

From the Field

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Coming Out Disabled: The Politics of Understanding
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The experience of being disabled is one path into Disability Studies. But is it? Is this assertion as straightforward as it first appears? That such experience is a path into disability studies remained unambiguous for me until I began to prepare for the 2000 Society for Disability Studies conference in Chicago. To whom does the experience of being disabled belong? How do we read and identify what counts as disability experience? In the midst of a context where disability experience can be understood to ground both identity and knowledge production, my invisibility as disabled began to haunt me as an absent-presence and my obvious, darn near iconographic, appearance as "one of the normals" was a presence I wanted to make absent. This has provoked me to shift a way from a critique of ablist forms of knowledge production and toward an interrogation of the standpoint of disability as a place for knowledge as well as toward a consideration of arguments regarding what counts as such a stance. This is the politics of understanding that I will pursue in this paper and I do so by turning to an examination of pluralistic and even contradictory experiences.

Experience, Identity, and Access

Experience *of*, identity *with*, and access *to* the stuff of everyday life are tied up together not only in relation to disability, but in all situations. For example, three years ago, after completing my PhD, I moved from Toronto to a small town in Nova Scotia in order to teach sociology at St. Francis Xavier University. In the province of Nova Scotia it is illegal to sell cigarettes to anyone under nineteen years of age. When I attempt to buy cigarettes, and despite the fact that I am thirty four years old, some store clerks do not grant me the identity of "being of age" and thus ask for picture-identification, particularly a drivers licence. Driving is something that I have not learned how to do. So, I invoke *experience* as proof that I possess the *identity* of being "of age" in order to *access* my desired end - cigarettes. I tell stories: "You know, I am 34." "I teach at the university." I show my faculty card. I show them too many credit cards. Certainly, I argue, an under-aged person could not carry so much credit. If all this fails, I look to

see if there are check-out clerks whom I know who might attest to my status of "being-of-age." Despite all this, somehow my experience of being "old enough" has been made invisible. Something to do with my appearance (long hair, style of clothing, stature, not-driving) covers over my age. Thus, I have to *work* to make my age appear to others. The obviousness of being old enough to myself marks those who seek out proof of it as ridiculous to me. As invisible as my thirty four years appears to some marks me as a little strange or as trying to pull a fast one. Some say, "Dear, think of it as a compliment." Regardless, I find my self trying to draw out my age for others.

In the face of trying to make visible to others what does not appear to them, the typical set of practices pursued is the seeking and the offering of "proof." This holds true, as much if not more, in relation to those lived experiences glossed by the terms "invisible disabilities" and "learning disabilities." The social-political consequences of seeking, securing, and offering proof of these disabilities are certainly more messy and dramatic, life altering and death defying, than those involved in the proof of age and the procurement of cigarettes.

The proving of learning disabilities is an incredibly messy situation: the proving enterprise has grown exponentially over the last couple of decades and the tendrils of diagnostic desires and procedures reach out into classroom practices, psychological and intelligence testing, brain imaging, gene mapping. Students who have "proof" of learning disabilities may, indeed, share very few experiences in common with one another: what counts as a learning disability is becoming more and more diverse. Some people have spent a life time being treated as learning disabled and others only a week or two. Learning disabilities are tied into the inequalities surrounding race, class, gender, state, and nation.

Diversity of definition, diagnosis and treatment, diversity of embodiment, and diversity of social location all impact on and organize the proof generating enterprise. Despite all this diversity, those learning disabled students who reach university in Canada or the United States will more than likely share in common the fact that all will have received a great deal of training on how to prove to others that they possess legitimate proof. (Professionals in the field of learning disabilities often refer to these proof-giving practices by the more sophisticated term of "self-advocacy.") The generation of proof requires the reconfiguration of diverse experiences into a single organized category of identity - dyslexia, ADD, mental illness, etc.

It was just such proof with which I was going to begin this paper. But, if I want to do more than conform to the normal order of things, I need ask: "If the experience of being disabled is a path into disability studies, who is understood as traveling this path, how, and what does this teach us?" This kind of questioning requires me to treat proof-giving practices as something to think about and not just something to do. I do not ask after the relation between the experience of being disabled and the doing of disability studies so as to draw unquestioned boundaries around qualified and unqualified speakers and researchers. Rather, I am considering this relation so as to gain some understanding of the social significance of disability experience conceived of as a critical space for critical inquiry while, at the same time, following through on the promises of understanding disability as just such a space.

So again, my preliminary assumption was that I should "give proof" - come out and self-identify - say "I am dyslexic." Unlike the clerks who do not sell me cigarettes, I would assume the reader's good will, I would not provide a medical assessment or brain image, but I may have told a story about my own or others' experiences with me that have come to count as dyslexia. I

could begin to describe that which I assume would otherwise remain invisible to the reader: anomalous and different relations to space, time, numerical and logical order, sequential, memory and linguistic mix-ups. I could tell stories about how dyslexia remained invisible to me too, the consequence being that I spent my childhood and adolescence thinking that I had a form of mental illness. In so doing, I would reconfigure diverse experience into signs of dyslexia thus making *not passing* as "ordinary and normal" an active practice.¹ Through such accounting practices (Garfinkel, 1967) I could begin to pass into and pass as an instance of disability.

Herein lies something unusual.

Coming Out

As a way to begin to consider the social significance of the activity of not-passing, consider a contrary experience as articulated by Rosemary Garland Thomson (1996:xviii) in her introduction to *Freakery*:

The notion that someone with a very visible physical disability might "come out" perhaps seems oxymoronic to those for whom the cultural assumptions that structure the normal remain unquestioned. Indeed, pressures to deny, ignore, normalize, and remain silent about one's own disability are both compelling and seductive in a social order intolerant of deviations from the bodily standards enforced by a quotidian matrix of economic, social, and political forces.

Here, passing as at-one-with, or as closely-connected-to, the "cultural assumptions that structure the normal" is depicted as a compelling activity. So compelling is such passing that one does not only come out *to* others, but one must come out *from under* the seductive power of an unquestioned sense of normalcy - come out *for* one's self. Practices of denial, of ignoring, of normalizing, and of silencing can be understood as the activity of passing, of not coming out, even if Ableist Others "see" this person as an outright example of, and nothing other than, "Disability." In Thomson's account, diverse experience is reconfigured into more singular unified identities - one is a passer or one is not-a-passer. Either way, both are achieved in relation to ableist assumptions that have already organized the complexity of another person's life into the sign of disability. The problem, implies Thomson, is that a person may be seen as, understood as, treated as, and contained by stigmatized conceptions of disability and yet, that same person may be engaged in activities, such as denial or silence, which unquestionably assume the good of securing a place among the cultural structures of normalcy. Through passing, stigmatized conceptions of disability, at best, remain undisturbed, at worst, are re-deployed. The activity of passing in light of a very visible physical disability is described as compelling, coming out as potentially oxymoronic. Whatever else disability studies says that disability is, or whatever model of disability one follows, visible disabilities are the signifiers in relation to which people develop identities (e.g., this person is a passer, that person is a conundrum) and in relation to which people can develop knowledge. In this case, we come to know that culture *propels* as much as it *compels*.

Coming out as disabled, in the absence of what a culture typically envisions as disability's typical presence, seems a slightly different matter. If a dyslexic person, for example, is to come

out, she must actively deny her own stance in, as Irving Zola (1993) has put it, the "world of the normal." It is the very visibility of normalcy that must be silenced, ignored, denied. It is the person's assumed and apparent stance in the ordinary that makes coming out as, and passing into, disability a different matter for people whose differences do not readily appear to others who unquestioningly assume, and thus "see" only, the structures of normalcy.

For the "very visible physically disabled person" to come out to and out from under normate² culture means making disability signify something other than what culture has in mind. In Thomson's account, disability must now come to signify something other than embodied lack separating one from the normals and something more than the supposed omnipresent desire to get as close as is possible to the structures of normalcy. And yet all this is done in the midst of the power and seduction of the structures of normalcy that serve capitalist economy and ablist culture. However, coming out does not mean freedom from normalcy. It does mean being in a position to question it. Yet, as Rod Michalko (2000) says, "The least normal thing we can do is to think about normalcy."

What makes this a difficult process is that everything about a visibly physically disabled person can be made to signify lack which is tied to on-going rationalizations of disabled peoples' marginalization. Passing as normal is not some sort of abstract ill state of affairs. It is seductive precisely because securing some sort of stance in normalcy is a possible path toward a version of participation (e.g., becoming "able" to serve, or be, the status quo). For those with non-readily apparent disabilities the difficulties are different - everything about us can be made to signify normalcy. Nothing "apparently" blocks our path into normal routine affairs. No-thing about us can be readily observed and used to justify marginalization. In other words, so called "invisible disabilities" are made invisible by something and that something is the multivarious but taken-for-granted appearance of normalcy. Disabilities are covered over, and made invisible, by the structures and assumptions of normalcy.

"Visible" or "invisible," the meaning of disability is bounded by, articulated through, and is often made apparent in "very normal ways." Visible or invisible disabled people who "come out" understand that their experience of disability has been organized in relation to the structures of normalcy.

As an adolescent, I made sense of my experience of having trouble negotiating my way through the physical and verbal realm of print culture by interpreting this trouble as mental illness. No one told me that I was mentally ill. Instead, "mental illness" is an identity category that our culture has ready made for anyone who deviates from the normal structuring of ordinary life for no "apparent" reason. At the age of 20, I found myself going to school in Mexico, trying yet again to learn a second language - a requirement for my B.A. In Mexico I lost "mental illness" and was diagnosed as dyslexic. Dyslexia now became my way to make sense of what I was unable to do.³

Notice that coming out from under the normal sense making device of "mental illness" means getting my experience to fit into another category structured by and for the order of normalcy. If I am to prove my experience is the experience of disability, I will have to rely on normal conceptions of disability in order to do so. I would have to say that I possess an embodied impairment and this means that I lack. Or, I could engage in the set of normal practices that are typically used to make this particular invisible impairment appear. I will have to show that despite my appearance of normalcy, I embody a difference that I want the reader to experience as

"disability" and I could be seduced into using a very normal conception of disability as lack and impairment in order to do so. Such self-identification does not adequately represent the disruptive power of coming out to which Thomson refers. "Coming out" cannot mean giving or receiving the "correct diagnosis" for this would simply mean that I am being compelled by "a social order intolerant of deviations for the bodily standards generated by a ... matrix of economic, social, and political forces."

Coming out so as to reveal the complexity of disability for identity, thought, and politics means, instead, questioning the connection between normalcy and disability. Such questioning arises in that space in-between assumptions structured by normative culture and the experience of not fitting neatly into those same structures. (Titchkosky, 2000) There are, after all, very normal ways to make disabilities appear that do not normally appear to others. Indeed, it is compelling to experience disability as ordinarily as is possible. This is not a coming out, but a sinking into the normal and ordinary ways our culture has ready made for all of us to imagine disability.

I could, for example, give you a list of the problems, readily apparent to me, that have come to be called dyslexia. I could dwell, as the social model theorist put it, on impairment. (Oliver 1996, 1990; Barnes 1998) But this is more than a focus on the wrong things. It is a non-self-reflexive focus. The problem lies not in the "object" (differential embodiment), the problem lies in what relations do we establish to these so called objective renderings of disability. Simply proving that I count as a disabled person does not necessarily move me, or anyone else, toward following through on the promise that disability can be a critical space for critical inquiry. In fact, engaging in proof-giving practices might do little else beyond showing the compelling and seductive nature of fitting in somewhere, some how. While fitting in, or as Cornell West (1995:16) says, that "deep visceral need to belong," is certainly a worthy end, much more worthy than the buying of cigarettes for example, coming out to face the complexity of disability experience means questioning *to what and for what do I belong*.

Like Thomson's very visibly physically disabled person, coming out means moving into that space that exists between the seductive world of normative culture and experiences that say "You are not that!" It is that space which allows disability studies' researchers and activists to begin to critically understand the unquestioned ways of making sense of both disability and of everyday life. This is the politics of understanding the experience of disability.

In an essay called "Understanding and Politics," Hannah Arendt (1994:307-327) attempts to think about what understanding totalitarianism might look like. Of the uniquely human faculty of *understanding* she says that it is a means to confirm and reconcile ourselves to a world where such things as totalitarianism are possible at all. In a world where totalizing, marginalizing structures of normality, are inscribed upon the bodies, minds, and senses of all people, disability studies has the uniquely human task of understanding how such things are "possible at all." The politics of the pursuit of such understanding, says Arendt, does not mean forgiveness nor does it mean a quick fix. Instead,

Understanding is unending and therefore, cannot produce final results. It is the specifically human way of being alive; for every single person needs to be reconciled to a world into which [s]he was born a stranger and in which, to the extent of his [/her] distinct uniqueness, [s]he always remains a stranger... Many well-meaning people want to cut this process short in order to educate others and

elevate public opinion... [But] Understanding begins with birth and ends with death. (Ibid.:308)

I have tried to use my experience of disability as an invisible-presence that I wanted to identify to the reader as an opportunity to think about what counts as the experience of being disabled and what disability studies can make of such experience. My initial inclination was to cut short the process of understanding and simply educate and inform the reader as to my desire to be identified as a person with a very *invisible* disability. Instead of this, I attempted to confirm and reconcile myself to my unique distinctness in a world structured by unquestioned standards of normalcy. This allowed me to use and provide an image of "disability experience," such as coming out, as that which is best understood as a strange experience, one that should not be ignored, but an experience that should be understood as a space for questioning.

Conclusion

To return then to the questions I initially raised: the experience of being disabled is one path into disability studies, but this is not a straightforward assertion. Disability experience, like all things uniquely human which do not make us readily "at one" with the world, is ambiguous. It seems to me that one of the primary tasks of disability studies is to make disability belong to the world even though it remains a stranger in this world. Being either visibly outside the normal orders that structure everyday life or being mistaken as an instance of such orders, are experiences that belong to the realm of that which needs to be *understood* and not simply enunciated.

Claiming disability is not enough. "Coming out" is entering into a space of questions: How do we experience the experience of disability? How is such experience possible? How can we relate to the experience of disability so as not to make it a once and for all project, nor a singular announcement, but rather an essential space of questions? While the emphasis is different, while the political and social consequences are different, both the appearance and the disappearance of disability mark the occasion of considering what it means to be positioned between visibility/invisibility, normalcy/abnormalcy, and ordinariness/extraordinariness, and thus being able to ask questions which are strangers in and to the normal order of things. "Coming out" is positioning, and thus identifying, ones self as such a questioner.

Endnotes

An earlier draft of this paper was presented at the Society for Disability Studies conference, Chicago (2000). I am grateful for the incisive audience comments as well as much encouragement.

1. For an account of such passing as it relates to Deaf and deaf experience see Brueggemann (1997:647). See Michalko (1998) for an analysis of passing as sighted when visually impaired.

2. "Normate" is a term that makes reference to unmarked categories of persons that are culturally regarded as "definitive human beings." (Thomson, 1997:8, Goffman 1963:128) The mythical American normate is, as Goffman (ibid.) says, the "young, married, white, urban, northern, heterosexual Protestant father of college education, fully employed, of good complexion, weight, and height, and a recent record in sports." Looking "normal" and operating from a "normal" stance means wielding authority and power that comes from fitting into the status quo. It also means being regarded as the "type" of person who is generally intended and expected by the normal order of interaction, the physical environment, and the structures of knowledge production. Insofar as normalcy is more of an ideological code (Smith, 1999:157-171) than actual embodied beings, "normate culture" is a way to refer to how this ideology works to exclude, oppress, and remove definitional power from so many different people. While disabled people face death, torture, and other severe forms of oppression under the normate regime, all people are oppressed by and within normate culture - even if they are positioned so as to wield its power.

3. A fuller analysis of this process can be found in my *Disability Stays* (manuscript under-review of University of Toronto Press).

References

Arendt, Hannah. 1994. *Arendt: Essays in Understanding 1939 - 1954*. New York: Harcourt Brace and Company.

Barnes, Collin. 1998. "The Social Model of Disability: A Sociological Phenomenon Ignored by Sociologists?" Ed., Tom Shakespeare. *The Disability Reader: Social Science Perspectives*. London: Cassell Academic: 66-78.

Brueggemann, Brenda Jo. 1997. "On (Almost) Passing." In *College English*. Vol. 59(6):647-660.

Garfinkel, Harold. 1967. *Studies in Ethnomethodology*. New Jersey: Prentice-Hall, Inc.

Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. New Jersey: Prentice-Hall, Inc.

Michalko, Rod. 1998. *The Mystery of the Eye and the Shadow of Blindness*. Toronto: University of Toronto Press.

_____. 2000. *Politics and Disability*. Unpublished manuscript.

Oliver, Mike. 1990. *The Politics of Disablement*. Hampshire, London: The MacMillian Press. Ltd.

_____. 1996. *Understanding Disability: From Theory to Practice*. New York: St. Martin's Press.

Smith, Dorothy. 1999. *Writing the Social: Critique, Theory, and Investigations*. Toronto: University of Toronto Press.

Thomson, Rosemarie Garland. 1996. (Ed) *Freakery: Cultural Spectacles of the Extraordinary Body*. New York: New York University Press.

_____. 1997. *Extraordinary Bodies: Figuring Physical disability in American Culture and Literature*. New York: Columbia University Press.

Titchkosky, Tanya. *Disability Stays: An Introduction to the Social Constructions of Disability*. (Manuscript under review at University of Toronto Press).

_____. "Mapping the Outer Limits: Cultural Conceptions of Disability." in Mairian

Corker and Tom Shakespear (Eds.). *Disability and Postmodernity*. UK: Cassell. Forthcoming
_____ 2000. "Disability Studies: The Old and The New" in *Canadian Journal of Sociology*. June. Vol 25(2):197-224.

West, Cornel. 1995. "A Matter of Life and Death" in *The Identity in Question*. Ed., John Rajchman. New York: Routledge: 15-32.

Zola, Irving Kenneth. 1993. "Self, Identity and the Naming Question: Reflections on the Language of disability." In *Social Science and Medicine*. Vol. 36(2):167-173.