
Introducing Disability Studies to Occupational Therapy Students

Pamela Block,
Melissa Ricafrente-Biazon,
Ann Russo, Ke Yun Chu,
Suman Sud, Lori Koerner,
Karen Vittoria, Alyssa Landgrover,
Tosin Olowu

This article is a work of collaborative ethnography about teaching and learning disability studies within the context of an occupational therapy graduate program. In spring 2004, 14 occupational therapy students were introduced to disability studies by their cultural anthropologist (nonoccupational therapist) course instructor. During the one-credit course, they were expected to complete readings, watch films, attend guest lectures, and make a site visit. The occupational therapy students were required to write a journal to record personal reactions and new insights gained from these experiences. This article focuses on a thematic analysis of the students' journaled responses to the film "Dance Me to My Song," and a site visit to a local Independent Living Center. Students were expected to analyze these experiences from both disability studies and occupational therapy perspectives. The article addresses philosophical and practical differences between occupational therapy and disability studies and identifies opportunities for collaboration between occupational therapists and independent living specialists.

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Pamela Block, PhD, is Clinical Associate Professor, Stony Brook University, Occupational Therapy Program, SHTM, HSC L2-439, Stony Brook, New York 11794-8206; Pamela.Block@stonybrook.edu

Melissa Ricafrente-Biazon, MS, OTR/L, is Practicing Occupational Therapist, Rehabilitation Medicine, Jack D. Weiler Hospital, Montefiore Medical Center, Bronx, New York.

Ann Russo, MS, OTR/L, is Practicing Occupational Therapist, Children's Learning Center, UCP-Nassau County, Roosevelt, New York.

Ke Yun Chu, MS, OTR/L, is Practicing Occupational Therapist, Mount Sinai Medical Services, Elmhurst Hospital, Elmhurst, New York.

Suman Sud, MS, OTR/L, is Practicing Occupational Therapist, Central Island Healthcare, Plainview, New York.

Lori Koerner, MS, OTR/L, is Practicing Occupational Therapist, Just Kids Diagnostic and Treatment Center, Lindenhurst, New York.

Karen Vittoria, MS, OTR/L, is Independent Contractor, Saint James, New York.

Alyssa Landgrover, MS, OTR/L, is Practicing Occupational Therapist, New Interdisciplinary School, Yaphank, New York.

Tosin Olowu, MS, OTR/L, is Independent Contractor, Jamaica, New York.

Introduction: Disability Studies and Occupational Therapy

The disability studies literature is replete with criticisms of medical and rehabilitation models and methodologies for addressing disability (Kielhofner, 2004, 2005). These critiques are primarily based in philosophical and theoretical differences about how disability is taught in medical and rehabilitation training programs (Block, 2004). Moreover, the first author has observed at professional conferences for anthropology and disability studies not just theoretical debate, but also visceral responses from disability studies colleagues to medical and rehabilitation models of teaching and practice. People cringe or melodramatically throw up their arms as if warding off dark forces. These reactions are reminders that critiques are, at times, full of emotion and supported by unfortunate negative personal experience. Because such reactions are part of disability studies and the disability rights movement, it is important for occupational therapists to be aware of them.

The first author is a cultural anthropologist by training who has studied cultural perceptions of disability in Brazil and the United States; intersections of race, poverty, disability, and sexuality; and most recently, health promotion and capacity building for individuals with spinal cord injury, multiple sclerosis, and related neuromuscular disabilities (Block, 1997, 2000, 2002, 2004; Block, Balcazar, & Keys, 2001, 2002; Block, Skeels, Keys, & Rimmer, 2005).

The American Occupational Therapy Association defines occupational therapy as follows:

Occupational therapy is skilled treatment that helps individuals achieve independence in all facets of their lives. It gives people the "skills for the job of living" necessary for independent and satisfying lives. (American Occupational Therapy Association [AOTA], 2004)

Occupational therapists use creative and holistic methods to design individualized therapeutic interventions. In comparison to other rehabilitation and medical models, their approach to disability is based less on physiology and more on

understanding and adapting to specific environmental and social contexts. The Society for Disability Studies defines disability studies as follows:

Disability studies encourages perspectives that place disability in social, cultural, and political contexts. Through our work we seek to augment understanding of disability in all cultures and historical periods, to promote greater awareness of the experiences of disabled people, and to contribute to social change. (Society for Disability Studies, 2004)

A key difference between occupational therapy and disability studies philosophies is the focus on individualized treatment as compared to the disability-rights and independent-living focus on community development and social change. However, there is nothing in the two statements that inherently conflict. Both disability studies and occupational therapy disciplines benefit from efforts to bridge this philosophical chasm. In the spring of 2004, the first author taught a 5-week one-credit disability studies course to the 14 women who comprised the program's first entry-level master's degree occupational therapy students class. Because this course represented an unusual opportunity to introduce occupational therapy students to disability studies concepts and themes, it was decided to undertake a collaborative ethnography with the students who were part of the course. The fundamental question of this ethnography is as follows: How do students respond and, hopefully, benefit from the inclusion of disability studies in their occupational therapy training program?

Methodology

The collaborative ethnography approach used here is conducted in the spirit of participatory action research (PAR). PAR originates from two sources: (1) anthropological and sociological methodologies of participant observation in which the observer or researcher also lives and actively participates in the community under study, and (2) organizational theory and practice emphasizing the application of participatory methodologies sensitive to sociocultural and community contexts (LeCompte & Schensul, 1999; Park, Brydon-Miller, Hall, & Jackson, 1993; Stringer, 1996; Whyte, 1991). This methodology has been developed for use in organizational and social movement research to work with disenfranchised groups (minorities, workers, etc.) to increase knowledge, build capacity, and attain social or systems change (Balcazar et al., 2004). The goal is to give groups previously excluded from research and policy decisions a "voice" in these processes and to recognize the formerly invisible contributions of these groups, in this case a group of students, to the success of educational, research, and policy endeavors.

The first author and the student coauthors engaged in a discursive dialogue about two learning experiences from the course that inspired diverse, passionate, and unexpected reactions: (1) viewing the movie *Dance Me to My Song* (De Heer, Pedersoli, & Procacci, 1997) and (2) a site visit to a local Independent Living Center (ILC). The student writings come from journals that were submitted as a course assignment. The participating coauthors contributed their journal entries as content for this article. Student writings concerning the film and site visit were organized thematically into the paper by the first author. As coauthors, the students reviewed drafts of this paper, provided additional commentary, and suggested changes that were incorporated into subsequent drafts.

Ethnographic Context: The Disability Studies Course

The course was organized around three main topics: institutionalization, deinstitutionalization, and community life. Required readings began with the history of institutionalization and sterilization of persons with disabilities. The class hosted guest speakers with and without disabilities, viewed the Australian film *Dance Me to My Song* (De Heer et al., 1997), and made a site visit to a local ILC. Students were expected to keep a journal, submit weekly discussion questions and a final paper, and watch two additional films depicting current and historical representations of disability experience.

The students already knew about the historical role of occupational therapy within institutions for persons with mental and developmental disabilities. The course addressed how these institutions came to exist. We discussed the eugenics movement, the invention of feeble-mindedness, and the political and social process by which hundreds of thousands of persons with mental and physical disabilities were institutionalized and/or sterilized during the 20th century (Goddard, 1912; Trent, 1994). Lectures included topics such as infantilization and the overprotection of persons with disabilities by their parents and caregivers. Readings covered how infanticide has been practiced in the United States in the recent past, as parents and doctors sometimes allowed babies with Down syndrome to die by starvation or by withholding simple life-saving measures (Dybwad, 1986). We discussed how the eugenics policies of Nazi Germany were first developed in the United States (Lifton, 1986).

Readings included the exposés of horrible living conditions in institutions like Willowbrook in the 1970s (Rivera, 1972). The students were shocked by the accounts of persons with disabilities denied privacy, sexuality, meaningful

activity, and basic humanity (Callahan, 1989; Ervin, 1997). Callahan's gibes on the uselessness of his occupational therapy also provoked the students: "I remember having my hands harnessed for long periods of time to a rolling-pin-like apparatus that sanded a piece of wood. A bright future as a finish sander stretched before me if I played my cards right" (p. 74). The first author used such writings to remind students that, unfortunately, such experiences, though sometimes decades old, still influence perceptions of occupational therapy within the disability community. Students learned of the Glen Ridge sexual assault and were disturbed by the inaction of the professionals who should have been protecting and advocating for the young woman (Lefkowitz, 1997). Most students were annoyed (but not surprised) at the gender disparities related to education, employment, and significant relationships for women versus men with disabilities (Asch & Fine, 1997).

The Film

Dance Me to My Song (De Heer et al., 1997) is a partially autobiographical movie, cowritten by Heather Rose, who also played the main character.* The movie is about Julia, a woman with cerebral palsy who uses a wheelchair and an electronic communicator. It focuses upon the escalating abuse and neglect she faced from her paid caregiver, Madelaine. Julia is left without access to food, water, and a bathroom for extended periods of time, her communication device is taken away, and her money is stolen. When Julia protests the mistreatment, Madelaine informs her that, without her caregiver's "help," Julia will be returned to an institution. Ultimately, Madelaine's behavior escalates to the use of physical violence. The film was chosen as a way to introduce disability studies philosophies and to prompt students to consider the relations of power and the numerous environmental and interpersonal barriers that persons with disabilities face on a daily basis. The journal entries indicated an understanding of the challenges persons with disabilities face in order to live independently in the community.

I learned a lot about the predicament of the disabled community represented by this film. . . . Julia does not strive to be "normal," she realizes that no matter how independent she becomes, she will always require the assistance of a caregiver. Her goal is to be treated with the respect deserved by every human being, regardless of their disability or limitations.

*Although this movie is not being distributed in the United States, it can be purchased directly from Vertigo Productions, 3 Butler Drive, Hendon, South Australia 5014, Australia, 08-8348-9349 (phone), 08-8348-9347 (fax).

The students recognized that disability is not necessarily a function of physiology, but that the barriers to independence can be located in the environment and in social perceptions and prejudices.

However, not all the students expressed an appreciation of the movie's complex and contradictory messages about interpersonal relationships and community life. One student distanced herself from Madelaine's actions by asserting that such abusive behavior only took place in the distant past. Another stated, "Since I have not had any direct or indirect dealings with an institution, it is hard for me to have a personal connection to this movie." Other students were shocked, upset, or disapproving of the level of drinking, the violence, and the graphic sexual scenes.

In addition to analyzing the film's messages about the challenges of community life, students were asked to consider the film from the perspective of an occupational therapist. Some students expressed concern with Julia's social relationships and her need for personal safety:

Occupational therapists need to be aware of their clients' safety and to be aware for signs of neglect or abuse. I believe the portrayal of Julia and her problems with home health workers was fairly accurate. This helped me to have an idea of how important it is that people who are disabled have reliable options for home health care so they remain out of institutions. Another consideration for occupational therapy is the area of social relationships. Julia's friendships in the movie were not necessarily healthy since her friends were depicted as marginalized and drinking a lot. On the other hand, they cared about Julia and protected her.

Other students focused on services and technology that might grant Julia increased autonomy and render her less vulnerable to abuse:

Julia could have benefited from the services of an occupational therapist in many ways. For example, Julia's assistive technology needs could have been assessed, and the occupational therapist could have recommended assistive devices that would have helped her to feed herself. In addition, an occupational therapist could have also helped Julia set up a financial management system through her bank so that she wouldn't have to rely on her attendant to withdraw money for her (a task that gave Madelaine the opportunity to steal from her) as well as set up accounts with local businesses such as the grocer for food delivery. Other services, such as something akin to Meals-on-Wheels in Australia, could have also been another resource that could have helped Julia lead a more independent life.

The students appear both comfortable and comforted in using their professional expertise to find ways to improve Julia's quality of life. In this way they distanced themselves from the abusive behaviors from the position, "We would never treat a client like that caretaker did." Many of the students expressed a desire to protect Julia from the dangers of

community life. One student's solution was to find "some kind of community program or day program for her to attend and become active in," not understanding that this might be perceived as another form of institutionalization. Although several of the students suggested that Julia should be more active in community life, no one suggested higher education or employment as possibilities for her.

Although the power disparity between Julia and her caregiver was glaringly apparent in the movie, it was unclear based on the students' journal entries to what extent they comprehended that such disparities are always present between persons with disabilities and their caregivers and service providers, including occupational therapists. Anyone in a position to judge and act upon the perceived suitability of another person's friends, activities of daily living, and ability to live independently is in a position of power. Unfortunately, occupational therapists work within a health care system where some individuals who desire occupational therapy services are denied, whereas others resent being pressured to accept services they do not want.

Disability studies theorists have accused rehabilitation and related allied health disciplines of having "minimal critical analysis within these fields of their paternalistic impulses" (Linton, 1998, p. 82). This is a systemic problem, but one that is articulated through individual interactions. Students were encouraged to be aware of how power relations are reproduced on the individual level, and to be sensitive to their own placement and power as professionals within this system.

The Site Visit

Students visited the local ILC. This organization provides information, referral, peer support, and mentoring to build the capacity of individuals with disabilities to maintain control of their lives and make informed choices about various aspects of community living. In the peer-mentoring model, persons with disabilities share knowledge and experience to help each other. The ILC professionals lectured to the students about the history and politics of the independent living movement and the peer mentoring model. The two ILC professionals who met with students did not have personal experience with occupational therapy. They engaged the students in a discussion about the occupational therapy profession and challenged the students to consider how the practices of ILCs and occupational therapists might complement each other, and how the two might collaborate. The discussion was heated at times, with clear differences of perspective and opinion. The journal entries pertaining to the site visit revealed a range of positive and negative responses.

Students were impressed by the peer mentoring approach, the emphasis on employing persons with disabilities, and that services were provided free of charge. One student stated, "They help individuals make informed decisions and promote self-empowerment." Another stated, "This center is a great resource to refer clients to when they need to discuss their disability with someone who truly understands from experience." Some of the journal entries described the similarities between occupational therapy and ILC approaches and opportunities for collaboration:

Both the occupational therapy profession and Independent Living Centers are focused on providing individuals with disabilities (mental, physical, or developmental), the opportunities to live an independent and meaningful life. I believe that both Independent Living Centers counselors and occupational therapists strongly advocate for individuals with disabilities to have the same rights and experiences as their nondisabled peers, whether it is by eliminating social, physical, or emotional barriers, pursuing a college education, being employed, being able to live independently, or being involved in community and/or social activities.

Occupational therapists have knowledge on activity analysis, assistive technology, and the physical functions of the body, which the Independent Living Centers' employees have real-life experiences, and an ability to navigate the system. How can we work together to provide the best possible care for clients? I think if Independent Living Centers educate therapists on what they can do and therapists educate these centers on what they can do, a wonderful collaborative relationship could be developed. The development of this relationship would really help the client to maximally achieve all their personal goals.

Most of the students viewed ILCs as an important resource for themselves and their clients. One student believed it a "disservice to society" that ILCs received so little recognition and visibility for the vital services they performed in helping persons navigate through the "red tape of paperwork."

However, students also recognized some of the differences and limitations for both the occupational therapy and ILC approaches to disability:

As peer counselors, the ILC providers give the consumers the necessary information to make informed decisions. As occupational therapists, we work with the client, the client's family, health care providers, and case managers to determine a feasible treatment plan and set realistic goals, and we also provide the information necessary for the client and his/her family to make informed decisions. Clinical reasoning is involved, however, and consequently, liability can be an issue if the client chooses to do something that may be unsafe.

I believe that ILC counselors are able to provide more client-centered services, because for them the reimbursement policy is not as strict as it is for an occupational therapist. Occupational therapists must follow the guidelines of

the facility that they work for and the services that they provide must be in the scope of the occupational therapy practice.

The most heated exchange between the ILC professionals and the occupational therapy students concerned the issue of individual or patient's rights versus the clinical judgment of what is safe and appropriate to facilitate or approve. The ILC professionals stated that they offered information to their clients, including a full disclosure of risks involved, but did not attempt to control the choices people made with this information. The occupational therapy students stated that for ethical and liability reasons they were required, at times, to limit the options available to their clients if they considered their health or safety to be at risk.

This points out that, in the future, it will be necessary to explain the differences between an ILC and an assisted living center. Prior to arriving at the facility, at least half of the students indicated a belief that they were going to visit a residential facility and were surprised and, in some cases, disappointed by what they actually found. Some of the students expressed very strong negative feelings about the site visit, including anger and disappointment that their time had been wasted: "There wasn't really much there that we didn't know already or haven't heard in other lectures throughout our college experience." More than half of the students felt that they were being "put on the defensive," "drilled," or "tested" about their knowledge of occupational therapy, assistive technology, and persons with disabilities and the concept of independent living.

I felt that they had little knowledge about occupational therapy can do for individuals with disabilities. They seemed to be drilling us with questions concerning what we should do in certain situations. I felt that they didn't realize that our profession works with the same population as them, and are very sensitive to the needs of these individuals.

Several students expressed that they perceived a need to defend their professional values and the quality of their interactions with persons with disabilities. One student recognized what she diplomatically referred to as the "potential tension between people advocating self-determination for those with disabilities and occupational therapists."

Reflections

Review of early submissions of the students' journals allowed for brief discussion during the final class about their reactions to the site visit. We discussed how some persons with disabilities experience the health care system negatively, leading to suspicion, distrust, and outright hostility to medical and allied health professionals (Blumberg, 1989). The discussion included a critique of "the medical model"

from a disability studies perspective in which persons with disabilities express perceptions of being treated by health care professionals as if they are broken and must be fixed (Gill, 2001). The first author described how disability rights activism advocates for persons with disabilities to be accepted *as they are*, not as medical, educational, or rehabilitation models profess they should be. The goal of the discussion was to underscore the historical context that may influence their interactions with some disability communities and highlight the importance of such public relations opportunities as the visit to the ILC. It became apparent that patience and tolerance might be required in order to regain trust and ameliorate the bad impressions left from prior negative experiences with the health care system. The students received an article from the *Disability Rag* called "The Revolt of the Easter Seal Kids" about the author's childhood experience in the 1950s as part of a fund-raising show run by occupational, physical, and speech therapists. The author considered the practice humiliating and exploitative. The smallest children demonstrated what they were unable to do, while the older children were supposed to show what they were now able to accomplish with the help of all the therapies. During a big fund-raising event, the children purposely and comically failed to perform as instructed, much to the therapists' embarrassment. The article ends with the following:

I am proud of what I did and of what I think the others did that night. Yet, I feel ambivalent about writing all this down, and am unsure about the proper note on which to end. The truth is that while the Center's therapists exploited us and did many things that were wrong, they also did things that were right.

They told us we had potential. They encouraged our parents to send us to public school. They allowed us to play, and they never physically hurt us—and in the "health-care community" of 1957 that was saying a lot. They permitted us enough self-esteem and enough sense of personhood that we could rebel against oppression—both as children and as adults. (Blumberg, 1989)

These final paragraphs contain an important message. Even though critical of the practices of the therapists and the agency, Blumberg also recognized the benefit and the quality of the services and encouragement that she received.

Although much of the responsibility for bridging the chasm between occupational therapy and disability studies remains with the clinicians, there are approaches that can be undertaken from the disability studies position that would facilitate future discussion and collaboration. Many occupational therapists are unaware that disability studies and disability rights perspectives contain critiques of rehabilitation approaches to disability, some of which are directed specifically to occupational therapy. If rehabilitation professionals

are automatically classified and treated as enemies, their response will be defensiveness or outright hostility to disability studies approaches. Disability studies scholars and activists should advocate and educate on disability studies topics in medical and rehabilitation contexts with the goal of promoting increased understanding and collegial relationships with occupational therapists both inside and outside academia.

Conclusion

Simi Linton (1998) states that:

Disability becomes the ring through the nose of practitioners that leads them to particular interpretations and interventions based on the idea that disability in general and specific disabilities in particular determine a constellation of psychological responses or that disabled people have such unique needs that they can be met only by specialists. (p. 82)

Linton is referring to health care and rehabilitation professionals in general, not just occupational therapists; but after reviewing the students' journal entries supplemented by classroom discourse, it appears that Linton's statement is only partially true of the occupational therapy students. These students demonstrated a strong understanding of the importance of empowering individuals with disabilities to be more independent. However, these perceptions were sometimes constrained within a patient–professional framework. Empowerment and independence were perceived as achievable in the therapeutic setting, rather than through self-advocacy and self-determination. Consider one student's discussion question: "The woman at the ILC spoke of helping the individual perform any activities they would like such as fishing, baking, going back to work. How can the employees at Independent Learning Centers actually adapt the activities for maximal participation without formal training?" The first author would respond by asking the student to consider the different benefits to be gained by learning through the trial-and-error of a real-life experience with the help of a peer mentor, as compared to acquiring skills only through the therapeutic interventions of professionals. The student coauthors wish to note that some of their perceptions and reactions are the result of inexperience, not necessarily disagreement with a disability studies approach.

Simi Linton (1998) exhorts:

If rehabilitation professionals believe in self-determination for disabled people, they should practice what they teach by adhering to an active affirmative action program in their own departments; by adopting the books and essays of disabled people into their curricula; and by demanding that disabled people have an active voice in conference planning and on the platform at conferences." (p. 141)

Although, no doubt, many occupational therapy curricula have already responded in ways to Linton's exhortation, there is still much work to be done. After achieving increased visibility and voice for individuals with disabilities within occupational therapy, a next step might be to better incorporate disability studies theories and philosophies into occupational therapy education and practice. In this way, disability studies can become a tool that occupational therapists can use to strengthen their practice, and occupational therapy practice becomes a medium for progressive social change within a disability studies framework.

In conclusion, the goal of the disability studies course was to challenge occupational therapy students to think of persons with disabilities not just as patients or clients but also as members of the community. Of course, many of my students already understood this, especially those who had family members with disabilities or had disabilities themselves. One such student wrote: "I believe that occupational therapists can work within the self-advocacy model while remaining faithful to our practice and core values. I think I would need to become more involved with ILCs to understand fully the issues they confront daily."

The experience of this course points to the value of:

- Educating occupational therapy students more about disability history and disability rights
- Requiring students to seek out additional disability-related experiences that fall outside the pale of fieldwork contexts which, understandably, involve client–patient therapeutic relationships
- Interacting with nontraditional, community-based programs and activist organizations in ways that challenge traditional understandings of the relationship between health care providers and persons with disabilities

Such efforts could help students develop a dual vision that incorporates therapeutic perspectives where appropriate, and also fundamentally recognizes persons with disabilities as citizens, neighbors, friends, and family members.▲

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References

- American Occupational Therapy Association. (2004). *Consumer information: What is occupational therapy?* Retrieved July 28, 2004, from <http://www.aota.org/featured/area6/index.asp>

- Asch, A., & Fine M. (1997). Nurturance, sexuality and women with disabilities. In L. Davis (Ed.), *Disability studies reader* (pp. 241–255). New York: Routledge.
- Balcazar, F., Taylor, R., Kielhofner, G., Tamley, K., Benziger, T., Carlin, N., et al. (2004). Participatory action research: General principles and a study with a chronic health condition. In L. Jason, C. Keys, Y. Suarez-Balcazar, R. Taylor, M. Davis, J. Durlak, et al. (Eds.), *Participatory community research: Theories and methods in action*. Washington, DC: American Psychological Association.
- Block, P. (1997). *Biology, culture, and cognitive disability: Twentieth century professional discourse in Brazil and the United States*. Unpublished doctoral dissertation. Durham, North Carolina: Duke University. (UMI No. 9727344)
- Block, P. (2000). Sexuality, fertility and danger: Twentieth century images of women with cognitive disabilities. *Sexuality and Disability*, 18(4), 239–254.
- Block, P. (2002). Sexuality, parenthood, and cognitive disability in Brazil. *Sexuality and Disability*, 20(1): 7–28.
- Block, P. (2004). Disability studies in the belly of the beast [Electronic version]. *Disability Studies Quarterly*, 24(4).
- Block, P., Balcazar, F., & Keys, C. (2001). From pathology to power: Rethinking race, poverty and disability. *Journal of Disability Policy Studies*, 12(1), 18–27.
- Block, P., Balcazar, F., & Keys, C. (2002). Race, poverty and disability: Three strikes and you're out! Or are you? *Social Policy*, 33(1), 34–38.
- Block, P., Skeels, S. E., Keys, C. B., & Rimmer, J. (2005). Shake-it-up: Health promotion and capacity building for people with spinal cord injuries and related neurological disabilities. *Disability and Rehabilitation*, 27(4), 185–190.
- Blumberg, L. (1989, March/April). The revolt of the Easter Seal Kids. *Disability Rag*, 9(2).
- Callahan, J. (1989). *Don't worry he won't get far on foot*. New York: Vintage.
- De Heer, R., Pedersoli, G., & Procacci, D. (Producers), & de Heer, R. (Director). (1997). *Dance me to my song* [Videotape]. Hendon, South Australia, Australia: Vertigo Productions. (Available from www.vertigoproductions.com.au/dance.html)
- Dybwad, G. (1986). Ethical and legal problems in rehabilitation medicine. In D. Warms (Ed.), *The changing rehabilitation world: Into the 21st century: Selected papers from an international conference, September 3–4, 1985* (pp. 10–15). New York: United Cerebral Palsy.
- Ervin, M. (1997). Coitus interruptus. In K. Fries (Ed.), *Staring back* (pp. 239–254). New York: Plume Books.
- Gill, C. J. (2001). Divided understandings: The social experience of disability. In G. Albrecht, K. Seelman, & M. Bury (Eds.), *Handbook of disabilities studies* (pp. 351–372). Thousand Oaks, CA: Sage.
- Goddard, H. H. (1912). *The Kallikak family: A study in the heredity of feeble-mindedness*. New York: MacMillan.
- Johnson, H. M. (2003, November 23). The disability gulag. *NYT: Magazine desk*, p. 59
- Kielhofner, G. (2004). Disability studies. In G. Kielhofner (Ed.), *Conceptual foundations of occupational therapy* (3rd ed., pp. 238–253). Baltimore: Williams and Wilkins.
- Kielhofner, G. (2005). Rethinking disability and what to do about it: Disability studies and its implications for occupational therapy. *American Journal of Occupational Therapy*, 59, 487–496.
- LeCompte, M. D., & Schensul, J. J. (1999). *Designing and conducting ethnographic research*. Walnut Creek, CA: Altamira Press.
- Lefkowitz, B. (1997). *Our Guys*. New York: Vintage Books.
- Lifton, R. J. (1986). *The Nazi doctors*. New York: Basic.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York: New York University Press.
- Park, P., Brydon-Miller, M., Hall, B., & Jackson, T. (1993). *Voices of change: Participatory action research in the United States and Canada*. Westport, CT: Bergin & Garvey.
- Rivera, G. (1972). *Willowbrook*. New York: Random House.
- Society for Disability Studies. (2004). *General information: Mission statement*. Retrieved July 28, 2004, from <http://www.uic.edu/orgs/sds/generalinfo.html>
- Stringer, E. T. (1996). *Action research: A handbook for practitioners*. Thousand Oaks, CA: Sage.
- Trent, J. W. (1994). *Inventing the feeble mind: A history of mental retardation in the United States*. Berkeley, CA: University of California Press.
- Whyte, W. F. (1991). *Participatory action research*. Newbury Park, CA: Sage.