

## Embodied Identity and Hidden Disability

*Timothy D. Epp*

### Introduction

In his study of ex-psychiatric patients in California, Edgerton (1967, 1993) suggests that individuals with 'mental retardation' are preoccupied by the task of passing as normal people, donning the 'cloak of competence.' In contrast, I suggest that all people, including those categorized as disabled, are engaged in processes of negotiating identity and identity roles in their daily life through various forms of embodied action and communication. However, these processes are often constricted by various factors and experiences, such as institutionalization, which take little account of the interconnectedness between self, body, agency, and community. In studying the disability self-advocacy movement, I have found that even by claiming membership in self-advocacy groups/organizations, individuals are simultaneously claiming and resisting classification and treatment as 'the disabled.' These processes of identification contribute to the continuous reconstruction of collective self-advocate organizational identity and to the model of the self-advocate in group discourse.

In this article, I will explore the concept of 'hidden disability' as it appears in the personal account of one member of a local self-advocacy group. A common theme in personal accounts of group members concerns the dys-appearance of the impaired body as individuals identify true disability as rooted in a fixed bodily state while self-identifying with the concept of 'learning disability' related to mind and changeable through education. In my conclusions I suggest that, while empowering for some members of the self-advocacy organization, this strategy of identification often shifts the able-bodied/disabled boundary without sufficiently challenging the concept of 'disability' and faces serious limitations in pressing for social change.

### Body/Mind

Following the path of Enlightenment rationalism, which has informed much of our contemporary biomedical discourse and practice, "the physical world provides the material evidence of an inner life (corrupt or virtuous) that is secured by the mark of visible difference" (Mitchell and Snyder 1997:3). While significant challenges to this model have been issued from both academics and activists, themes of outward difference as indicating inner essence, mind/body dualism, mind as experiencing and body as object to be controlled continue to inform both social discourse and individual models of self-identity.

The following data stems from my recent research with the self-advocacy organization People First, more specifically a local chapter of this organization in the province of Ontario, Canada. The organization's members often referred to learning disability as 'hidden disability,' a condition which was maskable, negotiable and changeable, in contrast to other individuals and group members with more pronounced and seemingly fixed physical impairments or who were using assistive devices. My questions regarding the meaning of the general category of 'disability' were redirected by respondents to focus on physical impairment as respondents would inform me that 'I just have a learning disability.' However, this modeling of one's sense of self in terms of mind, distanced from the body-as-object, belies the experiential foundation of embodied existence. We all negotiate our sense of identity and our relationship with the world through our material existence; experience is always embodied. In order to illustrate this, I will present several excerpts from field notes and interview transcripts with Martha, a member of People First, indicating the employment and expression of the body in constructing an identity of 'hidden disability.'

Martha

Martha is a thirty-one year old woman who identifies herself as having a 'learning disability.' She was actively involved in the local People First chapter when I conducted my research and enjoyed talking about her life with me. Our conversations inevitably included discussion of Martha's family, one of the most important aspects of Martha's life. In particular, Martha often referred to memories of her father, who had passed away when she was twenty-six and whom she felt she resembled in body ("I sort of look like my dad") and spirit. Although most of her memories of this man were positive, she also referred several times to an instance where she had invoked her father's anger. This was a particularly difficult memory for Martha in part because it appeared in stark contrast to the warm, loving memories she most often brought up, but also because anger had been an important theme in Martha's life. She took some satisfaction in telling me that, contrary to frequent outbursts in the past, she is now in control over her emotions: "I used to throw things, that's how I was." This sense of control over body function, appearance and emotion was central to Martha's discussion of selfhood and disability.

Martha also felt strongly about her own sense of independence which informed her relationships with support workers. She did not call her current support worker except when she "needs to talk...because I think I'm way to independent." However, Martha did rely on family support for some tasks such as transportation for grocery shopping. For Martha, symbols of personal independence included having her own subsidized apartment, her ability to get around her city by bus, bicycle, and foot. She often expressed a wish for her father to be able to see these accomplishments.

Creativity was also important to Martha who often liked to surprise people with her gifts of needlework in the process revealing to others that there is "more to me than meets the eye." Martha's apartment contains several examples of these works which she enjoyed talking about with me. Her residence also contained a large rack on a living room wall holding Wizard of Oz collector's plates and figurines, as well as movie posters. Martha showed me that she had even more Oz memorabilia around her apartment, provided me with movie trivia, and said that she had written a school paper on Judy Garland. Once again, Martha drew the conversation back to memories of her father as he was the person to first give her collective figurines of the movie's characters. The character of the tin man was particularly important to Martha as she associates this figure with her father. She also expressed dreams of marrying her current boyfriend in a wedding where all of the guests wear Wizard of Oz costumes and where the church aisle is the yellow brick road.

This blurring of fantasy and memory through the manipulation of physical space in the construction of identity suggests both bodily agency and a more diffuse sense of self than is presented in many contemporary approaches to identity. Martha's self-identity is inextricably intertwined with perceptions and memories of family, with her physical environment and her sense of community.

Although Martha saw herself as independent, she also realized that she needed considerable time to perform and learn new tasks in comparison to other friends and family members. This extra time was not always allowed for in her working experience. In one interview, I asked Martha to tell me her definition of disability and whether she thought of herself as disabled. She replied:

A disability is where you can't do something. Somebody always puts you down for trying to do things that people don't expect, you know things that you really want to do but people always put you down or people always call you things that shouldn't be.

She described herself as having a disability, but qualified this statement in contrast to categories of physical and mental disability which she felt were more problematic.

Some people treat us like a problem, but we're not a problem. We have hearts and dreams and minds like everyone else. Some people do have problems, they're born without limbs or brains. There was one man who had no arms or legs, but at least he had vision.

Neither body nor brain was a barrier for Martha who felt that she looked like an 'ordinary' person. Instead, she felt that other people were placing unrealistic expectations on her to complete tasks in a certain period of time.

Martha: But (my disability's) not...it's not physical.

Tim: Mm hmm.

Martha: And it's not....it's not really mental.

Tim: Mm hmm.

Martha: It's just a learning disability.

Tim: What's that mean?

Martha: A learning disability means that it would be hard for me to learn...it would take a long time for me to learn how to do money, and how to tell time, but yeah, if I had somebody to sit with me every day and to teach me how to do um...six forty-five (time) if they sat with me and showed me how to do six forty-five, yeah then I would learn how to do six forty-five.

While the 'physical' thus seems to disappear in Martha's account of disability and identity, the body reappears in her construction of selfhood. For Martha, disability is negotiable with the resources of repetition and time. In order to keep track of the days of the week, she blacks out the days on her calendar with a pen. For telling time, Martha wears a digital watch, as this is easier for her to read.

Martha: If somebody at work says, 'Martha, you have to be at work at ten thirty', I know ten thirty and I know one thirty.

Tim: Mm hmm.

Martha: But if they said 'you have to come to work at quarter after two, to go out on an outing,' but if they said 'at eleven o'clock...eleven...quarter after eleven,' then they would have to say 'eleven fifteen'... Because it's a di...digital watch; And one time I had a regular watch, and I couldn't tell time, so.

Tim: Mm hmm.

Martha: Yeah, need to tell time; somebody asked me what time it was, and I said what time it was, and they looked at me, Tim, like I was stupid.

Tim: Mm hmm.

Martha: And I figured that, from that day I would get a digital watch to tell me what time it was every day, so that I wouldn't feel that way. And she just made me feel more stupid than what I was. And it takes me a long time, like if my mom calls and says she's going to come and get me at...before ten o'clock to go to church, then I have to be ready before that time.

In these statements, Martha associates disability with states of emotional instability, abnormal physical appearance, difficulties in verbal speech and/or mobility, and inability to tell time. During a discussion on labeling, Martha recalled an experience on a vacation to Florida:

where a guy called me mentally retarded. I was walking down to get ice, and I didn't even see the guy, I didn't turn around to see who the guy was. I just kept on walking. I don't know why, because I really don't look retarded, I don't look different than anybody else.

She referred to learning disability as 'invisible', detectable through variations in speech and emotion.

See a lot of my family doesn't realize that I have a disability. I speak totally different from what...and it doesn't appear that I have a disability.

In her accounts of her experience of segregated education and employment, Martha often expressed a desire for integration with people besides those categorized as 'disabled.' In one interview she said that she had been offered a new job at a retail store. However, her mother was concerned about whether the employers knew her as a person with a disability. Martha did not think that the employer knew that she was working under a supported employment program as her appearance did not suggest this.

I don't want them to know that I have a disability, until the time that they have to tell me something that's totally different, or totally foreign, and that's the cash register, and that's the only time they'll know that I'm disabled. I don't know how to use it. And that's the only time, but other than that I'm just fine.

The new job gave her a sense of belonging. Customers would come up to her and ask for advice then thank her for this.

At (group home job) I don't feel that way. I feel like I'm lost, and none of the people that...no-one can say 'thank you' to me, or 'oh, we appreciate you when you feed us', they can't say that to me, because they can't talk.

Martha felt that her "brain was getting used more" at her new job and relished the thought of receiving "a good hourly wage" while hopefully retaining her disability pension. She also felt more secure working for the store as her previous employer was being faced with serious funding cuts. In her old job as a group home worker there had been little opportunity for career development and Martha felt that this job stigmatized her as a person with disabilities. She desired to be known as an "ordinary person."

Martha: I don't want to be put in one little box, just thought of as a person with disabilities. That's all I'm going to be in that little box. And, like I can't really have normal friends, other than people that have disabilities.

Tim: You said that you wanted to be known as...

Martha: Martha, and Bob's girlfriend, and maybe someday his wife and I want people to know that I'm more than just have a disability. I have other interests and other thoughts.

Martha: I want to be treated like a...no special treatment. I want to go grocery shopping, and I want to pay the same price that everyone else pays for the groceries. And if I got special treatment that way, I wouldn't go grocery shopping. That's why I don't have (worker) go with me, or (worker). Because I don't want people to know that I have a support worker. I don't want them to know that I need help grocery shopping. Tim, it's a long life out there. And if I got special treatment everywhere I went, I would feel useless, I would feel very, very useless.

For Martha, a sense of disability was not manifest unless her outward appearance was made 'stupid' or she was put in a situation where she was faced with a certain task such as telling time or learning a new task within a prescribed time period. For her, a disabled self was thus created at the juncture of body/task/world. Much of the time, these situations were

avoidable or negotiable through use of a digital watch and by having allowances from employers to learn tasks through extensive repetition.

### **Neo-Conservatism and the Double Bind of Hidden Disability**

Martha's account is similar in many ways to interview statements and my observations of other group members during the course of my research. While People First members often distanced their own sense of identity from the body, observations and accounts of the daily negotiation of identity suggest both a sense of the body as experiencing subject and the importance of manipulating the body-as-object in the construction of selfhood. As in Martha's example, negotiating disability in this way may open avenues for social relationships, employment, a more acceptable and fulfilling sense of identity. However, these strategies of identification do not deconstruct the concept of disability as much as they shift the division between 'able-bodied' and 'disabled' often re-enforcing this dichotomy. Those who are perceived as 'out of control,' whose appearance is marked by visible or audible signs of limitations in mobility, verbal speech and independence, become the 'truly disabled.'

An example of this may be found in the resistance of People First to recent policy initiatives under the current neo-conservative Ontario government. In a meeting with a politician from the provincial government, self-advocates (including Martha) who were protesting the introduction of a biometric scale of service assessment were informed that they were not the subject of discussion. The policy was directed to 'those in need,' i.e., those not in control over bodily functions and emotions who needed considerable assistance from caregivers. The articulate self-advocates were obviously not in this category as they were able to present their viewpoints through verbal speech without the use of assistive devices or staff support. As a result, those who were most outspoken at this meeting became increasingly concerned about losing supports in the face of the new funding which was directed to 'the needy.' Those 'in need' were perceived as under threat of re-institutionalization under the province's plan to regionalize services.

### **Conclusions and Suggestions**

Martha's account suggests the importance for people, including those categorized as disabled, to have the freedom and opportunity to negotiate their own sense of identity and the meaning of disability for their lives. However, in their strategies of identification, individuals and self-advocacy groups must be careful not to reconstruct internal divisions of able-bodied/disabled as this can facilitate perceptions of outsiders that those who are speaking out are merely the 'brightest and best' without critically challenging elements of societal oppression and exclusion which have a daily impact on the lives of persons categorized as disabled. I suggest that one way to begin to strengthen bonds within self-advocacy organizations, and between these organizations and other allies, is to recognize the fundamental commonality of our embodiment, to validate the body's lived experience and expressiveness, and the culturally constructed nature of the categories and concepts by which we live.

### **References**

- Edgerton, Robert 1967 *The Cloak of Competence: Stigma in the Lives of the Mentally Retarded*. Berkeley: University of California Press.
- Edgerton, Robert 1993 *The Cloak of Competence*, revised ed. Berkeley: University of California Press.
- Mitchell, David T. and Sharon L. Snyder 1997 Introduction: Disability Studies and the Double Bind of Representation. In *The Body and Physical Difference: Discourses of Disability*, ed. D. Mitchell and S. Snyder. Ann Arbor: The University of Michigan Press.