertheless, sex in disabled male/nondisabled female relationships is still treated with apprehension. Even though films are saturated with explicit sexuality, it is rare to actually see disabled/nondisabled sex on screen. When it is presented, the issue of the disability is highlighted emphasizing that this sex is not routine. In what follow, I argue that such treatment is symptomatic of the cultural fears of pollution and perversion that surround disabled sexuality. Focusing on the “freak show,” sterilization, and prenatal genetic counseling, I show how the
history of eugenics created the fear of pollution and sexual perversion and how such fears continue today.

**Sicko Sex**

As the section above makes clear, it is rare to see people with disabilities, especially women, in romantic relationships in popular culture. It is even more extraordinary to see disabled/nondisabled sex scenes, which is remarkable considering how sex saturated popular culture has become. I believe that the possibility for sexuality and intimacy in disabled/nondisabled relationships is often obscured because it is antithetical to care in our popular imagination. As Michael Davidson notes, “for many able-bodied persons, disability *is synonymous* with dependency, the former framed as a condition of tragic limit and loss requiring regimes of care and rehabilitation” (i). I would add to this astute observation that dependency *is synonymous* with child-like asexuality. Thus, representations of disability rarely include a sexual component. However, when disabled/nondisabled sexual intimacy is portrayed, other fears or cultural anxieties often becomes obvious—especially the fear of pollution and the fear of perversion. The fear of pollution is obvious in eugenics discourse that discourages reproduction that may create more people with disabilities. Because sex with a disabled person may produce more impairment, such desire has been labeled perverse. Sterilization and consent regulations are put in place to “protect” the disabled from such perverse desires. Analyzing why some things are labeled as “dirty” and “polluting” and others are deemed “good,” Mary Douglas famously suggests that culture’s are more likely to assign anomalies as a taboo to be avoided or eliminated. In other words, when
something does not fit the rest of society, or cannot be explained, it is pollution and it becomes taboo to touch, consume, or mingle with the contaminating element. Drawing on the work of Siobhan Somerville and Anna Stubblefield, I apply Douglas’s notion of taboo to disability, arguing that “perversion” and “pollution” are interrelated, bound together by eugenics ideals. This section offers an analysis of pollution and perversion anxiety to show how such tensions influence contemporary visions of disabled sexuality. I begin by framing perversion and pollution in Somerville’s and Stubblefield’s analyses of scientific racism and sexuality, and then follow by examining the fear of pollution surrounding the freak show, the motivation behind past and current sterilization and consent laws, and modern prenatal genetic testing. In each of these three “case studies,” the threat of pollution and perversion bifurcate sex from disability, further cementing in dominant ideology the relationships between disability, dependency, and asexuality.

Siobhan Somerville, writing in 1994, and Anna Stubblefield, writing in 2007, are both concerned with the eugenics movement popular in the late 1800s and first part of the 20th century in the United States and Europe. Eugenicists, spurred by new scientific understandings of heredity and genetics, promoted a form of selective breeding in which those deemed undesirable are discouraged or prevented from reproducing and those deemed superior are encouraged to have children. Although the popular understanding of eugenics is that it was primarily concerned with race, Somerville and Stubblefield show how other forms of difference are bound up with race in eugenics ideology, and how such discourse continues today. For example, Somerville points out that the invention of homosexuality/heterosexuality[^1] coincides with the rise of scientific racism, so that
eugenics is based on sexed and raced understandings of the body. Somerville contends that the “categories of race and sexuality were not only historically coincident but in fact structurally interdependent and perhaps mutually productive,” and offers three specific ways in which the discourses of scientific racism and sexology (science of sexuality) overlap (246). First, scientific racism and sexology in the late 19th century and early 20th century sought evidence of deviance on/in the body. Second, both wanted to draw distinct lines around “pure race” and “pure sex/gender,” and, finally, they were concerned with “perverse” racial and sexual desire (articulated as the “wrong” object choice). Anna Stubblefield extends Somerville’s analysis to show how a wide variety of traits—including homosexuality, non-whiteness, pauperism (the willingness to live off public welfare), sexual promiscuity, physical and mental impairments, and criminality—were considered inheritable forms of “degeneracy” that were linked together under the umbrella term “feeblemindedness” (164). Stubblefield argues that “the concept of feeblemindedness developed as a catchall category that linked the forms of white taint—poverty, off-whiteness, and lack of civilization-building skills—together into a single classification” (178). Stubblefield and Somerville are both useful to my analysis because they show how various forms of difference operated together in eugenics efforts to rid the world of polluting elements and perverse desires. Thus, in the following analysis I show how the visual documents that surrounded the “freak show,” the sterilization of people with disabilities, and modern prenatal and genetic testing are linked to fears of pollution and perversion embedded in eugenics.
The rise and fall of the “freak show” overlaps with the height of race and sexual science. Between 1840 and 1940, cartes de visite (“visiting cards”) and cabinet cards were distributed at the organized “freak shows” in carnivals and museums throughout the U.S. The carte de visite and cabinet card are examples of marketing materials used by individual freaks and their promoters. Cartes de visite (CDV) were cards with mounted photographs that usually measured 4½” by 2½” and were popular during the 1860s and 1870s (“Disability Museum Glossary”). The invention of the “set-plate” technique in 1851 allowed photographers to make many re-prints from one exposure. Freaks would be photographed in elaborately posed positions and sets that maximized their physical difference, and the text on the back would often describe their physical oddity and/or talent. The CDV’s were then sold for money by the freaks and the owners of freak shows. They were also used to promote themselves and find jobs, much like actors use “head shots” today. Cabinet cards were used much the same way; however, these cards were larger (usually 6½” by 4½”). Cabinet cards, which got their name because it was popular to display these cards in cabinets, replaced CDV’s in popularity by the late 1800s (“cycleback”). Although produced through the 1920s, cabinet cards were most popular between 1880-1900.

Freak show CDV’s and cabinet cards were wildly popular because they capitalized on the new technology of photography, our “ocularcentric” desires, and anxiety produced by physical difference. As Rosemarie Garland-Thomson argues, “photography authorizes staring…Disability photography thus offers the spectator the pleasure of unaccountable, uninhibited, insistent looking” (“Politics” 58). In her study
Garland-Thomson offers a taxonomy of disability photography: the wondrous, the sentimental, the exotic, and the realistic. The wondrous and exotic are often at play in CDV and cabinet cards of freaks. Wondrous images forefront the ability of freaks to perform routine, everyday tasks in order to “elicit amazement and admiration” (“Politics” 59). Images of Prince Randian, the “human torso,” who had no legs or arms, rolling and smoking a cigarette are a perfect example of the wondrous. The premise is that able-bodied or “normal” bodied people could not imagine learning how to perform such feats, thus the desire to stare at the wondrous tapped into spectators own anxieties about limitations. Garland-Thomson states that “the visual rhetoric of the exotic presents disabled figures as alien, distant, often sensationalized, eroticized, or entertaining in their difference” (“Politics” 65). The image evokes of form of viewing “characterized by curiosity or uninvolved objectification and informed by the proliferation of popular ethnographic photography” (“Politics” 65-66). In such images the freak is not shown performing any tasks, he or she is simply posed to highlight their difference for the spectator to investigate. Images such as those of united twins Cheng and Eng often highlighted their connected body, for example.

Surveying freak CDV and cabinet cards, I argue that an additional discourse emerges which combines the wondrous and exotic but focuses on sexuality. Frequently, freak cards featured the freak and their spouse and/or their offspring. Sometimes these marriages were fabricated to add to the sensationalism and to exaggerate difference, as in the case of unions between “fat ladies” and “skeleton men” (Fahy 8). However, Daniel Mannix notes that many marriages were authentic, the result of living and working
together in the carnivals and museums. Shunned from “normal” society, the “freak life” allowed those with extraordinary bodies to live in colonies with other people who accepted and even celebrated their differences. Nevertheless, once married, showmen were always quick to advertise the pair as “the World’s Strangest Married Couple, which greatly increases their billing” (Mannix 13). Percilla, the “monkey-girl,” and Emmett, the “alligator-skinned man” were one such famous and authentic union. Such couples would frequently appear on cards together, sometimes posed repeatedly in wedding gear to emphasize their coupledom. Charles Stratton and Lavina Warren produced several of these cards. Other examples of posed wedding pictures include the “giants” Mr. and Mrs. Patrick O’Brien, little people Commodore Nutt and Minnie Warren, the “giant” C. Urek and his “normal” wife, just to name a few. It was also common for freaks to include their children in the image, again signifying for anxious viewers their reproductive capacity. For example, Chang and Eng, the Siamese Twins, had several cards made that included their two children. Similarly, Eli Bowen, the “legless acrobat,” had cards made with his “normal” wife and children.

Even when the image itself did not signify the individual’s sexual relationships or reproductive history, the paratext did. Gerard Genette defines paratext as all the discourse that surrounds the text itself, including “peritext” and “epitext.” Peritext is the matter between and on the covers of a book, excluding the text itself; epitext is the public and private discourse about the text (Koenig-Woodyard). Applying such terms to CDV and cabinet cards, the peritext would include the title or inscription on the front of the card below the image, as well as the text on the back of the card. Typically this would
include, at minimum, the photographer’s name or studio. In the case of “sexual” freak cards, information about the people in the image was almost always included on the back of the card. Just in case the viewer wondered about the woman in the picture with Eli Bowen, the back of the card explains that this is his wife, eliminating any doubt about their sexual relationship.

Because freak CDV and cabinet cards were very popular collectables in the late 1880s and early 1900s, epitext frequently accompanies the image. A person visiting the carnival may purchase the CDV and display it in their home or put it in a photo album, writing their comments about the experience next to the image. For example, the epitext that was attached to the Eli Bowen card that I purchased at an antique store states “He married Mattie Haight who gave him 3 normal children.” The seller, perhaps even the original owner of the card, felt that it was important to include such additional information about the CDV.

I argue that these images, including the peritext that surrounds them, display “freak” sexuality in order to invoke the anxiety of the time. As many other scholars have argued, freak shows become popular in America during a century of uncertainty and rapid changes; thus, the freak show enabled Americans to define, categorize and shore up their “normaley” by staring at the racial, gender, physical and mental Other (see Garland-Thomson “Extraordinary”; Fahy). I agree with this historical analysis of the function of the freak show, but add that this period also overlaps with the eugenics movement. As Somerville points out, one of the main concerns of eugenics and sexology was the quest for “purity”—categorizing and separating forms of difference to establish the pure. Thus,
scientific racism and sexology yoked “together, at least rhetorically, two kinds of mixed bodies—the racial ‘hybrid’ and the invert” (Somerville 259). The sexualized spectacle of the freak show added physical and mental impairment as another form of impurity that may be inherited or even desired, putting the issues of genetics, Darwinism, and heredity front and center. The freak shows and the CDV and cabinet cards that circulated outside of the shows served as a catalyst for public debates about eugenics. Should such abnormal people be allowed to marry? To reproduce? Will their children inherit their “defects?”

The freak show played out amidst a legal and political backdrop that legalized forced sterilization for those considered “feebleminded.” Between 1907 and 1974, 32 states had sterilization laws on the books and about 64,000 Americans were forcibly sterilized (O’Reilly). Stubblefield points out that “sixty percent of those sterilized were women, and a large majority of those sterilized were white and poor” (162). Pamela Block’s historical analysis of the management of women with cognitive impairments notes that in the 1920s “sterilization and parole came to be seen as a more economically viable solution” than forced institutionalization (245). The model law, drafted by Harry H. Laughlin of the Eugenics Record Office, listed ten “socially inadequate” groups that were targeted for nonconsensual sterilization:

1) feeble-minded; 2) insane (including psychopathic); 3) criminalistic (including the delinquent and wayward); 4) epileptic; 5) inebriate (including drug habituees); 6) diseased (including the tuberculous, the syphilitic, the leprous, and others with chronic, infectious, and legally segregable diseases); 7) blind (including those with seriously impaired vision); 8) deaf (including those with seriously impaired hearing); 9) deformed (including the crippled); and 10) dependent (including orphans, ne’er-do-wells, the homeless, tramps and paupers) (40). (cited in Block 245).
What is clear from this model law is the desire to erase bodies that fail the expectations set by white, male, “civilization-builders.” The legality of sterilization laws were upheld by the famous 1927 Supreme Court Case *Buck v. Bell* in which Justice Oliver Wendell Holmes, Jr. wrote “Three generations of imbeciles are enough,” attesting to the belief that feeblemindedness—discursively linked to other forms of deficits including pauperism and sexual promiscuity—is inherited and a drain on society. Holmes argued that people with disabilities “sap the strength of the State;” therefore, it made sense to prevent further degeneracy, further costs.

Most nonconsensual sterilization laws were removed after World War II; however, O’Reilley adds that “today, 10 states still have eugenics sterilization laws on the books, although they are not used.” Although it is true that nonconsensual sterilization laws are not frequently used, it is not true that they are never used. For example, in 1994 Cindy Wasiek was sterilized using laws that were still on the books in Pennsylvania (Block 247). What is more common today is the use of so-called “substitute consent” laws. Such laws allow legal guardians to consent to sterilization if the disabled person is determined unable to consent. For example, in the recent “Pillow Angel” case, the doctors and parents of a six-year-old girl with severe brain damage created the “Ashley Treatment” in which Ashley’s uterus and breast buds were removed (to reduce the risk of rape and pregnancy, as well as to improve “comfort”) and she was subjected to high-dose estrogen treatments to close her growth plates and stunt her growth. Although the case sparked much controversy, it is testament to the continued presence of nonconsensual sterilization of people with disabilities.
Nonconsensual sterilization and substitute consent laws seek to differentiate the fit from the non-fit and to minimize the reproduction of “degeneracy” in all its many forms by controlling the disabled. In addition, desire for the disabled has also historically been (and continues to be) policed. As Stubblefield notes, anyone desiring someone considered “feebleminded” (whether by virtue of race, sexuality, class-status or other form of “degeneracy”) must also be “feebleminded.” People with such perverse desires do not “get” that reproduction must contribute to civilization building; “thus, failing to understand the importance of white racial purity was itself evidence of moronity in white women” (177). The eugenics discourse punished desire for people with disabilities and other degenerates by labeling people who love people with disabilities as unfit and in need of social control and sterilization. Today, however, policing continues through shunning and more subtle forms of discrimination. People who enter intimate relationships with the disabled are often scrutinized and viewed suspiciously. Writing in the British context in the late-70s, Wendy Greengross notes: “The principal problem for a marriage between an able-bodied and someone handicapped is one of motivation. It begs the cruel and unavoidable question: ‘What normal person would saddle him/herself with someone who will probably need a lifetime of care?’ Many ‘normal’ people when they enter a marriage of this nature are not marrying an equal but someone they want to treat like a child” (29). Indeed the steady flow of newspaper articles about the frequency of divorce when one partner becomes disabled\textsuperscript{xiii}, and the difficulty people with disabilities have finding partners (especially nondisabled partners)\textsuperscript{xiv}, helps maintain the norm. The
message is loud and clear: desire for a person with a disability is perverse and thus should be viewed suspiciously.

Both the freak show and eugenics became unpopular and began to decline during the 1940s as “freaks” transformed into people with pathologies, disabilities, and diseases in need of medical intervention, and as the atrocities of Nazi ideology in World War II were revealed. Laws that forced sterilization yielded to laws that emphasized “consent,” de-linking eugenics with modern medicine. As medical technology progressed, the possibility of solving the problem of the freak became more and more possible, and correspondingly, the problem was removed from the public spectacle, no longer the subject of debate. Doctors, scientists, and rehabilitation experts became the new “showmen,” the new keepers of the abnormal, and they promised “cure” and consensual management. This does not mean, however, that concerns about pollution and perversity have waned.

Today efforts to eliminate impairment through genetic counseling are routine. According to the American College of Obstetricians and Gynecologists “all women have certain routine lab tests,” including urine tests, cervical tests, and blood tests to screen for birth defects and maternal or fetal diseases and infections. If prenatal screening tests show a risk for defects such as Down syndrome or neural tube defects (e.g., spina bifida), diagnostic tests like Amniocentesis, Chorionic Villus Sampling, and Ultrasound are performed. Once birth defects are confirmed, women may choose to abort the fetus. According to a recent New York Times article, “about 90 percent of pregnant women who are given a Down syndrome diagnosis have chosen to have an abortion” (Harmon). Prior
to 2007 only pregnant women 35 and older, or those with suspicious prenatal screening tests, were tested for Down syndrome; however, “under a new recommendation from the American College of Obstetricians and Gynecologists, doctors have begun to offer a new, safer screening procedure to all pregnant women, regardless of age” (Harmon).

Advances in reproductive technology have led to a new procedure called preimplantation genetic diagnosis, or PDG, which diagnoses an embryo prior to implantation.

Feminist disability rights activists argue that women should have the right to abort, but complicate abortion rights discussions by asking us to reflect on what factors influence the decision. Because we live in a society that consistently devalues the disabled, and, importantly, does not offer adequate financial or social support for parents raising disabled children, disabled fetuses are likely to be aborted. Bringing a disabled child into the world is simply not a viable “choice” for many women. Thus, they argue that these new screening procedures are part of a new eugenics movement because they encourage surveillance of disability without offering solutions for successfully bringing disabled babies into the world. Their concerns are not unfounded. As “esteemed embryologist Bob Edwards said in 1999, ‘Soon it will be a sin for parents to have a child that carries the heavy burden of genetic disease. We are entering a world where we have to consider the quality of our children’” (Imparato and Sommers). Such rhetoric is eerily close to the rationalizations used to support sterilization in the early part of the 20th century—society should not be burdened with those considered degenerate. What is of particular concern is the ways in which prenatal testing has become a norm. Parens and Asch note, “As the ease of testing increases, so does the perception within both the
medical and broader communities that prenatal testing is a logical extension of good prenatal care: the idea is that prenatal testing helps prospective parents have healthy babies” (S1). Indeed, parents who choose to have a child with impairment have recently come under fire. In 2006, Dr. Sanghavi reported that some people with disabilities used the new PDG technology to select for disability. A survey of 190 PDG clinics revealed that 3% of clients were using the service to intentionally select an embryo with an impairment such as deafness or dwarfism (Sanghavi). The New York Times essay titled “Wanting Babies Like Themselves, Some Parents choose Genetic Defects” generated 183 responses, most of which were outraged. Interestingly, most disgruntled posters argued that such parents were “selfish;” however, few noted that it is equally “selfish” for fetuses with impairments like Down syndrome to be aborted. The difference seemed to hinge on the “cost to society.” For example, one commentator says,

Although a physician’s primary responsibility is to his or her patient, a physician also has a public duty to society. If the patient’s request would possibly be of some real harm to either the baby or to society, it simply should not be honored. Physicians should not be assisting prospective parents in knowingly choosing to bring to term defective children, as such a procedure is very harmful to the society which has licensed them to practice, as well as causing suffering to the children themselves.

Another says, “Producing children specifically for their disabilities is producing children who will make excessive demands on society and it is therefore not something medicine should support.” Such warnings about the financial cost of disability mirror the eugenics arguments less than a century ago; however, many of the posters argue that parents who select for disability are practicing a form of “reverse eugenics.” Again, the routine practice of selecting for “normal” or “healthy” babies, and aborting fetuses with genetic
defects, is not labeled eugenic. This discourse supports disability rights advocates fear of genetic testing—popular opinion supports methods of “weed out” disability, institutionalizing eugenics discourse under the guise of “health.”

**Conclusion**

Popular culture is rich with disability discourse, and, as this chapter has shown, much of the discourse supports the notion that disabled people are unsuitable intimate partners. They are either asexual, or, sometimes hypersexual and in need of state/institutional control. Most of all, they require a level of care that burdens the nondisabled partner, draining interpersonal relationships and state support. Significantly, these representations are gendered so that it is more common to see disabled women in dire situations. Women are typically the care-takers in heterosexual relationships. If they are disabled, they are rendered socially worthless as they are unable (according to popular culture logic) to care for others. However, it is already acceptable for men to receive care from wives and girlfriends; thus, the care disabled men require is not necessarily problematic. For the most part, however, disabled men and women are not favorable represented in popular culture. Disability continues to carry connotations of pollution and perversity, making it very difficult to intervene with “positive” sexual representations of disabled/nondisabled intimate relationships.

I argue that the images and beliefs outlined in this chapter influence the lives of people involved in disabled/nondisabled intimate relationships. In the following chapter I show how such discourse frames contemporary scientific research on disabled/nondisabled intimate relationships.
This policy can put people with disabilities at the financial mercy of their spouses because they no longer have their own income. Research on disabled women and domestic violence suggests that such financial concerns may lead some women to stay in abusive relationships (Olkin). In another example of this film’s racist undertones, Billie is played by an African American woman, setting up the final match between the “good” lily-white Fitzgerald and the “bad” black Billie. Thomas Youk had amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease. He lived in Oakland County Michigan and was 52 when Jack Kevorkian delivered a lethal dose of poison to end Youk’s life. Elphaba feels responsible for Nessarose because it is suggested that the potion their mother consumes to prevent her second child from being “green-skinned” caused Nessarose’s physical appearance (and her mother’s death during childbirth). Notice that this references “Thalidomide Babies”—babies born with physical deformities caused by Thalidomide, a morning sickness drug prescribed to pregnant women in the 1960s. Although the credits roll at the end of today’s films, they came at the beginning of films in the classical period. Two shots are a film technique in which the two people talking are filmed in the frame together. The other way of filming dialogue is called shot-reverse-shot in which only one person at a time is filmed and the sequence is edited together for continuity. Murderball had a mainstream theatrical release; therefore, I am counting the film as a “mainstream representation” even though it is an independent film. This gaze is reminiscent of Rosemarie Garland-Thomson’s category of the “wondrous” image/gaze, which places the disabled subject on high and elicits awe from viewers because of the supposedly amazing achievement represented (McRuer 171). Zupan is just dressing himself, but the long, silent takes of the camera emphasizes amazement that he can do even this. Five minutes fifty one seconds to be exact. It is fascinating that approximately 14% of the film is devoted to the men’s hegemonically masculine sexuality, including the burning question of “does it work?” As Somerville notes, the concept of a homosexual or a heterosexual as distinct kinds of people is a relatively “new” invention. In the late 19th century sexologists created these identities. Before this time, same-sex behavior was not connected to identity, per se. People with physical impairments were billed as “freaks” and adopted this terminology, thus, in this section I will use the word “freaks” to describe the people that made their living in freak shows, dime stores, museums, and carnivals exhibiting their extraordinary bodies. For example, CDV’s of Charles Stratton, known as “General Tom Thumb” were composed to emphasize Stratton’s short stature. The picture is taken from a long distance so that Stratton only appears in the lower half of the photo, leaving the top portion empty. For example, “Divorce Rate is Higher Among Disabled, Experts Say” (Kilborn); “Disability and Divorce (Vance); “In Sickness and In Health: Chronic Illness Interjects Complications into Marriage” (Eustice); and “Disabled Spouses Are Increasingly Forced to Go It Alone” (Kilborn). See, for example, “Something in the Way He Moves” by Mara Altman, 2007.
CHAPTER 2: BURDENED SPOUSES AND DYSFUNCTIONAL PATIENTS: THE VIEW FROM THE APPLIED FIELDS

Introduction

Popular attitudes about the meaning and nature of marriage and partnerships, care, independence and dependence all contribute to a long-standing cultural suspicion of relationships between the able-bodied and disabled. Professionals working in rehabilitation, nursing, medicine, social work, and psychology—what I am calling the "applied fields"—are not exempt from these attitudes. Professionals in the applied fields may hold discriminatory beliefs about people with disabilities and their partners, including the faulty assumption that there are only negative aspects to caregiving (Gordon and Perrone 29). For example, professionals may assume that the disabled partner is wholly dependent, unable to "give care" to the nondisabled partner and unable to meaningfully participate in social life. Likewise, they may assume that the care given by the nondisabled spouse is a burdensome activity that desexualizes the relationship and causes physical and mental harm to the nondisabled partner. These attitudes are characteristic of the medical model of disability aimed at curing and eliminating disability. Activists in the disability rights movement (which frames impairment as a benign social difference) have criticized the medical model approach, arguing that
professionals in the applied fields need to incorporate social and political discrimination, prejudice, and isolation into their studies of disability. In this chapter I examine whether or not the applied fields have heeded the calls for a paradigm shift by analyzing research published in peer-reviewed journals between 2003 and 2006. Although there are a few examples of ideological progress, most of the literature continues to support dominant understandings of care and sexuality between disabled/nondisabled partners. The analysis that follows details how caregiving and sexuality in disabled/nondisabled intimate relations are constructed and explores the varied ramifications of these views.

Understanding how health and rehabilitation professionals view people with disabilities and their partners is important because it is likely that couples will have repeated contact with the applied fields. Visits to doctors and nurses may be necessary to manage chronic illness and/or to care for acute conditions that emerge as a result of physical impairment (e.g., bed sores). Occupational therapists may be needed from time to time to help the disabled partner to improve or learn new skills for daily living (e.g., techniques for transferring from wheelchair to toilet), or, to introduce the disabled person to adaptive technologies that can be used in work environments (e.g., voice recognition software). Physical therapists help people with disabilities rehabilitate from acute conditions, but also may be needed periodically to improve physical function and flexibility to prevent acute conditions. Personal care attendants and home health nurses may visit the couple in their home to provide personal (“unskilled”) and medical (“skilled”) care. Social workers and home health nurses can provide training partners of people with disabilities. This training may involve how to dress and bathe the disabled
partner, or, it may involve highly skilled training such as maintenance of respirators and permanent bladder catheters. Finally, periodic assessment visits to doctors and physical therapists may be required by the government and private disability insurance companies. These visits are designed to ensure that the beneficiary is still “disabled enough.” That is, they are unable to work (or work enough) and thus still in need of financial assistance. These interactions create a matrix of health professionals involved in the lives of people with disabilities and their partners. At each iteration, professionals subtly or explicitly relay attitudes and beliefs about disability to the couple.

Disability rights advocates argue that the attitudes of health professionals contribute to feelings of worthlessness and self-doubt as ablest beliefs are internalized (Galvin 399). Rose Galvin reports: “[w]hether being patronized or pitied, singled out for unsolicited attention or treated as invisible, being stared at or reviled, participants reported that the negative attitudes of others greatly contributed to the development of negative self-perceptions” (397). Although low self-esteem often diminishes over time (especially as the disabled person places the “problem” of disability with society), the attitudes of other’s continue to influence and shape conceptions of self (Galvin 399).

Candy Mung-nga Li and Matthew Kwai-sang Yau report that health professionals’ attitudes are especially negative when it comes to disability and sexuality. According to Li and Yau, “when health professionals discuss sexual issues with their patients, they often do so in an overly pessimistic way. They may focus on likely difficulties without giving possible solutions, addressing fears, or reassuring patients that they are still sexual beings and can enjoy a meaningful sex life” (2). Stereotypical
understandings of disabled sexuality shape the ways in which health professionals approach sexuality with clients. Li and Yau highlight research on stereotypical attitudes in the nursing profession. They state:

Morris (32) points out that the common reactions of most nursing staff to sexual behaviors or questions from people with disabilities may include disbelief (“how could they be sexually active?”); revulsion or disgust (“anything but “normal” sexual activity is a perversion”); or avoidance (“if we do not discuss it, it will not happen”; “it is not my job”). Morris (33) further highlights that nurses commonly perceive people with physical disabilities as asexual, expressing embarrassment or disgust at the thought of their sexuality, as well as being unsure of how to deal with the specific issues of the patient’s sexuality. (4-5)

Doctors, social workers, and occupational and physical rehabilitation specialists hold similar attitudes (c.f. Parritt and O’Callaghan; Simpson et al.; Tepper “Providing Comprehensive Sexual Health Care”). These attitudes are also gendered so that the sexual lives are women with disabilities are more likely to be ignored in research and clinical practice (c.f Singh and Sharma). Based on sexist ideas about female sexuality, researchers assume that women are passive in the sexual encounter and have lower sexual drives than men (Li and Yau 3-4). Thus, a spinal cord injury does not disrupt a woman’s sexual functioning as it does a man’s because “all she has to do is lie on her back and open her legs” (Li and Yau 4). Because of these attitudes, it is more likely that disabled men, not disabled women, will receive some type of sex education in rehab (c.f. Li and Yau; Singh and Sharma).

In addition, health professionals’ attitudes and beliefs impinge on the lives of people with disabilities and their partners outside the immediate interaction. The research conducted in the applied fields is also disseminated in the larger culture; reformulated into thirty-second sound bites for the evening news; used as inspiration for
film and television scripts; taught in college courses. In other words, the affect of such research is far reaching, especially in societies that highly value and trust doctors and other health professionals.

In order to better understand how disabled/nondisabled relationships are represented by the applied fields, I conducted a content analysis of peer-reviewed journal articles published between 2003 and 2006 and indexed in the Academic Search Premier database. I experimented with various keywords that would yield articles about care and/or sexuality in disabled/nondisabled intimate relationships, including “sex,” “disability,” “care,” “carer,” “partner” and “spouse.” Ultimately conducting two separate searches proved the most productive. For the first search I used the keywords “caregiving” and “spouse” and retrieved 98 potential articles. In the second search I used the keywords “sexuality” and “disability” which yielded 179 potential articles. Then, I read each abstract from the search results to determine the article’s relevance and inclusion in the analysis. I excluded articles that focused on end-of-life or bereavement issues, intellectual or emotional disabilities, or relations other than intimate relationships. After this exclusion process, 23 articles from the “sexuality and disability” search (see Table 1) and 41 articles from the “caregiving and spouse” search (see Table 2) remained. One article appeared in both searches. Finally, I analyzed the 63 articles using a form (see figure 2) created for this study to ensure the same information was collected on each article. On each form, I recorded how the article framed caregiving, sexuality/intimacy in the relationship, and whether the authors were focused on the well-being of both or
only one of the partners. I entered these results for each article into NVivo so that various qualitative analyses could be conducted as need.

<table>
<thead>
<tr>
<th>Article Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q. Was this article found from the “Sexuality and Disability” search, the “Caregiving and Spouse” search, or both?</td>
</tr>
<tr>
<td>Q. Demographics of study participants (if relevant).</td>
</tr>
<tr>
<td>Q. Is the article primarily concerned with the disabled partner, the nondisabled partner, or both? Is there a rationale for this choice? Does the choice support the research question?</td>
</tr>
<tr>
<td>Q. How does the article represent the relationship?</td>
</tr>
<tr>
<td>Q. Does the article address intimacy or sex? If so, is it related to the discussion of care?</td>
</tr>
<tr>
<td>Q. Do the methods support the dominant image of care, or, do they attempt at uncovering other aspects of the care relationship?</td>
</tr>
<tr>
<td>Q. Describe any intertextuality.</td>
</tr>
</tbody>
</table>

Figure 2: Information Gathered for Content Analysis

In the following sections, I review the findings of this investigation. Although there are notable exceptions, the literature continues to support dominant understandings of care and sexuality between disabled/nondisabled partners because the literature is divided (i.e. when discussing care, sexuality is assumed to be absent and vise versa) and stereotypical assumptions about such relationships are embedded in research design and analysis.

A Divided Literature

It is interesting that there was only one article in common between these two searches (Svetlik et al.). Clearly sexuality and care are not conceptualized together in the literature. Instead, they are viewed as antagonistic needs. The assumption that a high need for assistance in tasks of daily living results in low levels of sexual and relationship
satisfaction appears to influence research design. Indeed, it is rare for studies concerned with high levels of care to even ask participants about sexuality and romantic relationships. Such a perspective results in a bifurcated literature, failing to conceptualize the disabled/nondisabled couple as both sexual and caring. When sexuality is the primary concern of the article, the focus is on the disabled partner. When care is the primary concern of the article, the focus is on the nondisabled partner. The needs and concerns of the nondisabled partner are considered opposed to those of the disabled partner. In fact, only 17 (27%) studies included perspectives from both partners, and three of these were literature reviews (Campbell; Gordon and Perrone; Wiegerink et al.). This dichotomization supports the view that the disabled partner is only the care-receiver, the nondisabled partner only the care-giver, and that this dependency dynamic creates low levels of sexual satisfaction.

Thirty-three articles (82.5%) from the “caregiving and spouse” search failed to mention sex or sexual intimacy. This is a notable omission because it seems logical to assume that high “marital satisfaction,” including sexual satisfaction and intimacy, would buffer “caregiver burden” in disabled/nondisabled intimate relationships. In other words, it makes sense that marital discord would be related to increased care-related stress. However, of the 7 (17.5%) articles from the “caregiving and spouse” search that do address sex or intimacy, only 2 (Choi and Marks; Gordon and Perrone) explore how sexual or intimate satisfaction may influence care-related stress. Significantly, both of these articles support the notion that marital satisfaction buffers caregiver burden.

Heejeong Choi and Nadine Marks note:
Perhaps one of the most important findings of this study is that, in comparison to noncaregiver peers, no differences in change in mental health outcomes were observed among biological parent or spouse caregivers who reported lower ratings of marital disagreement (i.e., better marital quality). This finding warrants further consideration because biological parent care and spouse care are typically two of the most demanding caregiving types. Low conflict marriage appears to protect new biological parent and spouse caregivers to the point of not only reducing but actually negating the potentially detrimental effects of caregiving on positive and negative affect (1719).

Regardless, studies that examine the relationship between martial satisfaction and caregiver burden continue to be rare. Of the remaining 5 articles that do address sex or intimacy, 2 (Fultz et al.; Ruiz et al.) discuss sex or intimacy (especially how sexuality declines with increased care needs) in the literature review sections only, failing to add relationship satisfaction measures to their studies; 2 (Joseph and Bhatti; Giarelli, McCorkle, and Monturo) do not relate sexuality to care-related stress; and 1 (Boeije and Doorne-Huiskes) conceptualizes the reports of low intimacy or love found in the study as the result of increased care-related duties. Clearly, the positive force sex or intimacy may play in the lives of caregiving disabled/nondisabled couples is under-theorized and under-researched in the literature.

Although there is a growing body of research on the sexuality of people with disabilities, much of it remains focused on sexual self-esteem, physical and psychological barriers to sex, and the problems disabled people face finding sexual partners. There continues to be little about disabled people in sexual relationships which explains why the “sexuality and disability” search yielded more results (179), but only 22 remained after review (most were about the disabled person outside of relationships). It is also interesting to note that 9 (41%) of the 22 articles in the search were from the journal
Sexuality and Disability. Published by Springer, this international quarterly journal aims to provide “original scholarly articles addressing the psychological and medical aspects of sexuality in relation to rehabilitation.” To date, Sexuality and Disability is the only journal focused on this particular intersection. Thus, the sexuality of people with disabilities is relatively isolated in the applied fields. And, like the “caregiving and spouse” search, few researchers examining “sexuality and disability” have considered the ways in which disabled/nondisabled couples experience both care and intimacy. Eight (36%) of the articles from the “sexuality and disability” search do not address care or caregiving. Of the 14 (64%) that do have some kind of discussion of care, only 1 (Melby) suggests that sex and care are related and that, like care, “sexual expression is an interdependent activity” (Melby 3). The remaining 13 articles discuss how care can be used to keep people with disabilities in abusive relationships (Hassouneh-Phillips and McNeff); the role of personal care attendants (PCA’s) in the lives of people with disabilities (Galvin; Mona); the way in which parents providing care can impede people with disabilities finding intimate partners (Wiegerink et al.); how women with disabilities suffer because they are viewed as unable to care for children (Li and Yau; Zitzelsberger); and how partner care can lead to sex-related problems (McCabe and Taleporos; Murray and Harrison; Singh and Sharma; Schmidt et al.; Taleporos and McCabe “Relationships”).

Thus, when care is addressed in the “sexuality and disability” literature, it is predominately framed as a problem for people with disabilities and their partners. Because care is so frequently associated with burden and relationship problems in the
literature, it is not uncommon for a study to attribute sexual problems to care burden even when no specific measure of care burden is used (e.g., Taleporos and McCabe “Relationships”). When sexual or relationship problems are found, researchers suggest that the source of the problem is the care-related needs of the disabled partner and other social and psychological factors are ignored. The next section explores the ways in which such underlying assumptions about the meaning and nature of care and sex influence research in the applied fields.

**Research Design and Analysis**

Negative assumptions about caregiving and receiving, as well as the sexuality of people with disabilities, are frequently built into the research. In this section I focus on four problem areas in the design and analysis of research in the applied fields: 1) a failure to conceptualize and account for the social dimensions of care and disability, 2) biased language, 3) instrumentation, and 4) a limited conceptualization of reciprocity in care relationships.

In most of the articles from the “caregiving and spouse” search, caregiving is conceptualized only as a negative activity which desexualizes the relationship and causes psychological and physical damage to the caregiver. Many of the studies hypothesize that care burden or care strain causes a variety of problems for the nondisabled partner (conceived as the caregiver), including increased psychological distress such as depression and anxiety (e.g., Choi and Marks; Druley et al.; Hirst), decreased preventative health care behaviors (e.g., Kim et al. “Quality”), and poorer physical health (e.g., Burton et al.; Lee et al.; Luttik et al.). Representative statements include:
Carers providing long hours of care over extended spells present raised levels of distress, women more so than men. Adverse effects on the psychological well-being of heavily involved carers are most pronounced around the start of their care episodes and when caregiving ends. Ongoing care increases their susceptibility to recurring distress, and adverse health effects are evident beyond the end of their caregiving episodes. (Hirst 704)

the care-related increase in depressive symptoms may result not from task-related burden, but from grief surrounding a loved one's illness, or from loss of relational reciprocity, for example. (Cannuscio et al. 1254).

It is evident that the older people's self-care ability is a key factor that influences caregiver burden; the more dependent the elder is and the more care they require, the great the burden felt by the caregiver” (Lin and Lu 725).

The increased dependence, especially on the partner--often with changing roles, can be a big strain on relationships (Cannuscio et al. 1206).

Most of the studies that framed care as a burden did indeed find that caregiving was a health risk to caregivers. Their findings are suspect, however, because of inadequate or flawed measurements and research design that sets up care-receiver and care-giver as antagonists. In addition, mediating factors, such as marital satisfaction, reciprocity, and social networks, are frequently omitted from care burden studies. For example, Hirst sets out to examine the relationship between psychological distress and caregiving using longitudinal, population based data. As the excerpt above highlights, Hirst finds support for the hypothesis that caregiving increases psychological distress; however, the British Panel Household Survey (BPHS) that Hirst uses as his study data is limited to the locus of care (e.g., co-resident or care for someone outside of the home), level of involvement (i.e., hours per week) and relationship of the care recipient (e.g., spouse, child, parent). Hirst excludes measures on perceived uplifts in caregiving, reciprocity, and marital satisfaction. Thus, the study fails to consider care as a relationship. Similarly, Cannuscio
et al. find that high levels of care equals high levels of depressive symptoms (regardless of employment status and only slightly moderated by social ties) for the caregiver; however, the researchers fails to consider the disabled partner's role in the relationship or the quality of the spousal relationship, both of which are factors that could affect the nondisabled partner’s mental health.

The language used in care burden studies helps illuminate why the research consistently fails to consider reciprocity, to look at care as a relationship. Disabled partners are often referred to as “patients” and the nondisabled partner as “spouse” (e.g., Giarelli, McCorkle, and Monturo; Laursen et al.; Luttik et al.). “Patient” brings to mind Talcott Parson’s sociological description of the “sick role” in which the ill or disabled person is exempted from normal social behaviors because he or she is supposed to focus on getting well. Normal behaviors that are expected of the non-sick, such as caring for others, are actively discouraged by those placed in the sick role. The only duty the person in the sick role has is succumbing to the technical expertise of doctors and other helpers. The “sick role” is the model of expected behavior in society’s characterized by the medical model of disability, like the U.S., in which the problem of the illness or disability can be overcome with science. Impairment is an individual’s problem that he or she must seek help in overcoming, assuming the sick role along the way. Clearly, the sick role is a completely passive role. “Patients,” the epitome of the sick role, do nothing but receive help, guidance, and care from professionals and family. Researchers who use the word “patients” to describe the disabled partners in their studies reveal their assumptions that the disabled partners cannot give care, cannot reciprocate in any way.
From this perspective the disabled and nondisabled partner are antagonists: the disabled partner can only take, the nondisabled partner can only give, and eventually, this dynamic leads to burden, stress, and a desexualized intimate relationship.

The language of “patient” is symptomatic of the way in which the subjectivity of disabled people is undermined by professionals in the applied fields. People with disabilities are not quite whole persons. Data collection procedures and reporting practices also demonstrate this bias. For example, some of the researchers interviewed the disabled partner, or included data on the disabled partner, but only reported consequences for the nondisabled partner. Thus, the disabled partner’s perspective was used only to illuminate the nondisabled partner’s situation. It was also quite common for researchers to gather data about the functional level of the disabled partner from the nondisabled partner (e.g., Bookwala et al.). Not only does this tactic literally silence the disabled partner, but it muddles the data as the nondisabled partner’s perception of function may differ radically from what the disabled partner knows he or she is capable of doing. In other studies, the researchers recruited couples but report only “caregiver” data (e.g., Boeije and Doorne-Huiskes; Kedde and van Berlo; Svetlik et al.). For example, in Boeije and Doorne-Huiskes’s study, both partners are interviewed, but the disabled partner’s data is just used as a data check. Svetlik et al. use data collected from the Family Relationships in Late Life (FRILL) study to examine the perceptions of relationship loss (due to caregiving) and declines in satisfactions with physical intimacy. FRILL collects data from both partners; however, Svetlik et al. only use data from the “caregiver” to conclude that increased care predicted perceptions of decreased intimacy.
and relationship loss. Svetlik et al. do not consider that the disabled partners attitudes and behaviors may bear on the “caregiver’s” perceptions of intimacy because the disabled partner is assumed to be passive. In one study the omission of the disabled partner is so egregious that the study participants complained. Hendrix and Ray tested an intervention that provided personal care training to the nondisabled partners of people being discharged from the hospital, and participants commented that the researchers should have included both partners to recognize that this is a "partnership of care." The norm, however, is to treat disabled and nondisabled partners as opponents: one needing care, one giving care.

Assumptions about disability popularized in the sick role influence research design and often set up the disabled and nondisabled partners as opponents. Thus, care measures, such as the “Caregiver Strain Index,” often contain only negatively framed items (see figure 2). Rarely do studies ask the nondisabled partner to describe positive aspects of caregiving. For example, in their meta-analysis of the caregiving literature, Pinquart and Sörensen found only 28 articles—out of 228--that mention perceived uplifts of caregiving (12%). Perceived uplifts included feeling useful, experiencing pride in one’s own abilities to handle crisis, and appreciating closeness with the care-receiver (ibid.). Physical and/or sexual intimacy, however, was not a perceived uplift, nor was sex a factor in the meta-analysis at all. In addition, the care the disabled partner provides to the nondisabled partner, or other family, members is never factored into the analyses of caregiver strain. Such absences reveal the assumption that the disabled partner cannot give care or reciprocate in any way. Thus, measures of reciprocity-- the ways in which
the disabled partner may give back or care for the nondisabled partner--are often not
included in care research.

1) Sleep is disturbed (e.g., because _____ is in and out of bed or wanders around at night)
2) It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)
3) It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)
4) It is confining (e.g., helping restricts free time or cannot go visiting)
5) There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)
6) There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)
7) There have been other demands on my time (e.g., from other family members)
8) There have been emotional adjustments (e.g., because of severe arguments)
9) Some behavior is upsetting (e.g., because of incontinence; _____ has trouble remembering things; or accuses people of taking things)
10) It is upsetting to find _____ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)
11) There have been work adjustments (e.g., because of having to take time off)
12) It is a financial strain
13) Feeling completely overwhelmed (e.g., because of worry about _____; concerns about how you will manage)

TOTAL SCORE (Count yes responses. Any positive answer may indicate a need for intervention in that
area. A score of 7 or higher indicates a high level of stress.)

Figure 3: The Caregiver Strain Index (Robinson)

Even when the study does include reciprocity or “caregiver gains,” the notion of
reciprocity operationalized is very limited and can influence study findings. The most
common understanding of what the nondisabled partner gets out of providing care is a
sense of pride or increased self-esteem (e.g., Ellenbogen et al.; Hash; Kang; Pinquart and
Sörensen “Associations”; Soskolne et al.). These studies find that caregivers often feel
good about being about to provide care to their loved ones. Sometimes this sense of
pride is also related to a feeling of role stability (cf. Hash) because the caregivers knows
what is needed and what to do, or, the caregiver may feel that he or she appreciates life
more (cf. Kang). Although these are important “gains,” they are not strong examples of
reciprocity because a sense of pride is not something the disabled partner is, necessarily, directly or actively giving to the nondisabled partner in exchange for physical care. One can feel a sense of pride and increased self-esteem by taking care of a plant or raising a puppy. Another form of reciprocity that is often employed in care studies is called “virtual” or “symbolic reciprocity” (e.g., Boeije and Doorne-Huiskes; Boeije, Duijnstee, and Grypdonck). The reciprocity is symbolic or virtual because the nondisabled partner explains that they give care because the disabled partner “would do the same for me,” or, “did the same for me in the past.” The actual ways the disabled partner gives care at the time of data collection is not addressed. Again this is a very limited notion of reciprocity that reflects the belief that there is nothing the disabled partner can currently and concretely give to the nondisabled partner.

To recap to this point, care is often only measured in terms of burden (or other negative items) and when “positives” such as caregiver gains and reciprocity are added into the study, they are often limited by stereotypes of people with disabilities as passive, inactive members of the relationship (if they are considered at all). Instrumentation problems are not limited to notions of care and reciprocity in the literature. Measures of sexual satisfaction and sexual esteem used with people with disabilities are also typically framed in negative terms. For example, the 10-item Physical Disability Sexual and Body Esteem Scale (Taleporos and McCabe “Development and Validation”) does not contain a single positively framed question about disability and sexuality (see Figure 4). Items include: “I envy people with ‘normal’ bodies,” “I feel that my disability is likely to prevent me from satisfying a sexual partner,” “My sexual expression is limited by my
disability” and “I would do a body swap with an able-bodied person if I could.” Clearly, the framing of the questionnaire assumes impairment can only have a negative repercussion on sexuality, and it may reinforce sexual stigma. In addition, the questions place the locus of the “problem” in the disability itself, not social and physical barriers the disabled person may face. Ablest attitudes about sex and disability or the lack of privacy experienced by people with disabilities are not part of the measurement. By focusing only on the subjective experiences of disability, the social dimension of disability, which may indeed cause much of the psychological distress found in the research, is obscured.

| 1) I feel that my disability interferes with my sexual enjoyment |
| 2) It is harder to find a sexual partner when you have a disability |
| 3) I would like to hide my disability as much as possible |
| 4) I feel sexually frustrated because of my disability |
| 5) I feel that my disability is likely to prevent me from satisfying a sexual partner |
| 6) My sexual expression is limited by my disability |
| 7) I feel that people are not sexually interested in me because of my disability |
| 8) I envy people with ‘normal’ bodies |
| 9) I believe that I experience rejection from potential sexual partners because of my disability |
| 10) I would do a body swap with an able-bodied person if I could |

Items are answered using a 5-item likert type scale that ranges from strongly agree to strongly disagree.

Figure 4: The Physical Disability Sexual and Body Esteem Scale (Taleporos and McCabe “Development and Validation”)

For the last several decades, the social model of disability has been the dominant way to examine disability from within the interdisciplinary field of disability studies. The social model draws attention to the ways in which the built environment and
discriminatory attitudes disable someone with impairment. In other words, the social model places the problem of disability outside the individual. The solution is accommodation and education. The social model is also a critique of the medical model of disability, which continues to dominate the applied fields, that places the problem of disability in the individual. Most of the 63 articles analyzed in this chapter employ a medical model of disability and therefore fail to interrogate social aspects that may exacerbate (or even create) feelings of caregiver burden and declines in physical intimacy. For example, in Raschick and Ingersoll-Dayton, an otherwise innovative study on the costs and rewards of caregiving\textsuperscript{vii}, the researchers revert to care styles to explain why men experience less care burden than women. They note: "Men have more of a managerial approach that potentially provides them with 'greater perceived control, the sense of being in charge, feelings of self-efficiency, as well as the ability to choose to act or not act'; women are bound by strong norms of nurturing responsibilities stemming from 'an internalized model of caregiving based on a parent-infant model'" (321). Social and economic reasons that may account for women increased care burden are not addressed. Similarly, Luttick et al. ignore social and economic factors that can create or exacerbate care stress, which they find is linked to decreased quality of life, increased illness and stress. There are many external factors that interact with the care relationship, including the affordability and availability of in-home care support or respite care, the cost of managing the impairment or illness, disability stigma, and the beliefs about care for partners that circulate in culture. As noted at the beginning of this chapter, the experience of disability requires interaction with doctors, nurses and other health
professionals. The social and economic costs of these encounters can qualitatively alter the experience of care for a couple. As Mona argues:

Given the fact that many people with disabilities often need to structure their life plans around public and governmental supports (e.g., Social Security benefits, Medicare), it becomes impossible to conceptualize their sexual life experiences outside of societal influences and socio-cultural norms (e.g., societal belief systems about disability and sexuality) within which they are immersed (212).

Research on care and intimacy between disabled and nondisabled people must account for this reality and build the social dimensions of disability into research design and analysis. Such changes will allow for the possibility of alternative findings, including examples of disabled/nondisabled couples that care without experiencing debilitating levels of burden or strain, couples that are able to remain intimate in spite of (or because of) care.

**Glimmers of Hope**

Although the vast majority of the research emerging from the applied fields fails to conceptualize the care relationship as one in which the disabled and nondisabled partners can participate together and create new meanings about intimacy, sex, disability and care in a social context, I found some studies in my literature review that offered glimmers of hope. For example, several articles include instruments that measure social aspects of disability (e.g., Fultz et al.; Sakellariou; Singh and Sharma), or, discuss social barriers in their implications and future research section (e.g., Hirst). Other articles focused on the relationship between the disabled and nondisabled partners because "disability does not just affect the individual but also his or her partner" (Li and Yau 22). Feld et al. conceptualizes care as a unit comprising both the disabled and nondisabled
individual as active participants, and discusses a history of reciprocity and current
reciprocity in the care relationship (for example, emotional care the physically disabled
partner may give the "care giver"). Similarly, Gordon and Perrone argue that perceptions
of equity are important to disabled/nondisabled couples, noting that:

Weinert and Long (1993) found that many participants in their caregiving study perceived their spouses to be the person they counted on the most for support even if the spouse was the ill partner. Consequently, although spouses may not be able to do the same chores or household tasks as they were prior to the illness, if they are perceived to be emotionally an equal partner, the relationship may be more satisfactory. (28)

Ingersoll-Dayton and Raschick suggest that helping behaviors—conceptualized as helping with chores, providing companionship, and giving money/gifts—can help mediate caregiving stress; while Ducharme et al. advocate that one way to improve services to older disabled/nondisabled couples is by reframing care for them—stressing benefits of care relationships, learning new things to do together, etc.

Some researchers acknowledged that intimacy may be reframed for both the couple and the researchers. For example, Gordon and Perrone acknowledge that intimacy is an important aspect of the relationship, and that previous research has shown care to impede sexual intimacy in disabled/nondisabled relationships. They suggest, however, that "intimacy may be defined broadly, to include intellectual, spiritual, and recreational intimacy as well as sexual intimacy. In addition, Speziale (1997) reported that it may be useful for couples to examine prior beliefs about intimacy and sexual behavior" (Gordon and Perrone 30). Alternative understandings of intimacy may facilitate greater understanding of disabled/nondisabled couples as well as provide new frameworks for couples to negotiate their relationship.
Conclusion

Overall, the applied fields approach disabled/nondisabled couples assuming that the physical care the nondisabled partner provides stresses the relationship. Thus, few of the articles that focus on care discuss sexuality or intimacy (and vise versa). Prejudiced beliefs about disability are evident in the language researchers use to describe the couple (e.g., “patient” and “spouse”), instruments that include only negatively framed items, and research design that conceptualizes the couple as antagonists. More researchers need to include social dimensions of disability, measurements of reciprocity (especially active reciprocity), and to conduct couple-level research that examines the care as a relationship. By improving research, practitioners working with people with disabilities and their partners will have access to more nuanced understandings of care and sexuality in relationships. This, in turn, can improve the treatment disabled/nondisabled couples receive in the applied fields.

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1 Now called “Academic Search Complete”
2 Searches that included both sexuality and care (or some version of care, such as caregiving, carer, etc.) yielded very few articles, therefore, I ultimately divided the searches into two so that I could mine the literature on sexual relationships of people with disabilities and partner/spousal care of people with disabilities. See “A Divided Literature” for more discussion.
3 Using the term “spouse” also highlights the heterosexual bias to the literature. Using “caregiving” and “partner” as the search terms produces only 42 results, most of which are not relevant to the intimate relationship. Those articles that are talking about intimate partners show on the “caregiving” and “spouse” search, which also produces more results in general; therefore, I ultimately used the “caregiving” and “spouse” search for this chapter. Thus, using partner instead of spouse did not reveal additional research about same-sex relationships.
4 Ruiz et al. does include a marital satisfaction measure; however, it is unclear if this measure includes items related to sex or intimacy because the author fails to publish items. I’m including it in articles that address sex or intimacy only in the literature review section of their papers because the discussion does not report any findings related to sex or intimacy; therefore, I am assuming that the measure leaves sex or intimacy out.
According to ISI Web of Knowledge Journal Citation Reports, *Sexuality and Disability* is not a highly ranked journal (0.133 was the journal’s impact factor for 2006). Indeed, the articles from *Sexuality and Disability* for this analysis had frequent grammar and spelling errors, and many articles had poor research design and analysis.

However, it is important to note that a few found “surprising” results—increased care was not always associated with negative health and well-being outcomes.

Raschick and Ingersoll-Dayton’s study is one of the few studies that looked at the disabled partners helping behaviors, constructing the disabled partner as an active participant in the care relationship. See “Glimmers of Hope” section below for more on these studies.
CHAPTER 3:
CARE AND INTIMACY IN DISABILITY POLITICS AND ACTIVISM

Introduction

The disability rights movement tries to provide an alternative to the medical model espoused in the applied fields (e.g., rehabilitation, nursing). Specifically, disability rights advocates seek empowerment for individuals with disabilities, liberation from medical control. At first glance, the disability rights movement would seem to be an obvious refuge for people in nondisabled/disabled relationships. Indeed, the disability rights discourse does provide positive representations of disabled people in intimate relationships (with both disabled and nondisabled partners). However, I argue that these positive representations continue to operate in the dominant discourse which privileges the notions of individual autonomy, independence, and self-sufficiency. Consequently, the realities of the disabled body, the need for care, and the relationality of care are often repressed in the disability rights movement. This chapter analyzes the disability rights discourse, especially the independent living (IL) movements in the United States (US) and United Kingdom (UK), to better understand how such repressions function and how disabled/nondisabled intimate relationships are marginalized in this discourse. I also offer suggestions on how to re-think “interdependency” in disability rights so that the
needs, concerns, and experiences of disabled/nondisabled couples can come forth. To
begin the analysis I will outline the contours of individual autonomy.

The Myth of Individual Autonomy

My argument throughout this chapter is that disability rights activism, especially
the IL movement, is in many ways ideologically aligned with political and economic
policies that promote individual autonomy, and that this alignment is, ultimately, harmful
to people with disabilities and harmful to the ethic of care that I argue is vital to
disabled/nondisabled intimate relationships (and relations in general). Thus, it is
important to clarify what individual autonomy is, how it became--to use Martha
Albertson Fineman’s words--a “foundational myth,” and how individual autonomy is
entwined with beliefs about care, dependence, and independence. Since autonomy is a
very slippery and poorly understood concept, this section provides a brief intellectual
history of the theory.

Put simply, autonomy is self-determination or self-government; however, the
word connotes a variety of other meanings depending on the context in which it is used.
As Catriona Mackenzie and Natalie Stoljar note, autonomy is a central concept to much
moral and political philosophy; however, “there is no consensus about what the concept
means or when it can be legitimately employed” (4-5). Thus, for example, “In bioethics,
autonomy is often equated with informed consent. In rational choice theory, autonomy is
equated with voluntary, rational choice. In other contexts, for example, within liberal
political theory, autonomy is considered to be an individual right” (ibid. 5). Depending
on the discipline, then, autonomy may lead to concerns over choice, rights or free-will.
Lorraine Code argues that in contemporary Western culture there has been a “gradual alignment of autonomy with individualism,” resulting in an abstraction she calls “autonomous man” (78). According to Code:

Autonomous man is—and should be—self-sufficient, independent and self-reliant, a self-realizing individual who directs his efforts towards maximizing his personal gains. His impendence is under constant threat from other (equally self-serving) individuals: hence he devises rules to protect himself from intrusion. Talk of rights, rational self-interest, expedience, and efficiency permeates his moral, social, and political discourse. (6).

As Code’s description of “autonomous man” illustrates, the particular version of autonomy used in the US (and the UK, albeit to a lesser degree) is a crude ideological understanding that has grown out of, but is not the same as, “individualism” in liberal political philosophy. The popular understanding of autonomy, now, connotes (and conflates) freedom, independence, self-sufficiency, and individualisms. However, autonomy does not, necessarily, equate to independence and self-sufficiency. Indeed, many moral and political philosophies understand autonomy is the capacity or state that occurs in relation with others. Nevertheless, autonomy is used in popular political and social discourse to signify separation and protection from others. To emphasize this particular version of autonomy, dominant in American ideology, I use the phrase “individual autonomy.”

Fineman argues that the myth of autonomy is “foundational” to American political ideology. According to Fineman, the Declaration of Independence, the Constitution of the United States and the Bill of Rights all put forth the ideal of self-government (autonomy) (18). However, this ideal has, over time, become narrowly understood as “linked to economic self-sufficiency and a sense of separation from others
in society” (xvi). Autonomy has become “the absence of economic dependence on outsiders. At the same time, autonomy is seen as the reward conferred by the government for economic self-sufficiency” (ibid. 9). As Fineman argues, this version of “individual autonomy” is particularly evident in the political and economic discourses of the last few decades as evidenced by a retreat from government sponsored social welfare programs and economic deregulation to encourage free trade, entrepreneurship and big business. Dependency and subsidy have become discursive weapons, dividing the gainfully employed from those in need of welfare—despite the fact that we all live subsidized, interdependent lives. Fineman states: “The language of the recent reforms is consistent with maintaining the myths of self-sufficiency and autonomy by requiring that families, in order to continue receiving aid, be engaged in activities that will lead to their self-sufficiency” (39). Privatization and personal responsibility become key terms in this rhetoric, and individuals become solely responsible for their own successes and failures.

As government sponsored programs, such as welfare, are rolled back (amidst talk of privatizing social security), there is a corresponding appeal to civil society (the voluntary sector) and the family to take up social provisions (Duggan 10). Lisa Duggan writes “This rhetoric promotes the privatization of the costs of social reproduction, along with the care of human dependency needs, through personal responsibility exercised in the family and civil society—thus shifting costs from state agencies to individuals and households” (14). Provisions that help people with disabilities and their families are removed so that individuals can “help themselves” gain independence, construed as freedom from state control. Such a discourse also implies that the need for assistance
with daily living and the inability to work (even with physical “access”) signify
individual failures. As Rose Galvin notes,

> When framed within a rationality which glorifies the ability to be self-reliant, the
need for help can only be seen as unpalatable and, when combined with the
principles of economic rationalism which are responsible for the shrinking of the
public sector and an increasing reliance on market principles, support for disabled
people is seen to be a matter for individuals and their families to sort out” (403).

Unfortunately, much of the disability rights movement reflects the values of “individual
autonomy,” especially in the promotion of independent living. In the next section I
provide a short history of the Independent Living movement, focusing on its ideological
influences.

**Independent Living**

As a subset of the larger disability rights movement, the independent living
movement focuses on the deinstitutionalization of people with disabilities—moving them
out of nursing homes and into homes of their own. IL proponents argue that
institutionalized living fosters isolation and a sense of powerlessness because all aspects
of one’s life, including when to eat, sleep, and even defecate, are controlled by the
institution. IL insists that people with disabilities should have the right to be part of the
communities they choose and to live on their own schedule.

Although there were similar activities occurring at the University of Illinois, the
“beginning” of the IL movement is typically attributed to Ed Roberts and other disabled
students at the University of Berkeley in California (Shapiro 53). Roberts, a quadriplegic
polio survivor, could spend only a few hours at a time outside of an iron lung. Roberts
did well at the community college he attended (and the state sponsored) and desired to
pursue his studies at the University of Berkeley because of their highly regarded Political Science program. His initial push to attend Berkeley was foiled by the State because it refused to pay for this more expensive tuition, claiming that it was “‘infeasible’ that he could ever work” (Shapiro 44). In addition, the school claimed it did not have a place to house Roberts and his 800-pound iron lung. However, Roberts and his family and friends fought back and he won entry in 1962. The University admitted Roberts, housing him and his iron lung in the campus medical facility.

Roberts’ entry into a four-year, respected University gained headlines and, soon, other students with severe disabilities followed him. By 1967 there were 12 students living in the medical facility. Such “access” was a huge breakthrough and the students enjoyed the highly politicized and intellectual environment of the campus; however, they grew tired of living in the medical facility because they were treated as patients instead of students, and they had to follow special rules (such as maintaining a high grade point average, carrying a full course load, and making “timely” progress) that the rest of the student body did not follow in order to maintain their special housing. In 1970, Roberts and other disabled students that were housed in the university’s hospital formed the Physically Disabled Students’ Program (PDSP), a self-help advocacy program aimed at assisting disabled students find accessible housing, transportation, and services that would help them attend college (e.g., attendant care services, wheelchair repair, etc.). The PDSP was a huge success, so much so that calls began to flood in from non-students who also wanted help navigating the system so that they could live in the community. Thus, the idea for the first Independent Living Center (ILC) was born. In 1972, the
Berkeley Center for Independent Living opened its doors. Today there are over 400 ILC’s across the U.S. funded by a mix of private, state, and federal monies (“Ed Roberts”).

In the United Kingdom, the Derbyshire Center for Integrated Living and the Hampshire Center for Independent Living were the first of their kind, both opening their doors in 1985. As Carol Thomas notes, ILC’s in U.K. began opening “in tandem with the implementation of the state’s deinstitutionalization policies in the 1980s” (100). In other words, “patients” were moved out of institutions and into a variety of “community care” settings. These changes, along with the influences of the U.S. IL movement, prompted the development of ILC’s in Britain. In the mid-1990s IL activists helped push though the Direct Payments Act which authorized cash payments directly to disabled people so that they could purchase services and employ personal assistants, providing for their own care needs.

ILC’s in both the U.S. and the U.K. act as information clearinghouses in their communities, connecting people with disabilities to services and resources. Although the exact services offered at an ILC vary, typical services may include wheelchair repair clinics, educational workshops, help finding a personal assistant, locating accessible housing, and assistance with navigating benefits such as social security disability income, medicare/Medicaid, and so on. In the UK, one of the main functions of the ILC has been to help people with disabilities manage the direct payment system. ILC’s are dedicated to people with disabilities helping each other, thus, it is important that people with disabilities lead the organizations. As such, ILC’s represent an alternative to medical
models of disability in which various experts instruct and monitor people with disabilities. ILC’s put power and control into the hands of people with disabilities.

Ideologically, the IL movement has also drawn inspiration from other, earlier social and political movements, including the Civil Rights Movement, women’s movement, and the consumerist and self-help movements (DeJong). The Civil Rights and women’s movements advocated for equality under the law and equal access to opportunities. The Americans with Disabilities Act (1990) is the legislation designed to guarantee people with disabilities equal access and treatment, similar to the Civil Rights Act of 1964\(^1\). The influence of the self-help movement can be seen in the IL movement’s demand that people with disabilities be in power in ILCs and other disability organizations. The consumerist movement’s impact can be witnessed in the ways the IL movement advocates that people with disabilities be empowered as consumers to demand quality disability products and services. In addition, the concept of mutual aid is evidenced in wheelchair repair clinics and other services housed in ILCs.

Although the ideological influences have been varied, the social model of disability—developed in 1976 by the Union of the Physically Impaired Against Segregation-- has been the discursive glue behind the independent living (IL) movements in the U.S. and the U.K. (Galvin 409). Whereas the medical model sees the disabled body as the problem to be fixed, the social model places the problem of disability in the physical environment (e.g., inaccessible building, transportation, etc.) and cultural attitudes (e.g., work discrimination). Proponents of the social model, such as Michael Oliver, suggest that “disablement is nothing to do with the body” (42). In the social
model perspective, impairment is separated from disability. SHAD, an ILC in the UK, states:

The Social Model sees the person as disabled by society. In this view, the impairment is not in itself a problem, even though it may produce a need for a different set of living requirements. Rather, society insistence on segregation in education and services, and the inaccessibility of things such as transport and buildings results in a general prejudice against an integrated community life for disabled people. (“about”)

By focusing on the physical and attitudinal barriers, the social model of disability offers a political strategy designed to level the playing field for people with impairments. The body and the actual impairment itself are considered inconsequential to access and equality.

Although the Americans with Disabilities Act and other legislation—influenced by the social model—have been significant, they have also created what Cheryl Marie Wade has called the “able-disabled”--the person whose disability is inconsequential once access and accommodations are in place (Wendell 146). Those who cannot independently organize their own care and whose autonomy is not simply limited by the physical environment are marginalized in this discourse. In the following section, I offer a critical discourse analysis of the meanings of care, dependence and independence in the U.S. and U.K. independent living movements. I argue that the social model of disability draws much needed attention to social and physical barriers, but it also hides the realities of the disabled body, including the need for care, and reifies dominant understandings of “individual autonomy” which values self-reliance and independence over community and mutual support.

“Care,” “Independence/Dependence,” and Sexuality in IL Discourse
As Gerben DeJong acknowledges in his landmark 1979 essay “Defining and Implementing the Independent Living Concept,” the IL movement has concentrated on mobilizing select people with disabilities: most notably those with spinal cord injury, polio survivors, and the more milder forms of cerebral palsy, multiple sclerosis, and muscular dystrophy. In addition, the movement has focused on white, young and middle aged adults. Notably missing from the activism and the discourse are people with mental or developmental disabilities, people with multiple or severe physical disabilities, the elderly, and the non-white (18-19). Although DeJong believed that this bias towards the white, young, able-disabled would naturally subside as the movement grew, the bias remains over 20 years later. For example, in the U.K., the original Direct Payment Act of 1996—policy driven by the IL movement discourse-- excluded mental health users, people with learning disabilities, people with HIV/AIDS, and those over 65 years old. Although the provision has now been extended to include those groups, the vast majority of direct payment users have physical impairments (Evans; Stainton and Boyce 445). In addition, people from ethnic communities are less likely to use the direct payment system or be involved in independent living centers (Evans).

I believe that this bias is the result of the reification of “individual autonomy” in much (but not all) of the IL discourse, and it will remain until we bring the body back into the picture and re-examine “care.” In the IL rhetoric, dependence and independence are often constructed as fixed, oppositional terms in which independence is the valued term, associated with self-reliance and control that the nondisabled have. The need for care, bodies that cannot or do not want to be integrated into the mainstream, and
dependency are all devalued terms. The mission statements of Independent Living Centers are illustrative. A New York ILC states:

   We seek to overcome the barriers faced by people with disabilities who choose to live independently. The independent living philosophy supports persons with disabilities having opportunities to make decisions that affect their lives just as their nondisabled counterparts do. (Regional Center for Independent Living, emphasis mine)

Similarly, a Florida ILC states:

   We promote the rights of people with disabilities to live independently, enjoy self-determination, make choices, contribute to society, and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of society. (Center for Independent Living in Central Florida, Inc.)

In both examples, the nondisabled are constructed as inherently self-reliant and independent. Seeking independence and integration into the mainstream—to be just like their nondisabled counterparts—are positive values, suggesting that dependency and non-integration are negative states. Furthermore, making decisions on one’s own or self-determination is equated with living independently. The two are not necessarily related (one can in fact live dependently and make decisions); however, they are intimately linked under the current manifestations of “individual autonomy,” especially in terms of the ideal of personal responsibility.

   The IL discourse assumes that all disabled people should want independence. Criticizing the “impaired role”—a social position for individuals whose condition is not likely to improve—DeJong says, “Persons assuming the impaired role have abandoned the idea of recovery altogether and have come to accept both their condition and their dependency as permanent.” Further, “the disabled do not want to be relieved of their familial, occupational, and civic responsibilities in exchange for childlike dependency”
Thus, choosing dependence is equated with succumbing to impairment and abandoning personal responsibilities. Such language may be alienating to a variety of disabled populations, but especially people of different ethnic or racial populations and people whose disability cannot be adequately managed by assistive technologies or accommodations.

The rhetoric of equality and inclusion is also prominent in mission statements and related literature produced by ILCs in the UK. The website of the Support and Housing Assistance for People with Disabilities (SHAD) states, “It is SHAD’s belief that people with disabilities should have control over every aspect of their lives and be able to expect the same freedom of choice that is available to the able-bodied” (“home”). Again, similarity to nondisabled people is emphasized. Empowerment and control are keywords found in many mission statements of ILC’s in the UK. For example, “Independent Living Advocacy promotes the empowerment of disabled people. Empowerment is the process of supporting disabled people to take control for themselves” (Independent Living Advocacy Essex). Frequently, empowerment and control are construed as qualities given to nondisabled people, thus gaining control and choice is equated with inclusion into the mainstream. The Herefordshire Centre for Independent Living offers:

Our focus is Independent Living. By this we mean the services and support that enable disabled and older people to have control and choice over where they live and what they do, including being able to work or volunteer, choosing where they live and with whom, having access to fulfilling and rewarding social lives with family and friends and leisure opportunities. Independent living is about enabling disabled people to have the opportunity to participate fully in society on equal terms with non-disabled people.
To be independent is equated with control, power over choices, and equality with the nondisabled.

There are, however, some important differences between the US and UK independent living discourses. In general, organizations in the UK will explicitly align themselves with the social model of disability, offering definitions and histories of this ideological perspective on their websites. Although the social model is certainly a main influence on US organizations, the connection is less explicit. Furthermore, since the Direct Payments Act, one of the main functions of ILC in the UK is to help users navigate this system, including hiring and training personal assistants, accessing independent living funds, learning how to supervise others, and so on. As mentioned earlier, Direct Payments Schemes have been taken up unevenly across the UK. People with mental, emotional, cognitive disorders, people of color, the elderly, and people with multiple and severe physical disabilities have been slower to embrace Direct Payments than other people with disabilities. Thus, to try to dispel myths, fears and concerns about using Direct Payments, much of the discourse on these websites is focused on what independent living is and is not. For example, Independent Living Association of West Sussex states, “Independent living means having choice over everyday life. It doesn't mean doing without assistance, but exercising control over that assistance.” The Southampton Centre for Independent Living even has a graphic that boldly says “Independent Living is not…doing everything for yourself” on the left in front of an angry red star shape and orange lightening bolt, and, “Independent Living is…having control over your life and a say over what happens” on the right in front of a gold star.
Thus, the UK ILCs seem to have a more nuanced notion of independence than US ILCs; however, in the UK literature there is also a simultaneous insistence that all people, no matter what, can live independently. As ILA Essex notes, “anyone, whatever their impairment, is capable of exerting choices.” So, the UK discourse distinguishes between independence with assistance and independence as total separation to assuage concerns that using Direct Payments will mean isolation and doing it on one’s own. The focus on anyone and everyone—regardless of disability—is aimed at increases buy-in from underrepresented groups.

The notion of “interdependency” is another way that IL activists attempt to increase buy-in and provide alternative understandings of Independent Living; however, I argue that “interdependency” is underdeveloped IL discourse. “Interdependency” is sometimes used to explain that needing help with personal assistance does not necessarily make one more dependent if it allows the person time and energy to do other “valuable” activities in the world. Zola writes:

> It is not always necessary that persons do everything for themselves, or do always what they are capable of doing, such as walking long distances, if that effort proves healthy but exhausting. The energy lost in physical exertion cannot be used elsewhere. A powered wheelchair might well diminish the amount of exercise an individual gets, but at the same time it enormously increases his or her social capabilities and networks. (58)

In this sense, interdependency explains the use of assistance so that one is able to do other things that are deemed more valuable or important. Interdependency is also commonly used to articulate the ways in which we are all dependent on each other. For example, we are dependent on public works systems to handle our sewage. Yet these limited usages of the term fail to interrogate the role of independence/dependence in
subjectivity and the notion of “valuable” activities. In effect, “interdependency” is used in these cases to advocate inclusion for people with disabilities. In this sense, this usage is more accurately called “liberal interdependency.”

The IL movement’s roots in consumerism and individual autonomy thwart radical interrogation of “independence.” As outlined above, there is a focus in IL rhetoric on “access to” the “same choices and control” as the nondisabled. Because the discourse fails to question the choices and control available to the nondisabled, and what inclusion into the mainstream may mean, the discourse is essentially asking for full participation in capitalism, which is, as an amazingly flexible system, all too happy to comply. Transformations to the environment are made to accommodate and even welcome the disabled as a minority identity into the capitalist marketplace. Because these demands do not necessarily question the system itself, they ultimately “serve the expansion of able-bodied identity” (McRuer 129).

In the 1980s, sociologist Gareth Williams waged a socialist critique of the IL movement, noting that the movements’ “approach in the US, in particular, celebrated an individualized, consumerist, free-market means of obtaining personal assistance—a stance that sat comfortably with US governments’ liberal individualist ideology” (Thomas 115). His critique was vehemently rejected by disability activists at the time because the advances made by the IL were so tenuous. Such critiques were seen as detractions to broader movement goals.

Related, tactics that brought attention to the body, impairment and the need for care were also viewed as politically dangerous in the 1980s and 1990s. Thomas suggests
three reasons for the marginalization of the body: “first, it was thought diversionary to dwell on impairment; second, illness and impairment were believed to be poor foci for political organization and campaigning—better to transcend impairment differences so as to make common cause against disablist; and third, illness, impairment and their emotional sequelae were deemed by leading male materialist to belong to the ‘personal and private’ domain” (122). The social model of disability focused on the social, political, environmental conditions that made body impairment a disabiling condition, and thus it was (and is) considered a politically robust model for disability activism. Yet, as feminist disability scholars made clear, obscuring the body, dependency, and pain—the personal and subjective aspects of the disability experience—did not meet the concerns and needs of all people with disability, especially women (Thomas 124-25). Jenny Morris notes:

> There was a concern amongst some disabled women that the way our experience was being politicized didn’t leave room for acknowledging our experience of our bodies; that too often there wasn’t room for talking about the experience of impairment, that a lot of us feel pressured into just focusing on disability, just focusing on social barriers. (qtd. In Thomas 124).

Thus for women, and all people with disabilities whose conditions are not ameliorated by removing social and physical barriers, the IL movement and the social model of disability IL are not necessarily emancipatory. The ILC can help find accessible housing so one can live independently, but it cannot ease the physical pain of multiple sclerosis. The social model may help a disabled person get a job by removing physical and social barriers to employment, but it will not improve the debilitating and unpredictable fatigue experienced by people with chronic fatigue syndrome.
The social model of disability also hides pleasurable aspects of bodies such as sexuality and physical intimacy (Shildrick “Contested Pleasures” 58). Indeed, sexuality remains marginalized in the disability rights movement, despite numerous rallying cries to “politicize our sexual oppression” (Waxman 82). Margrit Shildrick suggests that people with disabilities may be reluctant to raise the issue of sexuality and disability because it can invite more regulation and intervention (62) which can in turn lead to pressures to normalize sexual expression (63). This may be the motivation behind some of the reservations; however, I believe shame around sexual difference is the primary reason sexuality is elided in disability activism and scholarship. As Anne Finger succinctly puts it: “Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It’s easier for us to talk about—and formulate strategies for changing—discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction” (9 “Forbidden”). People with disabilities are socialized to believe that they do not have the right to be sexual beings, that they are ugly and will be unable to attract and/or satisfy partners (Shakespeare, Gillespie-Sells, and Davies 17-19). In addition, disabled people are often excluded from sex education classes (ibid 22) and/or physically segregated from interacting with potential nondisabled and disabled partners (ibid. 29). Thus, it is not difficult to imagine that many people with disabilities struggle with sexual self-esteem. Sexuality may not be part of the disability rights agenda because these negative attitudes are internalized. Furthermore, for many people with disabilities, sex and sexual intimacy does not conform to heteronormative expectations. Access to sexual interaction may even require physical assistance from a
caregiver (this is called “facilitated sex”). If sex could “look like” the sex that is socially endorsed it may be easier to people with disabilities to demand access to sex education and to combat negative stereotypes. The reality, however, is that physical, emotional, and/or cognitive impairment means sex and intimacy will look vastly different from the sex nondisabled people (supposedly) have. Just as physical pain and the excesses of the disabled body are considered politically risky under the social model, disabled sex and intimacy is risky because it further distances the disabled from the nondisabled. In other words, attention to sexual pleasure would draw attention to difference. There are, however, some disability scholars/activists who have begun to align with queer politics and theory in order to think through the risks and benefits of politicizing disabled sex and intimacy (c.f. McRuer; Sherry).

Because the social model hides both the pleasures and pains of bodies, I believe that today we are in a period in which critiques of the social model and the individualized, consumerist, free-market leanings of the IL movement are not only needed, but increasingly welcomed by disability studies scholars. For example, in “Critiquing the social model,” disability scholar Tom Shakespeare lays out many of the limitations that academics have begun to grapple with, including the role of impairment (the body) and the problems of a “barrier-free utopia.” Similarly, Robert McRuer has begun to examine how the social model of disability may serve the aspirations of the World Bank (“Taking”). Indeed, much of the openness to critiques reflects an increasing wariness amongst disability scholars about the connections between disability activism
and notions of individual autonomy that promote the retreat from government sponsored
support programs.

As outlined earlier, the popular understanding of individual autonomy is linked to
government deregulation and a rolling back of social welfare provisions, including
instrumental, health, and emotional care of people with disabilities and assistance for
caregivers. It is not coincidental that Independent Living centers emerge in the 1970s
and 1980s. During this period there is also massive cutbacks in social welfare programs,
in both the US and UK. In the UK context, as Carol Thomas notes, ILC emerge, at least
in part, as a response to the government deinstitutionalization of people with disabilities.
On the one hand, the development of consumer led, community focused initiatives seems
in line with the U.K.’s historical commitment to collectivism, as evidenced in their
system of universal health care. However, deinstitutionalization and the creation of
ILC’s in the U.K. can also be read as product of the growing tension between
collectivism and individualism that is most obviously marked by Margaret Thatcher led
governments from 1979-1990. Anna Marie Smith argues that “Thatcherism’s radical
departure from previous political regimes consists in its total rejection of the consensus
model for an individualist, monetarist and free market approach to the economy” (2). In
Thatcher’s terms, economic renewal “entailed a moral revolution: a return to individual
responsibility, free market entrepreneurialism and British nationalism” (Smith 3). Thus,
moving the concern for people with disabilities from the state, to the community, and
ultimately, to the disabled themselves, is perfectly aligned with the political and
economic shifts occurring in the Britain during the last several decades. ILCs step in where the government has receded.

In the US, government support for volunteer and consumer-led organizations like Independent Living centers can also be read as symptomatic of economic policy invested in individual autonomy. For example, a recent press release announces “Kennedy and DeWine Introduce Bill to Help People with Disabilities Overcome Barriers to Independence,” and then goes on to explain the US Senators’ plan to create a voluntary insurance program “based on the principles of independence, choice, and empowerment” that is financed through voluntary payroll deductions. Thus, the program is explicitly linked to work. The announcement says “It makes a simple pact with all Americans. If you work hard and contribute, society will take care of you when you fall on hard times.” Clearly, such efforts, framed in the discourse of independent living, are in line with the ideals of the social contract and individual autonomy. People become citizen/subjects with rights once they have contributed to civil society. The subjectivity of people with disabilities who cannot work (even with accommodations), who cannot provide for themselves or participate in civil society, is marginalized in such a discourse. Indeed, the press release never even mentions what would happen to those people who do not work, who will not contribute to the voluntary insurance fund.

As I’ve tried to make clear in this chapter, the discourse of the IL movement most often upholds notions of individual autonomy which support the rolling back of social welfare provisions. So, what appears to progressive, bringing disability into the limelight, out of the institutions, may ultimately disadvantage people with disabilities as
the radical potential of disability rights is usurped by economic interests. As Sothern notes, “the rhetoric of individuality, personal fulfillment, and entrepreneurial responsibility under which these neoliberal reforms were sold serves to deny the particularity and irreducibility of the disabled body, thus making the difference of disabled bodies rhetorically invisible even while their physical and discursive presence is foregrounded” (Sothern 147).

What becomes clear is the need to re-think the connections between disability rights/activism and individual autonomy. This is especially urgent considering the increasing power of scientific and medical enterprise in global economies. People with disabilities are major consumers of medical equipment, drugs, health care services, thus, “in the industry selling the promise of technoscientific solutions…disability occupies a privileged position” (Sothern 146). Robert McRuer has even gone as far as calling disability the global economy’s “golden child” (“Queering”). The pharmaceutical and biotechnology markets are already leaders in the global marketplace, and, considering that rates of disability will continue to rise globally as the technology improves and people live longer, McRuer’s statement is not all that far-fetched. Consider the following statistics. According to the Centers for Disease Control, more than 90 million Americans live with one or more chronic illnesses (e.g., diabetes, cancer, cardiovascular disease), accounting for more than 75% of the nation’s 1.4 trillion in medical care expenditures. The Biotechnology Industry Organization reports that “the biotechnology industry has mushroomed since 1992, with U.S. health-care biotech revenues from publicly traded companies rising from $8 billion in 1992 to $58.8 billion in 2006.” According to Frost &
Sullivan’s Emerging Technologies for the Spine Market, “The spinal devices segment (of the market), with a striking growth rate of 20 to 25 percent annually, leads the orthopedic market.” Finally, Espicom Business Intelligence notes that “The USA is the world’s largest and wealthiest pharmaceutical market, accounting for around 48% of the world total.” Clearly, disability and business have become bedfellows. People with disabilities can benefit from this connection; however, there are risks—such as reifying individual autonomy—that need considered. When individual autonomy, independence, and self-sufficiency are held up as ideals, the reciprocity of care in disabled/nondisabled intimate relationships, as well as the disabled body and human dependency, become hidden and devalued. Disability scholars and activists must be vigilant about the relationship between disability and economic and social policy, and encourage debate and dialogue about the meanings of independent living, dependency, and care.

**Interdependency Reconsidered**

In terms of the IL rhetoric, I believe one fruitful area to re-think is the concept of “interdependency.” As an alternative to the independence/dependence binary, interdependency has the potential to disrupt the connection between disability rights and economic and social policy that promote privatization and individual autonomy. This potential, however, has been largely unmined because of the influence of the consumerist and self-help movement on early IL rhetoric, and, I’d argue, a continued (if unconscious) desire to fit into the “norm,” the mainstream, by upholding the ideal of individual autonomy. A radical version of “interdependency,” however, is possible. In fact, it is a prominent feature of many autobiographies and memoirs by disabled authors, especially
women. I offer more thorough analyses of disability autobiographies and how these authors express interdependency in the next chapter, but here I will outline some of the key concepts behind what I’m calling “radical interdependency” so as to differentiate it from the rhetoric of independence and individual autonomy found in the IL discourse.

First, “radical interdependency” reflects feminist attempts to reconfigure individual autonomy. Mackenzie and Stoljar propose the term “relational autonomy” to describe a “range of related perspectives” that are premised on [the] shared conviction…that persons are socially embedded and that agents’ identities are formed within the contest of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender, and ethnicity. Thus the focus of relational approaches is to analyze the implications of the intersubjective and social dimensions of selfhood and identity for conceptions of individual autonomy and moral and political agency. (4).

In other words, relational autonomy is concerned with the influences of social location on self-government and it understands that agency is only possible when a person is embedded in caring relations.

Second, radical interdependency would highlight Jessica Benjamin’s concept of intersubjectivity, the way in which subjectivity, or identity, exists only in relation to another, undermining the entire concept of “individual autonomy” pervasive in Western discourse. As an alternative to ego psychology, which emphasizes separation and individuation as “healthy” self development, intersubjective theory focuses on the “need to mutual recognition, the necessity of recognizing as well as being recognized by the other” (Benjamin 23). Benjamin explains that, “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” (33). Thus, our subjectivity is fundamentally
connected to others. In terms of disability, intersubjectivity emphasizes that people with disabilities are neither only care-receivers, nor wholly independent and separate from others. Instead, people with disabilities are connected, necessarily, to others (as others are to them). One’s sense of self is impossible without another to recognize it, care for it, and appreciate it.

The IL movements’ focus on “independence” and “control,” however, prevent such recognition of connected lives, the ways in which disability and impairment are experienced in relation with others. The acknowledgement that disability affects both the person with the impairment and the people connected to his/her life is frequently suppressed in the IL literature. Perhaps the most obvious place such denial takes place is the discourse surrounding Personal Assistants and carers. The needs, feelings, and thoughts of care-givers or service providers are frequently, passionately dismissed.

Recounting a story told by Lex Frieden at a conference, Elias Cohen writes,

When he left his parents’ home after having had an accident in which he suffered a spinal cord injury, his parents drove him to an independent living center so that he could learn to live on his own. When evening came, he sought an attendant to help him get into bed….Lex wheeled over to [an attendant] and said, “Will you help me go to bed?” The fellow said, “Sure! Where’s your room?” and Lex said, “Over there.” The man just stood there and didn’t do anything. Lex asked, “Would you come with me and help me?” and the fellow accompanied him to the room—and just stood there. “Would you lift me onto the bed?” Lex asked, and the fellow said, “Sure,” and he lifted him onto the bed, but he didn’t do anything. Lex said, “Would you please put my feet up onto the bed?” and the fellow said, “Sure.” Lex thought the fellow was stupid and couldn’t understand what was going on. As he later told the story, Lex commented, “I had to ask him to take off my shoes, take off my shirt. I thought, maybe he isn’t stupid, maybe he’s stoned. But when I was in bed, in my pajamas, I realized that was the first time I had undressed myself since my accident.
For Frieden and Cohen, this short vignette demonstrates “independence” in the IL movement. Frieden may have an assistant help him get ready for bed, but since he is in total control of the situation, he is “independent.” While it may be easy to appreciate the desires outlined in the story, the total denial of the attendant’s subjectivity feels ethically suspect to me. A similar disavowal of the helper’s “self” can be found in Deaf circles—the interpreter is nothing more than a machine translating spoken words into visual language. The fact that the translator is also a human is rarely acknowledged. Such treatment understands “independence” as separation from others, and, once again, nicely aligns with the logic of economic and social privatization. This disavowal of the other runs entirely counter to the psychological processes of intersubjectivity outlined by Jessica Benjamin and other theorists. Thus, from the perspective of intersubjective psychology, I believe it is ethically and theoretically unsound for both care-giver and care-receiver alike.

Thirdly, but connected to the idea of intersubjectivity, is the role of the body in “radical interdependency.” Gail Weiss’ notion of “intercorporeality” and “body images,” drawn from phenomenologist Maurice Merleau–Ponty and psychoanalyst Paul Schilder, focuses attention to the role of the material body in subjectivity. Body image refers to a person’s sense of their physical body in space and accounts for posture, movement, and proprioception (the internal awareness of where one’s limbs begin and end, where body parts are in relation to each other)—in short, body images are another way to think of embodiment, being in one’s body. Weiss stresses the “intercorporeal aspect of the body image, that is, the fact that the body image is itself an expression of an ongoing exchange
between bodies and body images” (3). Thus, intercorporeality breaks down the
distinction between the material and social (discursive) body as the body image is the
result of the dialogue between and among the material and discursive. Weiss’ thesis is
that “human beings tend to have multiple body images and that these body images
overlap with one another and are themselves constructed, reconstructed and
deconstructed through a series of ongoing, intercorporeal exchanges” (165) and that
intercorporeality happens within and between bodies (169).

From the perspective of intercorporeality, who gives the care, and how the care-
receiver responds, matters. Recognition is only meaningful from another subject, thus, it
is important for us to consider how we come-into-being with other subjects. Discussing
the care relationship, Janet Price and Margrit Shildrick offer a model of embodied
subjectivity, similar to Weiss’ intercorporeality, that accounts for the ways in which we
are “actively and continuously produced through social interactions with other body-
subjects” (63). Caring or assisting is also an encounter between two bodies, and the act
of touching and recognizing the other occurs simultaneously from both bodies.
Intercorporeality acknowledges both bodies in the care relationship and how those bodies
impact the other’s subjectivity and body image.

Significantly, Weiss’ work updates Merleau-Ponty’s and Schilder’s on the body
by drawing on feminist accounts of embodiment to highlight the “definitive ways in
which bodies are marked by assumptions made about their gender, their race, their
ethnicity, their class, and their ‘natural’ abilities” (2). In other words, Weiss insists on
the historical and cultural specificity of bodies, of difference, by refusing to talk about
“the body.” Removing the definite article “the,” Weiss highlights difference and the specificity of a body. Such a move is important for our discussion of disability in relationships because it makes obvious the difference between disabled and nondisabled bodies, and how that difference affects the encounter and the respective experiences. Likewise, Price and Shildrick acknowledge that this recognition of the other’s body, of touching, inherent in the care relationship, can be riddled with anxiety because in those moments difference cannot be eclipsed; however, like Weiss, Price and Shildrick consider such ambiguity productive (70-71). Because Weiss’ conceptualization of intercorporeality and body images focus on difference between subjects, socio-historical specificity, and the relation between bodies, I believe intercorporeality and body images can help bring the body back into disability discourse without the abstraction inherent in some accounts of embodiment and without the individualizing of some narratives of the body.

Finally, radical interdependency makes clear the ethical dimensions of the care relationship. The care relationship impacts the subjectivity and embodiment of both participants, thus, we must attend to the moral and ethics dimensions of care. Based on her understanding of intercorporeality, Weiss suggests a need for an embodied ethics “grounded in the dynamic, bodily imperatives that emerge out of our intercorporeal exchanges and which in turn transform our own body images, investing them and reinvesting them with moral significance” (158). Influenced by the work of Weiss and Merleau-Ponty, Maurice Hamington argues that care is the “very foundation of morality rooted in our body and our bodily practices” (5). The premise of his book Embodied
Care is that care ethics have traditionally ignored the role of the body and that there is a need for a model of care that understands the vital role of the body to the care relationship. Hamington offers a model of care that is a “complex intertwining of caring habits (embodied practices of interaction), caring knowledge (the embodied understandings instantiated through habits), and caring imagination (extrapolations from embodied knowledge to understand situations beyond our immediate experience and to image caring courses of action)” (12). Our ever evolving body images, and our ability to imagine ourselves in other bodies, provides the basis for a strong identification with others that can motivate and underpin care (imagination), and, how to care is at least in part stored in our bodies’ memories of movement and response (knowledge and habits).

Embodied care is an ethics grounded in body relations and intersubjectivity and is therefore a much more suitable model for thinking through the care implications of radical interdependency. Understanding embodied subjectivity, how we experience our sense of self in relation to others (and others in relation to us), highlights ethical dimensions of care that the social model of disability, and much of the independent living discourse, frequently obscures.

Conclusion

To be clear, I am not arguing that the goals of de-institutionalization and empowerment are necessarily negative. I am, in fact, an advocate of the independent living movement, and I believe that the social model of disability is still politically valuable. What concerns me is the lack of critical dialogue about the meaning of independence, dependence, care and reciprocity in the Independent Living movement,
and the way in which impairment and bodies are repressed. In order to make the goals of IL a possibility for all, it is vital that we are reflexive about what “access to” means, and how such a goal may economic and social privatization. We need to consider what bodies the social model obscures, and dialogue about how to bring the disabled body back into disability discourse. Finally, we must acknowledge that the social model and the independent living movement often ignore those that care for, assist, and help people with disabilities, as well as the ways in which the disabled reciprocate. We must begin thinking about how to incorporate care-giving and care-receiving, reciprocity and mutuality, subjectivity and the body, and other related issues into political and theoretical models of disability so that all people with disabilities (not just the “able-disabled”) and the people they are connected to (partners, assistants, family and friends) are accounted for.

As I’ve outlined it above, a radical articulation of interdependency—composed of the key concepts of intersubjectivity, intercorporeality, and embodied care—offers a different way of thinking about self, other and care relations. In the following chapters I explore how these conceptions are used in self-representations of people in disabled/nondisabled intimate relationships.

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i There are actually a number of differences between the Civil Rights Acts and the ADA. See Ruth Colker’s Disability Pendulum for a detailed legal analysis of the ADA. Regardless, this comparison is regularly made because in the popular imagination the ADA is the disabled person’s Civil Rights Act.

ii People of color and marginalized ethnic communities may live in extended family living situations that value communal living and inter-generational support. The rhetoric of independence may not be as valued in these communities.

iii I use “liberal” here to describe a politics of equality and inclusion into the mainstream. Liberal politics do not question or try to change the mainstream.

iv There is a concurrent re-thinking and re-evaluating of GLBT movement political strategies (see Lisa Duggan; Robert McRuer “Queering”). Disability scholars can draw from these debates as we reconsider the IL movements free-market leanings, especially in the contemporary global environment.
Part II
CHAPTER 4: 
VOICES FROM AUTOBIOGRAPHY AND FILM

As the previous section demonstrated, care is typically represented as an isolating and divisive force within intimate relationships. Providing care is a mental and physical drain on the nondisabled partner; receiving care breeds guilt, shame, and dependency in the disabled partner. This dynamic inevitably destroys the couple’s sexual and erotic intimacy. Or so the story goes. But I knew from my own experience and from a few autobiographies written by people with disabilities that caregiving was so much more complex and nuanced, and that sexual intimacy was not only possible, but maybe even more available in disabled/nondisabled relationships. In order to illuminate alternative renderings of care and intimacy, the second half of the book is dedicated to exploring various self-representations: texts, images, and words used by people in disabled/nondisabled relationships to communicate their experiences to others. Self-representations often paint a very different picture of care and intimacy in relationships. This chapter examines two forms of self-representations—autobiographies and documentary films. Because each of these modes of representation has a distinct history, symbolic system and structures, I will consider each mode separately, starting with autobiography.
Autobiography Literature Review and Methodology

Today, a lot of autobiographies are written by people with disabilities and by people caring for the disabled. Illness narratives have become so common that several new words have been created to describe the stories. Suzette Henke offers the term “scriptotherapy” to illustrate the way in which life writing can be therapeutic for the author, so that writing about trauma and illness becomes a way to heal.

“Autothanatography” has been deployed by several critics to describe autobiographical texts about terminal illness, written by the dying subject (c.f. Bainbrigge; Egan; Miller). Finally, Thomas Couser has offered “autopathography” to describe autobiographical narratives of illness or disability. For Couser, autopathographies reveal the ways in which “bodily dysfunction tends to heighten consciousness of self and of contingency” (Recovering 5), but they are also a form of counterdiscourse “in which laypeople have responded to the dehumanizing tendencies of medical discourse” (Recovering 34). In other words, autopathographies explore the self and subjectivity by speaking back to dominant discourses that have traditionally silenced or even erased “patient” subjectivity.

Caregiving narratives have not, yet, warranted their own genre, but they are abundant. Of course, narratives written by parents caring for disabled children and adult children caring for disabled parents are, by far, the most common caregiving narratives. In Ann Burack-Weiss’s study of 159 caregiver autobiographies, only 17% (27) were written by the partner of an ill or disabled person. Fifty-one percent (81) were written by adult children caring for an ill or disabled parent, 21% (33) by parents of disabled/ill children, 7% (12) by a sibling, and 4% (6) by a friend. Interestingly, all of the narratives
written by partners are about experiencing illness or disability after the start of the relationship. Like Burack-Weiss, I was unable to find written published autobiographies by people who entered a relationship with a disabled/ill person. There is also a surprising lack of critical analyses of caregiving narratives. For example, I found only book reviews of the two caregiving narratives I analyze in this chapter; however, the three autobiographies written by people with disabilities that I examine have generated numerous scholarly articles, in addition to book reviews. Regardless, caregiving narratives, like disability narratives in general, are becoming quite popular, and as they do I expect scholarly attention will follow.

There are number of reasons for the proliferation of illness/disability narratives. Sidonie Smith and Julia Watson argue that “narratives of crisis, focused on injury, self-reinterpretation, and testimony, have proliferated in response to widespread illness and genocidal war, to profound changes in personal life, and to the growing audience demand for personal accounts as self-help” (147). Indeed, in many ways, medical advances deliver an increasing number of people with disabilities as more and more people live through catastrophic injury and illness. Autobiographical accounts of illness and disability testify to such advances and provide important resources for the millions of people whose lives are affected by physical, cognitive, and emotional impairment. Along with more people with disabilities, we have entered a period in which the truth and authority of medicine is questioned, and the line between sick and healthy has become blurred. Thus, the stories of real people’s struggles are increasingly popular. Arthur Frank reads this shift as symptomatic of postmodernity. In the modernist society, the ill
and disabled were supposed to adopt what Talcott Parson’s has called the “sick role,” giving over all control of self and body to medical professionals. The sick person’s story is told to doctors in order to find and define the malady and return the person to well-being. According to Frank, the postmodern “remission society,” is populated by those people who are “effectively well but could never be considered cured,” who are now telling their stories of living with chronic illness or impairment and surviving terminal illness (8). Indeed, “Many members of the remission society feel a need to claim their visa status in an active voice. Those who work to express this voice are not only postmodern but, more specifically, post-colonial in their construction of self” (ibid. 10). The stories are no longer for medicine, but for themselves and others. In addition, the disability rights movement and legislative victories such as the Americans with Disabilities Act (1990) have secured an increasingly visible place in American culture for people with disabilities. Disabled people are becoming “proper subjects,” with stories and histories that the disabled and nondisabled reading public are eager to consume (Couser Recovering 8).

Disability scholars and activist, 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” (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 (314). However, Mitchell argues that disability autobiography is just as likely—perhaps even more likely—to express a singular self (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 Frank calls “restitution narratives.” Such a narrative “affirms that breakdowns can be fixed,” easing the anxiety the nondisabled may have about illness and disability (Frank 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 disable the impaired, it would be best to have narratives that critique ablism and celebrate the disabled body instead of healing it. These narratives are out there (indeed, the autobiographies analyzed in this chapter are prime examples), but they do not, yet, out number the more popular story of overcoming.

Ironically, however, narratives that draw attention to the disabled body, even if it is a celebration of that body, may also be scorned by some disability activists and scholars. As noted in chapter 3, the body occupies a tenuous position in disability politics. Disability activists have worked hard to divorce impairment (the body) from disability (the consequence of attitudes and environments made for people with normative bodies). To speak of bodies, especially bodies so impaired that even the removal of barriers fails to guarantee them access to social life, is considered politically
risky because it draws attention to the reality that, for some, public policy is not enough. However, some scholars—especially those committed feminist disability studies—have begun to challenge the erasure of the body, calling for a turn toward the “visceral” in disability studies (Mintz *Unruly* 3). But this return to the body is not a simple retreat to the medical model of disability in which the impaired body is an object of science, separate from cultural experience. The new paradigm attends to the ways bodies and social/physical environments inform each other, foiling any easy separation between impairment and disability, bringing to light both the pleasures and the pains of the body. Tobin Siebers calls this the “new realism of the body.” As he explains, “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” (749). Similarly, Janet Price and Margrit Shildrick put forth a model of “embodied subjectivity” which accounts for the ways in which we are “actively and continuously produced through social interactions with other body-subjects” (63). 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” (Hughes 66).

From a feminist disability perspective, then, autobiography can be part of a politics that puts forth new paradigms about interdependency, the relationship between self and others, by highlighting the relationality of the body. In addition, I disagree with Mitchell’s analysis of the state of disability autobiography. It is true that disability autobiography can reify popular understandings of the self as separate and independent of others—in spite of the disability. While reading autobiographies for this chapter, I came
across several that fit this model. For example, Simi Linton’s *My Body Politic* generally obscures her disabled body in favor of a more traditional “supercrip” narrative in which disability is overcome. Since Linton is a prominent feminist, disability activist/scholar and is in a long-term and seemingly very loving and rich relationship with David, I was hopeful that her narrative would describe how disability and her body functioned in their intimate relationship. Instead, Linton’s autobiography details her political activism and offers only highly polished, superficial stories about her marriage and private life. The self she presents is the independent, whole self that the disability rights movement proudly supports. And there are plenty of other examples of self-representations that obscure the interdependent, messy and complicated selfhood that physical impairment elicits. However, in general, I agree with autobiography scholars such as Susanna Mintz, Paul John Eakin, and Thomas Couser who argue that many disability autobiographies eschew what Sidonie Smith calls the “certitudes” of autobiography—“chronological time, individuality, developmental selfhood, myths of origins, the fixedness of identity, bodily wholeness, the transparencies of referentiality, the will to knowledge, the unified self” (Smith 184). Each of the six autobiographies that I analyze below offer alternatives to one or more of these certitudes. Although this selection is not intended to be representative of the field of autopathography, they are not particularly exceptional in terms of style, content, and feel. In other words, the six narratives are not rare voices in the field.
Mairs’s autobiographical essay collection explores her experience of Multiple Sclerosis, her life as a writer, and her relationship with her husband, George.

Klein, a feminist filmmaker, details the stroke that left her permanently impaired, and her relationship with her husband, Michael.

As a trained anthropologist, Murphy’s text is part autobiography, part ethnography of the physically disabled. Quadriplegic from a spinal tumor, Murphy describes his physical dependency and his relationship with his (anthropologist) wife, Yolanda.

Cohen details her experiences of providing physical care to her husband, Jeffrey, who has Multiple Sclerosis. Cohen is a writer and mathematics professor.

Kondracke, a journalist, tells the story of his relationship with his wife, Milly, and their battle with Parkinson’s disease.

Figure 5: The Autobiographies

I selected these six particular pieces (see figure 5) because they speak to—and speak back to—the dominant representations of care and sexuality in disabled/nondisabled intimate relationships outlined in the first half of this book. 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 each I look for explicit ways in which the text takes up the issues of care and/or intimacy, through stories told to the reader about the author’s personal experiences and through commentary. Throughout my analysis, I draw on several key concepts from
autobiography studies, psychoanalysis, and philosophy. Thus, before moving on to the
analysis I want to briefly explain how these concepts can help make visible alternative
constructions of care and sexuality in self-representations.

First, “relationality” is a significant umbrella term that links together many
specific concepts used in this analysis. Simply put, relationality is concerned with one’s
relationship to other people and things. Importantly, underlying relationality is the
understanding that the self is not a unified or coherent entity. The relational self is
decisively anti-Cartesian. In his study of the relational self in autobiography, Paul John
Eakin uses the “relational life” to “describe the story of a relational model of identity,
developed collaboratively with others, often family members” (57). Eakin understanding
of “self” draws on Jessica Benjamin’s notion of “intersubjectivity,” a psychologically
ideal state of subjectivity in which “the individual grows in and through the relationship
to other subjects” (Benjamin 19-20). As an alternative to ego psychology, which
emphasizes separation and individuation as “healthy” self development, intersubjective
theory focuses on the “the need for mutual recognition, the necessity of recognizing as
well as being recognized by the other” (Benjamin 23). As Benjamin explains, “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” (33). Thus, our
subjectivity is intimately connected to others. There would be no “I” without another to
care for, recognize and be affected by it. Following this model of identity, all selves are
relational; therefore, all autobiography inherently describe a relational life. However,
Eakin wishes
to preserve the usefulness of the label by applying it to those autobiographies that feature the decisive impact on the autobiographer of either (1) an entire social environment (a particular kind of family, or a community and its social institutions—schools, churches, and so forth) or (2) key other individuals, usually family members (69).

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 part biography of the proximate other(s) (Eakin 86) or ethnography of the proximate community. 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 interdependency to emphasize how the disabled and nondisabled alike are dependent on others for daily survival. The authors I analyze below are very 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 intersubjectivity 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. Mirror talk includes all 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 autobiographical texts enact intersubjectivity, producing a self in relation to an other, 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.
Because the selves of the texts I analyze are marked by physical impairment, the role of the body in the process of intersubjectivity is paramount. The body becomes the “corporeal substratum of identity,” it shapes and is shaped by other bodies and environments (Eakin 26). The caregiver’s sense of self is affected by the disabled body it cares for; likewise, the disabled body’s sense of self is affected by the body that moves it. Since bodies are so important in the relational lives I analyze, I prefer to use Gail Weiss’s concept of “intercorporeality” to mark the intersubjective moments in the texts that take place through bodies. As Weiss notes, “the experience of being embodied is never a private affair” (5), it is an unconscious, “ongoing exchange between bodies and body images” (3). By “body image,” Weiss is referring to proprioception, 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” (Weiss 33).

Significantly, the body present in intercorporeal exchange in the texts that I analyze is not always a pleasurable and contained body. That is, a body easily manipulated for politic action. Sometimes the bodies of both the disabled and nondisabled alike are in pain, exhausted, violated, exposed, and uncontrolled. These may not be the bodies the disability rights movement has traditionally privileged as spokes-bodies; however, the authors let them loose in the texts to expose the angst and joy of
physical disability and care. This provides a new model of disability politics that acknowledges both the needs of the disabled body and the potential it gives in return. These bodies are part of the “new realism” paradigm shift mentioned earlier. As Siebers explains, “new realism” exposes the nitty gritty, painful realities of disability but does not render such narratives “politically impotent” (746). The realism of individual pain and pleasure is connected to a critique of cultural norms that establish body hygiene as private and self-performed (747). By connecting complicated body images to social/political realities, the “new realism” of the body adds teeth to making the body visible. Siebers’s “new realism” mirrors Cheryl Marie Wade’s plea, nearly two decades earlier, for disability activist and scholars to talk about disabled bodies, especially those aspects that “ain’t exactly sexy.” As Wade argues,

If I can’t talk about the need [for personal care], then I can’t talk about the choices, either. And yes, even the weak, vulnerable cripples have choices. But if our shame tells us that our needs lack dignity, that we lack dignity, then the next thing we hear our shame say is that it is more dignified to die than to live with these basic needs that take away our privacy and seem like such a burden. (90).

Thus, it is politically vital to expose the realities—both the pleasures and pains—of the disabled body.

“New realism,” intercorporeality, intersubjectivity, and “mirror talk” are all ways in which the texts analyzed below express relational selves. These relational lives provide important counter-examples of care and intimacy in disabled/nondisabled relationships. The texts emphasize connection and reciprocity between carer and cared-for, offering surprising anecdotes to the persistent belief that disabled/nondisabled relationships are de-sexed.
The Texts

All of the texts I selected emphasize the author’s connection with others and they are very aware of the progressive political potential behind relational lives. They explicitly connect their lives and writing to disability rights. Robert Murphy critiques at length the value Americans place on independence and self-reliance. He writes that “Lack of autonomy and unreciprocated dependence on others bring debasement of status in American culture—and in many other cultures…It is for these reasons that escape from dependency has been a central goal of the disability political movement” (201). Although all people are inherently interdependent, and all subjectivity relies on the others that participate in our lives, Murphy is upfront with the fact that physical impairment helped him fully understand this social reality. As an able-bodied, white male academic, Murphy had failed to register his intrinsic involvement with others. Disability, however, made the play between separation and connection obvious. He notes that the “oscillation between involvement and withdrawal” had “bedeviled me all my life, but” that it “grew stronger in my illness” (74). Although Murphy initially becomes depressed, suicidal and withdrawn because of his physical disability, Yolanda confronts him and explains how his retreat from life would impact herself and their children: “It was not my private affair, for, although our lives in theory may belong to us, they are mortgaged. My life belonged to my family, primarily, and also to many others.” (66). Murphy’s physical body made his own intersubjectivity palpable and helped inform his critique of social relations in general. Toward the end of his text, Murphy eloquently summarizes:

There is, then, a constant process built into all our endeavors in which we must reach out, relate, and love, while taking care not to lose ourselves…In the final
analysis, social life is made possible by keeping a delicate balance between falling inward and falling outward. The structure of all our moments is that we are constantly being pulled apart between the two. It is also the story of our lives” (227)

Thus, it is through the experience of disability that Murphy is able to articulate the fundamental intersubjectivity of all social relations—a radical political position indeed.

Similarly, Morton Kondrake writes at length about what his wife’s illness has taught him. He writes: “Milly’s diagnosis changed me. When it became clear in 1988 that she had Parkinson’s, I said to myself, ‘This is one thing in your life you are going to do right.’ I meant that I was determined to be a loving husband and to help Milly fight the disease” (109). Part of helping Milly “fight the disease” was to become political.

Kondrake uses his role as a journalist to access politicians and lobby for their support of research funding, especially controversial but promising research on stem-cells. He also politicizes his experience with caregiving. Kondrake details how he prepares Milly’s food, washes and dresses her, feeds her and helps her with shopping and other activities (122-124). Then he provides a very gender and class sensitive analysis:

I rarely resent this labor—mainly because I do not have to do it every day, all day…Without Effexor, and without Fell and Grelanda helping, both my stoicism and my Christianity would be sorely tested. My love for Milly would be tested. I think this because I finally did read Maggie Strong’s book Mainstay and realized how luck I am—that I am not a woman taking care of a chronically ill man, that I make enough money to hire people to help me, that my newspaper has excellent health insurance that has paid for Milly’s surgery and wheelchairs without argument…Other people are not so fortunate. They feel trapped, furious, oppressed, or depressed. (124).

Kondrake understands that men typically make more money and/or have better work-related benefits than their female partners. The loss of his job because of disability can financially devastate a family. In addition, paid outside help is frequently not offered
through government sponsored programs or is financially out of reach for the family. A good income, benefits, and help make his life as a caregiver workable and Kondrake is critical that the U.S. does not make family care reasonable for all people with disability.

Kondrake and Murphy understand how relational selves undermine myths of autonomy, and they are quick to connect their personal experiences with disability to social and political issues. However, the female authors in my sample seem to take relationality to a different—perhaps deeper—level. The selves that emerge in Kondrake’s and Murphy’s texts are relational, but they also look and feel as expected. In other words, they do not defy some of the “certitudes” that readers of autobiography expect. Kondrake’s narrative unfolds in a linear manner: he begins with his and Milly’s childhood, tells how they met, and then describes their experience of Parkinson’s. He uses “old Milly” and “new Mort” to describe fundamental and radical shifts and their personalities and roles in the relationship, but the reader can easily trace a discernable Mort throughout the text. Likewise, Murphy’s voice is clear throughout *The Body Silent*. He is changed by disability and his life is intimately connected to Yolanda, but he—and the reader—can always tell where he begins and others end. The self/other distinction seems a bit more slippery for the female authors.

Bonnie Sherr Klein’s *Slow Dance* is intersubjective in content and form, and there are points in the texts that it is hard for the reader (and for Klein) to clearly discern her voice from the voice of others. Largely, this is because Klein refuses sole authorship in a variety of ways. First, she uses a coauthor, feminist writer and performer Persimmon Blackbridge, to construct the text. As Klein explains in the preface, Blackbridge helped
her assemble and edit the journal entries that form the backbone of the book, but also asked her questions about her memories to help narrate the story, adding depth and texture to the account. Even though Klein did most of the writing and Blackbridge did most of the assembling, Klein says, “To say I ‘wrote’ the book and Persimmon ‘edited’ it would not acknowledge the reality of our collaborative process…The manuscript moved back and forth between us until we stopped knowing whose idea was whose” (xv).

Klein’s story emerges, literally, from the exchange between Blackbridge and herself. Thus, it is impossible to know for sure what is Klein and what is Blackbridge in the text, and that is precisely Klein’s point. Her life and work are so relational that the self/other distinction is lost.

In addition to using Blackbridge as co-author, she includes the writings of friends, doctors, and family members next to hers. Most prominent are the writings of her husband, Michael, and children, Naomi and Seth. Frequently their words are set off in blocks with the speaker’s name like the text of a play. Doctors and nurses chart reports appear throughout in a different text font than the rest of the book. And, in sections of the story in which Klein was unable to speak (because of the stroke she experienced a period of being “locked-in”), she represents her internal thoughts with italicized text. The block quotes, chart reports, and italicized text intermingled among the regular voice of the narrating Klein/Blackbridge create a truly dynamic reading experience. Sometimes these voices disagreed or complicated the picture for the reader. For example, during Klein’s “locked-in” period, she experienced terrifying nightmares and panic attacks. A portion of the text at this point reads:
Michael: The phone was next to your bed so that if you got particularly anxious, the nurses could call me and put the phone to your ear and I would talk to you. You couldn’t talk to me, but you could hear my voice.

I was afraid to sleep because that’s when the film loop would start. But I wouldn’t get well unless I slept. It went around and around. Michael was gone.

It took me a long time to get the nurse’s attention, and a long time to tell her what I needed. She refused to call Michael. She told me I was being a baby, that he had to eat and sleep and play tennis, so I would have to wait until he came back. She smiled and patted my hand. ‘He needs some time for himself.’ ‘No,’ I wanted to yell, ‘I don’t care what he needs. If he knew how desperate I am, he would want to be with me and save me.’ (143)

In this section the multiple voices—Michael, Klein’s memory of internal thought, Klein’s present voice, and the nurse—create a cacophony. At other points, the voices overlap, so much so that Klein writes: “Which memories are mine and which are Michael’s?” (95).

Together, these voices narrate Klein’s experience with becoming disabled through stroke because, as she notes, “we are living this together” (329). For Klein, telling her story with a singular voice would pervert the way in which her experience of disability has been interdependent. Her disability identity has been formed through the reactions, emotions, and thoughts of those important to her, thus, their voices are central to her story.

For Cohen, living with disability—and writing about it—is a family affair. Although Cohen is Jeff’s primary carer, their children—Marielle, Arin, Bret, and Devin—help out frequently. Even when not actively involved with the physical care, Cohen is conscious of how Jeff’s disability affects the whole family. Instead of thinking of the disabled individual in their family, Cohen thinks in terms of the “disabled family” because “Jeff’s MS makes the entire household disabled” (111). Everyone is impacted,
in both positive and negative ways. Cohen worries that the children will resent the way in which Jeff’s disability tied them to home much of the time. She also notes that Arin and Bret, two of the children who did a lot of physical care, both became emotionally and physically burned out with caregiving. When Jeff was living in the home (he is eventually placed in a nursing home), family time was frequently interrupted with requests for toilet assistance and other needs. Nonetheless, in-home care also meant that the family was together more and that care, fun, and work became integrated. Cohen writes:

If it was a scary home, it was also loving. Jeff’s illness meant we were together more; we often had to be. Sometimes we resented it, but what I remember is lounging on the big bed—Jeff, me, and the two youngest. I remember reading or drawing with Bret while nursing Dev. I remember Jeff helping Bret with physics. Or all of us parallel playing or parallel working—Bret drawing, Dev playing UNO or Lego, Jeff doing physics, me writing. We also spent some nights together on that big bed; that is, we had what’s known as “the family bed,” all of us sleeping together (76).

Care and disability were stressful, but it also glued the family together, making their connections explicit. Work, play, care became intermingled activities; therefore, Cohen’s identities of academic, writer, mother, wife, and caregiver are often impossible to tease apart in the text. “Family bed” was a positive aspect of her relational life; stress and burn-out when she was pulled in too many directions at once was the negative. By revealing both Cohen is able to provide a complex critique of home care in a society that devalues care, both socially and financially.

Nancy Mairs is very explicit that her intent is to bring her interconnected, embodied disability experience into the light, to make it public, “through the lens of my own experience and those of people I know well” (12). Describing her life with MS as “a
project, in which others must participate if it is to prosper,” Mairs’s narration from what she calls “a crippled female body” explicitly connects her body to the bodies (and experiences) of others (especially her husband, George) (71). Thus, the detailed descriptions of other people’s stories, such as the stranger, Jenny, who calls Nancy to discuss possible symptoms of MS she is experiencing, as well as the intimate details disclosed about George and their children, function to emphasize Mairs’s relationships to friends, family, and acquaintances. For example, George’s battle with prostate cancer continuously weaves in and out of Mairs’s stories. In fact, some of the chapters depend on the experience of other people. The chapter called “Young and Disabled” summarizes survey data Mairs has collected about the experience of being female and physically disabled, interspersed with her own commentary. In “Getting Byned,” Mairs ends by relaying some of the thoughts and experiences of the “patients” of Don and Joyce, the snake-oil salesmen mentioned earlier. These voices help situate Mairs’s embodied subjectivity and make visible the lives of other people with disabilities.

Yet Mairs is very careful to draw attention to her own specificity. She says, “At the outset, I want to make clear that I speak as an individual and not as a representative of ‘my kind’” (Mairs 12). “People with disabilities” are a very large and diverse group, and Mairs does not claim to speak for or represent all disabled people. Mairs’ preference to call herself “cripple” reflects this specificity of representation: “because it is a word that many people with disabilities find deeply offensive, I apply it only to myself, and so it reminds me that I am not speaking for others” (12). This acknowledgment of “separateness” is paramount to the intersubjective self because recognition is only
meaningful from other subjects. As Benjamin notes, “In the balance between self and other, disengagement (open space) is as important as engagement” (42). In other words, the other must also be a subject in his or her own right, distinct from Mairs’ self in order to enter into “mirror talk.”

To help make the voices of others more salient and thus emphasize the other’s subjectivity, all of the author—except for Murphy—frequently reproduce conversations they’ve had with others, sometimes even using quotation marks to authorize their words. For example, in “Taking Care,” Mairs uses quotation marks around her husband’s (74-75) comments about caring for Mairs. And in “Freeing Choices,” quotation marks are used around her daughter’s concern over having a child with a disability. In both these cases, quotation marks are ways to mark off and emphasize another’s subjectivity. Interestingly, Mairs also seems to be quoting from written texts at points. For example, “The Wider World” includes what appears to be a journal entry from George about their travels in England (207-208). And, in “Ups and Downs,” Mairs provides snippets from Anne and Matthew’s written response to the prompt “on being raised by a cripple” (34). It is important for Mairs to represent the other as a subject, separate—but connected to—her own subjectivity. Direct quotations help emphasize that Mairs is “narrating an individual (but affiliated) life” (Wong 174).

Kondrake also uses quotation marks to emphasize Milly’s separateness. In addition, Milly’s speech using the computer (which she uses when she is unable to use her voice) is represented in capitalized letters in the text. In addition, Kondrake includes Milly’s reaction to the books publication in the 2002 afterword, emphasizing both her
relation and distinctiveness to her husband’s text (215). Similarly, Cohen states that she waited to share her poems and prose about dealing with MS until Jeff was ready to “come out.” She also includes Jeff’s response to having someone take photos of their life for the book, noting that he limited access to “above the belt” photos. Including such permissions and responses is important for both Kondrake and Cohen because they are sharing private details about their partners. Without their partners voices in the text, they would risk objectifying them. Including their voices and responses emphasize that Milly and Jeff are subjects in their own right.

However, the other’s distinction is not complete from the author’s in these texts. For example, in Mairs’s text, the quotation marks draw a rather permeable boundary around the bodies/voices of those she is connected to. After all, citations do not accompany these quotations, thus the authenticity of these words is not concrete. And quotation marks are not used consistently to mark another’s subjectivity. Often, Mairs takes the liberty to paraphrase another’s words. This is done, for example, with the patients of Don and Joyce in “Getting Byned.” Their comments are paraphrased instead of quoted. Similarly, George’s opinions and thoughts often go unquoted, even when the content seems highly intimate and personal. Like other main characters, George’s own words are often set apart, but he also occupies much of the text outside the quotations, quite literally mingling in and out of the essays. For example we learn that George is impotent and has accepted his body and its functions outside quotation marks (48-49). By intermittently using and refusing direct quotations, Mairs seems to be emphasizing both the separateness and connectiveness inherent in embodied subjectivity.
Balancing separation and engagement is an ongoing struggle in relational lives, especially when engagement is necessary for basic physical needs like eating, toileting, and dressing. Care relationships can collapse when there is inadequate differentiation or inefficient connection. As mentioned above, Cohen ultimately becomes overwhelmed with in-home care and has to place Jeff in a nursing home. As Jeff becomes more physically impaired, Cohen writes:

I was too busy doing nights, lifting, and toilet, or worrying or tantruming about them. I was also buys sorting things out, protecting the me in me (finding time and space for writing, teaching, thrift shopping, singing) and protecting the mother in me, for the sake of both the kids and me…I was, in short, fighting for my life. (87).

The balance between self and other in Cohen’s relationship with Jeff begins to tip and she begins to feel consumed. Kondrake, too, is aware of this possibility for caregivers, but he has the race, gender, and class privilege to protect him from this fate.

Besides the need for financial and physical help from outside resources, reciprocity between caregiver and care-receiver was quite clearly the key to maintaining balance between self and other in disabled/nondisabled intimate relationships. Reciprocity emerged as a common theme across all the texts, demonstrating that care was not a binary relationship, that the disabled partner gives care and the nondisabled partner receives care and vise versa. Mairs’s chapter called “Taking Care,” highlights the reciprocity of care relationships. The argument throughout the chapter is that it is just as psychologically and physically important for Mairs to be able to provide some form of caregiving to the people she loves, as it is for them to care for her. Although she has had to change the way she takes care of others, she insists that she is more than a body cared-
for. Primarily her care-giving takes the form of intellectual and emotional efforts. In addition, she writes that “permitting myself to be taken care of is, in fact, one of the ways I can take care of others” (83). On a larger scale, writing is the crucial way that Mairs gives back to those connected to her self, including the reader. Describing her desire to fulfill a moral duty to community, Mairs states, “above all, I can still write, which for me has always been an act of oblation and nurturance: my means of taking the reader into my arms, holding a cup to her lips, stroking her forehead, whispering jokes into her ears...With such gestures, I am taking all the care that I can” (84). Mairs’ discussion of care emphasizes the need for mutuality, echoing Benjamin’s statement that “her recognition will be meaningful only to the extent that it reflects her own equally separate subjectivity” (24). She must be able to both give and receive care, although the reciprocity can come in different forms. Mairs’ embodied and relational subjectivity highlights the need to be a separate self that is distinct, but connected, to others.

Murphy, too, uses his brain to give back: “My brain was the only part of the central cortex that still worked well, but that also is where I made my living (66). Thus, as Murphy’s body slows and becomes completely immobile, he has to rely on Yolanda, students, and paid aids at work to help him move, eat, dress, and bathe. Such an extreme level of care means that Yolanda’s freedom has been limited. Murphy writes: “In a very real sense, we are both held in thrall by my condition—we are each other’s captives” (199). He is totally dependent in terms of physical care; however, he is still able to talk, think, write, listen and interact with the world. He writes, “In light of this position of passivity and dependency, my role as the chief financial support of the family has
acquired greater symbolic importance in my mind; it became a mainstay of my ego” (212). Thus, his income and benefits as a professor continue to support his family. He also provides advice and feedback to Yolanda, herself an anthropologist. And he acknowledges that Yolanda is dependent on him, albeit in different ways and to different degrees.

Throughout our ten-year siege, Yolanda has clung to me as I to her, for she has her own forms of dependency, and our need for each other has protected our bond in trying times. We have built around ourselves a universe; we have become extensions of each other; we have absorbed each other. But in some ways we have remained strangers, for in all our thirty-six years together, we have negotiated the tricky game of holding on to one another while not losing ourselves. There is always that residual inner self where we store private moods and memories, and where we dream strange things. And so Yolanda remains a mystery to me, but this is why the magic remains after these many years. (219).

Thus, Murphy’s relationship with Yolanda is characterized by mutual care. They are able to sustain the reciprocity by ensuring each has a role, that each experiences caregiving and care-receiving, and that there is also space for disengagement from one another.

Even Cohen, the one author of the sample who ultimately does “burn-out” on care, acknowledges that she did receive in the relationship as well—just not frequently and substantially enough to prevent collapse. As already noted, in-home care allowed a blending of roles that was suitable for Cohen’s writing, parenting, and partnering. In addition, Jeff remained Cohen’s emotional and intellectual support regardless of how disabled he became. Like Murphy, Jeff still had his mind to share with his wife. Cohen relays:

I wrote a poem, ‘That Room,’ about our bedroom, where, beginning two or three years ago, Jeff sat in the trike [wheelchair] almost all day, the room from whence ‘Mar!’ issued. I didn’t want to be there, and I got out of there whenever I could, but when something bad happened to me, or something good, I’d go zooming
right back in. Jeff was the one I wanted to tell, especially if it was a math problem or solution, or some incident with my calculus students. And he was the one who would say, ‘You’re great, Mar,’ or ‘Don’t worry, Mar’—just as he had when I was laboring with each of the babies. (94).

As this passage indicates, Cohen relies on Jeff for recognition and support, care tasks that he is able to continue despite his physical disability. In addition, like Murphy, Cohen is able to help the family financially, even from the nursing home he eventually resides in, through physics research (7).

Frequently, the acts of physical care yielded another kind of giving back in the form of intimacy. In these cases the giving and receiving was mutual and simultaneous. Writing about the physical care George gives, Mairs writes:

We carry on a constant, often hardly conscious, corporeal conversation regardless of our other pursuits and preoccupations. Without my disability to throw us together thus habitually, our bodies might spend their days racing separately from one activity to another, coming across each other only in time to tumble into sleep. (54)

and:

Our bodies conceptualize not only themselves but also each other, murmuring: Yes, you are there; yes, you are you; yes, you can love and be loved. (50)

These passages exemplify the constant tension between self and other; the ways in which she is connected, as well as separate from, George’s body. Mairs’ subjectivity and personal identity is quite literally formed through the process of “mirror talk” or mutual recognition as she explains that George “loves me into being” (50), but significantly, it is a subjectivity that is wholly dependent on bodies and thus reminiscent of Weiss’s notion of “intercorporeality.” Mairs’ reference to her body’s relation to George’s (and other’s) body makes clear that corporeal recognition is imperative.
From the caregiver perspective, Kondrake and Cohen both indicate that care tasks can be physically satisfying to them as well. Thus, when Cohen asks rhetorically “what happens when one of the lovers is, in twelve-year-old Bret’s words, in charge of both bodies,” part of that “answer” is the pleasurable oneness between lovers, between carer and cared-for (86). I too experienced this physical gratification when caring for Max. The experience is beyond words, but it is similar to the physical connection lovers feel when having really great sex, or, the connection a couple may experience during couples yoga. It is an in-tune-ness as bodies move together and communicate silently, but knowingly that is rewarding and sustaining. Maurice Hamington’s concept of “caring habits” in *Embodied Caring* comes close to explaining the physical satisfaction that can come with care. For Hamington, “care habits” are the “embodied practices of interaction” (12); “the body ‘knows’ many things, including how to care…Caring habits are practices of the body’s caring knowledge” (4). Drawing on Nel Nodding’s understanding of “engrossment”—the carer’s preoccupation with the cared-for—and Merleau-Ponty’s phenomenology of the body, to outline care habits, suggesting that care theory needs to attend to the embodied aspects of care. Nodding’s explains the state of engrossment as “I receive the other into myself, and I see and feel with the other. I become a duality” (30). As flesh connects in the act of caregiving, a “weaving relations between bodies” occurs as bodies familiar to each other “read” and “speak” through touch (51-53). This sensing is subconscious (habit), but pleasurable nonetheless, and Hamington sees its recognition as key to understanding how care is sustainable and ontologically fundamental.
I, too, think that recognition of physical pleasure in care is key to re-casting care. And each of the authors in this analysis are attentive to the physical pleasures of care. I read one of the photos that accompany Cohen’s text as illustrative. Jeff has his back towards the camera and he is sitting on the edge of the bed. Cohen is facing him (and us) with her arms wrapped around Jeff’s shoulders and neck. We know from the text under the photo that this is a break “between steps two and three of getting Jeff out of bed,” but it is also a very intimate moment (67). If it weren’t for the text, the viewer would simply think it was a couple embracing. It is not intimate in the sexual sense, but in the “constant, often hardly conscious” intercorporeal sense that Mairs writes about. Cohen writes that even now—with Jeff in the nursing home—their bodies remain pleasurably connected:

Now I sit with Jeff lovingly, my hand around his, his around mine. (I have to put his around mine. Just a few days ago, I remarked, ‘I know that was just a spasm, but it still feels good, your gripping my hand,’ and he smiled.) I sit with him, sometimes lie with him, if he’s been placed sufficiently to one side of the bed so there’s room for me. Long quiet looks, maybe some kissing, even petting, as much as the feeding tube and catheter will allow” (130).

In this passage physical intimacy also begins to blend into a more explicit sexual connectiveness. Other times the care moments seem to actually facilitate sexual intimacy, as when Cohen notes that “toilet” (helping Jeff in the bathroom) “at least at the beginning, had intimate overtones” (130). Likewise, Kondrake describe bath time as another opportunity for more sexual play:

I lift Milly from her wheelchair onto a shower-chair, give her a shampoo, and wash her back and face. She washes her chest. Then I ease her to a standing position and our joke is, ‘I’ll wash the backside, you wash the front.’ After a rinse-off, I wrap Milly in towels, making her look like a robed Arab prince, and wheel her to brush her teeth and then put her clothes on. We have another
standing joke when I help her get into her bra. I always say, as I move a breast into it, ‘Aha, this is the good part.’ And she always laughs. (123)

In all of these instances intimacy or sexuality is not normative—it is not the way in which readers may expect sexual intimacy, but the authors write about it passionately at length, indicating how important and pleasurably such blending of care and intimacy/sexuality can be for disabled/nondisabled couples. All of the authors (except for Cohen) continue to have more traditional sexual relations with their partners (some more than others), but the messy moments in which care blends into intimacy which blends into sexuality get much more play.

These renderings of sexuality, care and the disabled body expose both the sexy and the “ugly,” which, as Wade argues, is vital to correcting omissions in the disability rights movement. Writing about sexually intimate moments can help correct the belief that disabled/nondisabled relationships are sexless, and it can also show outsiders how sexual intimacy may look different in these relationships. In addition, it is politically necessary that the need for personal care be represented; otherwise, the realities of the disabled body are glossed over. As Cohen writes, we’ve got to “spill the dirty details;” otherwise, support for disabled people and their partners will continue to dwindle (26).

**Documentary Self-Representations**

Like the autobiographies analyzed above, documentary films can be a very effective way to reach nondisabled audiences and to articulate radical, new understandings of care and intimacy. Unlike written autobiographies, documentary films require much less “investment” from an audience and play on viewer assumptions about documentary cinema as “reality” or “truth.” Documentary viewers expect to learn
something, to gain insight into a reality not otherwise available to them. Thus, for
disability activists, documentary film can help inform nondisabled audiences about
disability issues and counter stereotypes about people with disabilities that are pervasive
in mainstream representations. As a tool of self-representation, documentary film is also
a location where new understandings of care and intimacy between disabled/nondisabled
partners can emerge. This section analyzes how four documentaries—*Shameless: The
ART of Disability* (Bonnie Sherr Klein 2006), *Want* (Loree Erickson 2007), *Sick: The Life
and Death of Bob Flanagan Supermasochist* (Kirby Dick 1997), and *Doin’ It: Sex,
Disability and Videotape* (The Empowered Fe Fes and Beyondmedia Education 2007)—
express interconnectedness, reciprocity, care, and intimacy in sexual relationships. I
argue that all four films offer nondisabled audiences new understandings of disability and
intimacy, and all four films engage in filmic practices that blur the boundaries between
self and other, highlighting interdependence. *Doin’ It*, however, fails to adequately
address care because it operates within a model of assimilation that downplays the
difference(s) disability makes. *Sick*, *Shameless*, and *Want* are more effective at
addressing the excesses of the disabled body, suggesting that care can increase (not
hinder) intimacy, and emphasizing reciprocity between partners. Since films made by
and for people with disabilities are a relatively new phenomena, there is not yet a
substantial body of work from disability studies to frame the study of these four films;
therefore, I will use literature from documentary studies and feminist film theory and
criticism. Like Rosemarie Garland-Thomson and other disability studies theorists, I find
feminist theory an excellent tool for beginning examinations of disability. As Garland-
Thomson writes, “Feminism’s insistence that standpoint shapes politics; that identity, subjectivity, and the body are cultural constructs to be questioned; and that all representation is political comprise the theoretical milieu in which I want to examine disability” (21). This study echoes Garland-Thomson’s sentiments by using feminist thought about documentary representation to ground an analysis of disability related documentary, which will help address the potential benefits and limits documentary film offers disabled filmmakers and their allies.

Using film to increase disability awareness is truly ground-breaking because, historically, the high costs and expertise required to produce and distribute a film have made documentary filmmaking an outlet only available to the privileged (white, male, nondisabled). However, with the advent of handheld, affordable video cameras, and now digital camcorders, film/video production is increasingly becoming a mode of self-representation available to the marginalized. For example, in the latter part of the 20th century, women, racial minorities and gays and lesbians began to turn to documentary filmmaking to represent their experiences, their “realities.” People with disabilities have been slower to pick up the camera, but with community programs dedicated to increasing access to artistic expression such as dance, theatre, and film, we are beginning to see a body of disability documentary film emerge.

Documentary filmmaking, however, brings its own set of ethical problems to issues of representation. Like Hollywood cinema, documentary relies on a realist tradition that invites spectators to accept the film’s version of the world. Both rely on cinematic conventions such as continuity editing that mask the construction of the text.
Documentary especially attempts to portray a neutral record of reality and is the mode that most inspires trust in spectators (Renov 84). “Neutral,” however, is highly problematic because all film, including documentary, is an assembled, edited, manipulated version of a particular vision(s). As film scholar Bill Nichols writes, “films present particular kinds of views. These views are ideological, and how we see them has everything to do with how we see ourselves, what we take our-selves to be, and what we want our-selves to become” (Ideology and the Image 5). Historically, the claim of “objectivity” or “neutrality” has masked dominant ideology that supports the position of those already in power. This has caused some feminist film critics to dismiss the revolutionary potential of documentary, opting instead for experimental forms that attempt to create new ways of representing women. Janet Walker and Diane Waldman, however, argue that documentary—even when it does appropriate realist strategies—can still be progressive because its focus and/or creators are the marginalized (12). Feminist documentary, like disability documentary, attempts to represent lives that have historically been misrepresented or unrepresented, and this inherently makes them “progressive” because they are using the tools of the privileged for their own purposes. Furthermore, it is unrealistic to expect marginalized filmmakers to work on creating alternative representations when there is a pressing need for visibility. As Jane Gaines’ notes: “Leftist media workers cannot afford to undertake an abstract analysis or make an educational statement about representation if it is politically imperative that they make a representational reference to a ‘brutal actuality’ in order to counteract its ideological version” (qtd. in Walker and Waldman 12). In other words, experimental mediations on
the politics of representation are less pressing than providing counter-images; plus, documentaries that employ realism can reach a wider audience and in this sense may be a more effective tool than experimental film.

Walker and Waldman also argue that unlike traditional documentary filmmakers who practice observational or direct cinema methods, “feminist filmmakers have thought long and hard about the politics of people filming people” (13). In feminist documentaries, the line between filmmaker and subject is often blurred. The filmmaker may also be the subject of the film, as in autobiographical films, or, the filmmaker may also collaborate with subjects, creating shared meaning. In Walker and Waldman’s words: “Documentaries initiated by people who take up a camera to film their own lives or by people and filmmakers coming together to tell common stories must be appreciated as at least potentially radical” (17). “Shared-goal filmmaking” in which the filmmaker and subject(s) are either one in the same or collaborators is especially important for people with disabilities because they have historically been the objects of medical and filmic gazes.

My own study of documentaries made by people with disabilities or about people with disabilities—called disability documentary from here on—takes form into account, but, following Walker and Waldman’s argument, does not dismiss the radical potential of realist strategies. In what follows I analyze four documentaries which, in some way, address disability, sexuality, and intimate relationships. My analysis of these four films is by no means exhaustive—each deserves a much more thorough examination of its content and form. My comments in this section are limited to each film’s treatment of
disabled sexuality, focusing especially on the role of care in intimate relationships. So that I can move freely between the films in my analysis, I begin with a short summary of each film, providing a little background about the context of the documentary and/or filmmaker(s).

The Films

_Shameless_ follows five disabled activist/artists in Canada—Bonnie Sherr Klein, Geoffrey McMurchy, David Roche, Catherine Frazee, and Persimmon Blackbridge—as they create self-representations for KickstART!, a disability arts festival. Along the way the five friends discuss disability discrimination, media stereotypes, love and relationships, the limits of the body, and other disability issues. _Shameless_ is Klein’s first film since her stroke in 1987. She is best known for her documentary film, _Not a Love Story_ (1981) about pornography and its negative effect on women.

_Sick_ follows another disabled artist/activist, Bob Flanagan, self-described “supermasochist.” At the time of his death in 1996 at age 43, Flanagan was the oldest living survivor of Cystic Fibrosis (CF), a hereditary disease that causes the body to produce excess phlegm in the lungs, resulting in difficult breathing, constant cough, pancreatic and bowel problems, and increased infections. The film chronicles Flanagan’s last two years of his life (including, eerily, his death) focusing especially on Flanagan’s relationship with his life partner Sheree Rose, their Mistress/slave relationship, and Flanagan’s BDSM performance art. Video excerpts from Flanagan’s earlier performances are edited into the film.
In *Doin’ It* we watch a group of young disabled women in Chicago called The Empowered Fe Fes become sexually enfranchised. The group is organized by Access Living, a Chicago disability rights agency and is coordinated by Susan Nussbaum and Ana Mercado. *Doin’ It* is the Empowered Fe Fes’ second film made with the help of Beyondmedia Education which,

> envisions a compassionate and just society where universal access to media tools and information equip women and youth to document and communicate their stories, serve as educators and role models for others, influence public policy, and generate social transformation. Beyondmedia Education's mission is to collaborate with under-served and under-represented women, youth and communities to tell their stories, connect their stories to the world around us, and organize for social justice through the creation and distribution of alternative media and arts (Beyondmedia.org)

In *Doin It* the young women talk with each other about sexuality, visit a feminist sex toy store, listen to guest lectures on eugenics and domestic violence, and interview people on the street about disability stereotypes.

*Want* is a short autobiographical film by Loree Erickson about her desire to be seen as more than a person with a disability and to make visible queer crip sexuality and community. During the first few minutes Loree makes out with a butch lesbian in front of the window of her apartment and then gives fellatio to her partner’s strap-on dildo in the bathroom. The voice over comes in and out of this sequence. Loree says, “I want to be a girl you picture naked…a girl you fuck in public…a girl you want to make come so hard, she can’t even scream…a girl that makes your skin flush.” There is then a cut to a black screen, silence, and pink text that reads:

> For the past 6 years the majority of my personal care needs (going to the bathroom, getting in and out of bed, cooking dinner, showers, laundry, etc) have been met by a collective of folks from my community. This collective started in
response to the inadequacy of public funding for personal care and staffing difficulties due to the homophobia of many of the paid personal attendants. I have been extremely fortunate to meet my care needs in this way. I not only receive care based on mutual aid, but share laughs, wisdom, and sorrows. It also enables me to express myself as a sexual being without fear of abuse or denial of care.

A sweet song by Mirah called “momentum” begins to play and we see a sequence of Loree receiving care—she enters the bathroom, receives help with removing her pants, is transferred to the toilet, uses the bathroom, is transferred form the toilet and dressed. After this sequence there is another voice-over speech about Loree’s desires to be seen as a full person, mixed with images of queer crip sex and rolling on the street, getting on the bus and so on.

Using Bill Nichols’ thorough topology of six modes of documentary address (poetic, expository, observational, participatory, reflexive and performative) as a lens, it is immediately interesting to note that each film primarily employs “alternative” modes of documentary filmmaking (e.g., participatory and poetic) that emphasize subjective, embedded experience, multiple truths and collaboration or community. This is a significant choice because audiences are likely much more familiar with more “traditional” documentary forms that use expository or observational methods. Expository documentary “assembles fragments of the historical world into a more rhetorical or argumentative frame,” and often uses an off camera (voice-of-God) or on-camera (voice-of-authority) narrator—typically a strong, male voice—to establish authority and guide the audience into a particular point of view (Nichols 105). Key to the expository mode is the “impression of objectivity and well-supported argument” (107). Similarly, the observational mode is heavily invested in establishing the
appearance of objective truth. Developed in the later part of the 20th century as film and sound equipment became more portable, observational documentaries take a “fly-on-the-wall” approach. According to Nichols, filmmakers using the observational mode relinquish control “over the staging, arrangement, or composition of a scene” to capture the “lived experience spontaneously” (110). Further, “honoring this spirit of observation in post-production editing as well as during shooting resulted in films with no voice-over commentary, no supplementary music or sound effects, no intertitles, no historical reenactments, no behavior repeated for the camera, and not even any interviews” (ibid.).

Feminist filmmakers critical of the expository and observational modes’ appearance of objectivity have historically resorted to participatory, reflexive, poetic, and performative strategies—all of which stress subjective “truths” and invite the audience to think critically about what they see. These films may still employ realist techniques, but the audience is also made aware that they are watching a representation of reality, not “reality” itself. For example, in the reflexive mode the filmmaker turns spectator attention to the artifice, to the process of making a film or creating representations, in order to foster a critical distance. Similarly, the performative mode emphasizes the construction of the image, of knowledge; and, the “poetic mode stresses mood, tone, and affect much more than displays of knowledge or acts of persuasion” (Nichols 103).

Finally, in participatory documentary the filmmaker is shown interacting with subjects. He or she may even become the main subject of the film. Nichols states that “Participatory documentary gives us a sense of what it is like for the filmmaker to be in a given situation and how that situation alters as a result” (116). Thus, situated knowledge
and engagement are stressed over objective truth. This is particularly important for
disability documentary because it places representational power and authority into the
laps of people with disabilities, people who have traditionally been the objects of
medical, rehabilitation, and institutional powers. In participatory documentary films,
people with disabilities can become subjects, narrating their own stories.

*Want*'s dominate mode is poetic. Whereas the other films rely on a clear plot,
with a “climax” and resolution, *Want* is composed of seemingly unrelated scenes,
 juxtaposed to call attention to community, belonging, desire, care and intimacy. Thus,
for example, we move from Loree giving fellatio to her partner’s dildo in the bathroom,
to Loree receiving help with toileting, associating care with sexuality and intimacy. The
care sequence is particularly innovative because it is composed of clips of at least five
different people helping Loree with toileting. Using a montage here emphasizes the
breadth, camaraderie, and intimacy of her community, even around something viewers
will likely consider very deeply private—using the bathroom. While *Want* does not tell a
traditional story, it does relay the filmmaker’s desires for recognition and inclusion, as
well as offering a snapshot of a life that blends community care, intimacy and queer
sexuality.

All four films employ the participatory mode at some point; however, it is the
dominant mode for *Shameless, Doin’ It, and Sick*. The fact that the subjects may change
as a result of the filming is, after all, one of the main goals of Beyondmedia—they bring
the tools of self-representation to underprivileged populations to encourage
empowerment and growth. In *Doin’ It*, Beyondmedia’s impact on the Empowered Fe Fes
is palpable. Going out into the streets to ask people their opinions about the sexuality of people with disabilities takes guts, but we see these young women—cameras in hand--approach strangers and talk publicly about sex with ease. Talking about the filmmaking experience, Fe Fe member Chaka Stovall says, “Holding the camera made me feel like I was in control. It was like, I can handle this. This is cool” (Roche).

Although less the intent of the films, the impact of the filmmaking process is also evident in Sick and Shameless. The opening lines of Shameless highlight the impact of the camera. As Klein is shown in her bathrobe, putting on make-up in the mirror, she says, “Try to hide the blemishes. As much as I talk about wanting to present true, authentic images, um, I’m conscious of wanting to look good!” Later, before filming David Roche’s stage rehearsal, Klein turns to the camera people and instructs, “So, I guess I wanted to tell you some things first about the shoot today, ok? This is David’s workshop; David paid to have Corey work with him today. But he’s very excited to have—he likes and audience, he likes the camera, so, and we’re all being very conscious that it is a film and we’re making a film, so you should feel free to be active and get right up there and run around with him.” Thus, the acknowledgement that the presence of the camera may change behavior—in this case for the “better”—is made explicit.

Sick is a bit different simply because the camera has been a constant feature in Bob Flanagan’s life even before filming the documentary. As part of Bob and Sheree’s slave/Mistress contract, their sexual exploits, Bob’s feelings and experiences with “slavery” and pain, were meticulously documented, and much of this material ends up in the documentary. In the additional footage shot for the documentary, Bob frequently
interacts with the person behind the camera, whether it is his partner Sheree or Kirby. At one point Kirby asks Bob from behind the camera,

Kirby: I read this quote about how biographers are vampires. In a sense I’m your, or one of your biographers. What is your thought—
Bob: I don’t think of it that way, no. I feel this is more of a collaboration, so I don’t really feel that way.
Kirby: Uh-huh.
Bob: But I don’t get that sense at all.
Kirby: Uh-huh, but now if for some reason the film, I mean, I mean, isn’t finished until, I mean, until after you die—I mean obviously Sheree’s still involved—
Bob: Right.
Kirby: I mean its still a collaboration, but—
Bob: Sure, absolutely, I mean maybe more of a vulture than a vampire—
Kirby: [laughter]
Bob: --that’s more like it…just waiting for me to cough, take off. Ya, you’re a vulture, I see you circling around right now, that’s what it is.
Kirby: What do you think about that?
Bob: Um, oh its funny, it doesn’t bother me. We’ve talked about it beforehand so its—its no different than what I’m already doing myself.

And then the film cuts to Bob’s “video coffin” exhibit—an example of the ways in which Bob’s life has been continuously documented by he and Sheree. The exchange between Kirby and Bob is illustrative of participatory filmmaking ethics, a commitment to collaboration and to open interaction between subject and filmmaker*

A primary result of the participatory mode is that the line between filmmaker and subject(s) becomes less finite, which helps emphasize “shared-goal” filmmaking. In all, the line between filmmaker and subject(s) is blurred, sometimes beyond recognition. In *Want* filmmaker and subject are one in the same. There is no meaningful distinction between Loree the character and Loree the filmmaker. The line becomes more demarcated in *Shameless* and *Sick*. Klein is listed as the writer and director of *Shameless*, but she is also a subject in her film, and the other main characters are listed as
collaborators. In addition, there are several places in the film in which the characters say “our film.” Thus, Klein’s ultimate control over the final product is recognized in her retention of the title of director; however, true to her feminist commitment she engages in “shared-goal filmmaking.” Similarly, Kirby Dick is listed as the director of Sick, but it is clearly a collaborative project in which Bob and Sheree are also filmmakers.

Blurring the line between subject/filmmaker and engaging in “shared-goal filmmaking” emphasizes relationality. Whereas the autobiographies outlined above often included the “voice” of partners and other loved ones, these films include the images and sounds of multiple filmmaker/subjects to emphasize interconnectedness.

And like disability autobiography that feature intimate relations, these films too emphasize the body. This is particularly significant because, as mentioned in chapter 3, disability activism in the U.S. has historically downplayed the disabled body, focusing instead on erasing differences between the disabled and nondisabled and creating physical access. The discomfort with addressing the disabled body is mirrored in the academic literature. As Dawn Reynolds notes, “Pain—and physical embodiment in general—is currently an understudied topic in disability studies, a field devoted, at least at this stage of its development, to the social conditions affecting disabled people” (42). The focus on the body, including pain and other “icky” aspects of the body, in Sick, Shameless, and Want reflects a recent turn towards what Tobin Siebers has called a “new realism of the body” in which disabled writers “have begun explicitly naming their impairments and their corporeal characteristics, including pain, in both their academic texts and their autobiographical works” (Reynolds 42). Of course, Flanagan was
infamous for using BDSM to control the physical and emotional effects of CF. His most famous BDSM act was nailing his penis to a board, but other public and private “tortures” included having an “S” carved into his chest (to signify he belonged to Sheree); being suspended upside-down by his ankles and naked, on display at Visiting Hours; being flogged, slapped, punched and otherwise beat; drinking Sheree’s urine; and eating his own feces (which he considered the ultimate act of humiliation). Having CF meant that Flanagan spent large amounts of time in the hospital in which he was subjected to humiliating and painful examinations and treatments. Even when he was “well” enough to be out of the hospital, Flanagan was frequently in pain. He could not control the pain and humiliation of CF, but BDSM could provide therapeutic amounts of temporary control and mastery over his body. As Reynolds puts it, “Flanagan was able to gain physical and psychological control over a body that was frequently out of control” (43).

On a much less extreme level, Shameless and Want also expose the disabled body and the need for care. The sequence in Want in which Loree is cared for by various friends. This sequence, combined with the emphasis in the sex sequence on Loree’s body and wheelchair, make visible the differences of disabled body. In the very last sequence of the film Loree and her lover are having sex and her lover accidentally turns Loree’s power chair on. The two laugh it off, but including this moment in the film demonstrates Loree’s commitment to “full” visibility, body/chair accidents and all. Similarly, Shameless refuses to edit out moments in which the excesses of the disabled body and its need for care become obvious. Early in the film the five friends are having a movie
night, watching examples of Hollywood representations of disability. Suddenly McMurchy’s legs have a spasm and his bowl of popcorn falls off his lap. It would have been easy to leave this moment out of the film, to minimize the difference disability does make, but Klein chooses to include it, as she does her own fall in her bedroom later in the film. *Shameless* is also reflexive about the tension in the disability community to present only “strong and able” images to the public. When Frazee suddenly falls very ill and has to be hospitalized, Klein talks openly with Frazee about how hard it was to see Frazee—a pillar of strength in the community—so frail and sick, and Frazee notes that her own denial of her body sometimes results in these moments of extreme illness. This conversation highlights the realities of illness and the need for medical attention and care from friends and lovers, while maintaining control over one’s life, autonomy, and serving as a source of strength for others.

*Shameless, Sick* and *Want* are careful to relay that the need for care in no way hinders intimacy between sexual partners. In fact, the films seem to suggest a blurring of care and sexuality, in which care contributes to the couples’ overall intimacy. For example, for Flanagan, regular floggings also had the therapeutic effect of clearing Flanagan’s lungs of mucus, thus explicitly blending “care” and sexuality (McRuer 182). Care and sex/intimacy is also blended in *Shameless*, albeit less explicitly. After Frazee returns from the hospital we see her and her partner at their cottage in the woods, enjoying nature and time together. The audience even becomes privy to a romantic bubble bath the two take. This sequence helps make clear that the care Frazee needs in no way hinders sex/intimacy. *Shameless* also includes an interesting sequence with Klein
and her husband Michael in which they openly discuss why Michael stays with Klein after the stroke. In voice-over Michael says, “The men of women who’ve had strokes leave their wives a shocking 80% of the time. Why didn’t I leave? Oh, poverty of imagination, I suppose. [Laughter] No, I didn’t leave because our relationship basically didn’t change. I mean that’s the major issue, that Bonnie takes care of me. And she took care of me when she was in the ICU and quadriplegic, she was taking care of Seth and me and Naomi.” While Michael says this we see him help Klein across a rocky beach and into a canoe that they then paddle together. As these films make clear, the excesses of the disabled body require a level of care between partners that increases intimacy.

Interestingly, Doin’It does not focus on the body, care, or connection between bodies. My suspicion is that the excesses of the disabled body, pain, and the need for care are repressed in Doin’ It out of a belief that such cleaned-up representations will help nondisabled audiences identify with the girls. The disabled body and its related concerns are omitted to reduce alienation, to help audiences rally behind the film’s cry for social change, including the removal of environmental and social barriers that limit sexual expression for women with disabilities. In this sense, Doin’ It is similar to Simi Linton’s autobiography analyzed above. Both reflect the belief that ignoring the disabled body’s specific needs is more politically viable than pointing out that people with disabilities need care and have bodies that will not fit, regardless of the accommodations the nondisabled majority provide.

Doin’ It’s investment in assimilation is also evident in the film’s treatment of sexual orientation. The girls are empowered to engage in heterosexual relationships.
While not explicitly homophobic, there is a concerted effort to fit the images of the young disabled women into heteronormative society. The intimate relationship highlighted in the film is between Tania Rodriguez—the original Fe Fe—and her boyfriend, Burnis. In addition, gay, lesbian and bisexual sexuality occupies only 23 seconds of the 35 minute film—the girls primarily discuss only heterosexual sex and relationships in their many meetings. *Want, Shameless,* and *Sick,* on the other hand, all take a much different direction. In *Shameless,* the lesbian relationships between Persimmon and Mac, and Frazee and Pat, have equal status to the heterosexual relationships between Klein and Michael, and Roche and Marlene. And *Want* and *Sick* are both entirely about queer sexuality. In *Sick,* *Shameless,* and *Want,* there are no efforts to recuperate the character’s failures of normativity, either in terms of disability or sexuality—on the contrary, non-normativity is celebrated. Thus, when the film is able to highlight difference instead of similarity, the film is able to make more radical articulations of care and disabled sexuality. Drawing from Robert McRuer, the “normalizing” of disability at work in *Doin’ It* depends on disciplining queerness (176).

Throughout this dissertation I have argued that repressing the disabled body and the needs for care does not serve people with disabilities and their partners. In addition, my analysis of self-representations has revealed that such repression is not even necessary—audience identification is still possible across the difference disability makes. For example, as Nancy Mairs does in writing, Bob Flanagan employs a “strategy of layered (un)familiarity,” frequently coupling scenes that “evoke a flash of shock and
pity” with scenes that encourage spectator identification (Mintz 266). Flanagan’s primary method of encouraging engagement was humor. Dawn Reynolds writes:

Laughter created collaborators: Those at Flanagan’s exhibit who understood his humorous touches were conspirators in his quest to open up conversations about and connections to sexuality, illness, and death. The artist’s use of humor served to disarm and put at ease even the most squeamish audiences. During one particular performance, in which Flanagan sewed his penis inside his scrotum, his monologue included jokes, which he believed put his audience off guard and distracted them from what he was actually doing. He argued that people would ‘accept it better if I’m sitting there telling jokes like I’m working on some macramé or needlepoint—well, this [scrotum-sewing] is a form of needlepoint!’” (47)

Thus, Flanagan’s performances could deal with “heavy” issues—BDSM sexuality, death, the physical pain of CF—without completely alienating his audiences. *Sick* recreates this layered (un)familiarity by juxtaposing scenes in which Bob and Sheree are mundanely talking with scenes of BDSM.

Similarly, *Want* and *Shameless* mix strategies that encourage spectator identification and distance. For example, to see Klein fall in her bedroom, to see McMurchy struggle with grasping and handling a set of springs, and to see Roche’s disfigured face all may provoke a sense of distance from nondisabled audiences, but each of these scenes stand next to images and acts that emphasize how similar people with disabilities are to the nondisabled. Roche is loved and massaged by his able-bodied wife, Klein talks about wanted to “look good” for the camera and put on make-up, and McMurchy talks about enjoying his independence. Thus, over the course of the film, *Shameless* shows filmmakers and subjects as both different and similar to nondisabled audiences.
*Want* uses the different channels of expression available to a filmmaker to simultaneously layer familiar with the unfamiliar. For example, during the care montage sequence in which Loree’s friends help her with toileting, on top of the music we hear Loree in voice-over say, “I want to be a girl you laugh with…a girl you have fun with…a girl who cares for your heavy heart…a girl you respect…a girl who makes you stop and think about the world around you…a girl you can be real with…I want it all.” Everyone, regardless of disability, can identify with Loree’s desires. The image channel, however, is showing an experience that is likely to be very alienating to nondisabled audiences. By coupling the two, image and sound, Loree increases the chances that audiences may be able to adjust, continue to engage the film, and perhaps begin to understand the disability experience.

Layering the familiar with the unfamiliar (theoretically) increases spectator openness towards difference. Thus, in *Want, Shameless*, and *Sick*, audiences can “take-in” the difference of disability and sexuality, including the need for care between intimate partners. *Doin’ It* is also palatable to nondisabled audiences; however, *Doin’ It* does not stress difference but similarity to nondisabled people. In terms of disabled/nondisabled couples, *Want, Shameless*, and *Sick* are able to represent—in both content (images and dialogue) and form (participatory or poetic modes)—care between partners that emphasizes increased intimacy, reciprocity, and love.

Overall all four films revise dominate understandings of disabled sexuality. Thus, according to Walker and Waldman, these films are inherently progressive because marginalized subjects make (or collaborate with to make) the images. In terms of
documentary film mode, all four films also blur the lines between filmmaker and subjects, emphasizing interconnection and interdependence. *Doin’ It*, however, is unable to clearly articulate innovative constructions of care and intimacy because it is invested in a normalizing project that rejects the queerness and the excesses of the disabled body, including the need for care.

**Conclusion**

The self-representations analyzed above—for the most part—offer readers and viewers alternative understandings of care and sexuality in disabled/nondisabled intimate relationships. Frequently, these representations are explicitly speaking back to, and critiquing, dominant representations that paint their relationships as burdensome, sexless, and tragic. These texts are not, however, entirely happy, “overcoming” narratives. They portray disabled/nondisabled relationships as complex, sometimes positive, sometimes negative, but ultimately valuable and sustaining. Such representations are not always easy to read. For example, I admit being uncomfortable with some of Cohen’s rants about “nights, toilet, and lifting.” As a nondisabled partner I wanted Cohen to paint the picture better. At several points I would become angry at Cohen for making the pains so visible. I know that Cohen also portrayed the joys, but the raw exposure of the tribulations made it difficult to ingest because I was so invested in showing a positive image of disabled/nondisabled intimate relationships.

The other night I was struggling with this very ambivalence, reading and re-reading Cohen’s text. It was hot in the bedroom, so I took off my bed-pants and slipped back into the sheets. As I was enjoying how good the cool sheets felt on my legs, I
realized that I had not experienced this feeling for over six years. When Max was alive he frequently ate meals in bed, especially when the MS fatigue was bad. It was simply easier to just eat in bed than work on transferring, dressing, sitting at the table, and the undress, and transferring again. This meant, however, that there were *always* crumbs in our bed. Even though I changed the sheets often, and I would nightly try to wipe out the crumbs, I could never get them all it seemed. At the beginning of our relationship I would try to sleep, as I had always done, in just a nightshirt, but inevitably I would be just like the girl in The Princess and the Pea. That one teeny, tiny crumb would feel like a brick and I would be unable to sleep. Eventually I resigned myself to this reality and got used to sleeping in pants.

So, almost a full year after Max’s death, I take off my pants and feel no crumbs and am happy. Then, I’m sad and feel guilty for being happy. The bed crumbs also meant that Max was always around, in-bed, and available for me to talk to. My office was in our bedroom, so I would write and grade and he could eat and watch TV or read, but through it all we were constantly together. There were crumbs, but I had a brilliant man that I could turn to at any moment and ask for another word for “complexity,” or ask how Emmanuel Kant viewed moral autonomy. Like Cohen, I hated some aspects of Max’s disability, but loved other parts. It was…complex, but beautiful.

Representations that unabashedly show this reality—the good and the bad—correct the dominant representations of disabled/nondisabled intimate relationships outlined in Part 1. But they are also not the lifetime movie version of care and disability, or the plucky, overcoming tale that David Mitchell cautions against. These
representations answer Tobin Seiber’s call for “new realism” of the disabled body by drawing attention to both the pleasures and pains of disability. And, as I’ve argued throughout, it is vital to expose the need and value of care and sexuality in disabled/nondisabled intimate relationships. Doing so not only improves the treatment of people in disabled/nondisabled intimate relationships, but it also shifts the meanings of care and sexuality for all people.

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1 I searched the following databases for reviews and scholarly articles: MLA International Bibliography, Academic Search Complete, and MEDLINE with Full Text. This search generated only one review of Dirty Details, interestingly located in the “Science and Technology” book review section of the Library Journal. Morton Konracke’s Saving Milly generated 12 book reviews. Nancy Mairs and Robert Murphy, two of the disabled autobiographers I examine, have numerous scholarly articles about their work.

ii Although I will use both interdependence and intersubjective to signify this fundamental connectivity, I prefer intersubjective because it foregrounds subjectivity. In addition, as noted in chapter 3, interdependence has been discursively deployed by the disability rights movement to emphasize disabled people’s autonomy once access has been provided, once again masking the substrative connection to others.

iii I suppose all intersubjective moments take place in bodies; however, I am reserving the term to describe moments in which the author is foregrounding their or their partner’s body in the relationship.

iv As noted in Chapter 3, personal care assistance is not paid for my the government except in a few areas that have secured grant funding to provide support to people with disabilities. There is no federal program and most of the local programs are geared to MRDD individuals—not people who become disabled due to spinal cord injury, MS, Parkinson’s, etc.

v Experimental or avant-garde film rejects dominant or established methods of filmic representations used in commercial (Hollywood) film. Since feminists argue that Hollywood film viewing practices are based on objectifying women, feminist experimental filmmakers have attempted to represent women without objectification. For example, in Riddles of the Sphinx (1977) Peter Wollen and Laura Mulvey use thirteen 360-degree pan shots to tell the story of a housewife’s liberation, rejecting more conventional methods like continuity editing, close-ups, etc. Some critics, however, argue that although such techniques provide useful experiments on how films create meaning, they fail as vehicles of social change because they alienate audiences.

vi In terms of disability, experimental film strategies may also be more problematic because they assume a nondisabled audience that is able to make connections and interpretations that may be difficult for spectators with brain injury or developmental disabilities. In this sense, then, realist methods improve “access” for a wide spectrum of audiences.

vii BDSM stands for bondage, dominance/discipline, sadism, and masochism.

viii “Crip” is a reclaimed word used by some disabled activists to connote a hip, in-your-face attitude about impairment. Like “queer,” it is a word which is not offensive when used by the marginalized identity group member.

ix It is interesting to note that in the credits the film director is listed as Salome Chasnoff. The members of the Empowered Fe Fes get first billing, but they become more like characters in the credits as they don’t even get camera work credit, which is quite odd considering the films emphasis that this is THEIR film and
we even see the girls holding film cameras. Regardless, the filmmaking is clearly a collaboration between Salome and the young women.

\(^3\) Many of Flanagan’s own work, too, connected artist, subject, and audience. As Carrie Sandahl notes, “in *Visiting Hours*, he displayed himself in a bed for eight hours a day over a six-week period and spoke with visitors as they encountered him. He engaged in dialogue about medicalization, body imagery and disease” (101).

\(^{35}\) Notice the contrast to the more mainstream films discussed in chapter 2. For example, *Murderball* (a theatrically released documentary NOT made by or for people with disabilities) suggests care—specifically dependence on partners for physical tasks—may hinder relationships. After Zupan and his girlfriend tell the cameras that they have a wonderful relationship, the film cuts to a montage of Zupan’s girlfriend pumping gas, loading groceries, etc. The camera in each of these shots lingers on Zupan watching passively, helplessly; thereby undercutting the assertion that their relationship is good.
The self-representations analyzed in the previous chapter disrupt the dominant image of disabled/nondisabled relationships by focusing on reciprocity and by blending sexual intimacy and caregiving tasks. To see if these findings were applicable to the experiences of “average” couples—those without the means to create self-representations—I wanted to conduct original research with area couples in which one partner has a physical disability and the other partner is nondisabled. How are these couples treated by outsiders? What do they feel about representations of their relationships? And, how do they experience care and intimacy in their relationships?

After exploring several methodological options (e.g. individual interviews, couple interviews, questionnaires, etc.) I selected the focus group, or “feminist group interview.” Focus groups, used for decades in market research, are becoming increasingly popular in the social sciences (c.f. Breen; Kitzinger; van Staveren) and are generally defined as a group interview, composed of six to twelve people, “that places particular importance on interaction between participants” (Freeman 492). Focus groups are particularly “appropriate for the generation of new ideas formed within a social context” (Breen 466).
I felt that focus groups best fit my research questions and goals for three reasons. First, focus groups allow participants to control the discussion and can, potentially, reveal information I had not previously considered because participants can build on and add to each other’s opinions (Freeman 492; Madriz 838; Reinharz 223; ). Focus groups construct collective knowledges among the participants. Hesse-Biber & Leavy suggest that focus groups create what they call a “happening” (19). Leavy explains that a “happening” is “a conversation that, while prearranged and ‘focused’ by the researcher, remains a dynamic narrative process. Within the context, group members communicate their thoughts, feelings, and experiences on their own terms” (173). The “happening” is the result of the unique interaction between participants. As Tim Freeman puts it: “Focus groups aim to promote self-disclosure among participants, by explicitly capitalizing on group dynamics in discussions. Participants are encouraged to question each other’s responses, elicit clarification and explore caveats to their statements” (492). Thus, the “happening” draws out new understandings for the researcher and the participants, creating a very rich data set. Joan Callahan explains that she chose the focus group methodology based on her belief that the women’s participation and the flow of ideas and information would be enhanced by being able to listen to each other’s experience and to interact with each other…a group interview format facilitates women building on each other’s ideas and augments the identification of patterns through their shared experience (qtd. in Reinharz 223).

In this sense, the focus group mirrors feminist consciousness raising groups. Marginalized individuals begin to notice common experiences and supposedly private,
individual problems become uncovered as collective battles. The focus group can expose
shared social experiences to the researcher and participants alike.

My second motivation for selecting focus groups is the long history of research on
people with disabilities (Barnes, Mercer, and Shakespeare 213-220; Swain, French and
Cameron 131-136). In particular, the sex lives of individuals with disabilities have been
“over-researched” in the applied fields (see chapter 2), thus, performing more individual
interviews risks reproducing this dynamic. Focus groups offer participants the space to
talk about the issues of care and sexual intimacy without focusing on the particularities of
their own lives, unless they so desire. In other words, information about care and
intimacy can be gained without putting individual couples “under the microscope.”
Kitzinger argues that focus groups are particularly good for reaching what she calls
“difficult” populations—groups that are socially marginalized, oppressed, or hard to
reach because the design provides “safety in numbers” and an environment of mutual
support among people with similar life experiences (112). Thus, especially for people
who feel that they have little to contribute to research, the process of group dialogue can
“help people explore and clarify their views and attitudes efficiently” (Freeman 493). In
other research modes, the researcher is more obviously “in control”—asking the
questions, setting the terms of the discussion, probing only when he or she belives the
participants’ comments are significant. In focus groups, the locus of power is more
squarely in the group—“priority is given to the respondents’ hierarchy of importance,
their language and concepts, their frameworks for understanding the world” (Kitzinger
As Madriz notes, “focus groups allow access to research participants who may find one-on-one, face-to-face interactions ‘scary’ or ‘intimidating’” (835).

Third, many couples that deal with disability report social isolation (Parker 114-115). Focus groups can, potentially, facilitate community building among couples experiencing similar forms of disability discrimination and isolation (Madriz 842). As a feminist researcher concerned with the transformative potential of research, I wanted to select a method that encouraged community building and the production of new, group knowledge (Olesen 252). Ideally, disabled/nondisabled couples could be a source of support for each other even beyond the one-time interaction of the focus group.

Focus groups are not, however, entirely ideal. Although all the participants share the experience of being in a disabled/nondisabled intimate relationship, they differ from each other in many ways. The couples in the focus groups varied in terms of age, class, education, religion, and race/ethnicity. Thus, power dynamics inevitably operate within the group, potentially silencing less privileged individuals. In addition, some individuals may not feel comfortable sharing personal information in a group setting, or, may not be able to think of pertinent information at the time of the focus group (Freeman 493; Kitzinger 110). To help mediate these potentially negative variables, I used a journaling or diary method as an additional, optional follow-up study to the focus groups. In the journals participants could write about their personal experiences, thoughts, and issues around care, sexuality, and disability during the two-week period following the focus group. The journals provide a space for participants to speak freely about topics they may have been unwilling or uncomfortable to discuss in the focus group. The journals
can also capture thoughts generated by the focus group discussion, yielding much richer data than the initial group meeting.

Finally, in order to help account for the power dynamics between participants and between myself and the group, I use feminist standpoint theory--as elaborated in the data analysis section below--to guide interpretation. Standpoint theory ensures that the ways in which participants, and myself, are situated in the social-political landscape, and how these locations may influence our knowledge production, are not eclipsed in the findings. In line with standpoint theory I disclosed my investment in the project at the beginning of each focus group. I explained that my partner had MS and that I helped with most of his personal care needs. Thus, it was clear to all the participants that the idea for the project was personal and that I was “one of them.” I also added my own stories next to their during the focus group conversations. I believe these techniques made participants more comfortable with me. I was the “researcher,” but I was also a group member; therefore the potential alienating power dynamic between researcher and subjects was, to a point, mitigated. Furthermore, following Kitzinger’s work on focus groups, I do not necessarily assume that the power dynamics in the group will compromise the data. She argues,  

Instead of generalizing about the effect of the ‘groups’ we need to pay close attention to the composition of the groups and how the characteristics of any particular group may influence what is said. We can then explore what this tells us about social pressures and the construction and the communication of knowledge (112-113).

After all, knowledge is always and inevitably formed in relation to others. Focus groups mirror this reality.
Methods

Like the chapter on self-representations, I did not focus on a particular physical disability in this part of the project. Instead, I limited the scope to physical disabilities that limit activities of daily living (ADLs) such as bathing, dressing, eating, toileting, and so on. Emotional and cognitive disabilities were excluded because the issues that these disabilities raise are very different than physical disabilities—especially around decision-making and political and personal autonomy. For example, family reaction to a couple in which one partner had a severe cognitive impairment and the other partner is nondisabled will likely be rooted in concerns about sexual consent in the relationship, not about the level of physical care the nondisabled partner provides. In addition, physical disabilities that do not limit ADLs were excluded because the focus of this research is on the caregiving relationship in which assistance is needed with instrumental and practical activities of daily life. Examining the relationship experience across physical disability is also a choice that reflects the demands of the disability rights movement. Limiting research to a specific disability, such as Spinal Cord Injury or Multiple Sclerosis, may suggest that the impairment itself impacts the relationship in unique ways. A pan-disability approach focuses, instead, on the ways in which society creates particular conditions, such as inaccessible buildings or bias towards people with disabilities, which impact the disability experience (c.f. Shapiro, Stroman). Such an approach encourages people with disabilities to form coalitions across various types of impairment, focusing on the ways in which they are similarly disabled, and to see themselves as a political, social, and cultural identity group.
For this part of the research project I recruited 12 couples into 4 focus groups in 4 different areas of Ohio. Group 1 was located in Cleveland and contained 4 couples; group 2 was located in Toledo and contained 2 couples; group 3 was located in Dayton and contained 3 couples; group 4 was located in Columbus and contained 3 couples. In each area of Ohio, I contacted regional disability-specific organizations (e.g., National MS Society office in Cleveland, Adapted Recreational Sports in Columbus) and Centers for Independent Living. I explained the research and asked for the organization’s support in recruitment. For some locations this meant sending a recruitment announcement through an electronic listserv. At other locations flyers were posted in their offices, or, mailed out to constituents. Regardless of the distribution method, recruitment announcements read:

Couples are needed for a research study on caregiving between intimate partners, in which one is physically disabled and the other is able-bodied. Eligible couples will participate in a focus group with other couples to discuss their experiences with caregiving and intimacy, and the representation of care and intimacy in popular culture.

Eligible couples include same-sex and opposite-sex couples that have lived together (with the physical disability) for at least one year. Participants will be compensated $30 per person for their time.

For more information & to determine eligibility please contact Sarah Smith at smith.2447@osu.edu or 614-202-1791. This project is being conducted by Dr. Christine Keating and Sarah Smith from The Ohio State University and has been approved by the Institutional Review Board (Protocol number 2007B0092).

When a potential participant contacted me, I provided more information about the study, including the expected time commitment (2 hours for the focus group) and answered any questions. If the person was still interested in participating, I asked a series of eligibility screening questions. In order to be eligible, the person had to answer “yes” to all of the
following questions: Are you currently in an intimate relationship? Does one partner have a physical disability and is the other partner able-bodied? Does the physical disability limit an activity of daily living? Have you lived together for at least 1 year (as disabled)? Do you currently live in Ohio? Are both partners aged 18-65? Finally, I asked if either partner had an emotional or cognitive (developmental/mental) disability. If they answered “yes,” I probed to determine if the emotional or cognitive impairment was severe enough to warrant exclusion from the study. Cognitive impairments like dyslexia and mild ADHD, as well as emotional impairments like mild anxiety or seasonal depression, did not render participants ineligible for this study. Major impairments like schizophrenia, autism and other disorders that may impact decision making warranted exclusion from the study so that the focus could remain on physical care.

If the couple was eligible and willing to participate, I took down their contact information and explained that once enough couples had been gathered in their area, I would contact them again to schedule the focus group. Recruitment continued until I had enough couples in a given area (minimum of 2 couples, maximum of 4 couples per focus group). If I had more than 4 couples recruited in a particular area, they were called back in order (e.g., the first couple to contact me in Toledo was the first couple I called to schedule the focus group). This process of quota sampling continued until all four focus groups were scheduled.

Focus groups were held in locations that would be most convenient for participants in that particular area and were conducted during September and October of 2007. Since many of the participants in Cleveland area had been recruited through the a
disability-related organization in that area, the Cleveland focus group was held in a board
room of the that organization’s offices after normal business hours. In Toledo, the focus
group was held in one of the couple’s homes because the two couples lived very close to
each other and knew one another. An independent living and disability rights
organization was the location for the Dayton focus group as they had been instrumental in
recruiting participants for the Dayton group (all participants had ties to the organization).
In Columbus, the focus group met in the community space of a local Panera Bread to
minimize driving distance for participants. Regardless of location, participants were
reimbursed for metered parking fees (or bus or cab fare if needed) and for childcare. This
was important so that economic barriers would not prevent lower income couples from
participating.

Upon arrival to the group, I reviewed the consent to participate form with each
participant, explaining that the focus group would be audio-taped but that their names and
other identifying information would be removed from the transcript to protect their
confidentiality. Participants were also told (verbally and in writing) that they could
refuse to answer any questions and that they could leave the study at any time without
negative consequences. They would be compensated $30 each ($60 per couple) for their
time, regardless. Because focus group participants may decide to share private
information with the group, each participant was also reminded that what was shared by
other participants should be kept confidential. The participant was provided a copy of the
consent form and a resource list that included disability rights organizations and
information about couples and individual counseling (see Appendix B). Since some of
the focus group discussions could dredge up negative emotions or spark disagreements for the couple, it was important that I provide resources that would help participants work through difficulties. However, no participants reported adverse effects or sought help after the focus group. Before beginning the discussion, each participant completed a short demographic questionnaire (see Appendix B).

The content of the focus group script (see appendix B) was based on the findings from other portions of this research project (outlined in previous chapters). As the chapters on popular culture, the applied fields, and the disability rights demonstrate, disabled/nondisabled couples’ lives are dominated by hegemonic understandings of love and sexuality that reflect ablest manifestations of dependence/independence. So, for example, providing personal care, especially with tasks such as toileting, is represented as interfering with the couple’s sexual lives. Physical care is understood only as a burden, and the disabled partner is viewed as wholly dependent. The focus groups asked participants to speak to these dominant representations and, as a group, construct self-representations that may understand care and intimacy differently. Importantly, the script was intentionally semi-structured and open ended so that participants could take the conversation where they felt it needed to go. All participants understood that the goal of the research was to better understand how they experienced care and intimacy in their relationship, and they were encouraged to deviate from these sections as needed to reach the shared goal of the group.

The script was divided into three sections: 1) how outsiders treat the couple, 2) media representations, and 3) personal definitions of care and intimacy. After briefly
introducing themselves to the other group members, I asked participants to begin discussing how “outsiders” (friends, family, physicians, even strangers) view their relationship. I probed as needed for stories about how such outsiders have treated the couples. Next, I brought up (if it had not already been done) media representations, asking participants whether they felt popular culture influenced how they are treated by outsiders. To spark further conversation, I showed each group a short television public service announcement (PSA) created by Mothers Against Drunk Driving (MADD). I selected this PSA because it quickly relays many of the ablist attitudes commonly found in popular culture. In the PSA, a young man is reading on a park bench and the screen reads “your best friend.” An attractive woman walks up and kisses him as the screen reads “your girlfriend.” The camera moves to the inside of an institutional-looking room with a man in a wheelchair gazing upon the pair and the text reads “you.” The screen fades to black and says “You have a lot to lose.”

Finally, I encouraged the participants to offer their own understandings of how care, dependence/independence, and intimacy/sexuality operate in their own lives. Typically, participants had already offered anecdotal accounts that countered dominant hegemonic representations of their relationships. As facilitator, I brought the conversation back to these accounts to probe for similar and different perspectives and experiences.

At the end of each focus group I explained the optional follow-up study in which each participant would journal about their thoughts on and experiences with care, intimacy, and disability for the following two-week period. If a participant chose to
complete this part of the study, they were given a blank journal and pre-addressed, stamped envelope to return the journal. Participants also had the option of completing the journal on the computer and emailing the entries. This option was especially important for those participants who could not write, but used voice recognition software to “type.” Either way, participants were paid $30 for this portion of the study. Like the focus groups, they could write as much or as little as they wanted.

Although I have kept in touch, informally, with some of the participants, and plan on sending each participant a copy of the book, I did not do member checks (in which they review the transcript and edit as needed), nor did I ask them to participate in data analysis. Ideally, I would have, at least, given each participant a transcript and asked for their feedback; at best, I would have asked them to interpret the findings with me. This is certainly what feminist researchers recommend (e.g., Kirsch). However, I chose not to collaborate with participants on data interpretation for several reasons. Primarily, it was a decision driven by time and financial limitations. Collaborative analysis and member checking can become messy (cf. Borland). As a dissertation project I was concerned that working with participants on interpretation would delay the completion of the project (and my degree), especially since the focus groups were only one aspect of a much larger research project. Additionally, I felt that it was only fair to offer financial compensation to participants who worked with me on collaboration or took the time to review the data; however, I could not afford to offer an monetary payment. On a theoretical level, I am not convinced that interpretative collaboration or member checks, necessarily, lead to “better” analysis. From the perspective of feminist standpoint theory, it is inaccurate to
assume that participant’s edits to the transcript will lead to more “valid” data (Acker, Barry, and Esseveld; Naples). As subjects situated by race, class, sexual orientation and so on, they do not have unmediated access to their “truth.” However, in retrospect, I wish I had been able to do collaborative interpretation with participants because I believe it would have improved the emancipatory goals of this project. In addition, the process of collaboration may have led to additional insights, adding another level to the data.

Data Analysis

The focus group audio recordings were transcribed into a Microsoft Word document. Participant names were changed and any identifying information (e.g., employer, children’s names) was removed from the text to assure participant confidentiality. The audio is transcribed largely verbatim; however, stutters, pauses, and other noises were not always noted--as some qualitative analysts suggest to do (e.g., Peräkylä; Yow 227-233)--because these such sounds are simply part of many of the participant’s normal speech patterns and do not necessarily indicate hesitation or nervousness. Laughter, non-speech sounds (i.e., moans), non-verbal behaviors such as eye rolling, and significant pauses that I was sure were not disability related were noted in the transcript text.

Once transcribed, I began coding the data into identify themes. The semi-structured interview schedule detailed above was designed to address some of the themes found in the applied fields’ literature (chapter 2) and in the self-representations (chapter 4). I used these same themes to begin data analysis and have outlined them in Table 3: Initial Coding Sheet (Miles & Huberman; Ryan and Bernard 781; Willms et. al.).
However, these initial themes were modified and substantially enhanced by drawing from the traditions of grounded theory and schema analysis (Agar & Hobbs). Grounded theory uses close, line-by-line reading of the data to allow new themes and relationships to emerge (Charmaz). As I did the first round of coding, I noted topics that did not fit into the themes on the initial coding sheet. These new topics became new themes if they appeared frequently or if I felt they could be particularly significant. With this method, theoretical understandings emerge from the data.

Grounded theory methods cannot, however, detect the effects of power operating within the group or capture the impact of social location on knowledge formation. As Charmaz notes,

most grounded theorists write as if their data have an objective status. Strauss and Corbin (1998) write of ‘the reality of the data’ and tell us, ‘The data do not lie’ (p. 85). Data are narrative constructions…They are re-constructions of experience; they are not the original experience itself (514).

The themes that emerge from the data are shaped by the interaction of the participants in the focus group, the time and day of the interview, the location of the interview, and the standpoint of the participant. These and other factors mediate what is said and not said. The standpoint of the participant is particularly important to feminist data analysis because it recognizes the impact of social difference on experience. Donna Haraway explains that “standpoints are cognitive-emotional-political achievements, crafted out of located social-historical-bodily experience—itself always constituted through fraught, noninnocent, discursive, material, collective practices” (qtd. in Olesen 243).

Considering the impact of standpoint and other factors, I did not approach the data as fully “transparent.” During coding, I made sure to pay attention to participants’ race,
class, disability status, and gender, noting where a participant’s experience of and beliefs about social difference become apparent. For example, “sexism” became a theme in the final coding. In addition, I drew from the tradition of schema analysis which is “based on the idea that people must use cognitive simplifications to help make sense of the complex information to which they are constantly exposed” (Ryan and Bernard 783). Using schema analysis I noted specific words that appeared frequently, metaphors, and absences—places in which explanation is not given because a participant assumes other group members understand or share belief/perspective. Drawing from grounded theory, standpoint theory and schema analysis, new themes were added to the coding sheet after the two rounds of coding. Using the Final Coding Sheet (Table 4), I entered texts and codes into NVivo Version 7, a qualitative data analysis software program. NVivo is an excellent data management tool—all pieces of text coded at a certain theme can be generated quickly for analysis.

**Demographics**

The demographics of all participants are displayed in Table 5. Although all 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 in terms of age. The mean age was 39 years old, ranging from 23 to 64. Based on representations in popular culture and research from the applied fields that indicates it is more likely for disabled women to be divorced or abandoned by male partners than disabled men (Singh and Sharma 29), I
expected the sample to be heavy with disabled men. However, the woman was the
disabled partner in ten of the twelve couples in this sample. As expected, only two of the
couples experienced the onset of the disabled after the start of their relationship: for the
vast majority of the sample, the disability was present when the pair met.

This group of selected couples is obviously not a representative sample, nor was it
intended to be. The intention was simply to talk with disabled/nondisabled couples
outside of a clinical, therapeutic setting in order to better understand how “average”
people experience disability, intimacy and care in their relationships. It is also important
to note that the sample I recruited was more likely to be happy with their relationship
because they are willing to talk in a group about their experiences. Couples experiencing
distress would most likely be reluctant to share such problems in a group (unless, of
course, that group is explicitly a therapy or support group). The demographics are
important, however, in guiding the data analysis as social location impacts disability
experiences and beliefs.

Findings

The major findings and themes discussed below follow the focus group script,
 grouping responses into 1) treatment by others, 2) media representations, and 3)
experiences. Not only does this outline help organize the data, but it also conveys the
ways in which personal definitions and attitudes, popular culture, and the beliefs of
strangers, friends, and family members interact. In other words, how one experience care
is influenced by how family members view caregiving and how it is represented on
television. These are not unidirectional relationships. Instead, these three domains influence each other (see figure 6).

![Figure 6: Domains of Influence](image)

In an effort to let the data speak for itself as much as possible, I quote participants at length to allow their voices to emerge and be heard. I have provided analysis, organization, and possible theories, as well as my own reactions and observations when relevant, but in an effort to reach for transparency and foreclose meaning, participant’s stories and conversations take up the bulk of the rest of this chapter. Overall, the experiences of these couples mirror the accounts relayed in disability autobiography and documentary film. The participants’ relationships were characterized by reciprocity and mutuality, and, frequently, sexual intimacy and caregiving were blended together. Unlike the autobiographies and films, however, participants actually become part of the theorizing and knowledge building, grounding theory in lived experiences. Because the
focus group asks participants to dialogue about the meanings of care and intimacy in disabled/nondisabled relationships, additional themes were able to emerge. For example, participants discussed active collaboration in maintaining equality in the relationship, the benefits and costs of personal care attendants, and sexist assumptions about their relationships. Below, I outline these and other themes and provide examples from the focus groups.

*Treatment by Others*

In general, negative treatment and discrimination was a common experience among participants. Although some of the experiences of ablism discussed in the focus groups were not specific to their love relationship, the *daily-ness* of such incidences significantly influenced their lives. Regular confrontations with prejudice elicited reactions of dismay, frustration, anger, and sadness. Some participants also admitted to avoiding public events out of fear of discrimination and struggling against internalizing ablest attitudes. The group atmosphere provided an outlet to vent some of these experiences. Frequently, after one incident of discrimination was shared, similar stories from other couples would also be aired, demonstrating the feminist consciousness raising function of the group interview. For example, several participants shared horror stories about restaurants. Olivia, the nondisabled partner of Randall who has Cerebral Palsy (CP), relays:

> I know a lot of times, we have people who at restaurants or just out in the public will ask, you know, “what nursing home we’re from” or something like that. We’ll be at a restaurant and you know, they’ll ask me what nursing home we’re from and Randall always tells them, “I’m paying your tip! You’re not starting off too good!” That happens a lot.
Richard, the nondisabled partner of Emma who also has CP, responds with a similar story:

[W]e were in a restaurant and there was a woman who was facing us—she was with another person so she was facing us—and I heard her drop something about, you know, why does she, why do they bring her out and upset everybody and ruin your appetite or something, you know, and then she turned around and turned her back to us and the other woman sat on the other side so she wouldn’t have to see.

In both of these stories, the routine activity of going out to eat becomes a site of confrontation with prejudice. Asking “what nursing home” one is from or changing seats to avoid seeing disability are both explicit ways to segregate the disabled from the nondisabled world.

Although reactions of disgust and/or distancing may not be directed at the couple per se, such incidences do impact the relationship because their status as a couple is denied. Frequently, participants reported that strangers interpreted the nondisabled partner as a paid caretaker. For example, Kay, the nondisabled partner of Dan who has a spinal cord injury, tells the group a story about an experience on an airplane.

Kay: We were flying to see my brother and they put people with disabilities on the plane first so you know you have plenty of you know room to get around and stuff, and the stewardess comes up and asks, starts—
Dan: I’m in the aisle.
Kay: He is in the aisle seat and I’m sitting next to him, starts to ask you know in case of an emergency what kind of procedures or whatever do we need to go through but she stops mid-sentence, leans over him and says to me, “can he speak?” [laughing]
Sarah: Oh, no!
Kay: I just kind of laughed and said—
Dan: And at that moment, I couldn’t [laughing]
Kay: I said, Yeah!
Gene: And probably a good thing, huh?
Kay: I just kind of like why couldn’t he speak? And she said, well you just never know, I thought wouldn’t you have first assumed that someone could speak until someone stopped you and said—
Gene: If they don’t respond to a question, then it’s appropriate to ask the question, can he speak.

Addressing the nondisabled person accompanying the person with the disability sends a clear message: the disabled person is not perceived as a subject, but as a ward of the nondisabled person he or she is with. This message is also relayed when strangers praise the nondisabled partner for helping or simply being with the disabled partner. When asked how strangers react to the couple in public, Gene, the nondisabled partner of Victoria who has Muscular Dystrophy, simply states: “God bless you for taking her out.” Kay confirms, adding, “I’ve gotten some of the, you know, ‘that must be hard,’ or, ‘you’re a very special person.’ These comments send the message to the couple that physical impairment is a burden on the nondisabled. The nondisabled person is doing a favor or a good deed by accompanying the disabled person in public.

Interestingly, when the nondisabled partner was male, the good deed of helping the disabled made them particularly appealing. Female strangers frequently made sexual advances.

Emma: I don’t know if it’s because I’m a woman and disabled and he’s a man, but it seems like women are more attracted to him because he is taking care of me—
Richard: --oh, yeah. [laughter]
Emma: It makes me mad! [laughter]
Richard: Yeah, they’ll come over and put their head on my shoulder, “oh, you’re so beautiful.”
Emma: “You’re so sweet.”
Richard: --“so sweet.” And I’ll say, “yeah, well you’ve been watching a little too much Lifetime television.”

In these cases the man’s apparent “sensitivity” makes him more desirable. In each case, the man’s non-hegemonic gender performance—his caring and attentiveness—gets
positive notice. Walking a dog or carrying a baby produces similar results. It is tempting to interpret such reactions as a positive indication that gender norms may be changing in ways that encourage male expressiveness and attunement to others; however, this change is at the expense of disabled women. Indeed, Emma notes that the sexual passes often persist even when her relationship with Richard is made obvious.

Emma: We were in a bar once and I still haven’t figured out if this lady thought he was my dad or my boyfriend—can’t remember if he was my boyfriend or my husband at the time, anyways, we were together, we were engaged, anyways—I was out of my wheelchair because I had to walk up steps and sit in a chair, so couldn’t move my arms, lucky for her! I would have—that is the only time I would have decked somebody. But, she was like hugging him and—
Richard: --yeah, it was embarrassing! I mean it was—[laughter]
Sarah: That’s funny—
Emma: And she was asking to pick him up and we had a bunch of friends there who were trying to—I mean she was drunk, ok she was drunk, but—they were really trying to explain to her that he was with me, but she—
Olivia: --she wasn’t listening! She had those beer-glasses on! [laughter]

Drunkenness aside, Emma was not perceived as a real barrier. In these public encounters she is literally no different than a puppy—a prop that makes the man more desirable.

Thus, such incidences are far from progressive.

Family members and friends were usually much more supportive of the couple; however, many participants reported early or ongoing concerns expressed by immediate family and close friends. For a variety of reasons, nondisabled partners are often viewed with suspicion (Asch and Fine 245). Writing in the British context in the late-70s, Wendy Greengross notes:

The principal problem for a marriage between an able-bodied and someone handicapped is one of motivation. It begs the cruel and unavoidable question: ‘What normal person would saddle him/herself with someone who will probably
need a lifetime of care?’ Many ‘normal’ people when they enter a marriage of this nature are not marrying an equal but someone they want to treat like a child (29).

Because physical disability is perceived to be a burden, the nondisabled partner’s motives for entering such a relationship are questioned. Friends and family may worry that the nondisabled person is looking for someone to control and manage. This may be especially true when the impairment is congenital and the family has cared for the disabled person all of his or her life. For example, Rachel, who has Spinal Muscular Atrophy Type 2 and is married to Jack, relates:

So, I started at 23 and my parents, you know they’re very open minded but they’re very protective on the same side. So my dad’s like, “wow, what is this guy’s intention? What does he want? How is he going to hurt you?” You know, they were very protective, my entire family. Then when I met Jack after dating for several years with other people, we met. And I kinda of knew he was the one. I mean, you know—because I had dated a lot, a while with other guys. And I knew that he was the one and my parents knew that I knew that, so they were scared. They were scared. And my family, they would constantly, “well, how is he with you? Well, what are you guys going to do? How does he act? Does he treat you OK?” “Yeah, yeah, its fine. He treats me great.” And they know that he does, but they’re still afraid. And its like—even now when we’re married—now that we’re married they’re ok, but we were dating for a while. Um, we just got married like last year, so…now they’re ok but its almost like they still need a constant—like, ok they’re coming to our house—“oh, you have a really nice house! Oh, and he does this!” They still need reassurance all the time that we’re fine. Now my parents don’t, my parents don’t, but my like indirect, immediate family, like aunts and uncles and cousins, they still are like, “oh, is he ok? Is he good to you? Oh, ok, does he take care of you?”

Rachel’s parents were wary of a nondisabled man’s interest in their daughter, particularly because she is severely disabled and needs “total care.” Their concerns are not entirely unfounded as spousal abuse between disabled/nondisabled partners does appear to be all too common (cf. Olkin). Thus, Jack had to prove himself to Rachel’s family.

Nevertheless, Rachel indicates that concerns remain. Although her parents may have
finally accepted Jack, she notes that her extended family remains worried. Jennifer reports similar family concerns. She says,

> As far as Frank’s family is concerned they were very accepting of me being in a wheelchair and after a while, they actually redid their bathroom with a higher toilet seat and everything and kind of made it accessible for me even though they’re older and they kind of considered me in their remodeling which is very nice and unexpected. And my Mom has pretty much accepted our relationship and I think my brothers and her ask a lot if he’s helping me. Is he helping you? Is he doing the laundry, is he doing, you know, is he vacuuming for you? And sometimes I say yes, sometimes no but I think they’re-- they, you know, want him to be helpful and always make sure that I’m getting the help I need.

Family members and friends are clearly concerned that the nondisabled partner is taking adequate care—doing what is needed without controlling or micromanaging their loved one.

Fear that the nondisabled partner will abandon the disabled partner may also be a source of worry for family and friends. Again, this fear is rooted in reality. Numerous studies with people with disabilities report divorce after disability (Singh and Sharma 29). Even within my own small sample, participants had experienced rejection from partners. Partners Adam and Sabrina, both of which have Multiple Sclerosis\(^\text{vi}\), tell the group:

> Adam: my first wife, you know, she didn’t want to be around me because I had MS and the same with Sabrina’s first husband. He’s basically—he said, “I didn’t sign up for this.”
> Sabrina: Three months after being married I got diagnosed and, or, I was in the midst of being diagnosed we were pretty sure what it was and uh he was like “this wasn’t what I signed up for” and he left!
> Others: ohh.
As Adam’s and Sabrina’s experiences indicate, it is not unreasonable for family and friends to worry that their loved one will be abandoned. Regardless, this wariness and distrust of the nondisabled partner can stress the relationship.

One way friends and family members temper this fear is by suggesting that the nondisabled partner should not be the disabled partner’s caregiver. This advice was given to both couples in Focus Group 2. First, Emma states:

Emma: Everybody warned me against having my partner or my husband as a caregiver.
Olivia: Hmm, They did us too.
Emma: They said that’s a big mistake because its gonna get all mixed up, you know, you’re not going to know when he’s your attendant or when he’s your husband. It’s not like that at all for when we’re together it all kinda, it doesn’t matter if he’s giving me shower or feeding me I can say anything I want because he’s my husband and don’t feel any kind of—

Emma clearly prefers care from her husband. And, as I will go into detail later, Emma does not feel as if the care interferes with their love relationship. Since Olivia and Randall said they received the same advice, I probed further.

Sarah: Why do you think people recommended that you didn’t let your able-bodied partner care for you?
Randall: Just because of the simple fact that—some people would tell me that it would take away from the relationship because, you know, they won’t think of you like a partner, they will look at you like a, a—you know, I got to do this, I got to do that, you know, it won’t be equal, you guys won’t be equal—

Randall does go on to say that he feared that a sense of inequality would develop or that the physical caregiving activities would complicate their sexual intimacy, but his partner, Olivia, was the one that insisted she do all the care—primarily out of a sense feminine duty (Olivia states throughout the interview that she feels it is a woman’s role to care for her man) and/or privacy. Randall explains:
It took her and my mom forever to get me to get rid of my PCA because that was my comfort zone, you know, all the other girlfriends that I’ve had, they usually walk away, you can walk away, I don’t care, but to get rid of those PCA’s, I can’t say you can walk away because I’m stuck! But I had to really trust, I had to trust her and that is part of getting married is to trust, the only difference, she trusts me to provide for the house, it’s the trust thing. [Olivia gets up to check on baby]

When I did get rid of my PCAs, I was scared to death. I was afraid that she, you know, I—she explained to me that I’m not going to have another woman come in my house and bathe you. I’m going to be the one to do that, you know, I’m not going to have another woman come to my house and see you naked, you know, I’m not going to do that. I didn’t really understand it because I didn’t look at it like that, I just said, you know, its not like that but the more I— it bothered her, the more I said all right, we’ll try it, you know, but, if it doesn’t work then we’re going to go back, you know, but, but, I think that’s when you know that you’re in love—when you can trust that person with every ounce that you have, and I just don’t, you know, some people don’t do it that way, but at my house that’s how we’re—because she assumes me is no different than her, if she is hungry, she eats!

Randall was reluctant to stop the use of a personal care assistant (PCA) because it would make him more dependent on his wife; however, Randall and Olivia were able to maintain a sense of equality within their relationship, and, like Emma and Richard, were able to blend care and intimacy.

Nondisabled partners reported that friends and family were worried that they were “getting in over their heads,” especially when the nondisabled partner was doing all the care. Olivia says,

A lot of people, when we first got together, you know, his family as well as mine, you know we have a lot of different barrier with I’m white and he’s black and he’s disabled and I’m not, so, everybody, I don’t know if it was just the disability but they questioned, “Are you sure you know what you’re doing?” “Are you sure this is what you want to do?” But, you know, once, everybody says that we’re more in love than anybody that they’ve ever met, so, I think once they met us and um got to see how we are together, we’ve been married for six years now and it seems like, I mean, nothing’s, I think we’re more in love now than before, but, everybody is really supportive of us. They just wanted to make sure that we knew what we were doing, what we were getting ourselves into.
In this instance the families wanted to make sure Olivia understood the physical and emotional stress care can cause—they wanted Olivia to avoid “caregiver burnout.” At times, however, this concern developed into rejection. For example, Richard says:

Well, when I first met her, um, people thought I was crazy. We met on the internet and I told them I was dating, later moving in, later getting married and so forth, and they just thought, you’re absolutely nuts! Do you realize what you’re doing? Do you know what you’re doing? So, I, my set of friends changed a lot, you know, cause there were a lot of people who were not very supportive. They just thought I was just a little crazy.

Richard’s friends—professors at a medium sized university—rejected his relationship with Emma and ceased the friendship. In this case, concerns that Richard was making a “bad decision” to be in a relationship in which he was also a caregiver were likely complicated with outright ablism. Although very smart and successful, Emma has speech impairment and has difficulty controlling her bodily movements. Richard’s former friends may have also been uncomfortable with his new partner. Ultimately, however, both couples were happy that they did not follow the advice of friends and family members—they preferred that their partners provide care and they did not feel that this arrangement harmed their relationship.

Although it may often be less explicit than concerns over care, friends and family may also be afraid that the nondisabled partner is sexually deviant vii. As Mitchell Tepper states:

The person attracted to someone with a disability automatically gets labeled as having a fetish or his or her motives are called into question. The partner with the disability is assumed unattractive, suggesting one must be imbalanced to be attracted to us. And the person who is actually sexually orientated to some aspect of a disability—whether it be a brace or a stump or a leg bag—is automatically assumed to be deviant in all aspects of his or her sexual relationship” (1).
None of the participants had friends or family come out with such fears, but I argue that discomfort with disabled sexuality shadows other reasons for discomfort outlined above. Thus, especially when the reasons for the dismissive attitudes were unclear to the couple, it is possible that at least part of the suspicion is rooted in a belief that people attracted to people with disabilities are sexually “sick.” Ted, the nondisabled partner of Sofia who has a spinal cord injury, says:

Ted: My parents are very supportive. They love Sofia, and they’re very supportive of everything that we do. I think her family was a little different. Like I had a great relationship with her father who passed away last year, but in the beginning like when we first met and were dating he, uh, he couldn’t understand it, I think, didn’t he say somethin’—
Sofia: They thought he had motives that aren’t – motives to be with me and you know, I guess he feared I was gonna get taken advantage of or what have you… And that faded.
Sarah: Once they got to know him longer.
Ted: Mhmm. Well it faded with your dad for sure, and with the family a little bit. I think there’s a couple members of your family that, they’re still thinkin’ something’s up because, I don’t know, I get a cold shoulder.

Some of Sofia’s family clearly has ongoing concerns about Ted’s sexual or other motivations. Although most couples report “problems with in-laws;” the participants felt as if a lot of their problems were related to ablism from friends and family and/or concerns about blending care in intimate relationships. In other words, they reported the same personality and/or political conflicts with family members that nondisabled/nondisabled couples face, but the presence of impairment added an extra dimension that they had to negotiate. For the most part, however, participants felt that their close friends and family supported the relationship. This support often took time to develop, but all participants were happy when it was finally there (or expressed a wish that family members would support them). Especially since reactions from strangers are
almost always negative, it was particularly important to have support of friends and family.

Reactions to Media Representation

As I argued in Chapter 1, popular culture can affect individuals by defining what is socially imaginable and by describing culturally acceptable ways of being. For nondisabled/disabled couples, the messages most often relayed position care as a burden that desexualizes their relationship, that the disabled body is a shameful manifestation that should be hidden and not reproduced, and that the disability experience is a painful and pitiable existence. Of course, disabled/nondisabled couples can impact popular culture by producing alternative representations (see Chapter 4) and by selecting what to, and not to, watch. It would be impossible, however, to claim that popular culture has no influence. As Shakespeare et al. note: “disabled people themselves are socialized within the dominant culture, and therefore hold conflicting views about desirable partners, and can have negative views of themselves” (49). This pervasiveness of dominant popular culture makes negative imagery one of the “main problems faced by disabled people attempting to assert themselves as independent adults and positive sexual beings” (Shakespeare et al. 68). Thus, the second major discussion I facilitated in the focus groups concerned participants’ relationships with media.

In the focus groups, I asked participants to talk about their opinions of popular culture—what representations of disabled/nondisabled love are available? How do they feel about the representations they see on TV, in film, or in the media? What affect do
representations have? And, what would they like to see differently? Initially such questioning provoked outcries of absent images.

Sarah: In terms of media, TV, do you ever see representations of disabled/nondisabled intimate relationships?
All: No! (laughter and other “no’s”).
Unknown: No, Never have.
Adam: You’re not supposed to!

But in each group—through discussion and group brainstorming--participants began thinking of numerous examples. For the most part, however, these examples are largely negative and/or inaccurate portrayals of disability.

Participants were epically upset by representations that were blatantly inaccurate.

For example, Connie who has MS and is married to Bob, brings up a problematic episode of *Law and Order*.

Connie: MS is not a--It's not like you hear that you have cancer. That you’re going to die—
Sarah: --that you’re going to die. Well, people still think that though.
Connie: --but, have you watched on TV—what program, we saw on TV and the guy died of MS, and it was like I was so indignant, I said I’m writing the producer of this television show, MS is not a terminal illness or whatever.
Sarah: Right.
Frank: You can’t catch it either, I’m not going to catch it sitting next to you.
Sarah: Right, you can’t catch it.
Frank: I’ve seen people do that, you have MS? [laughter] Really.
Connie: I was really upset.
Sarah: Yeah, I think I saw that show, I’ve seen it before ‘cause-- or have seen similar takes—
Bob: There have been several programs and movies where that sort of, that pronouncement has been a death nail.
Sarah: Right, you’re dead.
Bob: You know, its like, like Connie said, and, the following pause is always that, Oh, it’s the worse thing that could happen.
Sarah: Right.
In the episode the perpetrator’s excuse for his criminal behavior is that he is going to die soon (from MS) anyways—a sentiment that provides audiences with erroneous information about the disease. At one point in time MS was indeed a disease in which one could progress quickly and die; however, today there are many treatments that slow or even stop the progression for most people. Representing MS as a disease with a rather quick and inevitably fatal end perpetuates ignorance that can in turn negatively impact people with MS by treating them as if they are “terminal;” that MS is the “worst thing that could happen.”

Participants also felt the MADD commercial (discussed above) perpetuated inaccurate stereotypes of disabled people as isolated. This conversation among participants in focus group 3 is representative of all participants’ reactions to the public service announcement.

Sofia: Insulting.
Gene: Yeah, definitely.
Dan: And they view the person with the disability as locked away, and that’s where they should be.
Sarah: Absolutely.
Kay: I mean, I see the point that they’re trying to make, but they did it in a rather uncaring way. I mean there is definitely that—yeah, there’s just definitely that impression of oh yeah, you know, you lose your abilities and your life is basically over.
Gene: And you’ll never have love.
Kay: Yeah.
Ted: That’s the big thing, you know. I mean, having done my clinicals in a nursing home I mean that does happen you can get in an accident and you can end up in a nursing home and not be able to enjoy the things you once used to do, so I can see that end of it, but then showing on that relationship going on outside and you know, portraying that you can’t have one or whatever, that’s pretty wrong.

The young man in the MADD commercial generates the image of people with disabilities forced to live in institutions. Although many people with disabilities do indeed live
institutionally because they have no other viable options, this is certainly no longer
“standard.” More and more people with disabilities live in the community, have loving
partnerships, and families (as evidenced by the focus group participants). This reality,
however, continues to be absent in popular culture. Some participants also noted that
when a disabled person is portrayed as sexual, it is not a “loving” relationship.

Kay: There are a couple, but they’re not positive. I mean both in Forest Gump and
in Born on the Fourth of July I think, but they were both like prostitute or one-
night-stand-type anger. You know the man was just angry about his disability and,
I mean it wasn’t a loving situation at all.

There is a dearth of realistic or positive portrayals of people with disabilities and their
partners. For couples in the focus groups, these absences contributed to the prejudice and
discrimination they experienced, outlined above, in their daily lives. A lack of “models”
also made it difficult to resist internalizing ablist attitudes.

On related notes of “accuracy” and “absence,” participants in focus group 3
criticized the lack of people with disabilities playing people with disabilities. Indeed,
disability is a regular (and perhaps inevitable) part of human existence and disabled
characters are everywhere (cf. Mitchell and Snyder)—disabled actors, however, are not.
According to Screen Actors Guild (SAG) president Alan Rosenberg, “while 20% of the
U.S. population has some form of a disability, disabled actors have landed fewer than 2%
of the speaking roles in television in recent years” (Kroll). In 2008 SAG, along with
other actor organizations, launched an “I Am a PWD” to raise awareness about the lack
of disabled actors in the entertainment industry. All the participants in focus group 3
were linked to the local disability rights organization, so it is not surprising that they
linked participation by people with disabilities in entertainment with changes in
entertainment content and cultural attitudes.

Ted: Yeah, see if there was more disabled people in movies I think that would
change people’s perspective a little bit
Sarah: M’kay.
Ted: Or a lot depending on how much—
Victoria: Yeah, you’re right.
Gene: Or not necessarily in that particular—just in general.
Ted: Right, exactly.
Sarah: So it would increase awareness.

Participants in focus group 3 felt that an increase in real people with disabilities on
television and in film would have a positive influence on their lives because it would help
dispel stereotypes of people with disabilities as lazy, worthless, ugly, and isolated.

Jennifer, from focus group 4, felt that it was especially important to increase the number
of women with disabilities on television and in film:

What I think about is um Joanie, Friends of Joanie, I don’t know if you’ve ever
heard of--I can’t think of her last name right now but she is uh, she’s uh
quadriplegic and has been married for a long time and she was in a swimming
accident and now she has these huge like Christian empire, you know, with books
and movie, well not movies so much but, books and she has her own website and
speaking stuff and I guess, when you see that you think it is easy for someone, a
woman in a chair to have a, a able-bodied partner where in fact reality of it is it
isn’t that easy and the one thing that I remember when I in a rehab, they said 85%
of the people in chairs are men, and only 15% are women, so, you see more
coupling between um disabled men with able-bodied women than you see vise
versa, so that is just always out there in my head, and, you know, with my friends.

Indeed, as Chapter 2 makes clear, there are fewer images of women with disabilities in
popular culture, and those that do exist are particularly negative. Adrienne Asch and
Michelle Fine believe that this disparity is the result of sexism and ablism. Describing a
study about perceptions of disabled men and disabled women, they write:
when asked how women and men using wheelchairs became disabled, non-disabled students attributed male disability to external situations such as war, work injury, or accident. They attributed female disability to internal causes, such as disease. The authors suggest that attributing disability to disease may foster more negative attitudes because disease stimulates primitive fears of contagion or of the person’s inherent moral badness. Thus, the disabled woman may be viewed as more dangerous than a similarly disabled male, more morally suspect, or more deserving of her fate. (243)

Jennifer’s complaint about the lack of representation of women with disabilities and their particular struggles may tap into a form of gendered ablism. Women with disabilities create anxiety for (nondisabled) spectators and producers.

It may not be enough, however, to simply include people with disabilities in the entertainment industry. Participants were keen to point out a need to portray different kinds of bodies and different kinds of sexual possibilities. For example, Allison noted that even when disability is portrayed, the bodily difference is often minimized or erased completely.

Allison: --what about the uh *An Affair to Remember*? Doesn’t she get hit by a car and she’s she’s like supposed to meet him at the top of the empire state building and then she gets hit by a car and she becomes paralyzed and hides it from him
Connie: Right she hides it from him
Allison: she couldn’t, she hides it and she is sitting on the couch and he comes in and she can’t get up—
Sarah: Right.
Allison: --and then he realizes it or whatever, I don’t know.
Frank: That is why she never called him.
Allison: And that is why she never called him.
Sarah: Mmm..right, okay, but then at the end they do get together.
Allison: They do get together, yeah.
Sarah: So that is a good point.
Allison: But I don’t think they ever actually show her in a wheelchair [laughter] I think that she is just sitting on the couch with a blanket on her.

Although the example is dated\textsuperscript{viii}, the erasure of bodies that do not fit normative ideals remains. Twisted limbs, atrophied legs, and other deformities are the stuff of horror.
films. When mainstream film and television calls for a disabled character, his or her physical difference is covered up or neatly contained. Such “erasure” makes it difficult for the nondisabled to become used to disabled bodies and movement; therefore, in addition to more “real” people with disabilities, there needs to be more attention given to “real” bodies.

When one’s body is different, sexual activity and intimacy may also look different. The “normal” sexual position—man on top missionary position—may be impossible, for example, for a man with a spinal cord injury. Depending on the disability, genitals may not work “properly,” stamina may be impaired, and appearance may deviate greatly than what is culturally endorsed. Unfortunately, such functional and physical diversity is rarely represented in popular culture. In addition, it is rare for sexual health educators or for professionals in the applied fields to offer alternative models of sexuality to people with disabilities. Thus, education, popular culture, and the applied fields all contribute to sustaining heteronormativity, affecting the lives of all people, including the nondisabled. The authors of *The Ultimate Guide to Sex and Disability* candidly write:

> Watch any one of the thousands of mainstream porn films (or even regular films with sex scenes) released each year and you’ll get some idea of how sex is “supposed” to work. “Real” sex progresses from light activities like kissing to the “real” thing, penis-in-vagina intercourse, to simultaneous orgasm in ten minutes or less. You should also be able to have sex in a variety of different positions all in the same night. Everything we do sexually is supposed to progress toward that goal, and none of it is as important as the result itself. Thus “foreplay” is nothing more than a prelude to the main event. Oral sex is hot, but it’s still not as good as the “real” thing. (3-4)
The authors critique this heterosexist script, along with the notions that sex must be spontaneous, flow smoothly and beautifully, arguing that “this standard exists for us all, and harms us all” (2). Indeed, the sexual proscriptions about how and how often to have sex are detrimental to disabled (and nondisabled) people who are trying to forge a positive sexual self-image. Here, Rachel explains her conflicted feelings:

--so that is his little intimacy or he’ll just pick me up and he’ll transfer me, and they [the PCA’s] are like “well we can get her”, [and he says] “no I want to hold her right now.” So, so, that’s what, that’s what we do, but I still feel, you know, I’m still with the old values, you know, got to please my man, I’m not doing that, I’m not a good wife that kind of stuff and he says, I don’t care about that, I just want to be with you, I don’t care, I’m still trying to get that through my head, you know, its hard when you have media and everything around you saying you got to have sex, you got to have sex.

Rachel feels very close to Jack, and she can think of numerous examples of physical and emotional intimacy; however, she feels inadequate because she cannot replicate what is represented in popular culture and sex education.

Despite its largely negative role in the lives of the participants, popular culture can also help shape one’s sense of self. The discussion seemed to help some participants point to films or television shows that had a significant impact on their consciousness as a disabled subject. Allison who is blind and is partnered with Jason, says:

Allison: I guess the movie that kind of sticks out to me is the Val Kilmer movie At First Sight where he’s completely blind and she comes into this small town and meets him and he’s a massage therapist and the whole point is trying to get him to be sighted and then he realizes that that is not what he wants to be, he wants to be identified as being blind and having a disability and things like that, I think she finally, sometimes its hard because she wants him to, she thinks that if he’s sighted then everything will be okay—

Bob: --it will be better—

Allison: --and its not, and I think that initially, Jason would always do a lot of research trying to find out like new treatments and drugs and things like that, for, for my vision and the ways to help improve it, and a lot of times I said I don’t
really want to hear anything like that—like this is who I am this is what I am and, um, I think that is hard for my family, I think that is hard for him, I think that is hard for his family because I think a lot of time—not that they want to fix me, but they just think that that would make it better, and, you know, I’ve gotten to where I am because of this, so, this is part of me, this is the package, take it or leave it kind of a deal so I think that, um, that’s what’s kind of interesting about that movie to me.

Because of its very rare depiction of disability consciousness and identity, *At First Sight* provides Allison with a way to interpret her own experiences with Jason; their struggle to maintain a balance between the desire to be “normal” and feeling proud of her disability identity.

Overall, participants felt that media representations worked with ongoing prejudicial attitudes about people with disabilities, making life more difficult to navigate. They understood that their friends and family members learned about disability from popular culture and that this is the reason for much of the negative treatment they experienced. More realistic, balanced portrayals of disability in popular culture were praised and all participants indicated a desire to see more.

*Personal Experiences & Definitions*

For the most part, participants’ experiences differed markedly from popular culture representations. They were in loving relationships that in many ways defied gendered expectations about caregiving. After all, 10 of the 12 nondisabled partners were men providing physical, personal care for disabled female partners. No caregivers disclosed gender role anxiety or expressed caregiver burden or burnout—not even in the private, follow-up journals. In fact, only the disabled partners aired concerns about the viability of their relationships or themselves as sexual subjects. I interpret the worries
that did arise as examples of internalized ablist. Disabled participants sometimes had a
difficult time believing that their nondisabled partners were truly happy in the
relationship and that they wanted to stay together. For example, Ellen who had been
married to Kevin for only 1 year when she was diagnosed with MS, says:

That was the hardest part—I mean we’re—I mean everybody has different
situations, but when we got married we were married “normal”—as normal as
you can possibly could be!—and then you find out that one spouse has MS. I
think when I found out…do you still want to be married? That was the biggest
thing. Why would you stay with me? Do you really want to stay with me? I mean
this is before kids or anything and…and that was a scary, I think a scary thing, not
knowing where your relationship was going.

Connie, who also was diagnosed with MS after her relationship with Bob began,
expresses similar sentiments.

No matter how many times I’ve told him- I said you deserve somebody who’s
much more active —better in everything than I am. You know anybody that grew
up, if you were in control, you know, you were the one who drove the kids
(inaudible) and you know you were the one that did all the organizing and could
do all the stuff standing up in the house. The sexual stuff, could initiate or
whatever, if you can’t do it anymore, if you don’t have somebody that’s
constantly saying I don’t want to leave you, you know, I couldn’t find anybody
better. It does make a big difference.

In our society, women are expected to be able to drive the kids, clean the house, and be
sexually available, and as Connie explains, when these gendered tasks become
complicated by (or even made impossible by) physical impairment, it is easy to feel like a
failure. Both Connie and Ellen note that having a supportive partner who insists on
staying in the relationship and constantly reminds them that they are loved helps them
maintain a positive sense of self. Nevertheless, as citizens subjected to dominant culture
values, they have internalized ablist ideals; therefore, they must constantly work at seeing
themselves as worthy partners.
Participants with congenital disabilities, as well as those who became disabled later in life but met their current partners after they had become physically impaired, expressed similar worries. Neither a lifetime of living with impairment, nor meeting their partners “post disability” spared them from feeling like a burden or internalizing ablist assumptions about sexual relationships. In her journal, Rachel writes:

Sometimes in our relationship I feel that Jack does not get to do what he used to do before he met me because of my disability and me needing care. I hope that our relationship won't become strained because he feels that he is missing out. He doesn't at all make me feel this way, it is just a fear that I have deep inside. I guess it stems from feeling like a burden when I lived at home with my parents. Sometimes in doing care, my parents and my brother would complain about things. Now that I don't live with them anymore, they have a new found freedom. They go out every weekend with their friends and even go on vacations.

Even though Jack frequently tell Rachel that he did not marry her just to be cared for and that he does not feel any amount of burden, her fear remains. Similarly, Allison worries that Jason will get tired of the amount of responsibility he takes on in their relationship.

I was diagnosed with macular degeneration before—when I was nine, so it was pre-existing and I think Jason had some idea of what he was getting into when we started dating but I don’t think he really realized it. [Laughter] Especially, you know, we started dating when we were seventeen which is really young for um I think for him to have to deal with some of the stuff that he has to deal with and I think he has taken on more responsibility once we moved in together and we’ve been living together for over three years now. But I know that sometimes like going out and when we go shopping and me needing help to, you know, look at sizes or prices and things like that.

Jason helps Allison with looking at sizes and prices, reading menus, crossing streets and other visual daily tasks; however, according to Jason, the only area that ever feels a bit like a “burden” is the perpetual driving duty. Nevertheless, Allison worries that that accumulation of these tasks will eventually be too much for Jason, especially if and when
they decide to have children. Because caregiving is typically framed only in negative
terms in our society, and because people with disabilities are at increased risk of divorce
and abandonment, it is sometimes difficult for disabled partners to trust that their
nondisabled lovers are not building resentment or on the brink of care burnout.

Sexual concerns frequently added to the disabled partner’s anxiety about the
stability of their relationships. In focus group 1, Ellen admits to longing for the sex life
they had before her disability.

Ellen: But do you think sometimes too that the person with the disability
everybody is in a different situation, um, maybe the person with disabilities finds
it difficult to do things that they could not do maybe ten or five years or ten years
ago and you feel that maybe the relationship or the sex is one sided that the the
“good” partner [laughs at saying that] is doing all the work, and, I don’t know
how to put this [laughing], but its...because it happens with us I have tightness in
my inner thighs, you know, and the poor man, by the time we’re done is like
[ughh—making painful face]!
Tracy: Oh my gosh! [laughter]
Adam: I’m not trying to be creepy, but do you mind?
Kevin: No, its, its part of the intimacy!
Adam: Exactly! [laughter]
Ellen: But, you know, from my end of it, its like, I’m sorry, I apologize for my
muscles not working, that’s that’s not looking at you, but, that’s I was happy to
see you [to Rachel] I’m thinking cool, she is having the same problems I am!
Rachel: Oh, absolutely.
Ellen: But you know what there, there is still that intimacy, I mean, the snuggling
and everything else, its just, you wish you could go back to when you first had
your relationship where everything worked properly, you know! And everything
was relaxed.

Even though her partner, Kevin, is not concerned with Ellen’s physical functioning, she
wishes that she could get her nondisabled body back.

Decades after his injury, Dan continues to feel limited by his physical impairment.

In his journal, he writes:
As a male with a disability and not able to perform as an able body, it is mentally difficult to have sex. There are many things I wish I could do, but am limited in my mobility. I think this frustration has built up over the years and has lead to a decrease in sexual activity. This is strictly on my part and I know it affects my wife. She feels I don’t desire her anymore. I feel less than satisfied.

My wife says I haven’t adjusted to my disability and she is right. I see so many things I wish I could do. Also it keeps getting harder as I get older and my body changes. There is always something new to deal with. She says she understands my frustrations, but until you experience it you can’t know.

One thing she suggested was I help coach my daughter’s softball team. I told her you have to be able to show the kids what to do as to telling them. I can’t show them how to stand at the plate and hold a bat or how to field a ball.

Kay has only known Dan in the wheelchair. She knows that his body performs, sexually, different than nondisabled bodies, but in both the focus group and in her journal she notes her continued desire for Dan, her acceptance of his disabled body. Dan, on the other hand, is frustrated that his body will not perform as he wants it to, that he cannot do the activities a husband and father are supposed to be able to do.

Significantly, however, negative feelings about their disabled bodies and worries about their relationship were overshadowed by disability pride and the strength of their love relationships for all the participants. Dan may struggle with his sexual self-image, but he is also a disability rights advocate and, in general, feels like a competent citizen and worthy partner/father. The struggle between disability pride and shame is evident in Dan’s discussion about “cures” with the other participants.

Dan: I mean I often feel, you know, jeez, if I could just have one thing easier like if I had my hands and stuff like that, you know, but again I have to count my blessings because I’ve got friends who I can do more than they can, but it you know in all the stem cell research and stuff like that and it, if they can make me walk again, as much pain as I’m in now, that I can feel, I would hate to know what that pain would be like, if I had full sensation—

Kay: But you would take it if you could get it.
Dan: I, I, well, yeah, I don’t know, it would depend on what they could offer me—
Kay: --He would take it if he could get it.
Dan: I mean even, if they could say I could I could make you have full use of your arms, I’d be tickled, but then I’m sure after I got that I’d say, okay, lets go to the next step.
Kay: Yup.
Gene: Hey this is pretty cool! What else you got! [laughter]
Kay: I can, he stumbles, but I can tell you pretty sure assuredly he’d take it if he could take it.

Dan “stumbles” because he had contradictory feelings about disability—it is both a source of pride, a marker of difference that defines his identity (and career), and it is, in his experience, something that limits his physical activities.

The schema analysis of significant phrases and metaphors used in the focus group discussions also highlights the pride/prejudice contradiction. For example, in focus group 4, Connie and the other participants all express outrage when strangers act as if their disability is tragic; however, the participants themselves sometimes frame impairment as bad fortune. Notice how Allison and Connie construct Allison’s predicted vision loss in the following exchange:

Allison: It’s supposed to, but its been stable since I’ve been nine, um, which—they don’t know, I mean, it usually happens in adults over 65 so they, when I was diagnosed there was only 40 kids in the state that had my condition, so they were kind of looking at me like I was a pin cushion instead of like a person and um so its supposed to get worse but it hasn’t and I’m 23 now, so knock on wood, so.
Connie: Congratulations.
Allison: Thank you.

Likewise, Kevin and Adam, from focus group 1, use metaphors of overcoming (see italics):

Adam: I’m Adam, Sabrina’s husband. Um, I’m doing this because anything we can do to help MS and its research and help people that is going to help put the disease behind us, um, easier for them, the better.
Kevin: I’m Kevin, I’m married to Ellen. I’m able-bodied, and we’ve been through everything together and then some so, also the more we can do to help ourselves, help other people, I’m afraid there is a reason that we are here, you know, this has been entrusted to us, so I figure, well, march forward and help and do whatever we can to help other people as well….There is times, I know she’s had some rough times with things and well it doesn’t matter, we’ll figure out what to do, we’ll get through this, we’ll survive, we always have. We’re Catholics, we’re quite religious and the Lord gave us a test for a reason. He’s led us this far, he’s not gonna let us go now, so. There is always some support somewhere.

In both of these excerpts, the disability is constructed as a problem to move past, to get over. The metaphors of overcoming are used to frame disability as something outside themselves, an external, negative force that they must contend with and beat. The use of these metaphors contrast to the integration of disability and pride the participants discuss in other parts of the focus group. I read these contradictions as symptomatic of the struggle against internalized ablism, but also as evidence of successful coping. Drawing on religious and other meaning-making discourses provides a language for people to make sense of their situations. These phrases help the participants create useful “myths” to tell themselves and others. All the participants in the study would paint themselves and their relationships as “positive” and most have significant ties to the disability rights movement. Regardless, the language of overcoming is used as a stock narrative to frame aspects of their lives. Overcoming is the language dominant culture elicits from the disabled--these are the narratives the nondisabled want to hear; therefore, it is not entirely surprising that people in disabled/nondisabled intimate relationships would, at times, resort to such language and even internalize, on some level, the desire to be rid of disability.

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Of course, participants were always quick to point out that this struggle would be less difficult if society valued disabled bodies. While discussing his own frustrations about his physical limitations, Dan says, “well, society dictates that, this is normal, this is what normal people do.” So, Dan may not always feel full of disability pride, but he is well aware of the source of his negative feelings. Furthermore, the messages that participants received about disability were also shaped by gender norms. Dan is most upset about his “failure” to approximate specifically masculine norms around fatherhood and male sexuality. But, at least, Dan has received some positive messages about disabled male sexuality—he reports that he was told in rehabilitation that he could still have sex and father children. Sofia, however, received no information about sex or sexuality during rehabilitation for her spinal cord injury. Indeed previous studies of sex education in rehabilitation facilities report a marked gender bias (c.f. Li and Yau; Singh and Sharma). Since women’s sexuality is constructed as passive, receptive they often do not receive information about how to be sexual agents with physical disability. Disabled men and women both receive negative messages about their worth and attractiveness, but it is important to recognize that these messages are always gendered.

One way that both disabled men and women seemed to manage the negative messages was to “test” lovers during the dating phase. Sometimes this testing continued into the long-term relationship, periodically, to ensure that the nondisabled partner would stay, but, generally, it seemed that this testing was most pronounced during the early parts of the relationship. For example, Randall and Emma both used their speech (both have speech impairment from CP) as a “test” early in their relationship.
Olivia: --cause we talked online for like three months before we met, and I loved him before I met him. And then when I kept bugging him, like, “why won’t you let me call you?” He said, “you know, I’m different from everybody else.” And I said, “so I am too, you know, I’m from the country.” He said “no you don’t understand.” And that funny story, that, it always cracks me up, he always says, “you know, to describe how I talk, go drink a six-pack of beer and then listen to yourself talk and that is how I sound.” And so, he told me to call his pager--at the time, that is so long ago he had a pager--he said “call my pager. If you can understand my message on my pager, leave a message and I’ll call you back.” So, when I called his pager I repeated what he said on his pager and then we talked after that.

Emma: We kinda had the same experience. I was trying to discourage him from calling because I, um, I told him upfront that I was disabled but that can mean anything, I didn’t tell him what my disability was or how severe it was or anything [inaudible]. And then he said, “Why don’t we meet in the zoo or at the park or somewhere public?” And I’m like, “OK, its time to discourage him!” [laughter]. So I just tell him every bad thing I could think of so [inaudible] He said, “Oh, I can put your wheelchair in my car. Help you in the car. That is no problem.” And I thought when he heard my voice on the phone—we had to connect for some reason, you wanted to tell me something or—

Richard: --I don’t remember—

Emma: --we were forced to talk on the phone [inaudible]. I thought after hearing my voice, he’ll make up an excuse not to [inaudible]

Of course Richard and Olivia pass Emma’s and Randall’s respective “tests,” but it is important to remember that the disabled partners set up these tests in the first place because nondisabled people have failed in the past.

Frequently, the “testing” continued in the relationship. Rachel explains that she continues to “test” Jack.

Rachel: Yeah! I’m like, all right, and I kept testing him, remember I kept testing you? [laughter] I even to this day kinda do! Like, I think of some crazy thing, like, would you…--with your situation catheter or something [to Sabrina]—would you do IV fluids [inaudible] on me if you had to? Yeah. Would you do a pic line? Yeah. Okay. And I just constantly test him, you know, and, um, I did all through our relationship

Rachel’s continual interrogation of Jack’s limits helps assure her that he can handle anything he may have to do as a result of her disability. Because care is associated with
burden in our culture, and because participants had either had first hand experience with abandonment or knew a friend that had, the fear is real. The “testing” that most of the participants talked about was an attempt to “weed out” the potential flight risks. As Emma explains:

Yeah. Getting to—when he’s gone, he’s gone, so at the beginning of the relationship, like the first two years, I would tell him to go away, get lost, I don’t want you, I would say all kinds of horrible things just to get him to leave because I knew eventually if he did leave I’d be on my own again and I didn’t want that shock factor to happen—you know what I mean?

Testing is a form of protection, and it is integral to developing trust in the disabled/nondisabled relationship. It takes an enormous amount of trust on the disabled partner’s part to rely on the nondisabled partner for routine activities like toileting, bathing, eating, etc.

Once the nondisabled partner had “passed” all the tests, the couple still faced challenges. In the focus groups, couples identified two main, ongoing struggles: maintaining balance between care and self-reliance, and between the need for privacy and the need for outside aide. Almost all of the disabled participants noted that it was important that they be able to do some things on their own, to be “independent” in some areas of their lives. But they also understood that the need to be self-reliant one minute and then need physical help the next could be confusing to their partners and loved ones. Ellen says:

Our family’s wonderful, they’re great, um, being a person with MS I want my independence and I want to take care of my children and I want to take care of my household and do what I can possibly do—there is things I’ve learned that I can’t, but its hard when they see you struggling to do simple day tasks—this is how I get through, this is how I do the dishes or how I do the laundry or whatever the case may be. To me its not a struggle, this is what I do and the over-protectiveness—
wanting to jump in can drive you a little batty at times. It’s nice to have that compassion and to have closeness, but it gets [laughing] a little bit—even from a spouse too—it sounds very protective. And he’s learning [laughing].

Kevin: Yes dear. [laughter]

To feel like a full adult, Ellen needs to be able to do the laundry—even if it takes her twice as long and exhausts her. Allison and Connie in focus group 4 discuss similar desires to do things “on their own.”

Allison: —you know like the other day we were at dinner and Jason’s like you’re holding it upside down so why are you even holding it and but I don’t know, it’s just something I do—you know what I mean like I just-I don’t know I mean he’s really, really helpful I think that as we’ve grown up together — you know- he just knows when he can step in and knows when to step out. You know, he knows how to be helpful but he also knows when I should do things for myself and I never want it to be a relationship where he felt like he had to do things for me-like I want to still try to do things for myself and so we’re still working and building on that but – cause if it was up to him I could still do everything and I know that there are things that I can do and I can’t allow him to do all of that for me so ..

Connie: Isn’t that amazing? We have great guys- they want to do stuff for us, but I’m the same way it’s like I can walk up the stairs by myself—

Allison: Well it’s like the biggest thing is that like my parents did everything for me when I was in high school like all my cooking and laundry and everything and then when I get to college, you know, we had dorm food or whatever but then when we moved in together he does all the cooking like all the time. And he’s just afraid that maybe I would hurt myself or whatever but I really want to start trying that and I’m like-he’ll be like oh let me just do that and I’m like no stop it I want to try to do it myself so I think that’s the thing right now is like I just want to try to be more independent-at least in the kitchen and things like that but I mean I do most of the cleaning, I do most of the laundry and independently and I feel good when I can do something for the benefit of both of us but ‘cause I know that driving he has to do and helping me at the store he has to do and things like that so I feel like this is something I can contribute.

The balance between self-reliance and receiving help was an ongoing struggle that each couple had to negotiate. When successful, the couple was able to develop a sense of interdependence that allowed the disabled partner to “give back” and reciprocate for all the physical care they received from their nondisabled mates.

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About half of the participants also used some form of outside help, both in the form of respite care and personal care assistants (PCA) in addition to the partner. Outside help was both a relief and a source of stress for most of the couples. In the following conversation from focus group 1, several key problems with getting help emerge.

Adam: Did you ever notice that you guys, when they have somebody from the outside come in, that you fight more often then—
Rachel: Yeah
Adam: --the arguing is more.
Rachel: Yeah.
Sarah: Its like you guys were saying—its easier to handle, sometimes its easier to arrange the care between yourselves.
All: yeah
Sabrina: You almost feel like you have to entertain that person that is there to help you too.
All: right
Sabrina: Interact with them when if you don’t feel good and you’re tired anyways that is the last thing you want to do.
All: right
Sabrina: You feel they’re in your home so it’s your responsibility, you know.

Feeling the need to tend to the helper defeats—to a point—having a helper in the first place. Many of the “less disabled” couples used this as the reason they were avoiding outside help.

Some participants, however, had to use aides because their level of impairment required 24-hour care. Rachel, for example, used PCA’s when Jack was at work. For the people that had to rely on PCA’s lack of privacy and the instability of workers were the two major struggles. In fact, problems with aides dominated both Rachel and Jack’s follow-up journals. At one point Jack explains: “The only reason I keep bringing the aide issues up is because that’s where most of any friction between me and Rachel develops.”
Rachel and Jack talk about aides being lazy, treating Rachel poorly or abusively (e.g., refusing to feed her), being late or not showing up at all, and other transgressions. The irony of the situation is that Rachel and Jack are doing what most professionals recommend—they are using outside help so that Jack is not always Rachel’s caregiver. Writing about maintaining love and intimacy after disability, Elizabeth McNeff recommends that health professionals help couples:

> address the balance in the relationship between partner and caregiver roles. Couples’ expectations for a shared, balanced role within the relationship may become impossible with a disability. Both partners need to be aware that sustaining intimacy predominately depends on creating viable caregiving boundaries. (597)

Indeed, as the literature in chapter 1 demonstrates, professionals in the applied fields almost unanimously recommend that partners *not* function as caregivers in disabled/nondisabled intimate relationships.

The professional advice, of course, is based on the assumption that care is only a burdensome activity and that caregiving will desexualize the relationship. The participants in the focus groups, however, begged to differ. Outside help was most often the source of stress. In addition, the presence of that third person prevents “alone time” for the couple, time for the pair to be intimate and relaxed. Gene explains:

> Going back to sex for a second. [laughter] Something that she said in the frustration that the um, that the nurses present and generate some frustration and some tension with us, there’s, you know, we’re too tired at night and we have somebody else in the house in the morning when we’re not tired and we’re refreshed.

The lack of privacy, and how that affected their sex lives, was mentioned by all participants who used a significant amount of outside help. Nevertheless, some
participants had no choice but to employ outside help. Both Gene and Jack worked full-time and could not care for Victoria and Rachel, respectively, full-time.

For other participants, outside help was a choice and one that they felt was worth it, even with all its flaws. For example, Emma insisted on keeping her aides, even though Richard is retired and, technically, could care for her 24 hours a day. For her, aides provided a safety net and providing the respites was a way for her to care for Richard.

Emma: When I talk about caring, I think the way that I care for Richard, for husband is by having attendants come in once or twice a week because of his age and because I need to keep connected with the agency ‘cause if something ever happens to him, I still need to go pee [laughter]. I still need to poop, and my Dad gets so mad at me that how can you think of such a thing? Cause it’s a reality of our life, you know. I’m not being mean, I don’t want, I don’t want anything to happen to him, I’m not planning on it, but—

Richard: Right, she said to me, I said, she said, you know what the first thing I would think about if you died? Who’s going to wipe my ass? And I said, oh my God. [laughter]

Olivia: You can call me Emma!

Richard: That is how close I live to my body, that is how close I live to this reality of disability—

Emma: You know, I would feel—before we talked about it I felt so bad like, “how can you even think of that!” You know, like “how can you even think of that!” But the reality is that if something does happen to him, I still need help then, I still—

Richard: --yeah, that day! Maybe 20 minutes from then.

Emma: Yeah, yeah.

Because Emma must live so closely to the realities of the disabled body, as Richard so aptly puts it, she knows that if Richard ever leaves (or dies), she needs care immediately. Aides are her safety net for that situation. In addition, using aides are a way for her to “take care” of Richard, to give him a break. In fact, the couple builds in week-long respites in which Richard goes away to a cottage they own several times a year.
Contrary to professional’s expectations about the inability of severely disabled people to give back or provide care to their nondisabled spouses, reciprocity was perhaps one of the main themes in the focus groups. Couples consistently explained that they are careful to figure out ways in which the disabled partner can give care to the relationship. For example, Emma needs help with dressing, eating, bathing and toileting. Despite this level of physical care, she and her partner Richard insist that their relationship is characterized by mutuality and reciprocity.

Emma: -- I guess you can’t look at physical care as something that’s unequal in the relationship because I care for him by taking care of the bills and making a budget and remembering our calendar and, um, you know—
Richard: --ya, we try to maximize everything, maximize her participation in everything just by letting her—when she can do something its hers!

Emma and Richard are aware of the need for Emma to participate and give back in the relationship. Because Emma’s impairment limits what she can do physically, her form of care takes the shape of brain-work. In fact, non-physical care such as “brain-work” or emotional care were common methods of reciprocity for the couples dealing with more severe levels of physical impairment.

Olivia: I think my husband takes more care of me than I take care of him, and he needs more help than I do physically, but, I don’t know, I mean—
Randall: Our marriage, I mean—there is no such thing as a perfect marriage, but we really feed off of each other, I mean, its obvious that, um, the physical, she helps me more than I help her physically, but on the other hand, mentally I think we are equal, you know.
Olivia: I’m going to have to disagree. [laughter]
Randall: Just like issues that I have, that she [inaudible] it’s gonna be ok. Like bills, you know, I get worried about bills, she—
Olivia:--I could care less—
Randall: she says don’t worry about it, it will be ok, but, and then the house, I got to make sure that, you know, bills are paid, she is still happy, and my son is still happy, and now my daughter is still happy, and so its, it’s a lot. But, if you look from the outside [inaudible] people just say, you know, she takes care of him, but
I try so hard to be there for her mentally and you know I don’t go and brag about it, its just between me and her, you know. If somebody wants to say that its all on her, I mean I don’t, I don’t think—she knows what I’m doing, she knows how much I help her, you know, at first I was worried—I used to hear that a lot, you know, but I don’t hear that as much now. My in-laws are probably the best in-laws I could have, you know, because I rarely hear them talk about my disability. My sister-in-law is more jealous because her sister has more going on than she does and she’s the younger sibling, and I think that because when she goes home to see her family I think our marriage is so—I don’t’ know the word to use, but—Olivia: --inspiring—

Randall’s mental help, in exchange for Olivia’s physical help, makes the couple feel like equals. They are even the envy of their peers.

Similarly, Gene credits Victoria for keeping him focused, composed, and “together.” When asked how she cares for Gene, Victoria says “I do the cooking, that is about it!” But, Gene quickly corrects her, saying:

No, that is not nearly it! There have been some things that have gone on in life over the past ten years that I’m not sure that I would have known how to get through without her, both, from listening to me and talking me through things, but also in being around her and I’m not saying that you’re an inspiration to us all [laughing], um, the courage, um, that just kind of rubs off on me, I’ll put it that way, its not her, not just the courage, but the example that I was just talking about in her tolerance of other people where I would just like freak out, “get your ass over here and do this now!” She is very tolerant, she let’s people do things that has taught me a lot, and, that is not really responding to your caring question, um—
Sarah: Yeah, it is.
Gene: Um, the…there is and I can’t even believe that these words are about to come out of my mouth, there, in some circles I might say the nagging, but its not nagging its reminding and kind of bringing me back to reality, she knows how I am about things and I am focused on what I’m doing, when I can focus it is on what I’m doing, she helps me remind me helps to remind me that there are other things that I need to draw into the picture a little better, so she definitely watches over me.

Victoria’s watchfulness is what permits Gene to be successful. In fact, they are a particularly dynamic team in their local disability rights organization.
“Teamwork” was one of the ways in which couples framed the care and reciprocity in their relationships. As Allison notes:

I mean I feel like I try to do most of the cleaning and the laundry independently because that is something that I can do for us together because I know that, the driving and the cooking a lot of times that he takes over so I feel like when we do it together we’re doing it together for us and our household and not just for me doing for him and him doing it for me kind of a thing, so I feel like, we’re kind of working together as a team rather than him having to do stuff for me because I’m visually impaired and me just feeling like I have to do it back just to feel like we’re equal, you know, I just feel like we kind of work together as a team.

When imbalances of power did arise, or when the disabled partner begins to feel like a “burden,” couples were quick to find remedies.

Connie: And that is where Bob is brilliant about, I will say something exactly like that, along those lines to him, I feel like that is all I need I need you know, there is times that you never say to me, well you do this for us and you do this for us, you know, things around the house, cleaning the house, cooking, you know, that kind of stuff, but I just sometimes besides the everyday run of the mill stuff I need to do something that I feel like I’m contributing, you know, to stuff, and he will give me something that he needs done.

Sarah: Right.

Connie: If its work that he could have done at home, you know on the computer, he’ll put on there and stuff because he knows I’m good at figuring stuff out on the computer from my old job and stuff, he’ll make, he’ll give me something to make feel important.

Frank: Oh, I don’t believe that.

Bob: No, it helps me, if that is a by-product [inaudible]

Sarah: Right, its not just [inaudible]

Frank: She’s saying it makes me feel good—you don’t do it for that reason.

Bob: No.

Sarah: Right.

Frank: I want to defend him for that. I think he does it because he really does need the help.

Connie: I think in part he genuinely appreciates the help, I’m not say [inaudible], but he genuinely ap—but there’s times where he knows that if I got really down in the dumps because I don’t feel important—I don’t feel like I’m needed in any way he will give me something, it will make me feel—he could do the job himself—okay?

Frank: [inaudible]
Sarah: Right.
Frank: Somebody else could do it then.
Connie: Oh, he’s got a ton of people working under him he could give it to one of them, but if he gives it to me at home to do, okay, I could take my time at home and it makes me feel good because I’m doing something for him--
Bob: The flip side to that is, that, um, and a lot of couples say this and it sounds corny, but she truly is my other half and for me with stuff like that I know she thinks the same way I do, so I can ask her to do some of these things and I know darn well it would be done the same way that I would do it because we think along similar terms. It’s the same with, my position is HR related and so there will be times where there are people issues that come up at work and Connie is my sounding board.
Sarah: Right.
Bob: I go to her and I’ll say okay here is what’s going on, how am I going handle this? And, um, there have been times where I’ve changed the direction I was going because of something that Connie said, um, so, I—I—she appreciates it yes, and you’re right [to Frank], I’m not doing it just for those reason but it does help her and I can tell when she appreciates it.

Thus, part of the work of the disabled/nondisabled couple involves assessing what the disabled partner can do and assuring that he/she becomes responsible for those activities. As Dan, who has a spinal cord injury, explains, “I do those things because those are the things that I can do.” Dan can’t mow the lawn or do house maintenance, but he can vacuum the floors and do the laundry. Ways in which the disabled partner can reciprocate and give care to their nondisabled partner are actively sought and acknowledged in order to maintain a sense of equality.

Like the autobiographies and documentaries analyzed in Chapter 4, the couples in this study did not believe that the need for physical care “damaged” or desexualized their relationships. If fact, couples in the focus groups felt that physical caregiving activities often enhanced intimacy. For example, when asked how providing care interacts with sexuality or intimacy in the relationship, Richard and Emma respond:

Richard: It enhances it, I think. [laughter]
Emma: [inaudible] When you’re in the shower and he is bathing me its—its not sexual but yet it is, you know, I can’t explain it the right way—
Richard: --It’s a…um, high level sexual, but I mean, it is certainly not, certainly not intercourse but its its pleasurable, its pleasurable.
Emma: It is very intimate…it is a very loving, sensual, state-of-being

For Richard and Emma, the routine task of bathing has become part of their sexual intimacy. Another participant, Allison, who is blind, explains that holding hands with her partner Jason is a way for them to express intimacy and closeness even though, on a practical level, he is simply guiding her across a street. In both these examples, the disabled/nondisabled couple is able to eroticize care activities to enhance intimacy. The routine activities of daily care become opportunities for sexuality and intimacy because, as Olivia puts it: “You can be perverted whenever you want. “

In his journal entries, Kevin tracks some of the care activities he performs for Ellen, and his feelings about this “work”

I get to spend time each morning stretching her legs/feet to loosen up tight muscles for better walking. I consider this intimae because she trusts me and allows me to stretch her and not cause her pain.

I helped her into/out of bathroom stall. It could have been embarrassing and awkward for both of us, but (at least for me and I think for her) it wasn’t. We worked together and experienced an intimate moment that brought us closer and more comfortable and trusting of each other.

I helped Ellen get her legs up into bed tonight…seemingly an ordinary task—but I care for her and she doesn’t feel dependent…just…closer between us. Things “normal” couples don’t get to do for each other. We get to spend more intimate time together.

Looking over the past two weeks…I think we both show each other caring and enjoy intimacy—not like other couples—but maybe even better. We have developed a trust between us that has allowed us to experience a closeness that I don’t think many “normal” couples would ever experience. We have our ups and downs like all couples…but I think we’re doing alright.
As the participants wrote or talked about their experiences with caregiving, many, like Kevin, reached the conclusion that, perhaps, they were better off than “regular” couples.

For example,

Gene explains:

I’m trying to think of the best way to put this. There are times when it kind of increases intimacy, and I’m talking both sexual intimacy and just the closeness. In fact, I think we get a lot more closeness out of those up close and personal moments that we have together...Looking at other relationships before her, I would say this is the closest, strongest relationship, and I’m sure that that [physical care] has a lot to do with it.

Here, Gene is arguing that the physical care not only enhances sexual and emotional intimacy, but makes them stronger and closer than nondisabled couples. This sentiment is echoed by other participants as well. For example, Sabrina, who has multiple sclerosis says, “I think truly it makes you closer than it does other couples because you have to deal with things that you’d never have to deal with.” In Sabrina’s case, her partner Adam has had to catheterize her when she is unable to do it herself, thus, she feels that their relationship exhibits more trust and intimacy than nondisabled couples.

For many, it was precisely this knowledge of “private matters”—of their partners’ bladders, bowels, and other bodily functions—that provided the basis of this increased level of closeness and trust.

Kay: I think we know each other in a way that a lot of couples will never know each other [laughter.]
Sarah: Exactly.
Ted: That’s quite true there. [Laughter]

Kay: You know more about each other’s bodily, bodily—daily habits than maybe you’d—
Sarah: That’s a different way of looking at it, but—
Kay: …Than a lot of people do [laughter.]
Although Kay and other participants laughed at the “level of intimacy,” all did agree, on a very serious level, that such bodily knowledge facilitated intimacy. In his journal, Jack reflects:

Once home, it was bath time for Rachel, and on Friday’s it’s a shave night for her legs. How many guys get to shave their wife’s legs, so she trusts me, even though I sometimes nick her.

Comparing his level of intimacy with Ellen to that of his married friends, Kevin states:

--there is things you know talking to my buddies and stuff and other people at work and things you know “well, my wife never let’s me do this,” or “we never do that,” or just, I mean, other healthcare things [laughter] I’m not talking just about [laughter] as far as you know to the way hearing some of the wives talk that their husband won’t go anywhere near them during certain times of the month and they’re not allowed to touch them, they’re not allowed to do this and no way and it just, I help and I am involved in a lot more things than—I’m a therapist so I do this for a living as well—but just not only that, but with my wife I do things and we work together and we help with things and I’m a lot more involved in things than any of my buddies or any other guys I work with other than with their patients that they’re with, and so I think that is a wonderful thing because I know my wife a lot better than a lot of these guys ever will! And, I’ve—

Ellen: That is true!

People with disabilities simply cannot have the same kind of privacy and body boundaries as nondisabled people have been socialized to maintain.

In the focus groups, couples acknowledged that the disabled body requires physical, personal care. However, instead of hindering sexual intimacy, couples felt that this care helps intimacy. In fact, their words seem to suggest a blurring of care and sexuality, in which care contributes to the couples’ overall intimacy. Of course, bathing, dressing, toileting, and transferring are not normative forms of sexuality or intimacy. Because of this, I believe that disabled/nondisabled sexuality—even when heterosexual—is truly “queer” in the “queer theory” sense of the word. As this research makes clear,
non-heteronormative ways of expressing love and sexual desire are common in
disabled/nondisabled intimate relationships.

Conclusions and Reflections

I am confident that much of the data collected from the participants would not
have been gleaned in individual interviews or surveys. The interaction between couples,
between participants, is what brought to light stories of emotional and sexual intimacy
that fall outside of normative standards. I believe that couples would not have been
willing to share such stories. They knew that their sexual and emotional intimacy was
not “normal.” But in the safety of a group of other couples like themselves, they could be
disclosive.

For most of the participants, the focus group was the first time that they had been
in a group of people with experiences like their own, and they found the experience
particularly empowering. Reflecting on the research experience, Rachel writes:

I had a really good time at the first focus group meeting for the research project. I
have not stopped thinking about it since last night. It was great to meet couples in
the same situation that you are in and have someone finally understand what you
go through as a couple. Able-bodied couples that are friends of ours just do not
quite understand, and they may even in the back of their heads think that are
relationship is not "normal" or "weird". Or even think that possibly I use Jack in
order to get out of my parents house or avoid going to a nursing home to live.
Disabled people couldn't possibly be in love and be loved by someone else, that
idea is unacceptable in our society. Hopefully this research will open some eyes
of the ignorant, one would hope, but ignorance is bliss.

At the end of focus group 2, Randall says:

I think it would be nice if there was a group, like a retreat—
Sarah: for couples? That would be great! [everyone agreeing]
Randall: Yeah, a retreat like once a year, you know just getting together and talking and play games or something like that.

Clearly, the focus groups were a positive experience for Randall and the other couple in focus group two. They were among people that understood the struggles they faced as well as the joys they experienced. In fact, I received no negative feedback about the focus group experience.

Similarly, all people who completed the journals wrote that they really enjoyed the journaling experience. For some it was a good way to vent frustrations; for others it was a good way for them to reflect and see the events of the day more clearly. Several indicated that it was a practice that they planned to continue. Overall, both the journals and the focus groups were effective data collection methods. Each provided new information and rich details and stories about the experience of being in a disabled/nondisabled intimate relationship. In addition, both methods fulfilled my feminist research goals of empowering participants.

The focus group and journal data contradicts the binary and asexual relationship between disabled and nondisabled partners popularized in academic research and 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 recent, 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 (Butler 26, qtd. in McRuer 30). 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” (31). Disabled/nondisabled couples expose how limited 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.

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1 Shulamit Reinarz uses the term “feminist group interview” to distinguish the method from focus groups used for market research or sociology. For Reinarz, the feminist group interview is distinct from the focus group because it is dedicated to women’s knowledge and explicitly seeks to add value to the lives of women (instead of to a product or company). I primarily use the term focus group because it is, at this point, the more widely used term among qualitative researchers (including those outside of the business world). It should be clear, however, that like the “feminist group interview,” my focus groups were also dedicated to improving the lives of people with disabilities and their partners.
Two excellent examples of how people with disabilities are sometimes treated as objects and/or pin cushions by researchers are Anne Finger’s *Elegy for A Disease* and Kenny Fries’s *Body, Remember*.

There is little in the feminist literature about the use of journaling as a data collection method; however, it is similar to other “feminist” research methods such as content analysis of pre-existing diaries (Reinharz 147) asking participants to write their oral history/narrative (Reinharz 143). Journaling or diaries are, however, prominent in health research that seeks to measure daily health-related behaviors (e.g., safer sex practices, eating habits, etc.). For a rather innovative examination of the use of journals in social science research see Välimäki et al. In their study, Välimäki et al. tested the usefulness of diaries for family caregivers of people with Alzheimer’s disease. They found that diaries provided good research data and seemed to “help” participants: “The writing experience had been pleasant, even therapeutic, in some families, helping: ‘me to think more clearly about this’” (73).

In her review of the focus group methodology literature from sociology and anthropology, Irene van Staveren says that “three to four groups on one subject are generally enough and a duration of one to two hours per group is advised (132).”

Kinzinger recommends using a “group exercise” in the focus group to maximize participation and minimize facilitator involvement (107). Drawing attention to the exercise—such as having the group sort ‘cards’ into various categories—asks participants to work together, to reach consensus or to clarify disagreements. Using the PSA asked participants to discuss their reactions to the image and help “warm up” the group for a good discussion of popular culture.

Adam was considered the “nondisabled” partner in my study because he was largely not symptomatic. Sabrina was the “disabled” partner in the pair because she did need help with one or more activity of daily living as a result of the Multiple Sclerosis. As is the nature of the disease, Adam will also likely need help with ADLs as the MS progresses.

Its quite possible that Richard’s former friends also saw the relationship, and now Richard, as sexually deviant.

*An Affair to Remember* was released in 1957.

Two couples reported that they self-pay for in home care (this may include housecleaning or other assistance), and 5 couples said that they used personal care assistants (PCA) paid for by outside sources (e.g., state funding).

Respite care is care provided to the person with a disability while the regular carer (in this case the partner) takes a break. The break may be for a few hours to several weeks.
CONCLUSION

As I demonstrated in Part I, the applied fields and popular culture mirror each other, projecting a coherent image of disabled/nondisabled relationships. Drawn from dominant understandings of autonomy and independence, the need for care is framed as an emotional and physical burden on the partner. The disabled partner is rendered helpless, as only care-receiving. The nondisabled partner is portrayed as saddled with duty, tired and overwhelmed from caregiving. Because of this care dynamic and the taboo around the disabled body and mixing care and sex, these partnerships are rarely represented as sexual.

The disability rights movement’s intervention into this discourse has attempted to reframe the disabled person’s need for care by advocating for personal assistants (PA) and distancing disability from “care.” Tom Shakespeare has suggested that “care” be replaced with “help” in the disability rights discourse because, as Watson et al. outline, care is:

- associated with the confinement of disabled people, the modern equivalent to the custodial strategy that was the stand social response to disabled people by incarcerating them in ‘total institutions’ (Goffman, 1961) and constituting them as object of medical scrutiny...[Care] locates power with the caregiver rather than the recipient. (335)

“Help” is a less politically loaded term for people with disabilities. Thus, PA’s give help and support to their employers; they do not “care” for them. Such a reframing does
indeed shift the power away from the PA/caregiver; however, as I argue in Chapter 3, these tactics are ultimately limiting because they fail to undermine dominant understands of autonomy and independence. Arguing that disabled people can be “just like” the nondisabled with the use of PA’s reifies the supposed distinction between disabled and nondisabled people and obscures those people whose impairments are disabling. Ramps and PA’s may help some people with disabilities live like the nondisabled, but there are many disabled people whose lives continue to be different despite access and inclusion. Pain, fatigue and other body realities are not erased by the presence of PA’s or consumer-controlled payment schemes (i.e., the UK’s “direct payment” program).

In addition, this solution fails to acknowledge the material and social reality of caregivers, as well as the relationship between “worker” and “employer”. Women, people of color, and poor people are the typical care workers. These jobs are physically and emotionally exhausting, and they usually pay low wages with no benefits. Furthermore, Watson et al. note that there is “some evidence that disabled people and their assistants do not experience personal assistance in purely contractual, unemotional and instrumental terms” (338). Indeed, the nature of the work connotes a level of trust and intimacy that is not found in typical employer/employee relationships. In addition, this instrumental frame is difficult, if not impossible, to apply to the many disabled people who “employ” family members. In advocating for the disabled person’s right to control his or her own care, the disability rights movement has failed to consider the rights of the carer and the interpersonal dynamics of the care relationship.
On the other side of the care debates are feminists who are concerned with the well-being of the caregiver. Grounded in a materialist framework, these feminist care researchers have “focused on the ‘burden’ of care, and documented various ill-effects that could result from caring…including stress, limitations and emotional impacts (Fine and Glendinning 603). As I mentioned in the Introduction, their work has spurred much activism around improving the lives of caregivers. In the last several decades, organizations to support informal carers, such as the National Family Caregivers Association and the National Alliance for Caregiving, have popped up. These organization link informal caregivers with resources (such as respite care), provide social support, and keep members aware of policy that affects community care. Some of these organizations, along with NOW’s campaign for Mothers and Caregivers Economic Rights, advocate for privatizing care by paying family caregivers and regulating their working conditions.

All of these efforts, however, focus exclusively on the caregiver. In this framework, the compensation is paid to the informal carer (not to the disabled person); the caregiver essentially becomes a state employee (not the disabled person’s employee). It is easy to see how this simply transfers power to the caregiver, rendering the disabled person as passive recipients. Additionally, some feminist thinkers, such as Virginia Held, are weary of this “marketization” of care. Held argues that these tactics fail to consider the ways in which the market can pervert the emotional and ethical aspects of the care relationship. She agrees that “moving an activity that was previously unpaid to the side of being paid is often a gain, not just for the person doing the work but others also and for
the quality of the work” (23). However, “subordinating caring labor to the norms of the market” can also be dangerous (ibid.). Markets have not, to date, been able to “express and promote many of the values important to [care] practices, such as mutually shared caring concern” (32). Indeed, in both remuneration schemes outlined above, the care relationship is eclipsed.

Other feminists, those I have called feminist care philosophers, have attempted to rescue care through non-market means. As Fine and Glendinning explain, “rather than emphasizing the negative (‘burdensome’) features of care,” these theorists have developed “a discourse on the ‘ethic of care’ [emphasizing] its socially positive and desirable features” (604). Feminist care ethics is concerned with social value of care, the ways in which care promotes collective responsibility and empathy. Some of these philosophers, such as Joan Tronto, argue that care ethics is a precursor to justice and that “the right to receive and to give care needs to be thought of as an issue of social justice (Fine and Glendinning 605). In this framework, care is an esteemed activity and caregivers are valorized.

Problem with all of these tactics, however, is that they are concerned with either the caregiver or the care-receiver. Hughes et al. provide the following succinct characterization of the political split:

Generally, for feminist scholars, the emphasis is on the giver of care (usually female), whilst in disability studies the recipient of care (male or female) is the locus of interest. Given the political agenda and standpoint of these two social movements, the contrast in focus is understandable. However, whilst these groups have a different agenda, both regard the parties involved in the caring relationship as constituted and colonized by its dynamic. (260)
Like feminist disability scholars before me, I do not believe this divide is inevitable. In fact, both movements can inform each other and strengthen their individual agendas. However, this divide will not heal until feminists and disability activist/scholars work towards a coalitional politics concerned about both givers and receivers of care.

Following Morris, Whalmsley, Lloyd and other disabled feminist scholars, I argue that a first step is to undermine the notion that people in care relationships are either only caregivers or care-receivers. In other words, we must highlight the reciprocity and mutuality of care relationships. As the self-representations analyzed in Part 2 demonstrate, disabled/nondisabled intimate relationships are characterized by mutual support. Couples pay special attention to help maximize the ways in which the disabled partner can give care in an effort to create a sense of equality in the relationship. Thus, a coalitional politics between disability and feminist activist/scholars must be based on care relationships.

From this coalitional politics grounded in relationships, new perspectives on old problems can develop. Three potentially fruitful areas for future coalitional scholarship and activism include the privatization of care, radical interdependency, and queer theory. First, I believe disability and feminist activist/scholars alike must retain a healthy skepticism of market-based solutions to care. Both direct-payment systems and feminists efforts to monetize housework have problematic side-effects. I do not advocate, however, abandoning market strategies altogether because previous research and the findings of this dissertation suggest that families that deal with disability face economic hardship (Clarke and McKay). Furthermore, McCann and Evans found that finances
were one of the main concerns for people receiving care—they were concerned “about the level of financial support for themselves and their carers,” as well as the health and well-being of the caregivers (228). Care-receivers recognized that caregivers may sacrifice other financial or social opportunities in order to provide care. Disabled “care-receivers” also felt that they should not have to rely solely on the caregiver for financial and physical support. Clearly, disabled/nondisabled couples need a variety of support, including respite care, money, and flexible services. It may be that some level of market-based assistance is inevitable and useful. The key will be working together to develop sophisticated assessments of the costs and benefits of privatizing care, and proposing policy solutions that work for both disabled and nondisabled alike.

One of the main problems with privatizing care, as noted above, is that the market solutions have not been able to promote the sense of “radical interdependency.” As I outlined in Chapter 3, radical interdependency is based on feminist understandings of autonomy as inherently relational and physical. In other words, we experience a sense of self because of our body’s connection to other bodies. Care relationships can make radical interdependency obvious, however, all people, not just disabled people, are interdependent, formed in relation to others and maintained by the recognition conferred by peers. Feminist and disability scholars/activist must work on ways to celebrate and advance radical interdependency.

Because queer theory foils the public/private distinction, I believe queer frames may be a particularly useful way to think about intimate care for the disabled body, including the ways in which this care is sexualized both inside disabled/nondisabled
intimate relationships and outside. I believe that care and sexuality in
disabled/nondisabled relationships are taboo subjects because of heteronormative ways to
think about bodies, erogenous zones, and proper sexuality. However, as I highlighted in
Chapters 4 and 5, care activities often become part of the couple’s sexual intimacy in
disabled/nondisabled relationships. Future work should consider the implications of
queering disabled/nondisabled intimate relationships, as well as queering care more
generally.

Finally, disability and feminist scholars/activists must work on providing new
images and new narratives of disabled/nondisabled relationships. These images can help
dislodge the negative, demeaning representations enforced in dominant discourses and
illuminate new ways of relating that can inform all social relationships. Drawing on Luce
Irigaray’s notion of otherness and the later work of Michel Foucault, Hughes et al.
“propose that the feminization of care in a phallocentric culture makes participants in the
caring relationship—regardless of gender identity—necessarily subordinate” (260).
Relegated to the realm of the Other, disabled/nondisabled couples that give and receive
care are misrepresented or not represented at all. Their existence is unspeakable in the
language in dominant culture. Thus, Hughes et al. suggest that “those involved in caring
relationships” need to represent “its delight and drudgery and to fashion a dignified
‘aesthetics of existence’” (271). For Foucault, “life as a work of art is characterized by
creativity, and attained through work on the self [which] involves the intensification of
relations to oneself” (McLaren 70). Dedicated to the care of the self in social and
political context, “an aesthetics of existence is thus an ongoing project that requires
ethical work” (ibid.). This dissertation adds to the literature by offering glimpses of “beautiful” lives.

More research on disabled/nondisabled relationships—especially those imbued with other forms of social difference such as sexual orientation and race—is needed. Much of the research to date, including this project, has examined white, heterosexual couples. In addition, future research should consider how other domains, such as the influence of children, public policy, and support organizations, influence the experience of care and sexuality in disabled/nondisabled relationships. Most of all, we need new images and new narratives. In an effort to add new images and narratives about care and intimacy in disabled/nondisabled relationships, I conclude with one more story about Max and I.

Max could not stand without a walker, and even then he was mostly using the strength of his arms to keep him upright. To maintain bone density and flexibility, he was supposed to stand using the walker several times a day. We did it once or twice a month. I actually enjoyed helping him with this task because it was one of the few times we stood face to face. It was always quite shocking to me and I would become giddy from the novelty, and we would gaze into each other’s eyes and kiss. Sometimes, if he was feeling energetic, he would also wiggle his rear-end and do a little jig to make us both laugh. Despite the fun we did have with the exercises, he avoided them like the plague because it was so exhausting. Two or three sit-stands wiped him out. I also think it was scary for him. The MS sometimes interfered with his sense of balance; he would become dizzy or disorientated suddenly when he was just sitting in his chair. Loud noises or fast
movements startled him badly and could cause instant vertigo. So, he was very worried about falling during these exercises and would check and double-check with me to assure that I was braced and ready for him. I was always ready, but he never did fall.

In the water, however, he could stand—even walk—without the exertion. And, wrapped in a life jacket, he was not (as) worried about falling. He would stand, chest-deep in the water, and walk along the edge holding onto the wall for balance. Of course it was a lot of work getting to the YMCA, dressed in swim trunks, lowered into the pool with a mechanical lift, and then lifted out, dried and dressed again. So, unfortunately, we did not do this type of exercise often either, but we did do it often enough that he eventually felt safe enough in the water with me to go without the life jacket. I would stand behind him and wrap my arms around his chest and start walking backwards, slowly and steadily, but at a good enough speed to lift his feet and legs and let him “float.” In this position he could stretch and slowly kick his legs, moving muscles that he never could on land. It was excellent exercise and it was one of the ways I cared for Max, but it was also a very intimate, erotic experience. I will always remember what it was like to feel Max’s whole body move with mine in the water. Although we laid next to each other every night, it was only in the water that our whole bodies could move freely together. So among the children just learning to swim and the old ladies doing water aerobics, we would glide through the water, heads together, deeply in love.

1 Foucault’s “aesthetics of existence” has been criticized by many feminists for celebrating autonomous male individuals; however, following Margaret McLaren I read Foucault’s work on the “beautiful life” as open to all people and as inherently involving social relationships. See McLaren (68-74) for a good review of the feminist discourse on the “aesthetics of existence.”
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Table 1: Articles Analyzed from “Sexuality and Disability” Search (n=23)

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<tr>
<th>Authors</th>
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<td>Barnoff, Sinding and Grassau</td>
<td>Listening to the Voices of Lesbians Diagnosed with Cancer: Recommendations for Change in Cancer Support Services</td>
<td>Journal of Gay &amp; Lesbian Social Services</td>
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<td>Christopherson et al.</td>
<td>A Comparison of Written Materials vs. Materials and Counselling for Women with Sexual Dysfunction and Multiple Sclerosis</td>
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<td>Gagliardi</td>
<td>The Experience of Sexuality for Individuals Living with Multiple Sclerosis</td>
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<td>Hassouneh-Phillips and McNeff</td>
<td>“I Thought I Was Less Worthy”: Low Sexual and Body Esteem and Increased Vulnerability to Intimate Partner Abuse in Women with Physical Disabilities</td>
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<td>Karimzadeh et al.</td>
<td>The Psychological Impact of Infertility in the Male Able Bodied and Spinal Cord Injured Population</td>
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<td>Sexual Satisfaction and Sexual Self Images of People with Physical Disabilities in the Netherlands</td>
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<td>Laursen et al.</td>
<td>Ongoing Pain, Sexual Desire, and Frequency of Sexual Intercourses in Females with Different Chronic Pain Syndromes</td>
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<td>Li and Yau</td>
<td>Sexual Issues and Concerns: Tales of Chinese Women with Spinal Cord Impairments</td>
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<td>Murray and Harrison</td>
<td>The Meaning and Experience of Being a Stroke Survivor: An Interpretative Phenomenological Analysis</td>
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<td>Sexuality in Multiple Sclerosis</td>
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<td>Svetlik et al.</td>
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<td>Social and Sexual Relationships of Adolescents and Young Adults with Cerebral Palsy: A Review</td>
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<td>Zitzelsberger, Hilde</td>
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### Table 2: Articles Analyzed from “Caregiving and Spouse” Search (n=41)

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<td>Risk Factors for Potentially Harmful Informal Caregiver Behavior</td>
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<td>Blake, Lincoln and Clarke</td>
<td>Caregiver Strain in Spouses of Stroke Patients</td>
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<td>Boeije and Doorne-Huiskes</td>
<td>Fulfilling a Sense of Duty: How Men and Women Giving Care to Spouses with Multiple Sclerosis Interpret This Role</td>
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<td>Boeije, Duijnste, and Grypdonck.</td>
<td>Continuation of Caregiving Among Partners Who Give Total Care to Spouses with Multiple Sclerosis</td>
<td>Health and Social Care in the Community</td>
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<td>Bookwala et al.</td>
<td>Concurrent and Long-Term Predictors of Older Adults’ Use of Community-Based Long-Term Care Services: The Caregiver Health Effects Study</td>
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<td>Burton et al.</td>
<td>Transitions in Spousal Caregiving</td>
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<td>The Effectiveness of Family Interventions for Physical Disorders</td>
<td>Journal of Marital and Family Therapy</td>
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<td>Cannuscio et al.</td>
<td>Employment Status, Social Ties, and Caregivers’ Mental Health</td>
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<td>Chappell</td>
<td>Correcting Cross-Cultural Stereotypes: Aging in Shanghai and Canada</td>
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<td>Choi and Marks.</td>
<td>Transition to Caregiving, Marital Disagreement, and Psychological Well-Being: A Prospective U.S. National Study</td>
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<td>Cremeans-Smith et al.</td>
<td>Spouses’ and Physicians’ Perceptions of Pain Severity in Older Women with Osteoarthritis: Dyadic Agreement and Patients’ Well-Being</td>
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<td>Druley et al.</td>
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<td>Ducharme et al.</td>
<td>Older Husbands as Caregivers of Their Wives: A Descriptive Study of the Context and Relational Aspects of Care</td>
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<td>Ellenbogen et al.</td>
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<td>Journal of Vocational Rehabilitation</td>
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<td>Feld et al.</td>
<td>Expansion of Elderly Couples’ IADL Caregiver Networks Beyond the Marital Dyad</td>
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<td>Feld, Dunkle and Schroepfer</td>
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<td>Fultz et al.</td>
<td>The Impact of Own and Spouse’s Urinary Incontinence of Depressive Symptoms</td>
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<td>Giarelli, McCorkle, and Monturo</td>
<td>Caring for a Spouse After Prostate Surgery: The Preparedness Needs of Wives</td>
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<td>Gordon and Perrone</td>
<td>When Spouses Become Caregivers: Counseling Implications for Younger Couples</td>
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<td>Hash</td>
<td>Caregiving and Post-Caregiving Experiences of Midlife and Older Gay Men and Lesbians</td>
<td>Journal of Gerontological Social Work</td>
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<td>Hendrix and Ray</td>
<td>Informal Caregiver Training on Home Care and Cancer Symptom Management Prior to Hospital Discharge: A Feasibility Study</td>
<td>Oncology Nursing Forum</td>
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<td>Carer Distress: A Prospective, Population-Based Study.</td>
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<td>Ingersoll-Dayton and Raschick</td>
<td>The Relationship Between Care-Recipient Behaviors and Spousal Caregiving Stress</td>
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<td>Joseph and Bhatti</td>
<td>Psychosocial Problems and Coping Patterns of HIV Seropositive Wives of Men with HIV/AIDS</td>
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<td>Kang, Suk-Young</td>
<td>Predictors of Emotional Strain Among Spouse and Adult Child Caregivers</td>
<td>Journal of Gerontological Social Work</td>
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<td>Kim et al.</td>
<td>Quality of Preventive Clinical Services Among Caregivers in the Health and Retirement Study</td>
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<td>Gender Differences in Caregiving Stress Among Caregivers of Cancer Survivors</td>
<td>Psycho-Oncology</td>
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<td>Lee et al.</td>
<td>Caregiving and Risk of Coronary Heart Disease in U.S. Women: A Prospective Study</td>
<td>American Journal of Preventative Medicine</td>
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<td>Lin and Lu</td>
<td>Hip Fracture: Family Caregivers’ Burden and Related Factors for Older People in Taiwan</td>
<td>Journal of Clinical Nursing</td>
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<td>Luttik et al.</td>
<td>For Better and For Worse: Quality of Life Impaired in HF Patients as well as in Their Partners</td>
<td>European Journal of Cardiovascular Nursing</td>
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<td>Martire et al.</td>
<td>Older Spouses’ Perceptions of Partners’ Chronic Arthritis Pain: Implications for Spousal Responses, Support Provision, and Caregiving Experiences</td>
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<td>Mbanaso, Shavelson and Ukawuilulu</td>
<td>Elderly African American as Intragenerational Caregivers</td>
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<td>Pinquart and Sörensen</td>
<td>Ethnic Differences in Stressors, Resources, and Psychological Outcomes of Family Caregiving: A Meta-Analysis</td>
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<td>Raschick and Ingersoll-Dayton</td>
<td>The Costs and Rewards of Caregiving Among Aging Spouses and Adult Children</td>
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<td>Smith and Toseland</td>
<td>The Effectiveness of a Telephone Support Program for Caregivers of Frail Older Adults</td>
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<td>Soskolne et al.</td>
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<td>Toseland et al.</td>
<td>Supporting Caregivers of Frail Older Adults in an HMO Setting</td>
<td>American Journal of Orthopsychiatry</td>
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<td>Wolff and Kasper</td>
<td>Caregivers of Frail Elders: Updating a National Profile</td>
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Table 3: Initial Coding Sheet

OE= others perceive/treat equality in relationship
I= inequality experienced
R= reciprocity
OL= others perceive/treat love and intimacy in the relationship
L= love/sexuality/intimacy
OA= other perceive/treat relationship and/or person asexual
A= asexual feelings experienced
OB= others perceive/treat burden
B= burden experienced
CS= care facilitates sex/intimacy
CNS= care does not facilitate sex/intimacy
NM= negative media, impact
PM= positive media, impact
C= what needs changed, what couple desires to be different and how that might come about
AB= absent, what is not said, what is assumed to be understand amongst group
MP= metaphor/proverbs
W= repeated or significant words
**Table 4: Final Coding Sheet**

### Other Perceptions/Treatments:

- **DR** = Dismissive of relationships (others)
- **OE** = others perceive/treat equality in relationship
- **OL** = others perceive/treat love and intimacy in the relationship
- **OA** = other perceive/treat relationship and/or person asexual
- **OB** = others perceive/treat burden
- **FS** = Family/Friend Support
- **FC** = Family/Friend Concern
- **C** = Cure
- **ABL** = Ablism
  - **(GD)** Discrimination, general
  - **(ED)** Discrimination, economic
  - **(INF)** Infantilizing
  - **(ST)** Staring
- **IA** = Internalized ablism
- **DM** = Disability management
- **M** = Marker for help (visible disability)
- **MG** = Medical gaze
- **NPT** = Nondisabled partner treated as hero, saint, or super-desirable
- **PIT** = Pity

### Experience:

- **DOD** = Dating/online dating
- **I** = inequality experienced
- **R** = reciprocity (is also figuring out tasks for each partner)
- **L+** or **L-** = love/sexuality/intimacy (differing sex drives/needs)
- **A** = asexual feelings experienced
- **B** = burden experienced
- **ELR** = Early learning in relationship & testing
- **PHC** = Partner help/care
- **SR** = Self-Reliance
- **RQ** = Relationship quality
- **IK** = Intimate knowledge (of body, bladder, bowels)
- **SX** = Sexism
- **CSA** = Care as second nature
- **IND** = indifference
- **CD** = Care defined
- **RES** = respite or planning on help distribution
- **ACT** = activism
- **DP** = Disability Pride
T=Trust
DIFF=Other forms of difference

F=Financial difficulties/finances
PRIV=privacy
CS= care facilitates sex/intimacy
CNS= care does not facilitate sex/intimacy

**Representation**

NM= negative media, impact
PM= positive media, impact
AR=Absent representation
MED=media (both positive and negative)

**Misc.**

H=Humor
ES=Erotic segregation
CHIL=Children
C= what needs changed, what couple desires to be different and how that might come about

**Schema Analysis**

AB= absent, what is not said, what is assumed to be understand amongst group
MP= metaphor/proverbs
W= repeated or significant words
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<th>Disability</th>
<th>Relationship Status</th>
<th>Gender</th>
<th>Duration</th>
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<tr>
<td>Frank</td>
<td>M</td>
<td></td>
<td>White</td>
<td>Not Married</td>
<td></td>
<td>Before Hetero</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Jennifer</td>
<td>F</td>
<td>44</td>
<td>White</td>
<td>Not Married</td>
<td>Disabled (SCI)</td>
<td>Before Hetero</td>
<td>1</td>
<td>1.5</td>
</tr>
</tbody>
</table>
Focus Group Script

1. Consent Forms

2. Introductions

This focus group is about the meanings of “care” and “sexuality or intimacy” in relationships in which one partner is physically disabled and the other partner is able-bodied. I have a list of topics and suggested questions, but the conversation does not have to follow these guidelines; therefore, please add comments and questions where you see fit.

As was explained during the consent process, I will be audio-taping the focus group. This tape will be transcribed and all identifying information about you—such as your name—will be removed from the transcript. Once transcribed, the audio-tape will be destroyed.

We’ll be taking a break after an hour.

Remember, you do not have to respond to any questions that you are uncomfortable with. You can leave the focus group at anytime. You will not be penalized for not participating or leaving—you will still receive the $30 for your participation.

Are we ready to start? [Start recorder]

Let’s begin with introductions. Please let everyone know your name anything about you or your relationship you would like to share from the outset.

3. Response to representations

How are your experiences of care, sexuality, and intimacy typically viewed by “outsiders.” By family? Friends? Doctors? Physical and occupational rehabilitation people?

What do you think of how relationships such as yours are represented in popular media? (TV, film, magazines, etc.) How do such representations affect you?

I have a sample to share with you, if you’d like. It is a commercial made by Mothers Against Drunk Driving. [Show commercial] What do you think?

4. Self definitions

How do you define “care”? What does that mean?
How do you define “intimacy”? What does that mean?

5. Improving representations

How do you wish care was understood in popular culture, in rehabilitation, by your family?

6. Conclusions

Does anyone have anything they’d like to add to the discussion about care, relationships, and intimacy before we end?

Thank you for your time. [End tape]

7. Inquiry about follow-up study

Anyone interested in participating in a follow-up study? For the follow-up, I will give you a journal for two-weeks. You are encouraged to write any thoughts about the meaning of care, sexuality, intimacy in your relationship; how “care” and “intimacy” are perceived in your relationships; or anything else related to these topics that occur to you. For this effort, you are compensated $30. Please let me know if you are interested in participating.

8. Payments and Resource list

Give each participant the Resource List

Pay participants
Resources

General:

ADA-Ohio: is a state wide non-profit organization that provides information, technical assistance and training about the Americans with Disabilities Act (ADA) to individuals, businesses, state and local government agencies or municipalities. Anyone who has a question about the ADA is encouraged to call our office. http://www.ada-ohio.org/ or 1-800-ADA-OHIO.

Disability Network of Ohio-Solidarity: Statewide 501 C-3 non profit organization developed to promote an ongoing spirit of advocacy on behalf of people with all types of disabilities. DNOS is run by and for people with disabilities. Offers annual “Solidarity” Conference. www.dnos.org

Disability Resources Ohio: Website is a clearinghouse of all sorts of disability-related organizations, groups, etc. in Ohio. http://www.disabilityresources.org/OHIO.html

Ohio Statewide Independent Living Council: Established in 1992 by amendments to the Rehabilitation Act of 1973, the Ohio Statewide Independent Living Council (SILC) contains eleven representatives from Ohio's disabilities community. The Ohio SILC is an independent agency created by the Governor's Executive Order in accordance with the Rehabilitation Act that requires each state to establish a SILC to be eligible for federal funding under the Act. The Ohio Statewide Independent Living Council (SILC) is committed to promoting a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and systems advocacy, in order to maximize leadership, empowerment, independence, productivity and to support full inclusion and integration of individuals with disabilities into the mainstream of American society. http://www.ohiosilc.org/web06/index.php

Counseling:

Su Reddy, Counselor, M.S.Ed., PC., CDCA.
Heartland Wellness LLC, 110 N. High Street, Suite 204, Gahanna Ohio 43230
(614) 440-4801

OSU Harding Hospital
1670 Upham Drive, Columbus Ohio 43210
(614) 293-9600

OSU Rehabilitation Program: Rehabilitation Psychology
Dodd Hall, 480 Medical Center Drive, Columbus Ohio 43210
(614) 293-3830
Written Questionnaire
“Able-Bodied” Partner

Name: _____________________________________

1) Demographics:

Gender:__________                          Sexual Orientation:_________
Race/ethnicity:___________  Age: __________

Describe the nature of your partner’s
disability:________________________________________

2) When did your relationship to your partner begin?

3) When did you begin living together (approximate date)?

4) When did your partner become physically “disabled”?  

5) Are you legally married to your partner?

If yes, when did you get married?

If yes, did your marital status change the services/benefits you receive?

If not, do you plan to marry? Why or why not?

6) What benefits do you use? (check all that apply)

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Not eligible</th>
<th>Unsure if eligible</th>
<th>Eligible</th>
<th>I use</th>
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<tr>
<td>Medicaid</td>
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<td></td>
</tr>
<tr>
<td>Paid in-home care (not self-pay)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Private health insurance</td>
<td></td>
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</tr>
</tbody>
</table>

7) Services (please check all that you have used in the past YEAR):

__ Center for Independent Living
__ Support groups: ___online, ___ telephone, ___ in-person
__ Paid in-home care (self-pay)
__ Unpaid in-home care
Written Questionnaire
“Disabled” Partner

Name: ___________________________________

1) Demographics:

Gender:__________                          Sexual Orientation:_________
Race/ethnicity:___________  Age: __________
Describe the nature of your disability:________________________________________

2) When did you relationship to your partner begin?

3) When did you begin living together (approximate date)?

4) When did you become physically “disabled”?  

5) Are you legally married to your partner?  
   If yes, when did you get married?
   If yes, did you marital status change the services/benefits you receive?
   If not, do you plan to marry? Why or why not?

6) What benefits do you use? (check all that apply)

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<tr>
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<td></td>
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</tr>
</tbody>
</table>

7) Services (please check all that you have used in the past YEAR):
   ___ Occupational Therapy
   ___ Physical Therapy
   ___ Center for Independent Living
   ___ Support groups: ___online, ___ telephone, ___in-person
   ___ Paid in-home care (self-pay)
   ___ Unpaid in-home care (besides the help of the able-bodied partner)

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