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AUTHOR Rocco, Tonette S.
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ABSTRACT

Little research has been done on disability disclosure in education and employment. Instead, most research on disclosure has examined the effect disability has on the comfort level of the able-bodied. In order to explore how an adult with a disability learns to communicate to an instructor or employer what is needed for accommodation, interviews with 8 students with visible disabilities were conducted and analyzed with a constant comparative method to generate grounded theory. The students were asked questions about disclosure in the following areas: comfort level, under what conditions, describing the disability, reactions of others, and coaching or advice received. These five themes emerged: (1) how full disclosure differs individually; (2) how disclosure is a way to lessen tension for both the disabled student and others; (3) how disclosure affirms that the disability is a part of the disabled student; (4) how other people's responses to disability can vary greatly; and (5) how coaching or training on disclosure received through rehabilitation, counseling, and family support can also vary. (Contains 11 references.) (MO)

"My Disability Is Part of Me": Disclosure and Students with Visible Disabilities

Tonette S. Rocco

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"My disability is part of me:" Disclosure and Students with Visible Disabilities

Tonette S. Rocco, Ph.D.
Florida International University, USA

Abstract: Self-disclosure is "any information exchange that refers to the self, including personal states, dispositions, events in the past, and plans for the future" (Derlega & Grzelak, 1979, p. 152). An individual's disclosure creates comfort or discomfort in the person receiving the information in the disclosure (Chelune, 1979). The level of (dis) comfort created affects the response the receiver of the disclosure has. Disclosure can increase interpersonal intimacy and decrease interpersonal distance however it can produce the opposite effect, rejection (Wright, 1982). It is also assumed to be reciprocal in ordinary social relationships. The work done on disclosure and disability most often examines the effect disability has on the comfort level of able-bodied individuals (Elliott, MacNair, Herrick, Yoder & Byrne, 1991; Elliott, MacNair, Yoder & Byrne, 1991; Stephan, Stephan, Wenzel & Cornelius, 1991). Little research has been done on disability disclosure in education and employment. Learning is considered a major life activity under the Americans with Disabilities Act. The purpose of accommodation, under Section 504, is to provide students with disabilities an equal opportunity to achieve equal results (Biehl, 1978) with the intent of preventing exclusion based on disability status (Mangrum & Strichert, 1988). Accommodation is "an adjustment to the learning environment that does not compromise the essential elements of a course or curriculum" (Schuck & Kroeger, 1993, p. 63). In order to access the learning environment certain accommodations may be needed. The student discloses disability status, requests an accommodation, and the instructor complies with the request.

Method

The purpose of the large study was to explore this question: How does an adult with a disability learn to communicate to an instructor or employer what is needed for "accommodation?" Interview data were analyzed using a constant comparative method to generate grounded theory (Glaser & Strauss, 1967). Three samples were compared; composed of 9 faculty, 8 students with visible disabilities (swvd), and 7 students with invisible disabilities. This paper discusses the emergent themes from the sample of swvd. There are eight students in the visible disability sample, two women and six men. Four of the men became disabled between the ages of 16 to 33 years old due to accidents. One man and one woman lost their sight gradually due to congenital illnesses while the other man was born blind and a woman was born with spina bifida. Five were students: four undergraduates and one graduate student. The other three had recently graduated, one with a master's degree and two with undergraduate degrees. Their academic areas included communication, engineering, social work, psychology, and education. Members of each sample answered questions about disclosure: comfort level, under what conditions,

describing the disability, reactions of others, and coaching or advice received. Interviews lasted forty-five to ninety minutes. Transcripts from each sample were checked against the audiotapes, read, and read for coding. Several months went by between coding on each sample to allow categories to emerge from each sample independently. Comparisons between samples were made after all samples were completely coded, and the categories were written up into descriptive text (Wolcott, 1994).

Themes

Five themes emerged: (a) "what is full disclosure?" (b) loosen up the tension, (c) my disability is part of me, (d) other people's responses to disability, and (e) coaching on disclosure.

"What is full disclosure?"

Full disclosure was viewed as doing or saying anything necessary to satisfy an instructor that the accommodation request is valid. While in an employment interview full disclosure was important to give the interviewer permission to ask questions about the disability. Roc stated that full disclosure is saying "Anything that I'm going to need to get my education and have my educational needs met, full disclosure means everything that is required." Drake thought it meant handing a professor a form. Sandy felt the question, "How can we work together so that I can participate in your class?" sufficed for full disclosure. These two students have visual impairments; one is blind from birth while the other has a degenerative condition. They felt it was unnecessary to discuss the disability with the professor believing it was obvious to a sighted person that neither one could see. Disclosure during an employment interview was a different matter. A few participants disclosed on their resume by listing activities like "member of United States Disabled Swim Team" (Bess) or speaking engagements on behalf of disability issues. Jed who speaks for "Think First" felt it was important to disclose at the beginning of the interview. He told me,

Many of them (interviewers) said afterwards I wasn't sure what to ask I wanted to but I was afraid to ask. ...The way I see it is I don't want to have to go there and surprise them. I don't want the uncomfortable situation. The way I see it, if they don't want to hire me because I have a disability...then I don't want to work there. (Jed)

Pat said, "I usually tell them some time at the beginning of the interview that I'm open with my blindness because I know they have a lot of curiosity." Pat continued "[the interviewers] put me into a situation and ask me how I would handle it since I do have a disability." Both Pat and Jed were engineering students who were interviewing with companies. Jed had one job offer and Pat felt that one was imminent for him. Pat summed up sentiments they both felt by observing, "dealing with the professors throughout most of my college career has helped me out for interviews. I'm pretty much at ease in an interview."

Loosen up the tension

The comfort level of the interviewer, instructors, peers, and strangers was important to participants. Bess disclosed to the other teachers in her school where she worked, "that I have a disability because I thought their students might be asking and they needed to know what to tell their students." Bess continued she had "done some disability awareness sessions for other teachers," because she felt it was her responsibility to inform the students in the school. Drake described why he disclosed during his job search, "in a couple of cases when I thought there was a high level of interest and they wanted to know more information about me before the interview. I did mention that I was blind and how I dealt with my blindness and any obstacles that I had." He felt that telling a prospective employer about overcoming obstacles demonstrated his adaptability. Pat felt it was his duty "to make people feel more comfortable around me" to "try to be open with my disability" because he knew "people have got questions in their mind about me." Sandy explained,

I've learned this through my disability, through a lot of research I've done, through a lot of training I've had in the area, people naturally feel uncomfortable around people with disabilities and primarily that is because of uncertainty and so that uncertainty if its not taken care of gets in the way of the relationship.

Pat eased the tension by, "crack[ing] a joke or something and if that doesn't loosen up the tension maybe we'll start up a conversation about it."

Disclosing is a way to explain some difficulty beyond the control of the individual. Mel was embarrassed to share, "I have to explain to them about my problem with falling asleep because I don't want to insult the professor." Another story illustrated the difficulty created by simple things, "if it's a first thing in the morning class and they haven't shoveled the walk...I'm not going to be able to get to class that morning."

Where an instructor's cooperation was important Jed said, "It didn't bother me because I wanted it to get [it] fixed. So I just went--sure it kind of sucks having to do it (disclose) but under the circumstances it was about worth it." In order to get cooperation these two participants felt they had to reveal personal information about themselves that a student without a disability would not have been required to do. Even though they are comfortable with the disability, because it is part of who they are, disclosing is not necessarily comfortable to do.

My disability is part of me

Participants felt the disability was part of them so they had an obligation to answer questions of other people. There were limits however depending on the relationship and what the person was doing at the time. When participants did answer questions they believed the best tactic was to keep it simple. Jerry said,

I start out kind of vague, just saying that I'm paralyzed and then if they really want to know something they'll ask more. So I keep it as basic as possible and then if they want to go further, with it fine and if not then I feel like I've answered their questions.

Bess said it also depends on the relationship or "on the situation, but I answer questions." She also took a proactive approach doing "a lot of speeches about disability awareness" and teaching the children in her school "that they can ask me any questions they have. I always read a book 'My Teacher is in a Wheelchair' for them and talk about my disability at the beginning of the year." Jerry shared, "If I'm at a party or with friends I'm pretty open about everything. I'll tell them as much as they want to know at a party. Maybe even more than they want to know and I'll joke about it." At work however, "I gauge my answers depending on what kind of relationship I have with the person at work." Relationships aside, Drake felt an obligation to discuss the disability because, "My disability is part of me. It's part of what makes me a person and I figure if I can't talk about it then I'm ashamed of it and I'm not happy as a person."

Jed just preferred to disclose because, "It's too easy to assume and assume the wrong thing and they're stupid. ... The best way to deal with ignorance is through education. The more people you teach the better off."

Other people's responses to disability

The fourth theme examines other people's responses to individuals with disabilities. Jerry felt that "five years ago [I saw people avoiding me] but in the last few years no. I don't know if it's the area that I've moved into or the change in perception." He moved from a working class suburb to a gentrified central

city neighborhood. Pat had a similar observation, "I would say the younger generation is more accepting. I would say the older generation I get a lot of stereotypes." A striking example of generation differences was in the reaction of young children and their parents to a person with a disability. As Mel described,

The biggest reaction I have a problem with is with little children. Children are naturally inquisitive so they want to know and that doesn't bother me ...but the parents who grab their children like I have some major disease that bothers me.

People's responses to disability varied from "empathy [to] some apathy, some proclaim sympathy but I don't think they understand the definition of words" (Roc). Thinking that people don't understand the difference between empathy, apathy and sympathy might have been because of some common reactions like "most people just stop and stare and that's about it" (Mel). Or when "people treat you like you're younger, like you're a small child. ...Like pat you on the head or talk real loudly. Speak in simple sentences sometimes," (Bess) or talk about the person with a disability as if they didn't exist. Often "if there is to be a negative reaction pretty much it's not done to my face" (Sandy) instead,

I get a lot of 'I really admire you'. Once in a great while it's done in a patronizing way. Most of the time it's very sincere even though I think they shouldn't admire me because there is nothing to admire. People think that whenever there's something wrong with you if you are doing the same things as other people it's just really outstanding. (Sandy)

People have walked up to Roc and said, "It's so unfortunate. You were so unlucky. You're doing a great job with what you have left." Roc went on to make the observation that, "Those are all statements that weren't well thought [out] before they were spoken." Jed responded to such sentiments with, "It could have been worse." The injury he sustained was a broken neck paralyzing all four limbs and impairing his speech. He said, "I have my shoulders and my hips back and my mental facilities back." The doctors predicted brain damage after his motorcycle accident. For Jed, that would have been worse.

Usually one thinks of stereotyping, as happening between strangers and that knowledge of a person will eliminate it. As Pat described his experience, "I was in a serious relationship when I was first going blind. A lot of stereotyping went on there and I basically broke off the relationship. ...[They] assumed I would be in their quotes 'a panhandler or dishwasher' for the rest of my life." He was in college at the time working on an associate's degree. Stereotyping of people with disabilities included the notion that they needed help, help that would not be offered to an adult without a disability. Drake, a teacher, said of his students, "They're real ignorant about different people or people with differing abilities or just different people in general and they put the blind part first and a lot of them try to over extend their help to me..." The help extended to taking liberties, for instance, "people will come up and want to grab my arm and say here, I'll walk with you and then I'll say no," (Drake) or "trying to put my chair in the car for me. I'll just tell them that it's fine. I can do that" (Bess). The same individuals might become indignant if someone took their arm to show them where to go without even asking if the person was lost.

Pat described an academic counselor, "from the beginning she was straightforward and honest and said I don't know how we're going to do this. We've never had a visually impaired person make it through the program." This honesty kept communication open between them. Jed said, "I do well and I'm like the first one with a visible disability going through the department. I do well and they want to see me do good. So they've been very accommodating." The counselor's desire to see the student succeed was instrumental to the whole process. Professors struck Pat as being "at ease with it. I don't know if it's maybe all the years that they've been teaching on campus. They've maybe met blind people walking down the street. Maybe helped one or two into a building. Talked to them about it."

Coaching or training on disclosure

The fifth theme examines the types of professional training or coaching participants received on disclosure, which included rehabilitation, counseling, and family support. The experiences with rehabilitation services ranged from Drake saying, "they were real helpful in terms of talking with me, figuring out what I wanted to do," to Jed saying sarcastically, "we call it quad utopia ... everything is idealized, everything is perfect." For Jed and Jerry that meant they did not learn how to exist independently in the world as it is. In Jerry's experience, "they focused on everything that could possibly go wrong...to the extent of ...borderline discouragement." Participants did not recall any discussion of how, when, or what to disclose in educational or employment settings. This was exasperated for Mel who had been a delinquent with little positive experience at school. Mel described the difficulties he had when he first entered college,

I had no idea what to do when I got sick. ...I had no idea how to contact the people who gave me the grants or anything and let them know I'm not there. If there's a chance for a refund or whatever. I knew nothing about it. So what I do is I get sick and end up in the hospital. Then I came back to school and try it again and then get sick again. I tried for a tutor but they were never there. I mean it was like I was stuck out in the middle of nowhere and I could have done these things. All you've got to do is go up and I could go to these professors as long as I know to do that but I had no experience with college. My experience in school was in the lower grades so I was promised a great deal and left just hanging there. And supposed to figure these things out on my own. I went over and bought some books my first quarter. I bought some--it was my second quarter. I bought some textbooks and everything for the classes. I was driving down the hallway and this woman came out and she said she's been looking for me for two quarters. I was supposed to come in and meet her and give her the receipts for the books and she would pay me for them and everything. I didn't know that. I didn't know that I was supposed to get--what a program was. I thought I had to pay for my schooling. So when I was sitting at the nursing home and all of a sudden I got a certified letter in the mail. I went over and it was \$750 for a program check. I didn't know I was getting that. I didn't know what it was for. I was scared to death to cash it.

Mel had been a ward of the state from an early age, as he was when apprehended by police in an incident that resulted in his broken neck. At the time he was sixteen, he had been frequently truant from school and had little experience with high school. After the accident, he spent a year or so flat on his back in a nursing home with no one advocating on his behalf for a wheelchair so he could get out of bed. Knowing these facts about his life, it seems reasonable that he would have no context for college and would need a lot of advice. Rehabilitation counselors did not counsel him on how to proceed with administrative aspects or succeed in the academic aspects of college instead,

They would talk among themselves and treat me like an outsider...they tell you you've got brains but then they ... talk around you like an idiot. Like you couldn't possibly know what to do and they throw you in the middle of it and say here, sink or swim. (Mel)

For all but two participants, the disability occurred after adolescence so family members did not assist them with learning about their disability. Family assisted the two participants who were disabled at birth. Bess described the conversations with her parents as "it just kind of came up. They told me what spina bifida was because I obviously didn't know what it was when I was little. They ...explained it to me so I could explain it to other people."

Some participants received help from counselors in disability services. As Drake said,

The first day disability services ...told me this is what you need to go talk to your

professors about. You need to go tell them who you are. You're in the class. What you'll need and how you need it. Be straightforward and be directDon't go overboard...

While Sandy felt she would need assistance from counselors in her academic program to help her in employment interview situations. She said, "I'm going to need coaching from the people in my department as to what is the best way to approach the situation." She was hopeful by then she will know what to ask them so that the academic counselors can help her. Sandy also thought the key to securing their assistance "is do the best job I can here in terms of establishing myself in the courses." She assumes counselors in her department will know what to tell her about disclosing disability related information in order to secure accommodations in a work setting.

Importance

This work is important to adult education because it increases awareness of issues faced by students with visible disabilities and as more students with disabilities take advantage of educational opportunities they will want their experiences to be acknowledged by educators. Disability must be included in adult education's discussions of power, diversity, and identity politics as well as how particular and specific socio-cultural experiences affect learning. This paper will discuss a specific aspect of that experience, disclosure.

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Organization/Address: Florida International Univ, 11200 Tamiami Trail, Miami, FL 33199
Telephone: 305-348-6151
E-Mail Address: rocco07@fiu.edu
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