

Coming Out: Claiming Disability In and Out of the Classroom

In this narrative, two social work educators, one with a visible disability and another with an invisible disability, tell us about their experiences with disability and how their decision to disclose has informed their students and colleagues and helped them claim disability as part of their identity.

by
Tom Bucaro
and
Rosalind Kopfstein

Tom Bucaro, M.S.W., D.S.W., Associate Professor and Director, Social Program, College of Staten Island, City University of New York, New York; Chair, Commission on Disability and Persons with Disability, Council On Social Work Education, Staten Island, New York.

Rosalind Kopfstein, M.S.W., D.S.W., Assistant Professor of Social Work, Rhode Island College; Co-Chair, Commission on Disability and Persons with Disability, Council On Social Work Education, Providence, Rhode Island.

"Should I tell my supervisor that I am in Recovery?" "How should I answer clients who ask personal questions about me?"

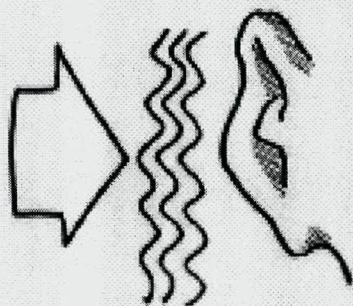
Issues regarding how much one should disclose to clients (and colleagues) come up early in social work practice classes. Some students use self-disclosure as a means of reducing anxiety or as a means of short cutting the path to establishing rapport or building a relationship with clients. Most experienced practitioners urge the usual cautions when dealing with beginning relationships. The rule of thumb is that personal inquiries, at least for beginnings, should be deflected and one common technique is to ask the inquirers why it is important to them to know. Also, we teach that personal disclosures should be purposeful, that is, related to the nature of the contracts between the parties, and that self-involving responses are better used later than earlier in the relationship.

Yet, with the greater recognition of diversity within the profession and the larger society, some identity-related attributes, such as race, gender, ethnicity, and even disability, may be involuntarily disclosed. These factors immediately become part and parcel of the

change-directed interactions and present opportunities for promoting or correcting stereotypes on both sides of the relationship. In the classroom, where the experimental norm is encouraged, the social work educator has much more latitude than the practitioner to explore these elements. In the end, though, the key to the effective use of self, including self-disclosures around identity-related issues, is achieved through the development of self-awareness of one's differences and one's relationship to the culture associated with those differences. In this narrative, you will hear the voices of two social work educators, one with a visible disability and another with an invisible disability, tell us about their experiences with disability and how their decision to disclose has informed their students and colleagues, and helped them claim disability as part of their identity.

Tom

Even though I have been a social worker educator with a visible disability for more than 25 years, it is only within the past seven or eight years that I have begun to identify myself as disabled and to share relevant disability-related feelings and experiences in the classroom. I



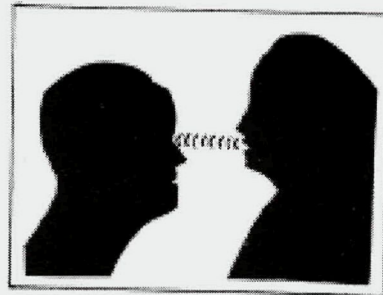
can't say with complete honesty that I am altogether comfortable with it yet. Even this narrative was harder for me to write than I originally thought. It is a narrative about the external and internal forces that led me to this point and how I learned ways to use my experiences as a person with a disability to enhance the education of my students.

It is not that I am a stranger to presenting controversial or provocative issues. I often freely express my thinking around issues of race, gender, sexual orientation, or religion, in my classes. Included are the racist and sexist residues of my working class upbringing that I use to provoke social work students to dig more deeply and honestly into their beliefs around minorities and other human differing. Frequently, I find that because they live in a diverse and urban society, or because they have friends who are of another race or gay and even disabled, they think that they are bias free and have escaped unscathed by the subtle forces of society. It is kind of a reverse bias or snobbery. I challenge them by presenting situations for discussion that test the limits of their acceptance of others, including those of clients and communities who may not see the world in quite the way they do.

Yet, despite the fact that I have a hearing impairment, made visible by the use of hearing aids and a discernable "deaf" accent, unlike my openness in discussing other aspects of diversity, with disability issues I set up walls that were ap-

parently well respected by students. Obviously, I had yet to learn my own lesson on the importance of taking risks to develop self-awareness around human differences. Instead, in the microcosm of the classroom, I replicated the Faustian arrangement I had structured long ago with the larger society. And the arrangement was not unlike that fabricated for people with different sexual orientation, "you don't ask and I don't tell." I had long ago accepted life's lesson that disability, like sex, was not suitable for public discussion or display. And, as in my case, if you could "pass," that is hide or minimize your disability, all the better to win the "normal" rewards of mainstream society, such as relationships and employment.

To understand how I "passed" in the world of the non-disabled, I need to tell you a little about the particulars of my impairment. First, while some disability writers use the terms interchangeably, I think it is important to make the distinction between "hidden disabilities" and "invisible disabilities." I reserve the former for those situations where people with disabilities actively seek to hide them as opposed to those who have a disability that is not readily apparent or visible, such as a heart condition.



I experienced a progressive sensori-neural hearing loss at about three or four years of age. The exact cause has never been determined. For me, it means that I can hear words but I cannot discriminate between them easily, especially if words sound alike, or if someone is speaking with an accent, or if I am in an environment where there is too much background noise, like in crowded restaurants. Since I started wearing reading glasses, I find that I can make a comparison to my hearing loss that

many people understand. It is comparable to the frustration of trying to discriminate the letters and words on a page without glasses—sometimes your arms are just too short. Unlike reading glasses,

though, even with hearing aids my hearing is not fully corrected. I remain highly dependent on lipreading and various adaptive strategies for day-to-day communications.

Lipreading was an adaptation I picked up on my own and, ironically, it was one of the reasons my impairment was not identified until I passed through several grades of elementary school. I was a failing student, who, at one point, common in those days, was diagnosed as mentally retarded. I never realized that my hearing abilities were so different from everyone else's. I survived marginally through lipreading and by try-

ing to remain as socially invisible as possible, in and out of the classroom, to avoid being humiliated. Once the real problem was discovered, invisibility became impossible.

I was moved to the front of the classroom and fitted with two, large, body-type hearing aids that were held in holsters underneath my shirt. Only the ear molds with a large button and thin coiled wire were exposed. I suppose the idea was to make my "disability" less visible and to spare me any embarrassment. It did not surprise me, and I am sure you will not be surprised, to learn that it didn't work. I was routinely taunted at school and in the neighborhood by my peers. It was not the first, nor would it be the last, reminder that being disabled was not a "good thing."

After several surgeries, my hearing was restored enough for me not to need hearing aids. However, by the second year of high school, though I resisted as long as I could for the obvious reasons associated with adolescence, I needed to wear smaller but visible hearing aids. As my hearing progressively deteriorated again, I dropped out of college. Years later, by the time I was ready to return to school, technology had advanced so that I could wear behind the ear (BTE) hearing aids, and I have worn them on both ears for most of my life. Even if they had been available at the time, I would not have been able to wear the more popular hearing aids that fit entirely or almost entirely in the ear (ITE) because they are not adequate for a person with

a profound hearing loss like mine. Even if they were powerful enough, I am not sure I would buy them now. They are much more expensive than the BTE type and do not have some of the other features that I need, such as directional microphones and features that ease the use of the telephone. More to the point, I don't have the same need today to hide my disability that I did when I was younger.

Without hearing aids, for all practical purposes I am essentially deaf, but in situations where I can make good use of my hearing aids and by lipreading, I can pick up 85-95% of what is being communicated. (When using the phone, my hearing capabilities are reduced by half or more of that percentage.) The balance of what I do not hear, I adlib or make up through sheer pretense. It means smiling or nodding affirmatively or making some gesture that leaves the speaker with the impression I am hearing them when I'm not. It means laughing when I see other people laugh even though I have not heard the punch line of the joke. Saying "yes" when I mean "no"; of course, there are times when my responses are inappropriate; but once I pick up on it, it is not hard to say I misunderstood. Of course I meant "no" instead of "yes." It means attending plays or movies knowing that I will miss much of the performance as well as voices of friends who whisper comments in my ear during the performance. It is in those darkened theaters with multiple avenues of human communication that I feel the

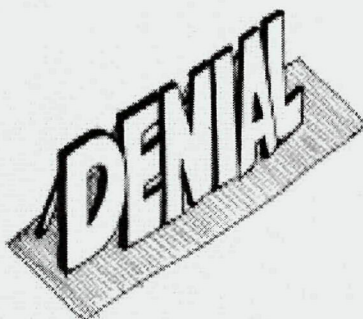
most thoroughly alone. The feeling that "I didn't know whether to laugh or cry" is a common one among people with disabilities. For example, overcoming barriers to communication through pretense meant eating seemingly odd meal combinations in restaurants and assuring friends or servers that it was exactly the meal I wanted—smiling all the way, of course. Never complaining and never demanding are ways of hiding one's disability and remaining invisible to others, and helped me "pass" in the world of the hearing.

Consequently, I imagined that I had learned to manage my disability but I had only learned to manage my impairment. Like many others with disabilities, based on accumulated pain, shame, guilt, and societal rejection associated with differences in abilities, I had internalized my disability as a negative part of my identity and directed much of my anger inward. And because it was possible for me, I denied my disability status in every way possible. How could it have been otherwise? I grew up and came of age when the operative community value was on assimilation and not on respecting diversity. Further, disability had been medicalized to the point that disability-based discrimination, often disguised as pity, benevolence, or treatment, was not as readily recognized by society or by people with disabilities as it was with other diverse groups.

Somewhere along the line, however, at first no doubt unconsciously and then consciously, I decided to act as "nor-

mal" as possible. This deception of self and others was not as grand as that of President Roosevelt, but it received the same overt and covert societal support. Family, friends, and the larger society prefer avoiding the subject of disability and adopt aversive behaviors toward people with disabilities. When it was first recognized that I was hard of hearing, professionals cautioned my parents against the "evils" of learning to sign and actively discouraged me from associating with people with hearing loss or other disabilities. None of the members of my family, my closest friends, and not surprisingly, colleagues or students has ever used the word "deaf" or "hard of hearing" with me or has engaged me in a discussion about it. I was socialized to the same disability-based biases and aversive behaviors as they were. I fulfilled my part of the arrangement by denying that part of my identity and, in effect, validated the negative evaluation of the mainstream culture. The reward of "passing" in the hearing world was that I was able to participate in its cultural activities, but never fully, such as never admitting that I could not catch everything at a movie or a play or missing a joke at a party. The cost of living an inauthentic life is that it supports the internalized negative devaluation of self that further erodes self-esteem and confidence. Also, the constant anxiety of being discovered and not "passing" ironically reinforces self-excluding behaviors and social isolation.

The power of denial can never be underestimated. After earning my MSW degree, I worked in the mental health field and advocated for and with people with developmental disabilities and mental illnesses for improved rights and services. However, I did not identify myself with their struggle. My denial was so deep that though I was part of an incipient disability-rights movement, I was not truly aware of it. Even the passage of the all-important Americans with Disabilities Act in 1990 passed by me with little notice.



A crack in my wall of denial occurred after teaching for several years in a college-level human services /social work program. I was asked to serve as its Section 504 (1973 Rehabilitation Act) Compliance Officer. Though I received financial benefits from the "Rehab Act" when I returned to college, I didn't know that much about it. It was not included in the curriculum when I went to social work school in the mid -70's. Disability was taught from a clinical or medical perspective and still is, for the most part, rather than from a socio-politi-

cal or cultural perspective. Nevertheless, I took the job seriously. At first, still unconnected (or "clueless" as it is said), I expended much effort toward maintaining a professionally "detached" and even had a "there but for the grace of God go I" attitude toward the students with different disabilities. They were not me, and I was not them. I had asked for few, if any, "favors" or accommodations, either as a disabled student or as a teacher. Nevertheless, I found myself becoming increasingly angry when faculty or staff demonstrated stiff resistance to making even the most reasonable and easily achievable accommodations. I found myself talking with highly educated people who were insensitive to the needs of the students and who did not have a clue about disability or disability rights.

One of the psychology professors came to speak to me privately one day to tell me that she did not mind making special testing arrangements for learning-disabled students in her classes. However, she thought it would be more efficient if all disabled students were placed in one class. I was literally in shock that she couldn't see the blatant discrimination, prejudice, and inhumanity of her statement. The lines from a poem about the Holocaust immediately came to mind, "First they came for the Jews . . . [actually it was the disabled]." Another professor in the sciences had his class vote to decide if a sign interpreter should be allowed in class to accommodate a deaf student. I encountered

administrators and campus planners who hid behind technicalities. One could repeat like a mantra that a ramp "was in compliance with code" (and it may have been technically) even when he could observe that students using wheelchairs could not negotiate it. I began to connect with disabled people who were treated as nonhuman or objects of pity without rights. Oddly, I could also empathize with my co-workers because I was raised in the culture of the ableist.

However, what I was learning from the students about the disability experience was more compelling: that disability and dignity could coexist and that people with disabilities were entitled to equal rights and inclusion. I began to have what might be called "flashbacks" to my own experiences. I remembered the teacher from high school who thought my hearing aids were radios and demanded that I take them off. I remembered the language professor who would not permit me to substitute a written translation in place of an oral one. She insisted that I would speak German, even though I tried to explain that I could not read lips in German.

The crack in the wall of denial broadened when I joined a few other professors with disabilities from the different branches of the large university where I was employed. They had formed a coalition to push the university to implement the unfulfilled promises of the Americans with Disabilities Act. An immediate sense of commu-

nity emerged upon meeting my peers with disabilities, who, despite differences in the type and degree of impairments, expressed common aspects of oppression. Unlike myself, many of them had long-term associations with other people with similar disabilities, albeit often in institutional and segregated settings, and across disabilities as part of their active political participation in the Disability Rights Movement. I remember feeling envious and laughing to myself as I realized for the first time the "benefits" of being part of a community of disabled people. A nascent feeling of disability pride emerged—a feeling that I never associated with my hearing loss before. With the support of the group, I proudly became more public about my disability. I was even more proud when we made demands on the university to comply with the law and ultimately filed a complaint against the university with the Office of Civil Rights, U.S. Department of Education.

I continued to learn more and more about disability culture as I enlarged my community of people with disabilities by becoming a member of a local chapter of SHHH (Self Help for the Hard of Hearing, a support group for people who are hard of hearing) and by joining the Society for Disability Studies that supported the development and inclusion of disability studies in the academy. At a national conference of social work educators, I became involved with other social workers, only some of whom were disabled, who had established a

task force to foster new sociopolitical and cultural representations of disability into the curriculum.

Although I was undergoing a political transformation and psychological reintegration of disability-related aspects of my personality in a positive way, it was not enough yet to eclipse years of shame and inauthenticity. I remained tentative and ambivalent about whether I should or how I could bring my disability into my classes. I thought that part of my ambivalence might have been gender related. While I considered myself a man who was gender sensitive and one who could ask for directions when lost, I had not reconciled traditional male traits—sexuality, achievement, etc.—with disability. Nevertheless, my personal transformation continued and insidiously spilled over into my role as a social work educator. First, I rationalized that since the students were aware of my activities to make the campus more accessible to students with disabilities, I could safely and appropriately use my work to illustrate a community organizing lesson on matching community change strategies and tactics to the issues and players involved. In a social policy class, during a lesson on the role of values in the shaping of societal decisions about distribution of goods and services, I asked students to identify the values underlying the allocation of special parking for people with disabilities in the environment of scarce resources—parking spaces on campus. Parking was a hot

issue on campus and the immediate real life relevancy of the situation made the ensuing discussion one of the liveliest of the semester. It became a reference point for many students when we discussed issues of equity, compensation, and fairness in other policy spheres.

The integration of self and educator advanced and there was no turning back. Since humor is a strong component of my personality and central to my collaborative approach to teaching, it was a natural way to open myself more in my practice classes and to encourage the students to inquire about the disability experience. I wanted them to learn what I was learning: that Disability was diversity—it was another way of being in the world and had its own culture and subcultures; That disability was not always a negative, and it could even be a positive. After a role play of an interview with a client that was not going well for a student, I took over and, of course, performed perfectly. Since beginning students tend to get discouraged when they are first learning to conduct an interview or a group, I reminded them that I have been doing it for several decades. And if I did not know how to do it by now, I might be in the wrong profession. Then I added that they shouldn't be too hard on themselves because as hearing people they were just learning to focus and develop good attending skills, while since I have been deaf or hard of hearing most of my life, I had to learn early "how to focus and listen for the verbal and non-

verbal clues." They saw the humor and the truth of my remark, and it opened the door to other questions about disability.

On another occasion, one student felt comfortable enough to ask me why it took so long for my hearing loss to be detected. I sensed from the non-verbal clues that other students were uncomfortable with the question. As most of my students come from the surrounding Italian-American community, I half-jokingly responded, at the risk of perpetuating stereotypes, that I grew up in a poor, working class Italian family that shouted a lot when they spoke, so it wasn't until I went to school that anyone noticed that I had a hearing problem. This use of humor relieved the tension and moved us into a discussion of how ethnicity added to the variations of the disability experience in the same way it shaped the gender, race, or sexual orientation experience.

One of the illuminating lessons that has emerged from my integration of self and disability occurred during a lesson on human behavior and social environment. I related a recurring experience that I have, one that is familiar to many people with visible disabilities when they interact with non-disabled people. It goes like this: I will be waiting in line in a bank or a movie theater and invariably, a parent, usually a mother, will be in front or behind me either carrying or standing with a young child. I note that the younger the child is, the more apt he or she is to notice differences among people—skin color, hair style, or

the tiniest hole in clothing—and will be fearless about announcing it. This is something properly socialized adults rarely do. Much to the chagrin and deep embarrassment of the mother, the child will stare suspiciously at my hearing aids, point at them, and might even ask, "What's that in your ear?" Usually before I can even begin my already prepared explanation to the child, which includes a wonderful analogy to the volume control on a radio or television, the parent(s) without fail will admonish the child severely. Some parents even attempt to physically punish them while I attempt to reassure them that it is OKAY.

Most students remember when they were children being similarly admonished never to stare at the unfortunate person in a wheelchair, or the person who walks or talks funny, etc. They were able to relate to those early socialization experiences that generalized to avoiding contact with people with disabilities, who were to be pitied or worse. Even those students who reported having friends with disabilities and thought they were disability bias free related that it was still their first tendency to avoid eye contact with people with disabilities whom they didn't know. The retelling and exploration of this common, shared interaction between disabled and non-disabled people impressed upon them how they might be unintentional partners in a societal arrangement that excludes and segregates people with disabilities in a way that makes them

invisible.

The more comfortable I have become with my disability, the more authentic I have become in and out of the classroom. But, I am still not completely comfortable. Disabled people, for many reasons, make non-disabled people anxious. I am not ready to share with them the depth of the pain and anger, at the primal level, that many people with disabilities feel toward a society that has segregated and excluded them for so long and continues to oppress them. And I still "sweat" when a student from the back of the room asks me a question while covering his mouth with his hand. Only, now I explain that I read lips and that I can't communicate well if they cover their mouths. I am not ready to share with my students how exhausted I become from the strain of a hard day of listening, how I look forward to taking off my hearing aids, like a pair of tight shoes, and reading the closed captions on the television broadcast of the evening news.

Since I have added appropriate disability content into my teaching, I know that both the students and I are enriched. And as a social worker educator with students who will face a rapidly aging population, I am concerned that our texts and our curriculum do not include complete and accurate information about the many themes and variations of the disability experience and its impact on the lives of our clients. I am distressed that my colleagues do not seem to be informed about the struggle for equal rights for people

with disabilities—and that almost 10 years after the passage of the American Disabilities Act, the landscape remains cluttered with architectural and social barriers. I am upset with the mixed reaction of my colleagues, as well as the social work profession, to the demands of faculty and students with disabilities. And I am perplexed as to how the profession will make its transformation to new understandings of disability as diversity when students and faculty with disabilities remain virtually "invisible" on its campuses.

Rosalind

Disability takes many, many forms: some you can plainly see, some you can hide to pretend they do not exist, and others are hidden. You cannot see my disabilities; I look "normal" and do not need anyone's help most of the time. The world assumes that I know nothing about the world of disability since I do not appear to be disabled. As a person with a number of invisible disabilities and chronic medical conditions, I am disabled all of the time but you cannot see my physical conditions or understand what I must endure in order to survive every day. I am a long-time insulin-dependent diabetic with chronic visual difficulties along with other medical conditions that are not readily apparent. My diagnosis of diabetes came when I was 17. The doctor did not believe me and thought I was pretending to be sick so I could skip school; I was in a diabetic coma for three days following his dis-

belief of my symptoms. This initial disbelief of my medical problems continues to this day among friends, family, and the medical system. When I returned to high school following my initial diagnosis, some friends were afraid of hanging out with me since I was now different. My best friend in high school happened to be a person with epilepsy because disabled people seek each other out for support.

Many times, I am annoyed when others only see me as a normal, temporarily able-bodied person (TAP) and do not understand the requirements of managing my diabetes. Many people do not know how to help me when I do require physical assistance, but I have gotten wonderful assistance from people who have lived with diabetics or from those I have instructed. Since you cannot see my medical complications, no one assumes I am disabled at all. Opposing reactions are part of my life.

I attend many professional conferences. When I participate in discussions or attend conferences with people who do use assistive technology devices, I am considered an outsider and not identified as one of THEM. Instead in their eyes, because my disability is not visible, I am a TAP. When I present information about disability issues, some wonder why this healthy looking person is talking about disability. I sense that physically disabled people are throwing questionable looks at me; I know they are wondering, "Why are you here with us?" I

sometimes feel like stating loudly: No, I do not have the same type or degree of disability as you but you cannot see my hidden problems. I want to say I do fit in and I am one of you—let me be part of the group. Do I have the credibility truly to understand being mobility, sight, or hearing impaired? Yes, to a limited extent, I have experienced these conditions at different times in my life. However, I have to convince others by telling my story and explaining my issues since they are invisible. Then, with a sense of realization, I am told that the others had no idea that diabetes can be so disabling.

At times, accommodations to my physical needs have been non-existent. In my current and previous roles as a social worker, doctoral student, adjunct faculty, and even now as a full-time faculty member, class and meeting times were not geared to meet my eating schedule. As a doctoral student, I was required to take a demanding class when I needed to eat lunch. The schedule did not permit a break between morning courses. I did not do well in that course, missing many of the lectures because of having to take care of my medical needs. At another academic location, I requested a revised schedule of classes and changes in meeting times. I was only given sympathetic looks. Oh, we are sorry but we really cannot change our routine just to meet your "essential must eat" times. Why not just have a snack and then you can eat later? This advice was not only patronizing but unneeded. My

direct request for a change in the schedule was ignored and I did not feel comfortable demanding extra attention. When I requested large-print materials while attending an undergraduate conference for social work educators, I was given a magnifier sheet of plastic instead. These magnifier sheets do not work well and do not replace large print materials. Although this group felt they were providing an adequate substitute, they did not understand the difference between reasonable accommodations and convenience for themselves. Many other conferences have provided excellent large-print materials with ease. How hard should I fight for my needs? Demanding accommodations requires effort; Why can't others simply understand? Failure to respond appropriately contradicts their best intentions and serves to exclude me.

Living with a disability is a challenge. I do explain to students, colleagues, and clients that I occasionally need a brief break to take care of my medical needs. Many understand my medical requirements and have offered helpful assistance, while a few have formally complained. Helpful actions have been carried out by students and colleagues familiar with diabetes. Others have looked at me when I was having a severe, low blood-sugar reaction and gave me a sympathetic look. They did not offer to get me a glass of juice or a high sugar snack. They felt sorry for me—I hate that. At a professional conference on mental retardation, I joined a group of the conference organiz-

ers along with the keynote speaker for breakfast. They offered to share their abundant breakfast with me. I said yes, but I also need some protein. The keynote speaker (a psychiatrist, a minister, a man born without arms) immediately offered to share his omelet with me. He heard me say, "I need," and he knew what to do and responded graciously. When I socialize or work with other disabled people, this acute sense of tuning in is so evident and so refreshing. I can only hope that more students and faculty will learn about and be more interested in tuning into the world of disabilities.

I wear an insulin-infusion pump which requires intensive monitoring. A few years ago during the beginning of a three-hour practice class, my pump started alarming. I had to stop to take care of the problem; it was an emergency. Because I really had to take care of myself, I gave the class an early break. I was lucky that I could fix the insulin delivery problem quickly, since my blood sugar had already risen to a very high level. A few students were very worried and talked to me afterward; this group understood that disability is part of everyday life. In class, I try to generalize about my disability and about a broad range of disabilities and demonstrate that disability does not mean only negative things. Our school has a "Take a Professor to Lunch" program where I can answer more personal questions.

Social work educators need to sensitize students to the

positive aspects of adapting, coping, and managing a disability without pathologizing the person. Discussing diversity concepts in my classroom always includes disability content. Students must be educated about disabilities, focusing on the coping strengths rather than on the problems of disabled persons. "See the person first" ideology or strengths perspective thinking is the critical element, not the problem-oriented perspective. For many students, this is the first time they appreciate the difference between pathology and strengths. For many faculty, hearing about a disability in a different and positive way opens their understanding of disability as just one part of a person's life. This is exciting.

Among persons with disabilities, horror stories are universal. They range from simple insensitivity, blatant discrimination, obvious ignorance, intensive curiosity, to just plain insults. One of my horror stories involves a "sympathetic" comment from a colleague. I believe she wanted to compliment me for my skills and bravery in handling my medical condition. She said: "Ros, you handle your diabetes so well, you do not make us feel uncomfortable." I did not react because I did not know what to say to her. Should I have said, "I am glad you do not cringe when I test my blood sugar or demand a rescheduling of classes"? I still vividly remember this comment because this highly respected colleague was so unaware and insensitive to its full implications. I only wish she

admired my strength and skill in handling my medical problems. I still wonder what she meant or what I should have said.

When I mention to someone that I have diabetes, a typical first reaction is: "Do you have to take shots; I could never give myself shots; I hate needles." I respond politely and say "you might change, only if you wanted to stay alive." My primary reaction is why did you even say this? I then counteract by saying, "Many people in our field have significant problems in living, would you respond in a similar fashion by reflecting, I could never live in your neighborhood?" I am disappointed because I am treated as "different" from others. Cultural sensitivity is essential to social workers; we emphasize the "isms" of society. Why is disability left out of these concepts?

I attended a "Low Ropes" Retreat in the great outdoors. It's a way of bonding closer to your colleagues while engaging in outdoor exercises. I was worried about participating in the program due to potential low-blood-sugar problems; I prepared as much as I could but I did have a number of diabetes-management problems that day. I informed the others that I may need their help with snacks. To my chagrin, no one helped me during this long day. Later when discussing my experience of being abandoned by the others, the leader of the group said: "We are all responsible for ourselves—you can't expect us to take care of you." The irony of this message is that this was a group of medical educators—occupation-

al and physical therapists, social workers, and nurses—bonding together to create a new gerontology program. Apparently these medical educators have a far road to travel to really learn about strengths, accommodations, adapting, and giving help before they can teach others how to treat people with respectful care.

I became more aware of my differences as I felt more excluded from professional and social activities such as not eating the same food at the same time as everyone else. In having to take care of my disability-management needs before participating in these activities, I realized that I was set aside and not fully part of the group socialization. I would make requests for accommodations and they were dismissed; I knew that I needed to make a stronger stand to gain credibility. I did not want to be labeled a "whiner" but simply as a person with a chronic illness who needs flexibility and consideration at times. In connecting with other social work faculty with disabilities, I felt included and connected. Meeting with those who have experienced these exclusions was illuminating and enriching. I did not have to explain why or if I needed some help; the assistance came gracefully and with care. I felt a strong connection to this group, as powerful as the diabetes support groups I attend.

Students with disabilities present many more challenges in surviving academia. I use my own story of medical diagnosis in class to explain

many social work concepts such as access to medical care—I almost died before I finally got diagnosed; uneducated consumers—my parents were unable to learn how to take care of me, so at 17 I became responsible for my own care at diagnosis; and accepting and facing my own problems by seeking help—knowing when to ask for help. Knowing when you need help and knowing when you can survive without help are important wisdoms for me and how I teach social work practice. I see many students with disabilities who are afraid to request any help. One of my biggest challenges in working with these students is to have to almost plead with them to ask for help from those around them and from the formal support system. For some, asking for help represents defeat, being labeled as disabled, losing independence, and simply being treated as different and less capable than others. For others, the awkward formal system enables them to reach their academic goals. Many students seek me out because of my disabilities; they share their stories with me and I try to encourage them to ask for help. We commiserate about disability ignorance in society and the need to explain again and again so THEY finally understand. If disability were seen as a normal and expected part of life, then asking for help and receiving assistance would not brand us as different. These concepts are directly related to social work practice interventions—enabling people to ask for assistance when they need it

without labeling them, providing help when asked in a supportive non-labeling manner, and creating alternative, innovative solutions to problems.

Instead of separating those with disabilities as different, social workers need to be more inclusive and better educated, and social workers with disabilities can help by claiming their disability and “coming out of the closet.” Remember, hidden disabilities are just that—not obvious. Don’t assume that a person you see using a handicapped parking space is illegally parking there as a TAP. You cannot see many disabilities, so we do not really know what is happening. Assumptions get us into trouble. Sympathetic looks are unnecessary; instead ask about the person’s condition but don’t invade anyone’s privacy. I want to teach you about disability; give me the opportunity to tell you about my condition and my perspective and what I have struggled with. Acknowledge that you do not know much and want to learn more; I would like to teach you.

Social work practice focuses on diversity and oppression. When I teach about practice and oppression, I use my life experiences to illustrate feeling different, losing friends because of your diagnosis, lost opportunities, and oppression. Currently, disability is not a key component in teaching about cultural diversity. Faculty are unfamiliar with and also uncomfortable with the topic, so disability is usually a brief mention in a few courses. Instead, all of us need to learn more about disability.

Disability issues also identify valuable skills for all social work practitioners. Social workers must become tuned into these concepts, soon. Disability, whether it’s hiding, hidden, or visible, takes endurance, skill, commitment, and knowledge.

Tom and Rosalind

“Having come out, the disabled person no longer regards disability as a reason for self-disgust, or something to be denied or hidden, but rather as an imposed oppressive category to be challenged and broken down” (Swain & Cameron, 1999, p. 76).

Similar to gay men and lesbian women, the coming out process for disabled people is a declaration of identity outside the norm. For disabled people it is the redefinition of one’s personal identity that includes a self-declaration, or claiming of that difference, rejecting its devaluation by the larger society, and integrating it into a healthy self-concept (Corker & French, 1999; Swain & Cameron, 1999). Corker (1996) identifies the coming out process as one of the “key tasks of identity formation” for people who are oppressed.

Acknowledging your disability, asking for help when needed, and then demanding accommodations can be a humbling experience for those of us with either visible or invisible disabilities. It takes courage, insight, and support from others to come out to the community.

Yet we have found disclosing disability can be a powerful tool to encourage students

to explore this aspect of human diversity, in much the same way that they discuss issues of sex, gender, color, etc. The experience has been a positive learning one for both students and teachers. On the other hand, it has been our experience that students are much more receptive to disability and its accommodations than our social work colleagues—most of whom, like ourselves, have been socialized to regard disability with negative emotions of shame, guilt, and fear. And they have been resistant to embrace the emerging discourse on disability under the rubric of disability studies, a discourse that correctly distinguishes “impairment” from “disability” (Linton, 1998). While social work educators do not have to have a disability to bring the subject into the classroom, until the profession “claims” and reintegrates the new disability discourse as part of the curriculum, it will not be whole or inclusive, in or out of the classroom.

□

References

- Corker, M. (1996). *Deaf transitions: images and origin of deaf families, deaf communities and deaf identities*. London: Jessica Kingsley.
- Corker, M. & French, S. (Eds.) (1999). *Disability Discourse*. Buckingham: Open University Press.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York: New York University Press.
- Swain, J. & Cameron, C. (1999). Unless otherwise stated: discourse of labeling and identity in coming out. In M. Corker and S. French (Eds.) *Disability discourse*. Buckingham: Open University Press.

Copyright of Reflections: Narratives of Professional Helping is the property of Cleveland State University and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.