Are Birds Free From the Chains of the Skyway?
Balancing Freedom, Responsibility and
Reflexivity Disability Service Provision

Beth Omansky Gordon, Ed.S.
The George Washington University

Abstract

Using personal experience narrative, I will discuss the
role of disabled disability service providers as agents
in an emancipatory process. Reflexivity is required in
order for disabled disability service providers to be
effective change agents on behalf of other disabled
people without falling into the trap of imposing their
own theoretical paradigm or personal agenda onto their
disabled service consumers.

Ah, my friends from the prison, they ask unto me,
"How good, how good does it feel to be free?"
And I answer them most mysteriously,
"Are birds free from the chains of the skyway?"
Bob Dylan

Introduction
     In "Ballad in Plain D," (1964, Track 10), Dylan reflects
upon a classic existential dilemma: no matter how free we
appear or believe ourselves to be, we are, nevertheless, bound
to forces beyond our personal facticity. We are in relation to
and with others and we cannot help but experience our lives
within contextual and intertextual frames. Ironically, even
though we, as disability advocates, academicians, and service
providers strive to free ourselves from the bondage of medical
and social constructs of disability, the very essence and
nature of our work is inextricably chained to what we oppose.
Our discipline was born out of reaction to oppression and our
freedom comes with responsibility to help shape the future.
     As an activist and disability studies scholar, I learned
to refute societal stereotypes, to reframe my disability
experience, to cast off the chains of internalized oppression.
Now, in my role as a disability service provider at a
university, I want to "share the wealth" with my students -

people who have been indoctrinated (note the etymological link to "doctor") into the medical model of disability by society in general, and medical, educational, and service professionals in particular. But this agenda is mine, not the students. Never has even one of our students expressed awareness of such terms as "social model" or "medical model." They believe that their disabilities belong to them individually and that it is up to them to "adjust," "adapt,' or be granted "special" treatment to support their efforts to "overcome" their "challenges." Their school experiences reinforced such beliefs. In summary, they know only the medical model of disability.

In my role as a consultant, I have the opportunity to educate my students about an epistemology of disability that can be encouraging, enlightening, and, most of all, empowering. Yet, I find myself in a two-fold dilemma. First is the ethical imperative to place my students' needs in clear and firm priority above any personal/political agenda I may have. Next, I have an ideological commitment to the social model of disability while representing an institution whose services are designed around and bound up in the medical model of disability.

Balancing Agendas

For the last two years I have worked with Regina, a 36-year-old returning student who was diagnosed with multiple sclerosis during her first semester at our university. As her symptoms progressed we adjusted her classroom accommodations accordingly, she maintained an excellent GPA, and completed her final semester last month. Two weeks before graduation, Regina came to my office and said, "I just came from the Graduation Office. Can I use my cane when I walk across the stage to get my diploma?" Perhaps because our office was in the throes of a difficult advocacy effort on behalf of a wheelchair-using student who required ramps on both sides of the stage in order to participate in Commencement in the same manner as the other graduating seniors, I immediately suspected that someone in the Graduation Office discouraged Regina from using her cane. I was acutely aware that I needed to exercise reflexivity - to monitor my inner reactions and outward response. I did not express my suspicion aloud, but simply replied, "Of course you can use your cane when you walk the stage. You can do whatever works for you." Regina asked, "Well, how am I going to hold my cane, accept my diploma, and shake the person's hand all at the same time?" Regina needed practical advice, not advocacy and not a lesson in theory. So, Regina and I practiced how she could accomplish this and in a few minutes she was on her way knowing that she was prepared for that cherished moment of recognition of her academic achievements.

On the one hand, my professional counseling training instructs me to meet students in their present situation as they perceive it, to encourage them to set their own agendas, to accompany them on their journey. On the other hand, I

remain committed to helping facilitate students' emancipation from the social and psychological constraints of the medical model. I look to social constructionist psychotherapy literature for guidance. Gonzales et al. (1994) explains that social constructionist theory posits, "there are no universal truths, no `right' way of thinking or behaving: rather, there are multiple outlooks which are considered equally valid" (p. 516).

In my search for understanding reflexive praxis and its relationship to freedom, I turned to existential psychotherapy literature. Gregory (1984) writes, "some... conditions of consciousness appear also on the reflective plane, which is to say, the kind of self-consciousness that is genuinely positional, as when we take up the stance of another with respect to our own being" (p. 694). In person-centered terms, that is simply known as `empathy.' I can empathize with people, yet disagree with their worldview. Part of being reflexive is to understand that we each have the freedom to decide our own realities, our world views. Gregory (1987) describes a link between reflexivity and freedom:

> [I]magining and questioning and doubting are "models of human freedom" (p. 694). Therefore, reflexivity is an exercise in freedom... "Good faith" is an "undistorted conception of the relation between free consciousness and all that one is in the way of body, character, actions, past, and so forth... The fundamental character of interpersonal relations is thus a confrontation of freedoms, which Sartre sees as generating relations of conflict (p. 695).

In other words, we are the sum total of our experience, and we each have the right to interpret our existence in our own ways. Such a conflict of freedoms can flare up when service providers decide they know their consumers better than their consumers know themselves. Whenever I examine my motives, responses, counter-transference, etc., I am helping to ensure that I engage in egalitarian relationships based on good faith.

This past semester, I was invited to be a guest lecturer at a sociology course in which I would speak about the social model of disability. It so happened that one of my students, Michael, was enrolled in the course. Michael survived a car accident two years earlier, but sustained a closed head injury, which, according to both self-report and reports from his mother, altered his personality. People treated him differently than they had before the accident.

His professors and I encouraged Michael to tell his story to the class on the day I was to lecture. He was very enthusiastic about doing so because he wanted to share the message that he felt was critical for his classmates to know: the importance of wearing seat belts. I wanted him to address his social experience and he wanted to share his individual experience. It was his story to do with as he saw fit, and my

only responsibility was not to take away Michael's freedom to tell his story as he understood it. After all, if I assert that his view of himself as a disabled person is incorrect and that my view of his experience is the accurate one, then I become just another oppressor who considers his ontological frame to be a symptom of dysfunction.

By maintaining a reflexive stance as I introduce students to social model thought, I am better equipped to dodge a modernist trap. Modernist thinking asserts that therapists (counselors) conceptualize the "case and or the specific treatment plans" (p. 519) while social constructionists approach asserts that the therapist is not the expert in the same way, but assumes what Anderson (1991) has called a "not-knowing stance: `not-knowing' as

> a general attitude and belief that the therapist does not have access to privileged information, that the therapist can never fully understand another person, and that there is always a need to know more about what has been said or what is `not-known' (p. 3).

This stance is antithetical to how disability service provision has been rendered with students not only at the university where I work, but at most institutions of higher education.

Facilitating Institutional Change

In general, disability support services at American colleges and universities were instituted prior to the enactment of disability civil rights legislation and are firmly fixed in the medical model. As disability studies' influence increases within the academy and as disabled persons engage in self-advocacy, disability support services are being persuaded (or forced) to approach service provision in new ways. In the meantime, the medical model prevails on all fronts.

Standard operating procedure in our department has always been for students to bring "appropriate documentation of a disability" to their first appointment. The "advisor" would then "determine" which accommodations, aids and services the student would have in order to access their education. Students were expected to accept the suggested accommodations passively and those who balked, chose not to use certain accommodations, or who self-advocated for additional or unoffered services were often labeled "difficult," "trouble," or "in denial." Sometimes fear about potential lawsuits against the university erupted and then relations between students and service providers grew tense and defensive. At no time were students allowed to direct their own service provision. According to Barnes (1998),

> ...despite the rhetoric of advocacy, partnership and user involvement which permeates much of the most recent literature on professional intervention, professionals

and their organizations have continually failed to
support and implement policies designed to enhance
disabled people's empowerment and have embraced those
which compound their disadvantage (p. 104).

As a former consumer of our office's services (I was a student
at the university), I knew firsthand that change in service
provision was critical in order for students to experience
emancipation, empowerment, and self-determination. Here was a
place ripe for advocacy. Barnes (1998) defines advocacy as
"exerting influence within conventional structures of power"
(p. 104).

Advocacy within the academy can be a tricky matter,
especially when the same institution you are seeking to change
underwrites your paycheck. Fortunately, I found an environment
that was open to new ideas, and to the social model. When I
was hired, the department head charged me with the
responsibility of facilitating paradigm shift from the medical
to the social model. The situation called for reflexivity at
all points in the process as well as a good deal of "elegant
challenging." The model of elegantly challenging
discriminatory practice consists of:

Being tactful and constructive rather than personal
Avoiding cornering people
Is appropriate in time and place
Non-punitive, avoiding unnecessary hostility
Acknowledging the possibility of 'bad practice' in those
presenting the challenge
Presenting in a spirit of compassion and commitment to
social justice (Thompson, 1998).

Believing that language represents our attitudes,
feelings, and values, I began by advocating that the
department modify its name from "Disability Support Services"
to "Disability Resource Center," which was adopted after a few
months. Next, I worked to change the language used to describe
services including writing a new mission statement reflective
of the social model replacing "determine" with "collaborate"
in brochures and other department literature. Then I applied
the new language in appointments with students, in staff
meetings, and in conversations with faculty, staff and
administrators. This method kept the dialogue away from the
personal.

I engaged in non-threatening dialogues with other
disabled faculty and staff on campus. We discussed models and
theories of disability sometimes agreeing, sometimes agreeing
to disagree. Once in a while, my passion for the social model
got the best of me. Although I was not always successful in
unconditionally accepting other persons' right to their
opinions, I managed to remain reflexive enough to be aware
when I was being aggressive rather than assertive.

After three years of advocating for our office to be
separated from its controlling parent department, we became a

stand-alone unit on July 1, 2000. We are establishing a real resource center. We openly talk about the social model of disability. We will work toward having a service center that is user-led, a place where students will learn self-determination rather than reinforced dependence. And, for the first time, students with disabilities are being included in the university-wide diversity dialogue, which will help the entire community understand societal aspects of disablement.

Conclusion

Students should not have to lose their own stories in favor of anyone else's worldview. Gonzales et al. (1991) describe potential problems in the therapeutic process: "seeing truths as fluid, thus always changing, may be a particularly knotty problem... all understandings are taken as potentially practical and valuable alternative narratives" (p. 522). As long as I practice reflexivity, I will be less likely to become just another person imposing my worldview and better able to establish and maintain egalitarian relationships with the students. By doing so I become a model of how they might expect and demand to be treated in the future. Additionally, if we establish relationships based on mutual respect, I am in a better position to invite students to learn about the possibility of other than medical models. I may help them to expand their horizons.

The administrative decision to make us a stand-alone unit demonstrates the university's expanded commitment to disabled students and disability issues. The people in our new chain of command have expressed a commitment to the social model. Now it is our small staff's responsibility to broaden the scope of the model, to advance it throughout the university community and beyond, and, most importantly, to meet our students' practical needs and educate them about all models of disability so that they can exercise their freedom to decide for themselves. It is my earnest desire to have each of our students internalize the message that they have the right to pursue their full human potential, to know that the sky's the limit.

Note: Student names are fictitious. This paper was first presented to the annual conference of the Society for Disability Studies, July 1, 2000, Chicago, IL.

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