Disability: Discourse, Experience and Identity

Tim Epp York University

Introduction

Much attention has been given in the social sciences and humanities to a shift away from perceptions of identity and self as monolithic and static entities, and towards an emphasis on dynamic processes of identification. Studies of disability have more recently joined in this discussion. In contrast to earlier studies (e.g. Goffman 1963) which suggested that identity was "spoiled" by social stigma, or that disabled people were consumed by processes of "cloaking" incompetence (Edgerton 1967), Rapley et al. (1998) indicate that identity for people categorized as disabled may be as multifaceted as for the rest of society.

In my own research, I have seldom found people who self-identify solely on the basis of disabled, as other categories of identity are often more meaningful to the individual in the negotiation of everyday life. Similarly, Wendell (1996) questions the usefulness of the category "people with disabilities," as it fails to attend to the great diversity of people categorized in this way, and to other social categories which may be more meaningful to the individual than disabled, such as gender and ethnicity. Paterson and Hughes (1999) urge studies to focus on the lived experience of disability and impairment, challenging models which reduce the body to a passive recipient of social forces, and human agency to strategies of resistance against societal oppression.

Studies of identity must not only focus on agency, however. It is important to combine phenomenological or social constructionist approaches with analysis of the material, social and discursive constraints facing disabled people. Just as individuals engage in processes of acceptance or rejection of societal categories of identity, they also face material, social and discursive constraints to these negotiations. Disabled people interact and live within society, drawing on and negotiating dominant societal models of personhood, body, mind and competence in their personal and collective pursuits of identity.

Generalizations of disability and disabled experience within the disability rights movement itself may be quite different from the models of identity which individual members of self-advocacy groups may live by. Discourse of self-advocacy and disability within the disability rights movement presents and reproduces models of body, mind and competence that are both potentially empowering and also potentially marginalizing. Vernon writes that "disabled people, like non-disabled individuals, are socialized into a culture that is characterized by the binary divisions of 'normal,' 'abnormal,' and superior/inferior with regard to actual or perceived differences of race, gender, class, sexuality and age" (Vernon 1999).

This article will examine individual and collective models of disability as presented by People First (PF), a prominent self-advocacy organization for persons labeled as developmentally disabled, and the members of a local People First chapter (People First of Welland, PFW; People First of Ontario and People First of Canada are noted here as PFO and PFC, respectively). In particular, focus will be on binary opposites which inform individual and collective discussion of disability, and which center around themes of bodily control in terms of mobility and speech.

In examining statements made by many interview respondents which identify two other group members as representing the "truly disabled," while other group members depict these men as personifying undesirable characteristics of selfhood in terms of mobility and speech, interviews and participant observation with these individuals reveal them as also engaged in processes of negotiating the meaning of embodiment and identity. The closing will add to other recent studies in calling for attention to the embodiment of communication and identity.

The data presented here are drawn from eighteen months of ethnographic research with People First of Welland in the province of Ontario, Canada, between 1997 and 1999. Methodology included participant observation, semi-structured interviews and field notes

taken at meetings and events. In this article, the language "disabled people" is used in order to emphasize processes of disablement impinging on individual processes of identification. These processes emanate both from sources external and internal to the disability rights movement.

The People First model of the articulate issue-oriented self-advocate, while providing an effective model for political activism, presents speech as abstracted from more general processes of embodied communication and gesture, marginalizing those who do not identify with this model of self. This is not to say that PF leaders are not aware of the diversity of their membership, but rather that the ideal collective and individual selves which are constructed and promoted through the organization represent a strategic use of the essentialism of disability and self-advocacy in a scrupulously visible political interest, one which is necessarily self-alienating in that it reifies the category of disability and the disembodied voice, and suggests a homogeneity of experience which contradicts the inevitable complexity and diversity of embodied experience for those it purports to represent (Spivak 1988:205). As such, People First has been perceived as not representing the larger population of disabled persons (e.g., Collingwood Community Living 1984).

We Are People First

The concept of the person is central to People First discourse as primary category of identification for the organization's members. Lafave and McWhorter comment on this emphasis:

The status of being a person supersedes and overrides the status connotations of labels that denote a handicap.... Because citizens who live with mental handicaps perceive that society behaves toward them in a manner that denies and threatens their status as people, they have chosen a collective name to express both a judgement about what is at issue and a positive statement about their fundamental concern (Lafave and McWhorter 1981:95).

The current pamphlet of PFO presents this message through words and images:

People First! Of Ontario Who are we? We are people who know what it feels like to be labeled. We have been called: mentally retarded, mentally handicapped, developmentally disabled. We don't want to be known by a label [symbol of a packaging tag with a censor line through it]. We want to be known as *people* first! We are *self advocates*. We are speaking up for ourselves. [Pamphlet contains a drawing of a trumpet] PFO Together we can do it!

The speech of disabled persons thus reveals the truth of their subjectivity, humanness and agency which labeling ignores. As mentioned earlier, the most offensive of these labels for many PF members is "mental retardation," a term considered so degrading that people balk at the mention of it. My own interpretation is that agency and subjectivity are claimed by PF members particularly as a constellation of disembodied mind/heart/vision/verbal-speech triumphing over the impaired body. The term "mentally retarded" encompasses mind, the seat of personhood, as the limiting factor in disability. In contrast, "learning disability" refers to a task of the mind which is negotiable in its fulfillment. Through personal experience and collective discourse, PF members associate the phrase "mental retardation" with oppression of the person who is supposedly deficient in mind and thus personhood through practices of incarceration, segregation and sterilization. Labeling, then, is reductionistic, and group discussion of labeling often includes phrases such as "don't label us, we aren't cans of beans."

Martha, a PFW member, talked to me about labeling as an underestimation of the person's capacity to cope and negotiate tasks of everyday life.

Tim: What does it mean to be labeled?

Martha: Well, it's very hard to get anything... it's very hard to deal with

things in the community. Like people that know me know that they don't call me certain things that ... like they don't call me certain names.

Tim: Mm hmm.

Martha: Yeah, and that's very hard, like if someone said that I was retarded, or I couldn't...or I wasn't ...I couldn't learn to do something. That...that's hard, that's really hard. When people think things, and...yeah.

Tim: Why is it hard?

Martha: Well, because there's always a way around it. Like if you can't do something, there's a way around it. That you can learn how to do it.

Labeling imposes an artificial identity upon the person, disregarding individual accounts of self and experience. In this way, language may be seen as a form of power exercised over the individual, individual diagnosis acting as a signifier for future professional decisions as to where the person should work, live, be educated, and what type of treatment regimen their body/mind should be subjected to. This disregard for individual processes of identification and definition of needs/desires is hurtful to the person.

Tim: But what's hurtful about being labeled? Jim: Some hurt is that you're retarded, and that's not right. To the person themself, they're not

retarded. To other people, they think we are retarded, and we're not.

Goffman described this conflict between self-ascribed and imposed identities in his theory of stigma, as the revelation of socially devalued attributes in the person which results in the spoiling of individual self-identity and the identification of the person as a tainted, discounted being (Goffman 1959, 1963). However, I found that respondents at times rejected a disabled identity, while in other contexts these same people aligned themselves with models of the impaired body, negotiating their own sense of identity in terms of disability.

For example, while identifying with physically and more severely disabled people in protesting against cases of euthanasia, the same group members also distinguished themselves from people with physical disability through emphasizing the malleableness of mind in the category of the learning disabled. In contrast to the disabled body, which is often depicted as a passive object, subsumed by assistive devices, mind can be changed and improved through education. Several respondents made comments suggesting that both societal factors and the disabled body pose barriers to the empowerment of mind. Efforts of self-advocates with mobility impairments were often discussed as being done in spite of the person's body. In one interview, a former PF leader commented on people who seemed to be content with group home living or sheltered workshop employment. He replied that these people simply did not know their options.

Disability Discourse in PFW

Identity thus appears not as a fixed state, spoiled by processes of labeling, but contingent, always in a state of tension between objectified representation and pre-objective embodied experience. However, in discussing the nature of disability with PFW members, I gradually became aware of these conversations centering around key themes of body and mind, often expressed in the form of binary opposites.

During the early period of my fieldwork, I drove to PFW meetings with the president of Hamilton PF. One evening, on our drive back from Welland, I asked this man if he considered himself to have a disability. He replied "no, that's the people in wheelchairs." He prided himself in his ability to be mobile in Hamilton, attending a seniors' group downtown. We discussed disability further, and it appeared that he associated three criteria with disability: limitations in mobility, communication and a more general category of "doing things for yourself." These categories were also invoked by PFW members in interviews. However, an examination of interview statements reveals additional categories including: physical appearance, morality, learning and emotion.

(i) Mobility

For my respondents, the wheelchair was the prime symbol of impaired mobility, along with other assistive devices including canes and walkers. One of my respondents, Leia, provided me with a description of people who were disabled:

Leia: People with walkers, people in wheelchairs, some people with canes. How about them in Welland, some of them use the handi- I mean, the community bus. Sid used to go to (workshop) before he got in the wheelchair. And there's scooters.

Tim: Anything else?

Leia: There's somebody in our building with a disability. Um, crutches, you know, crutches that you attach to your arms when you're walking.

These images were invoked to depict persons who were "less fortunate" or "more severely disabled" than the speaker, or to position the speaker as a proclaimer of empowerment to the people using these devices. These assistive devices were in all cases associated with a state of dependency on the part of the user.

(excerpt #1) Lori: At People First we talk about problems and helping people. There's some people who need more help, some people been that way, needs us to get him up to put him to bed, he's in a wheelchair. That's at George's home. Another girl at (George's home) is real sick, needs my help to get up to the washroom, to put her on her chair.

(excerpt #2) man at PFO Annual General Meeting: Workshops should stay open for the people in wheelchairs. Not to mention any names. I figure they need the help. It helped me out, it did because I'm out in the community now and working. And I feel it should stay open for people in wheelchairs who need the help.

In contrast, respondents often informed me, with pride, of their skills in walking, bicycling, and using the public transit system. One group member informed me that fare hikes did not bother her very much, as she most often walked or rode her bicycle, only using the transit system if she was in a hurry or in severe weather conditions. She stated with pride that she had biked to the neighboring town to see her brother's family, much to his concern. Two men in the group also enjoyed bicycling. Another PFW member was able to tell me about the personalities of several bus drivers.

Discussion of mobility, however, was not limited to the individual's body, consistently appearing in the form of transportation issues at monthly meetings. Increases in bus fares were consistently discussed at PFW meetings throughout the period of my research. Transportation was also an issue in terms of getting to PFW meetings. When I began attending monthly PFW meetings, many of the evening's participants would go out for coffee together after the meeting. However, this proved to be a strain on the advisors, who had to pick up and drop off many of the group's members. This service was discontinued later in the period of my research, and members were encouraged to find volunteer drivers.

(ii) Communication

Respondents also discussed disability as related to communication, primarily to verbal speech. At times themes of communication, mobility and dependency were combined.

(excerpt #1) Dan: (Tracy Latimer) was in a wheelchair. She was more like disabled. She had a lot of disability problems. Can't speak...I think (disability's) the body can't move or anything. The arms. Can't speak like we are now 'n that. Kind of hard when a person's trying to say something. Kind of hard to understand their talking. Saying'n that. George at first, I

couldn't. Don't know why. Trying to say something. Could't understand what he was trying to say 'n that. At first I couldn't understand what people were trying to say'n that. Like this one girl, she has cerebral palsy 'n walks with a walker and problems trying to speak. Kind of hard to understand a person. That's when they try to say something, her counselor helps her out 'n that.

(excerpt #2) notes from PFW meeting: Doug tells the advisor that he has to work hard at speech. He speaks with a lisp, and has told me in an interview that disability to him means "the letter s and long words."

One woman in the group also invoked the theme of communication in her story of a resident at the senior citizens home where she works under a service agency's supported employment program. However, she recognized this person's use of alternative communicative methods.

(excerpt #3) Reba: We've got one resident, she's in a wheelchair. She's only got a brain stem left. And her head is mostly water so she has a bigger head capacity because of all the water in it. And if they drained it, the water was actually protecting the rest of her brain stem, if they drained all that liquid out, she would be worse than she was, she would be more of a vegetable. She can go like this, wave at me like that. She makes little noises. With the brain stem you have no speech at all. She goes da da da and they were surprised that only having a brain stem she was able to make noises.

Another respondent said that one of the most horrible institutional experiences was being called "squawkbox" by other residents. One man reported that persons with disabilities were "loud," and a woman stated that "mentally retarded people speak differently," using the example of another resident at her group home. She often complained to me about this man being a "chatterbox" and snoring loudly at night. However, this woman was very talkative herself and also complained when other PFW members at a conference she attended did most of the talking.

(iii) Physical Appearance

For people in the Welland group, disability was also related to physical appearance, often phrased in terms of "looking normal."

(excerpt #1) Natasha told me that she felt like people were staring at her at PF meetings and at her school. She said "they told me that I looked like a mentally retarded person." I asked her to explain, and she said "they said that I looked handicapped...crippled." Natasha walks with a limp due to a hip operation.

(excerpt #2) Notes from PFW meeting: A young woman is attending the meeting for her first time. She seems confused about the discussion on labeling, and says that she doesn't feel labeled. Martha replies that she doesn't look disabled.

Natasha's statement suggests a disabling gaze, reminiscent of another man's statements on persons with disabilities "hiding" and one woman's statement about her "low-functioning" brother needing to be "watched."

(iv) Dependence and Self-Care

This theme often appeared as a general reference to "doing things for yourself." However, key symbols in this category include one's own apartment and physical assistance in certain tasks such as maintenance of personal hygiene. Statements valuing abstinence from smoking and drinking, and of completing tasks such as cooking independently fall into this category.

Respondents also provided stories of helping others, positioning themselves as a relatively independent helper. Three women in the group worked at seniors' residences, through the supported employment program. Rachel, Reba and Natasha informed me that they helped in the running of Bingo games, and I accompanied Rachel to this job one day.

(excerpt #1) field notes: Rachel sits beside Anne, three Bingo cards in front of her. She slides red transparent squares across the numbers when they correspond with those called by a co-op student at the front of the room. Rachel is fairly quick at recognizing numbers and reacting. Anne sits beside her in a chair, talking in slurred speech, repeating the letters that are called, but not manipulating the markers or the card, which appears to be Rachel's job. Rachel says "I'm helping Anne." Rachel refers to Anne in the third person, not talking to or looking at Anne as she covers the numbers. Rachel turns to me and says "This isn't one of her days, all the wrong numbers. That"s one Anne won before, didn't ya?"

Rachel did allow Anne to clear her card after the game and did talk to her at that point. However, at many points in the game she appeared to take over the game from Anne, speaking for her and reducing her to passive sitting.

(v) Morality and Functioning

Respondents often discussed disability in terms of morality, being a good person vs. being disabled, especially persons with physical disabilities who were "worse off."

(excerpt #1) Harold: The counselor calls me handicapped. I'm not handicapped, I'm a good person.

(excerpt #2) field notes: Strong themes of health, work and family emerged several times during discussion with Richard, his mother and brother. Upon Richard's birth in Austria, his parents had been given the impression by doctors that something was "wrong" with their child, but they weren't given a specific diagnosis. Once in Canada, Richard's mother was told "about handicapped children like that," and was advised by doctors not to spend money going to other physicians for second opinions, as "nothing would make a difference." At that point, his mother said, "I was still dreaming that if I took him to a specialist, he'd be a normal child again." The doctor had also cautioned her that Richard would not be "a healthy child like the others," and wouldn't be able to work like the rest of the family. This was partially related to a curvature of Richard's spine from birth, and a resultant difference in the length of his legs. Richard realizes this and what it has meant for difficulties in his balance. He comments on this: "That's terrible." His mother was left with the diagnosis that Richard had cognitive difficulties. Richard does not currently read or write. Richard was present in the room when I was talking with his mother. Upon mention of this diagnosis, he joined in "but I'm a good guy anyway."

Carla talked about her cerebral palsy, then referred to a woman with a more involved form of a similar condition as being "worse off." Similarly, Reba speculated on the process of draining the fluid from the brain of the woman in her story: "then she would be worse." Reba

and Rachel also invoked the high/low dichotomy of bodily functioning. High-functioning people appeared to be relatively independent in daily living tasks, walking and using articulate verbal speech. Low-functioning people were not able to express themselves verbally, and were dependent upon staff for daily living tasks.

(vi) Learning

Respondents also discussed disability in terms of learning. The mind is negotiable, improving through education, whereas the body ("legs and stuff") of physical disability is often "confined" to a wheelchair, revealed as a passive object. Often responses were phrased in terms of "I just have a learning disability."

(excerpt #1) Dan: I have problems, a learning disability. It's just a learning disability that I've got. I don't have no other physical disabilities. A learning disability is all I've got.

Tim: So what's a learning disability?

Dan: Well some people it's kinda hard to get to learn stuff like other people. I think that's slow learning disability, like I've got. It's kind of hard for me to get things, sink in 'n that. That's what I've got. Kind of measuring 'n that. It's kinda hard for me when the teacher says three quarter inch mark. I need help, somebody helps me out. This guy I know comes to the same course wood working as I do. On the lathe or whatever and I appreciate the person's help. On the table saw, I need someone on the other end for cutting wood. I just move over tell him where to put it. Other times if I'm not busy, someone calls me to help them. I go over to help what they're doing on the table saw.

(excerpt #2) Reba: My disability is learning, it takes me longer to do things. It's harder to remember. My reading has improved, it's a lot better than it used to be, it's just math now...If I had a child with a learning disability, I would give it Hooked on Phonics (child linguistic program) and the ABCs and all those things I didn't have. Disabled and handicap are the same. Learning disabled is a little different than a person in a wheelchair and stuff. That's because it deals with our mind. Learning you have in your brain here. Physical is more your legs and stuff. You can't walk or...disabled is more with people who can't walk . . . Some people don't know I have a learning disability until I tell them. Some people think you have a learning disability and you don't...My foster parents think that my disability is due to my placement in so many different foster homes, I never had a chance to settle down and find what my capacity was. If Hooked on Phonics and ABCs were around then, I would probably be in college like me sister-in-law.

Reba's account suggests that learning disability is negotiable. Mind is changeable through education, and one can negotiate the identity of disability with the resources of time and educational technology. However, according to Reba, physical disability simply means limitation.

(vii) Emotion (in/out of "control")

Several respondents discussed disability in terms of emotion. In each of these cases, anger was the focus of discussion. Two of these respondents informed me that they used to express anger more readily, but now they had greater control over this emotion through anger management training, and were less disabled.

Betty, another PFW member, is one person who has struggled to deal with managing her anger. She sees PF as a group to come and "talk out" your problems "cause you don't want

to hold it in too long, because it might be worse if you hold it in longer." Bill saw his disability as learning to manage anger and relax. Dan had also struggled with anger and depression.

Someone like Tracy Latimer, have someone helping out, have help. More support for a kid than for myself. I need someone to take care of me if I get out of control, then I need help. But I'm doing okay myself.

Dan recognizes that he becomes depressed more easily in the winter, and combats this with the use of a halogen lamp.

(viii) The Fragmented Body

I have already suggested that these criteria for disability inform each other and are often invoked in combination. Impairment in the body blocks the critical bodily functions of mobility and speech, corresponding to a dichotomy of high-mind/low-body. Similarly, greater physical impairment is viewed as worse, in contrast with success stories of independent living. However, perhaps the most critical categories for People First's approach to disability are mobility and communication. Of the two, communication seems to be the most critical. For example, the stigma of three persons using assistive mobility devices on the PFC executive is outweighed by their participation in formal discussion panels on key PF issues. At a regional meeting, a memorial display for a PFO regional rep who had passed away included one of his statements as follows:

We are human beings just like you, we have real feelings, dreams and personal thoughts. We have a heart, soul, mind, and spirit and we need you to understand us. I feel that I have a right to have a meaningful life. I am worth it.

These perceptions of disability seem to inform, and be informed by, official PF discourse on the active, advocating, articulate self. Again, this is an image against which some PF members strategically position themselves in narrative and action, an image which corresponds with the representation of an issue-oriented self-advocacy group. The construction of these personal and collective identities also involves the "othering" of individuals who appear to be more limited in their abilities to be mobile and use verbal speech.

The two PFW members most often identified by other respondents as disabled persons are individuals who personify these limitations. George has cerebral palsy, walks with a uneven gait, and vocalizes but does not use articulate verbal speech. George receives twenty-four hour care in a group home. Furthermore, he seems quite open with his emotions, often bearing a wide smile, but also openly crying at PFW meetings. Sid is an individual who uses a wheelchair, does not speak much, and is considered an angry person. However, a closer examination of the lives of these two men reveals that what is considered as restrictive at times reflects agency, and what is considered a lack of communication suggests again the embodiment of all communication.

Sid and George

Sid is a thirty-two-year-old man who currently lives in one of WDACL's group homes. Within the PF group, he has somewhat of a reputation of being cranky, although I found him to be quite pleasant in interviews. I think that part of this reputation has to do with his manner of speaking in short, abrupt sentences. Sid seldom makes eye contact when he is in his chair, as his head sags with his chin near his chest. Part of the reason for this relates to Sid's early childhood, when he was diagnosed as having fluid on his brain. Sid still bears the scars of the operation he went through, in which a shunt was placed in his skull to drain the fluid. He also has a past history of Tourette's syndrome.

Sid was not very interested in talking about his past, and answered "I don't know" to many of my questions. Staff at his group home informed me that he really could talk about these matters, but that this was a signal of his unwillingness to do so. However, I was also informed that Sid enjoyed talking about his life through the medium of the Jerry Springer show.

In one of our interviews, I asked Sid about a new plan he was working on with group home staff, which allowed him one outing per week, provided he completed his responsibilities around the house. I asked Sid where he would like to go on his outings. Sid said that he would probably go to Toronto, and "just hang around." Then he perked up and said, with a look of adventure in his eye, that he would really like to go to Chicago, to be on this talk show with a band. He would play the drums, while his father played guitar, while his friends from the sheltered workshop joined in on various instruments. In this way, Sid drew on themes of family, work, and media to construct a dream, in turn constructing and presenting his sense of self at that moment.

On another day, I was pushing Sid in his wheelchair to a favorite coffee shop. On the way, Sid talked about his "tics." I asked him what a tic was, and he gave a sudden jolt to his entire body, catching me off guard. He explained to me that a tic was "when your body does something you can't control." On returning to his group home, staff encouraged him to show me another example. Sid stared at the wall and said in a loud voice "Holy Fuck!" Staff informed me that in the past, Sid had done this repeatedly, along with his physical contractions. On several occasions, Sid informed me that the finer things in life included smokes, women and sex. These elements of coarseness, rough speech and behavior, seemed to form a constellation of identity characteristics which Sid negotiated in his self-presentation through manipulation of body and speech.

As I came to know Sid, he informed me that his use of the wheelchair, which other PF members had interpreted as a sign of disability, was actually a choice he had made, as opposed to using a walker or furniture as supports in walking around. This was made evident in his accounts of visiting his mother, who would not allow the wheelchair into her residence. Sid showed me several times that he could move around his room with considerable skill, leaning on his bed and walls. The very thing which seemed to others perceived as limiting Sid to the category of the disabled was also a sign of Sid's own agency and decision-making. For this reason, group home staff often perceived Sid as refusing to use his walker in order to be lazy.

This negotiation of mobility and the meaning of Sid's legs were also played out in other discussions. When I asked Sid for his definition of disability, he replied "when your legs don't work like they should," suggesting the control of body by mind. He said that there were times when he felt like he had a disability. However, in his dream of playing on the Jerry Springer show, Sid makes no mention of his legs being an obstacle, regardless of the fact that his drum sets are kept downstairs at the group home (Sid at other times said he could not manage the steps), or that he may need to use his feet when playing drums. Sid's legs also disappeared as an obstacle in some of the sexual fantasies he revealed to me. Sid also talked about an incident in a workshop he used to attend, where he uses the metaphor of "broken legs" to accuse another man of laziness.

Sid: Yeah. They have one guy like...one guy, he got some of the other workers mad. Tim: Oh yeah? What'd he do?

Sid: He was sitting at his desk (bangs table) coffee! I want coffee!

Tim: Oh, he was banging on the desk?

Sid: I said: "you got broken legs?" Get your own coffee; I had a hammer in my hand.

Tim: What happened then?

Sid: I almost threw it; I did throw it.

Tim: You did?

Sid: Right at him.

Tim: Yeah?

Sid: Yeah; the day after I threw it, he's getting his coffee ever since.

The disappearance of Sid's legs in his fantasies and dreams, the agency invoked in choosing to use a wheelchair, and the use of "broken legs" in the above statements of "othering" suggest that for Sid, the meaning of legs and wheelchairs was fluid and open for negotiation. Moreover, his own experience with Tourette's syndrome provides another example of the embodiment of communication, the body "speaking for itself."

George is a fifty-one-year old man who also lives in a WDACL group home. He was a regular participant at PF Welland meetings, although his vocalizations contrasted with the generally verbal orientation of those sessions. When George was born, he had cerebral palsy, which is usually explained by others as the basis for the uneven gait of his walk and his very limited use of articulate speech. As I have illustrated, George appeared in several accounts by PF Welland members who thought of themselves as more able than George. Two other group members worked with George on a regular basis, one at the local sheltered workshop and one at the Friendship group which Carl also attended. However, regardless of his seeming limitations, George revealed himself to me as actively participating in his own processes of identity formation. For George, however, identification took the form of body language: hugs, smiles, bodily proximity. He enjoyed showing me his photo album, and would point to photos of people he liked while saying "aay!" and smiling.

I visited George at his sheltered workshop several times, where he showed me around the workrooms and the cafeteria. We also spent time working at his computer. I would often find George sitting by himself in front of the computer, sometimes with a game on the screen, sometimes with a repeated message telling him to re-enter his password. George had some difficulty with fine movements such as clicking the computer mouse and negotiating the cursor on the screen. I would ask him if I could take his hand, he would nod "yes," and together we would find a game he enjoyed and play it hand-over-hand. His workshop staff told me what I already knew, that George was involved in communicative processes with those around him.

While George had experimented with the use of pic-symbols, his sister informed me that George preferred to point at the objects he wanted to obtain or discuss, and that in this way George's gestural vocabulary far exceeded the range of pic-symbols available to him. George's sister also said that he was creative in the use of bodily metaphor. When asked at one point if he liked the group home staff of his current residence, George had apparently taken off his sock and placed it in his mouth. His sister interpreted this as an indication of his dislike for this staff.

While learning disability is referred to as the "invisible disability" by PF members, people such as Sid and George who use assistive devices for communication or mobility, are often discussed as the truly disabled. However, the accounts presented here suggest that these individuals are also involved in dynamic processes of communication and self-formation. This is not to ignore the recognition by some PF members of relationships between verbal speech and other bodily gesture in the communicative patterns of Sid and George.

At one PFW meeting, a woman asked if George had a voice. The group's advisor said that he had a good voice, but that the part of the brain controlling word formation was not working. Another PFW member joined in "but George communicates with his eyes." However, this statement again implies the triumph of vision and upper body over the body as a whole, ignoring the subjective experience of embodiment for George and Sid. Through gesture, and the use of his symbol-book and photo album, George was constructing a sense of his own experience, and therefore reconstructing a sense of his self, as actor in these memories.

The Importance of Embodiment

As suggested earlier, the accounts presented here suggest that People First members often position their sense of identity in relation to categories of morality, body/mind, disability, and self-care which are present in discursive formations of the larger society. These processes of positioning are often expressed in terms of binary opposites: while respondents expressed self in terms of goodness, mobility, high-functioning, self-control, verbal communication and an able mind, the disabled "other" is depicted as potentially bad, low-functioning, needing supervision or control by others, non-verbal and rooted-in/confined-to the body.

People First members do value being physically present with each other through social events such as dances and year-end barbecues. However, the focus on verbal speech, mobility and independence in PF discourse, and the marginalization of the disabled body in collective and individual processes of identity formation become problematic especially when those external to the PF movement interpret this emphasis as a failure to represent those who are truly disabled or truly "in need."

Battaglia draws attention to this process of opposition, but leaves her discussion at the level of rhetoric, calling for "critical consideration of why we or our subjects take up one rhetorical position or another, of to what feared or hoped for effect we engage in the rhetorics we do" (Battaglia 1995:7). However, I think that we need to move beyond this level of discourse, recognizing the embodied nature of all communication and the position of verbal speech within the continuum of embodied gesture. The other alternative, which I propose is not acceptable for a critical awareness of disability and personal experience, is to participate in the reification of speech and independence, and thus in processes of disablement.

References

Battaglia, Debbora, ed. 1995 Rhetorics of Self-Making. Berkeley: University of California Press.

Collingwood Community Living 1994 OACL: A Federation in Conflict? A Draft Discussion Paper prepared by the Board of Collingwood Community Living. October 1994.

Csordas, Thomas 1990 Embodiment as a Paradigm for Anthropology. Ethos 18:5-47. Csordas, Thomas 1997 Language, Charisma and Creativity: The Ritual Life of a

Religious Movement, Berkeley: University of California Press.

Edgerton, Robert 1967 The Cloak of Competence: Stigma in the Lives of the Mentally Retarded. Berkeley: University of California Press.

Foucault, Michel 1988 Technologies of the Self. In *Technologies of the Self: A Seminar with Michel Foucault*, ed. L. Martin, H. Gutman and P. Hutton. London: Tavistock.

Frank, Gelya 1986 On Embodiment: A Case Study of Congenital Limb Deficiency in American Culture. *Culture, Medicine and Psychiatry* 10:189-219.

Goffman, Erving 1959 The Presentation of Self in Everyday Life. Garden City, NY: Doubleday, Anchor Books.

Goffman, Erving 1963 Stigma: Notes on the Management of Spoiled Identity. Englewood Cliffs, NJ: Prentice Hall.

Gordon, Colin 1991 Governmental rationality: an introduction. In *The Foucault Effect: Studies in Governmentality*, ed. G. Burchell, C. Gordon and P. Miller. Chicago: University of Chicago Press.

Kleinman, Arthur and Joan Kleinman 1995 Suffering and its Professional Transformation: Toward an Ethnography of Interpersonal Experience. In A. Kleinman, Writing at the Margin: Discourse between Anthropology and Medicine. Berkeley: University of California Press.

Lafave, Hugh G. and Alan McWhorter 1981 Consumer Advocacy: Strategies and Techniques of the Developmentally Disabled, Parents, and Guardians, to Establish and Preserve Self and Legal Rights of People Living with Handicaps: Introduction. In From the 60s into the 80s: An International Assessment of Attitudes and Services for the Developmentally Disabled. New York: Young Adult Institute and Workshop.

Mead, George Herbert 1956 Mind, Self and Society. Chicago: University of Chicago Press.

Paterson, Kevin and Bill Hughes 1999 Disability Studies and Phenomenology: the carnal politics of everyday life. *Disability and Society* 14(5):597-610.

Rapley, Mark; Patrick Kiernan and Charles Antaki 1998 Invisible to Themselves or Negotiating Identity? The Interactional Management of "Being Intellectually Disabled". Disability and Society 13(5):807-827.

Spivak, Gayatri Chakravorty 1988 In Other Words: Essays in Cultural Politics. New York, London: Routledge.

Vernon, Ayesha 1999 The Dialectics of Multiple Identities and the Disabled People's Movement. *Disability and Society* 14(3):385-398.

Wendell, Susan 1996 The Rejected Body: Feminist Philosophical Reflections on Disability. New York, London: Routledge.