The Case of Sharon Kowalski and Karen Thompson: Ableism, Heterosexism, and Sexism

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Today's debate over the legalization of same-sex marriage can seem abstract and distant from daily life. Furthermore, it tends to ignore the question of whether rights should be granted on the basis of marital status. But the case of Sharon Kowalski, left disabled and in a coma after a car accident, and Karen Thompson, the partner who fought to be part of her recovery, illustrates the practical importance of recognizing the rights of same-sex couples. Since Kowalski and Thompson's relationship was not recognized by the state, Thompson spent years fighting Kowalski's parents in the courts to have her rights recognized. As you read this article, think about whether this case might make people who are opposed to same-sex marriage rights rethink their position.

In November, 1983, Sharon Kowalski was in a head-on collision with a drunk driver, suffered a severe brain-stem injury, became paralyzed, and lost the ability to speak. Sharon was in a committed partnership with Karen Thompson. Serious conflict soon developed between Karen and Kowalski's parents, erupting in a series of lawsuits that lasted eight years. Karen fought to secure adequate rehabilitation for Sharon as well as access to friends and family of her choice. In 1985, acting under Minnesota guardianship laws, Sharon's father placed her in a nursing home without adequate rehabilitation services an prohibited Karen and others from visiting her. Karen continued to fight through the courts and the media. In 1989, Sharon was finally transferred to an appropriate rehabilitation facility, reunited with lover and friends, and, in 1991, finally allowed her choice to live with Karen.

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In this article I tell the story of Sharon Kowalski and Karen Thompson. While the story shows violations of their human rights, it is more than a story of two individuals. The injustices they encountered were modes of oppression that operate at a social-structural level and affect many other people. These oppressions include ableism, discrimination against disabled persons; heterosexism, the structuring of our institutions to legitimate only heterosexual relationships; and sexism, discrimination against women. Their story shows the power of structural discrimination, the intertwining of both our medical and legal systems in ways that denied both of them the fullest quality of life.

A History of Events

By November 1983, Sharon and Karen had lived in partnership for almost four years. Karen was thirty-six, teaching physical education at St. Cloud State University, devoutly religious, conservative. Sharon was twenty-seven, a fine athlete who had graduated from St. Cloud in physical education and just accepted a staff coaching position. She had grown up in the Iron Mine area of Minnesota, a conservative world where women are expected to marry young. Defying such expectations, she became first in her family to attend college, earning tuition working part-time in the mines. After she and Karen fell in love, they exchanged rings, bought a house together, and vowed lifetime commitment.

After the accident Sharon lay in a coma for weeks, and doctors were pessimistic about her recovery. Karen spent hours, daily, talking to her, reading the Bible, massaging and stretching her neck, shoulders, and hands. It is essential to massage and stretch brain-injured persons in comas, for their muscles tend to curl up tightly and incur permanent damage. Early in 1984, Karen saw Sharon moving her right index finger, and found that she could indicate answers to questions by moving it. Later she began to tap her fingers, then slowly learned to write letters and words.

The Kowalski parents became suspicious of the long hours Karen was spending with her, and increasingly Karen feared they would try to exclude her from Sharon's life. After consulting a psychologist, she wrote them a letter explaining their love, in hopes they would understand her importance to Sharon. They reacted with shock, denial, and rage. As the nightmare deepened, Karen consulted a lawyer and learned she had no legal rights, unless she won guardianship. In March, 1984, she therefore filed for guardianship, and Donald Kowalski counterfiled.

Guardianship was awarded to Kowalski, but Karen was granted equal access to medical and financial information and full visitation rights. She continued to participate in both physical and occupational therapy. Sharon improved slowly; Karen made her an alphabet board, and she began to spell out answers to questions. Later she began to communicate by typewriter, and in August spoke a few words. But conflicts continued. The day after the court decision Kowalski incorrectly told Karen she did not have visitation rights, and later tried to cancel her work with Sharon's therapists. When Karen and others took Sharon out on day passes, he objected, subsequently testifying in court that he did not want her out in public. In October, Sharon was moved further away, and Kowalski filed to gain full power as guardian. Karen counterfiled to remove him as guardian.

Months elapsed while the legal battles were fought. Sharon was moved several times, regressed in her skills, and became clinically depressed. The Minnesota Civil Liberties Union (MCLU) entered the case, arguing that under the First Amendment Sharon's rights of free speech and free association were being violated. A tri-county Handicap Services Program submitted testimony of Sharon's capacity to communicate, including a long conversation in which she stated she was gay and Karen was her lover. At Sharon's request, the MCLU asked to represent her and suggested she might testify for herself. The court refused both requests, finding that Sharon lacked understanding to make decisions for herself. In July, 1985, Kowalski was awarded full guardianship. Within a day, he denied visitation to Karen, other friends, the MCLU, and disability rights groups; in two days he transferred her to a nursing home near his home with only minimal rehabilitation facilities. In August, 1985, Karen saw Sharon for what would be the last time for over three years.

As this summary indicates, the medical system failed Sharon in at least three respects. First, it failed to supply rehabilitation in the years when it was vital to her recovery. Stark in the medical record is the fact that this woman who was starting to stand and to feed herself was locked away for over three years with an implanted feeding tube, left insufficiently stretched so that muscles that had been starting to work curled back on themselves again. Second, she was deprived of the bombardment of emotional and physical stimulation needed to regenerate her cognitive faculties. Once in the nursing home, for example, she was forbidden regenerative outside excursions. Third, although medical staff often recognized Sharon's unusual response to Karen, they failed to explain to her parents its importance. Despite an urgent need for counseling to assist the parents, none, except for one court-mandated session, took place.

The failure of the medical system was consistently supported by the legal system. Initially the court ruled that Sharon must have access to a young-adult rehabilitation ward. But once Kowalski won full guardianship, he was able to move her to a nursing home without such a ward. In 1985 the Office of Health Facility Complaints investigated Sharon's right to choose visitors, a right guaranteed by the Minnesota Patient Bill of Rights, and found that indeed her right was being violated. However, the appeals court held that the Patient Bill of Rights was inapplicable, since the healthcare facility was not restricting the right of visitation, the guardian was.

The deficiencies of guardianship law are a central problem in this case. First, a guardian can restrict a person's rights, without legal recourse. As is often said, under present laws a guardian can lock up a person and throw away the key. This is a national problem, affecting the disabled, the elderly, anyone presumed incompetent. Second, guardians are inadequately supervised. Under Minnesota law, a guardian is required to have the ward tested annually for competence. Kowalski never did, and for over three years the courts did not require him to. In 1985, Karen first filed a motion to hold him in contempt for failure to arrange testing and for failure to heed Sharon's wishes for visitation. The courts routinely rejected such motions.

Between 1985 and 1988, Karen and the MCLU pursued repeated appeals to various Minnesota courts, all denied. Karen began to seek help from the media, also disability, gay/lesbian, women's, and church groups. She recognized that the legal precedents could be devastating for others, e.g., gay/lesbian couples or unmarried heterosexual couples. The reserved, closeted, conservative professor was slowly transformed into a passionate public speaker in her quest to secure freedom and rehabilitation for Sharon; and slowly she gained national attention. The alternative press responded; national groups such as the National Organization for Women were supportive; the National Committee to Free Sharon Kowalski formed, with regional chapters. Finally the mainstream media began publishing concerned articles; Karen appeared on national TV programs; state and national politicians, including Jesse Jackson, spoke out. Meanwhile Sharon remained in the nursing home, cut off from friends, physically regressed, psychologically depressed.

The first break in the case came in February, 1988. In response to a new motion from Karen, requesting that Sharon be tested for competence, testing was ordered. In January, 1989, she was moved to the Miller-Dwan Medical Center for a 60-day evaluation. Kowalski unsuccessfully argued in court against both the move and the testing. Sharon immediately expressed her wish to see Karen. On February 2, 1989, Karen visited her for the first time in

three and a half years, an event which made banner headlines in the alternative press across the nation. She was, however, highly depressed, with numerous physical problems: for example, her feet had curled up so tightly that she was no longer able to stand. More significant was her cognitive ability; to this day, her short-term memory loss remains considerable.

The competency evaluation nevertheless demonstrated that she could communicate on an adult level and had significant potential for rehabilitation. The report recommended "her return to pre-morbid home environment," and added:

> We believe Sharon has shown areas of potential and ability to make rational choices in many areas of her life. She has consistently indicated a desire to return home . . . to live with Karen Thompson again.

Donald Kowalski subsequently resigned as guardian, for both financial and health reasons, and the parents stopped attending medical conferences. In June, 1989, Sharon was transferred to a long-term rehabilitation center for brain-injured young adults. Here she had extensive occupational, physical, and speech therapy. Again Karen spent hours with her and took her out on trips. She had surgery on her legs, feet, toes, left shoulder and arm to reverse the results of three years of inadequate care. She began to use a speech synthesizer and a motorized wheelchair.

Karen subsequently filed for guardianship. Medical staff testified unanimously that Sharon was capable of deciding for herself what relationships she wanted and where she wished to live. They testified that she was capable of living outside an institution and Karen was best qualified to care for her in a home environment. Witnesses for the Kowalskis opposed the petition. The judge appeared increasingly uncomfortable with the national publicity. While in 1990 he allowed Sharon and Karen to fly out to San Francisco where each received a Woman of Courage Award from the National Organization for Women, he refused Sharon permission to attend the first Disability Pride Day in Boston. He issued a gag order against Karen, which was overturned on appeal. Finally, in April, 1991, he denied Karen guardianship and awarded it to a supposedly "neutral third party," a former classmate of Sharon who lived near the Kowalski parents and had testified against Karen in a 1984 hearing. This decision raised the alarming possibility that Sharon might be returned to the inadequate facility. Karen appealed it.

In December, 1991, the appeals court reversed the judge's ruling and granted guardianship to Karen, on two bases: first, the medical testimony that Sharon was able to make her own choices; and second, the fact that the two

women are "a family of affinity" that deserves respect. This is a major decision in U.S. legal history, setting important legal precedents both for disabled people and gay/lesbian families. Sharon and Karen now live together.

The Three Modes of Oppression

Sharon and Karen were denied their rights by three interacting systems of oppression: ableism, heterosexism, and sexism. Originally Karen believed that their difficulties were merely personal problems. All her life she had believed that our social institutions are basically fair, designed to support individual rights. In the book[1] she co-authored with Julie Andrzejewski, she documented her growing awareness that widespread social/political forces were involved in their supposedly personal problems and that the oppression they experienced was systemic.

Ableism was rampant throughout. Sharon's inability to speak was often construed as incompetence, and her particular kinds of communication were not recognized. Quite early Karen noticed some did not speak to Sharon, some talked loudly as if she was deaf, others spoke to her as if she were a child. One doctor discussed her in her presence as if she was not there. When Karen later asked how she felt about this, she typed out "Shitty." Probably one reason she responded to Karen more than anyone was that Karen talked extensively and read to her, played music, asked questions, and constantly consulted her wishes. Although the MCLU and the Handicap Services Program submitted transcripts of long conversations with her, the courts did not accept these as evidence of competence, relying instead on testimony from people who had much less interaction with her. A major article in the St. Paul *Pioneer Press* (1987) described the Kowalskis visiting the room "where their eerily silent daughter lies trapped in her twisted body." Eerily silent? This is the person who typed out "columbine" when asked her favorite flower, answered arithmetical questions correctly, and responded to numerous questions about her life, feelings, and wishes. She also communicates nonverbally in many ways: gestures, smiles, tears, and laughter.

Thanks to ableism, Sharon was often stereotyped as helpless. The presumption of helplessness "traps" her far more severely than her "twisted body." Once a person is labeled helpless, there is no need to consult her wishes, consider her written communications, hear her testimony. When Sharon arrived at Miller-Dwan for competency testing, Karen reported with joy that staff was giving her information and allowing her choices, even if her

choice was to do nothing. Most seriously, if a person is seen as helpless, then there is no potential for rehabilitation. As Ellen Bilofsky[2] has written, Sharon was presumed "incompetent until proven competent." If Karen's legal motion for competency testing had not been accepted, Sharon might have remained in the nursing home indefinitely, presumed incompetent.

Finally, ableism can lead to keeping disabled persons hidden, literally out of sight. Kowalski argued against day passes, resisted Karen's efforts to take Sharon out, and testified he would not take her to a church or shopping center because he did not wish to put her "on display . . . in her condition." Although medical staff could see that outside trips provided Sharon with pleasure and stimulation, both important for cognitive rehabilitation, they cooperated with the father in denying them. According to an article in the *Washington Post,* he once said, "What the hell difference does it make if she's gay or lesbian or straight or anything because she's laying there in diapers? . . . let the poor kid rest in peace."

Invisible in the nursing home, cut off from lover and friends, Sharon had little chance to demonstrate competence. The wonder is that after three and a half years of loss, loneliness, and lack of care, she was able to emerge from her depression and respond to her competency examiners. To retain her capacity for response, through such an experience, suggests a strong spirit.

The second mode of oppression infusing this case is heterosexism, the structuring of our institutions so as to legitimate heterosexuality only. Glaringly apparent is the failure to recognize gay/lesbian partnerships. When Karen was first to arrive at the hospital after the accident, she was not allowed access to Sharon or even any information, because she was not "family." Seeing her anguish, a Roman Catholic priest interceded, brought information, and arranged for a doctor to speak with her. Although the two women considered themselves married, in law they were not, and therefore lacked any legal rights as a couple. If heterosexual, there would have been no denial of visitation, no long nightmare of the three-and-a-half year separation. While unmarried heterosexual partners might have trouble securing guardianship, married partners would not.

Because of heterosexism, Sharon's emotional need for her partner and Karen's rehabilitative effect on her were not honored. Because of Sharon's response, Karen was often included in the therapeutic work. Yet, prior to 1989, medical staff often refused to testify to this positive effect. Perhaps they feared condoning the same-sex relationship, perhaps they wished to stay out of the conflict. One neurologist, Dr. Keith Larson, did testify, although stipulating that he spoke as friend of the court, not as witness for Karen.

> The reason I'm here today is . . . to deliver an observation that I have agonized over and thought a great deal about, and prayed a little bit. . . . I cannot help but say that Sharon's friend, Karen, can get out of Sharon physical actions, attempts at vocalization, and longer periods of alertness and attention than can really any of our professional therapists.

Why was it necessary to "agonize" over this testimony? Pray about it? Make such a tremendous effort? Clearly, were one of the partners male, Larson would have had no difficulty. He simply would have reported that the patient responded to her partner. Some medical staff did testify positively, without effort; and after 1989, testimony from medical personnel was strong and unanimous. However, repeatedly, the courts ignored it.

Finally, heterosexism is evident in a consistent tendency to exaggerate the role of sex in same-sex relationships. Many believe that the lives of gay/lesbian people revolve around sex, though evidence from all social-psychological research is that homosexual people are no more sexually active than heterosexual people. Further, gay/lesbian sex is often perceived as sexual exploitation rather than an expression of mutual caring. The final denial of Karen's visitation rights was based on the charge that she might sexually abuse Sharon. A physician hired by the Kowalskis, Dr. William L. Wilson, leveled this charge:

> Karen Thompson has been involved in bathing Sharon Kowalski behind a closed door for a prolonged period of time. . . . *Ms.* Thompson has [also] alleged a sexual relationship with Sharon Kowalski that existed prior to the accident. Based on this knowledge and my best medical judgment . . . I feel that visits by Karen Thompson at this time would expose Sharon Kowalski to a high risk of sexual abuse.

Accordingly, Wilson directed the nursing home staff not to let Karen visit. Even though under statutes, Karen could have continued to visit while the court decisions were under appeal, the nursing home was obliged to obey the doctor's order.

In this instance, ableism and heterosexism merge. If they were unmarried heterosexual partners, sexual abuse probably would not have been an issue. If married, the issue would not exist. Ableism often denies disabled persons their sexuality, though a person does not lose her sexuality simply because she becomes disabled. Also, a person who loses the capacity to speak has a special need for touching. What were Sharon's sexual rights? When she was starting to emerge from the coma, she once reached out and touched Karen's breast, and later placed Karen's hand on her breast. At the time Karen did not dare ask

medical advice for fear of revealing their relationship. Even to raise such questions might have exposed her to more charges of sexual abuse.

While same-sex relationships are often called "anti-family" in our heterosexist society, actually such relationships create family, in that they create stable emotional and economic units. Family, in this sense, may be defined as a kin-like unit of two or more persons related by blood, marriage, adoption, or primary commitment, who usually share the same household. Sharon and Karen considered themselves married. Karen's long pilgrimage over almost nine years testifies to an extraordinary depth of commitment. Sharon consistently said she was gay, Karen was her lover, she wanted to live with her. While marriage has historically occurred between two sexes, history cannot determine its definition. In U.S. history, marriage between black and white persons was forbidden for centuries. In 1967, when the Supreme Court finally declared miscegenation laws unconstitutional, there were still such laws in sixteen states.

Sexism is sufficiently interfused with heterosexism that they are hard to separate. Often sexism enforces a social role on women in which they are subordinated to men. Women in the Minnesota world where Sharon grew up were expected to marry young and submit to their husbands' authority, an intrinsically sexist model. According to this model, her partnership with Karen was illegitimate. Sexism also is apparent in awarding guardianship to the father. Had Sharon been a man rather than a twenty-eight-year-old "girl," such a decision might be less possible; but in a sexist society, it is appropriate to assign an adult woman to her male parent. Finally, our society devalues friendship, especially between women. Once, very early, a doctor advised Karen to forget Sharon. The gist of his remarks was that "Sharon's parents will always be her parents. They have to deal with this, but you don't. Maybe you should go back to leading your own life." Friendship between the two women was unimportant. Ableism as well as sexism is apparent in these remarks.

This case makes clear that the modes of oppression work simultaneously. Like Audre Lorde[3], I argue that "there is no hierarchy of oppression." Disability was not more important than sexuality in curtailing Sharon's freedoms; they worked together seamlessly, in her life as in the legal and medical systems. Admittedly, any individual's perspective on the case may reflect the issue most central to her or his life: e.g., the gay press, reporting the case, emphasized heterosexism, and the disability rights press emphasized ableism. Working in coalition on this case, some women were ill at ease with disability rights activists; and some disability rights groups were anxious

about associating with gay/lesbian issues. But there are lesbians and gays in the disabled community, and disabled folks in women's groups. Karen experienced the inseparability of the issues once when invited to speak to a Presbyterian group. They asked her to speak only about ableism since they had already "done" gay/lesbian concerns. She tried, but found it nearly impossible; she had to censor her material, ignore basic facts, leave out crucial connections.

In each mode of oppression, one group of persons takes power over another, and this power is institutionalized. Disabled people, women, gay men and lesbians, and others are all to some degree denied their full personhood by the structures of our society. Their choices can be denied, their sexuality is controlled. On the basis of ableism, heterosexism, and sexism, both Karen Thompson's and Sharon Kowalski's opportunities for the fullest quality of life were taken from them. Sharon lost cognitive ability that might have been saved. As the Minnesota Civil Liberties Union put it, "The convicted criminal loses only his or her liberty; Sharon Kowalski has lost the right to choose whom she may see, who she may like, and who she may love." To change this picture took nearly nine years of struggle by a partner who lived out her vow of lifetime commitment and the work of many committed persons and groups.

Conclusion

Many national groups joined the struggle to provide rehabilitation for Sharon and bring her home, including disability rights activists, gays and lesbians, feminists and male supporters, and civil rights groups. In addition there were thousands of people drawn to this case by simple human rights. After all, any of us could be hit by a drunk driver, become disabled, and in the process lose our legal and medical rights. The Kowalski/Thompson case stands as a warning that in our deeply divided society, freedom is still a privilege and rights are fragile.

People living in nontraditional families need legal protection to secure legal and medical rights. Karen Thompson stresses the importance of making your relationships known to your family of birth, if possible, and informing them of your wishes in case of disability or death. Also, it is essential to execute a durable power of attorney, a document that stipulates a person to make medical and financial decisions for you, in case of need. Copies should be given to your physician. While requirements vary between states and pow-

ers of attorney are not always enforceable, they may protect your rights. Information about how to execute them may be found in your public library, in consultation with a competent lawyer, or in Appendix B of the book *Why Can't Sharon Kowalski Come Home?*

Endnotes

[1]Karen Thompson and Julie Andrzejewski. *Why Can't Sharon Kowalski Come Home?* San Francisco: Spinster/Aunt Lute, 1988. All quotations in text are from this book.

[2]Ellen Bilofsky. "The Fragile Rights of Sharon Kowalski." *Health/PAC Bulletin,* 1989, *19,* 4–16.

[3]Audre Lorde. "There Is No Hierarchy of Oppressions." *Interracial Books for Children Bulletin,* 1983, *14,* 9.

Questions

1. Explain how this story provides evidence of structural discrimination in the medical and legal systems.
2. List the ways in which ableism, heterosexism, and sexism are manifested in this case.
3. How do ableism and heterosexism intersect in this case?
4. Give an example of how at least two forms of oppression/privilege intersect in your own life.
5. Consult the laws of your state and find out whether Kowalski and Thompson's experiences might be similar or different today.
6. Use this example to make a case for the recognition of same-sex marriages.