

Disability Studies and the Language of Mental Illness  
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**Abstract:** Much has been written about the dangers of mental illness, both by psychiatry as an empirical reality and by anti-psychiatry as a cultural category (Szasz, 1960). This paper considers how the language of mental illness, and more specifically, the discipline of psychiatry, structures how we relate to our everyday lives. I examine *how* the language of mental illness, and the psychiatric practices which have made this language possible, have conditioned the development of a disability studies community, culture and identity. This examination will involve a critical analysis of writing in the field of disability studies which illustrates the complex interconnections and interdependencies between self-identifying as a disabled person and rediscovering the aspects of oneself that have been stolen or stamped out by the imposition of a language of mental illness. This paper also aims to uncover some of the implicit assumptions about the nature of the relationship between language, culture, identity, and community.

**Key Words:** Disability Studies, language, community

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*The language, similar to any skill or tool, becomes part of my bodily "I can."* (Leder, 1990, p. 121)

### The "New" Disability Studies and Its Methodological Approach

Maurice Merleau-Ponty (2008) writes in *The World of Perception*, "The contact I make with myself is always mediated by a particular culture, or at least by a language that we have received from without and which guides us in our self-knowledge" (p. 66). My lived experiences as someone whose body, mind, and senses bare the mark of the mental health system have led me to wonder whether simply avoiding the language of mental health and illness may in fact help to justify the marginalization, if not outright removal, of some people, bodies, and experiences from reflective consideration within conversations in disability studies. My being named mentally ill led me to view myself as a problem, my histories and experiences as deficient, defective, and the products of an unfortunate chain of events, and my perceptions as delusional. My being named this way also brought me to disability studies, which has in turn brought me to a more critical awareness of myself as an embodied being, and has helped me to realize that my experiences, histories and perceptions are both valid and valuable.

This paper turns on a central question, "What does it *do* theoretically to say that disability studies does not adequately address issues of mental difference?" In asking this question, I am trying to make sense of my desire to make mental disability something that can be viewed as "just-as-visible" as physical disability. What is the theoretical work that is being done when it is said that disability studies does not adequately address issues of mental illness? Both my question and my response make use of interpretive methods in what Tanya Titchkosky has

referred to as the “new” disability studies. According to Titchkosky (2000), it is important to note that,

“Whatever is deemed ‘new’ about Disability Studies is not attached to a concrete historical moment of birth, and is not due to a single transformative movement in time. Instead, the new appears to mark a movement, a movement from a seamless unified concept of disability to disjunctive and multiple conceptions of disability” (p. 213).

The “new” disability studies begins with the assumption that disability is, as Rosemarie Garland Thomson (1996) says in *Freakery: Cultural Spectacles of the Ordinary Body*, “always an interpretive occasion” (p. 1). Phenomenological methods play an important role in making the “disjunctive and multiple conceptions of disability” more explicit. According to Sara Ahmed, the significance of phenomenology is that, “Phenomenology asks us to be aware of the ‘what’ that is ‘around’” (2007, p. 151). Thus, what makes the new disability studies “new” is its use of phenomenologically-informed methods. In making use of interpretive methods, the new disability studies has become more conscious of itself as a form of political education.

Paulo Freire and Donaldo Macedo (1987) assert that a political education is not the kind of education that can happen overnight. Political education offers new ways of making life meaningful that celebrate, rather than dissect, the living significance of bodies (p. 33). Instead of merely *taking* time and effort, a political education requires new understandings of the ordinary ways we have of relating to the meaning of time and effort. A political education is not the kind of education that can be communicated in summaries and charts. Its relations refuse summarization, mechanical memorization, or memorialization (p. 34). Such an education is founded on the recognition that, “Mechanically memorizing the description of an object does not constitute knowing the object” (Freire & Macedo, 1987, p. 33). A political education rather involves an “a critical reading of reality, [...] critical perception, interpretation, and *rewriting* of what is read” (p. 36). In producing new shared understandings about how it is “human practice or work that transforms the world,” such an education is “counterhegemonic” (Freire & Macedo, 1987, p. 36). This is the kind of education that begins with the worlds we each inhabit, the worlds we live. It relies on our experiential knowledge of these worlds to develop new relations to the words that are our worlds meaning. It returns us to the worlds that first brought us to words, and the words that brought us to where we are today; the world re-invented and we re-born (Freire & Macedo, 1987). This is an education that makes time and gives effort to deliver. There is no guarantee how or when it will be received, or what will be made of it.

The interest in the formulation of a political education which I suggest underpins the “new” disability studies shares a certain affinity with psychiatric knowledge, insofar as both the new disability studies and psychiatry share an interest in childhood. The new disability studies asks students to think back to their first encounters with disability and the images and assumptions these encounters engendered. In re-establishing our connections with the words that first gave us disability we can occasion new points of contact with and in the world that makes the phenomenal event of disability a reality. Thus making disability matter differently (Michalko, 2002); not as a problem, but a social and political project (Michalko, 2002; Mitchell & Snyder, 2006; Linton, 1998, 2007; Titchkosky, 2007). As Freire says:

“In the effort at recapturing distant childhood, trying to understand my act of reading the particular world in which I moved, permit me to say again, I re-created, re-lived in the text I was writing the experience I lived at a time when I did not yet read words. And something emerged which seems relevant to the general context of these reflections. I refer to my fear of ghosts. The presence of ghosts among us was a permanent topic of grown-up conversations in the time of my childhood... As I became familiar with my world, however, as I perceived and understood it better by *reading* it, my terrors diminished” (1983, p. 7).

Psychiatry, however, has a different way of relating to the child and childhood: as a means of objectifying disability as a negative value and locating it in the individual. As a practice, psychiatry recovers the terror. But, rather than reading terror as an expression of particular ways of relating to and in the world, psychiatry treats the appearance of terror as a sign or symptom of our separation from the world. Michel Foucault has written extensively on psychiatry and its role in the constitution of the individual through notions of mental illness (Foucault, 1973; Mills, 2008, p. 97). In *Psychiatric Power: Lectures at the Collège de France 1973-1974*, Foucault (2006) writes of how psychiatry orients to the child and childhood in terms of a means of expanding its domain, enlarging its resources and reproducing its authority. According to Foucault, “Childhood becomes the center, the target of psychiatric intervention indirectly, insofar as what one asks the mad adult is precisely, his childhood: let your childhood memories come, and through this you will be psychiatrized” (2006, p. 125). Rather than reading representations of childhood as an expression of our current relationships with the world, the psychological perspective orients us to our memories of our initial encounters with the world as a way to explain, and thus contain, the origins of our present difficulties.

Psychiatric practices have the effect of securing as the only valid perception the view that the present is itself a difficulty that must be overcome. At best, we can learn to tolerate – or live with – our difficulties in healthy ways. Learning to tolerate our difficulties involves identifying them as problems and engaging in practices that help us put these problems behind us. Our capacity to learn and teach tolerance of ourselves, others and the world is thus contingent on our capacity to uncover the true origins of the appearance of problems. Then we can commit to projects that we can expect will mitigate the likelihood of their re-appearance. In this context, disability is something that we can either learn to cope with or work to eradicate (Titchkosky & Aubrecht, 2009).

In treating childhood as no more than a question that can confirm or dispute the reality of one’s perception of self, others, and the world, psychiatry insulates and protects itself against any alternative or oppositional interpretations of disability. In relegating our relations to the languages we learned as children as proof of any and all present disadvantage, psychiatry teaches us with subtle precision that we are better off leaving childhood behind. Only in learning to forget our differences, and put our pasts behind us, can we secure our positions as normal, healthy individuals and communities. For psychiatry, the expressed desire to return to childhood, to the *when* and *where* one first made contact with the words which have shaped how and what one can now do is akin to a declaration of madness (Foucault, 2006, p. 125).

Throughout this paper I use the phrase *disabled person* with deliberation. In contemporary politics, the phrase *person with a disability* is often championed as a progressive,

socially-inclusive and politically viable way to display shared recognition of disability. However, as Titchkosky asserts in the article “Disability: A Rose by Any Other Name? ‘People-First’ Language in Canadian Society,”

“People-first language has been ubiquitous for many years now, and still the United Nations (1996) reports that disability is a worldwide ‘silent crisis’ leading to abysmal economic and social conditions for ‘people with disabilities.’ People-first language has not led to a greater understanding of disability and subsequent reduced levels of discrimination, nor to reduced levels of planned exclusions” (2001, p. 132).

What does this right way of relating to the wrongness of disability do to the way we conceptualize disability identities? If people-first language, “has not led to a greater understanding of disability and subsequent reduced levels of discrimination, nor to reduced levels of planned exclusions” (2001, p. 132), what has it led to? In the encounter with the cultural imperative to use people-first language we must pause to consider the potentially alienating effects of this way of describing one’s relationship to disability. Even as this version of disability identity validates personhood, the inclusion of the word “with” frames disability as an add-on requiring a supplemental claim to personhood. One which must be identified, reported, evaluated, and confirmed within a medical frame of reference in which disability is largely perceived as the result of personal or biological deficiency (Titchkosky, 2001, p. 129). Since one of the fundamental aims of this paper is to question the role of language in organizing social relations, my description of myself as a disabled person reflects an interest in reclaiming the living significance of disability in how I understand what it means to be recognized as a person *within* ablest social and cultural environments. In identifying as a *disabled person* and not as a *person with a disability*, I seek to “transgress” (p. 137) the normative demand to remove and distance myself from disability through use of the word “with.”

Understanding the importance of the act of engaging a notion of disability studies as political education, and shifting the attention from “people with disabilities” to the social and political contexts within which disability is made to appear as an individual problem of personal or biologically deficiency involves what Dorothy Smith (1999) has referred to as “writing the social.” According to Smith, “Writing the social profits from the dialogue between what we mean to say and what we discover we have said, and of course, the work of rewriting to embrace what we find we have said that is beyond or other than our intentions” (p. 9). The “discovery” so central to writing the social and embracing that which lies “beyond” our intentions necessarily involves the act of reading the social and more particularly, the social phenomenon of disability, differently (Titchkosky, 2007). I take as my starting point the relationship between disability studies and psychiatry as I have lived it as a disability studies student and someone whose identity has been conditioned by the language of mental illness. In the act of re-reading and rewriting this relationship we can discover new ways of relating to ourselves, the disability community and the new tradition of disability studies which our work is helping to realize.

Take, for instance, Rod Michalko’s (1998) depiction of his relation to his discovery of blindness at nine years old and how it brought him to a notion of trust in *The Mystery of the Eye and the Shadow of Blindness*. Michalko describes how one day he lay crying on his bed after he overhears his mother and grandmother talking in “their first language” about how his grandmother could not see or hear well and soon would die. He realized that he could not see the

blackboard at school for a few days now and had been hit in the cheek after losing sight of the line-drive, which led him to think that he too must be dying (p. 36). After that day, he says, he “spent the next few days testing my hearing to make sure that it was holding up” (p. 36). Michalko writes of his relation to this recollection:

“This is a story about going blind. This is my story. This is what I remember. This is a story of something gone wrong and a story of how wrongness is given life through the recognition that a life must be lived within the paradoxical awareness of the necessity and desire for life itself. It is the story of the necessity of diagnosis (what is wrong) and the desire for discovery (being wrong)” (1998, p. 37).

Michalko’s story about going blind shows us how the practice of returning to and beginning with the lived experience of disability can provoke a rediscovery of oneself and the world which makes this self possible. In storying how blindness had become significant as “something gone wrong,” Michalko depicts how a return to the language that gives life to blindness puts us in touch with how we value life and give life value. Rather than an object for psychiatric intervention, stories of a return to childhood in disability studies represent identity claims. They are stories of reclamation, and they are at the core of the disability studies community’s strength; as a way to re-read the words that give our lives meaning in terms of “something gone wrong,” reclamation stories offer new possibilities for resistance and rebellion.

It is in the spirit of resistance and rebellion, made possible by a practice of beginning with disability and privileging the disability experience that I have come to my question. My aim is not to fix disability studies. I do not aim to rehabilitate its body, nor do I hope to restore it to a more complete version of itself. To do so would be to invoke the significance of the new disability studies practice of beginning in-and-with the body (Michalko, 1998) in name only. On the contrary, I have come to my question by engaging in the very practice that I think makes the new disability studies what it is: new. That is, relevant: a living language of the present time.

In the remainder of this paper I trace out how I have come to think of the articulation of the experience of *something wrong* can serve as a reminder that there are always many more other ways of thinking and making sense of the worlds we live than we could ever hope to capture. Other ways of thinking which speak using words that read and write, as Smith says, “beyond or other than our intentions” (1999, p. 9).

### Disability Studies and Psychiatric Survivors

In his article, “What Have Madness and Psychiatric System Survivors Got to Do with Disability and Disability Studies?” Peter Beresford (2000) asks an important question: “What have psychiatric system survivors, madness and distress got to do with disability, the disabled people’s movement and, indeed, with disability studies and this journal, *Disability & Society*?” (p. 167). Beresford says that if thought differently, the very things that appear to be barriers to a relationship between psychiatric survivors, people who have survived psychiatric diagnoses and treatments, and the disabled people’s movement may actually provide for a common ground (p. 167). More specifically, Beresford understands impairment, a notion which he says once created a divide between psychiatric survivors and the disabled people’s movement opening up new discussions in which we can “advance our understandings of each other, exchange our

experience, knowledge and learning, and foster links, alliances and solidarity” (2000, p. 171). Beresford notices that despite progress made by the disabled people’s movement, “The situation for psychiatric survivors, however, has unambiguously worsened” (p. 168). He is most troubled by what he perceives as the political perception of the failure of community care, and the trend towards “compulsion” coupled with a “renewed commitment to institutionalized provision” (p. 168).

According to Beresford, what little attention is paid to psychiatric survivors in disability studies has the effect of obscuring rather than enlivening the relations between disabled persons and psychiatric survivors. He also notes that while some disability studies scholars have worked to include a consideration of psychiatric survivors in their conversations, their ways of representing the mad, distressed or psychiatric survivor experience seem to “accept a medicalised individual model of ‘mental illness,’ where there would be little likelihood of them doing the same with impairment and disability” (Gabel, 1999, as cited in Beresford, 2000, p. 168). Ignoring questions that point to conflicts in the relationship between psychiatric survivors, madness, distress and disability will have serious consequences for both psychiatric survivors and people who have been disabled by society’s inability to accommodate bodily, cognitive, emotional and sensorial difference. Beresford says this is not only because there are “significant overlaps between the two populations,” but because “however, *we* as disabled people or psychiatric system survivors may think of ourselves, we are still lumped *together* within the same externally imposed definitions, administrative categories and statistics,” and “we are both subject to discrimination and oppression” (original emphasis; 2000, p. 169). Here, Beresford raises an important point about one of the dominant ways we come into contact with disability identities – through the language and institutions of psychiatric knowledge.

### Transient Interpretations and Identity Shifts

*... our togetherness, our relations are always made on uncertain ground. Therefore, we are always caught between possibilities, always moving in the mysterious shadows of uncertainty.* (McGuire & Michalko, 2011, p. 164)

In *Deaf Transitions: Images and Origins of Deaf Families, Deaf Communities and Deaf Identities*, Mairian Corker (1996) writes about her experience of finding herself in-between deaf and Deaf culture. Even though she was not born deaf, and British Sign Language (BSL) was not her first language, Corker nonetheless identified with the Deaf community. The Deaf community does not understand itself as a medical problem, but a culture with a language. Corker describes how needing an interpreter *and* being recognized as a hearing person by the Deaf world was a difficult situation to negotiate. Corker writes, “It can be very difficult to face oppression from both hearing and Deaf people, but it is more difficult and more painful to cope with when it comes from Deaf people” (1996, p. 165). There are many people within the disability community who do not necessarily appear disabled in the conventional sense of what is “normally” or immediately recognized as disability. Corker’s words reminded me of occasions in my own life when I had experienced and witnessed the refutation of a claim to a disability identity by other disabled persons. It is not always enough that people assert a disability identity; they do not have a secure place or a voice in disability studies until they can show that they have fully incorporated its language and practices.

The language of mental illness is a language made possible by psychiatric knowledge and practices. Psychiatric knowledge instructs us to interpret disability as a disadvantage suffered by individual persons to varying degrees depending on their distance from what Western culture has informed us is a normal healthy life (Foucault, 2003). Accepting the authority of this knowledge and using it as a standard against which realities can be said to be more or less true makes us complicit in the ongoing subjugation of already marginalized and oppressed peoples. Simi Linton asserts that in the disability studies community:

“The question of who ‘qualifies’ as disabled is as answerable or as confounding as questions about any identity status. One simple response might be that you are disabled if you say you are. Although that declaration won’t satisfy a worker’s compensation board, it has a certain *credibility* with the disabled community” (Added emphasis; Linton, 1998, p. 12).

In disability studies, just saying you are disabled has “credibility.” If this is so, what provides for the question orienting this paper? Perhaps it is not just *that* we say we are disabled, but that we say it in a *certain way*. What specific practices, what dialects, shape how a claim to disability is received and received as having just been said? Leaving such questions unasked, we risk negating the significance of the social and political processes that organize our relations to ourselves and one another. “Person-first language” has provided a powerful mode of articulation, the use of which displays knowledge of how relationships to disability identities ought to be expressed. I do not want to dismiss the significance of this form of identification as it is lived and experienced by some people. However, person-first language is a way of knowing disability that has been challenged by disability scholars and activists (Titchkosky, 2001; on the grounds that it locates disability in individual people. In placing people first, disability becomes a problem that individual people have. The power of person-first language lies in its capacity to transcend embodied difference. According to Titchkosky, “Separating the person from his or her disability is the aim of people-first language, an aim that does not acknowledge that the social consequence is the alienation of persons from a political understanding of disability” (2001, p. 133). The suggestion that this one way of articulating disability identity is the one and only correct form of address guide us away from questions concerning the societal and environmental barriers to equal access and full participation which *disable* people. What discussions and debates about the appropriate way to describe and, therefore, define disability identity can teach us, is that it is vitally important to think about the social and political contexts in which language is used. They serve as a reminder, not only of the highly contested nature of disability identity, but the importance of paying attention to the power of language in organizing perceptions of disability.

The language of mental illness provides a means of collecting experiences which exceed the unified structure of Western culture’s overtly medicalized way of perceiving and making sense of the world. In *Disability, Self, and Society* (2003), Titchkosky describes an experience of being caught up in this language and how it created barriers to self-understanding. Not yet diagnosed with dyslexia, she had come to believe that she had “a kind of mental illness”:

“Since about the age of thirteen, I went to garage sales and bought every introductory psychology textbook I could find, and I spent many weekends in a downtown public library also looking for a definition of my problem. I was searching for a name, which I never found, for my symptoms. What I conceived as mental illness took shape in strange ways: at times, I would have a terrible anxiety, hear a voice that said, ‘You can’t do that,’ and begin to imagine a garbage-dumping ground standing between me and the visible world, especially the world of print” (2003, p. 33).

Reading Titchkosky’s account, a number of questions arise: What provides for the immediacy with which we turn to psychology for a way to account for the problem and secure its solution? How is it that when we experience difficulty we know that we can and must educate ourselves in psychology; to the point where, like Linton, we aspire to become its teachers? What provides for the desire to stand out against, or stand over and above, the garbage-dumping grounds that stand in our way and keep us at a distance from the “visible world”? In her narrative Titchkosky opens a space for questioning how the requirements of the visible world are made visible. Is all that disability is, anything that is totally visible or invisible? Is disability only either in our way of belonging to normate culture or our only way out? Corker writes:

“If disability is indeed ‘*any* departure from an unstated physical and functional norm,’ binary thought leads us to the conclusion that disability is the transient yet ever-present embodiment of dis-value – a category of ‘other’ designated as a dumping ground for anything that cannot be valued” (2001, p. 47).

In “We Were Never Identified,” McRuer (2006) asks what we, as disability studies scholars and activists, are to make of those of us who never make it to diagnosis and discovery, or to those of us whose arrival we have not anticipated. Asking this question disrupts a common practice in the language and culture of disability studies. It draws attention to the need to think about what established assumptions and accepted practices condition the cultural resonance of a disability story that starts with madness and ends with a name. A story that starts with the kind of thinking which can be perceived by the thinker as out of order and ends in a legitimization of this thinking that takes the form of a qualified disability. The question, however, also limits our inquiry by relegating the ways we have of thinking about madness to unfinished beginnings or premature endings, both of which are represented as so horrifying, it would have been preferable to never have been born. Such thinking is embodied in Lynn Manning’s (2003) story of his re-birth in *Weights*:

“I slowly become aware that something’s not right. There’s this nebulous fog of colors swirling before my eyes. Whenever someone enters the room, a reddish silhouette appears amidst a fog, and more people enter, more silhouettes appear. No matter what the people in the room are doing, these silhouettes stand stark still. If I lie back in bed, they remain before my eyes. If I squeeze my eyes shut, the apparitions are still visible. It’s not until the last person leaves the room that they slowly dissolve into the fog. I’m both fascinated and terrified by these visions, but I don’t tell a soul about them. After the surgery comes the medicine. Alone in my hospital room and cruising on painkillers, I discover that I can manipulate the colors on my mental canvas. I quickly progress from childlike finger paintings and primary



colors to near photographic renderings of places and faces. It's a pleasurable distraction, but is this blindness? Or madness?"

In *Weights*, Manning describes how "something akin to joy surges through me" when the doctor tells him that he is blind. He says the doctor asks him if he understands what he has just heard. Manning responds, "I understand. I'm blind, I'll probably be blind the rest of my life. As long as I'm not doing it to myself I think I can handle it." Here, Manning illustrates his knowledge that to be mad is a fate worse than blindness. This, even though, as he informs the audience earlier in the performance, he is a firm believer in "Murphy's Law" and as an adolescent he tried to imagine the worst thing that could happen to him and decided that would be blindness. Manning shares that after he decided blindness would be the worst thing that could happen to him, he secretly prepared for blindness. He did this by walking around with his eyes closed.

And then he is blind. After learning he was blinded by a gunshot wound to the head, Manning says he could "handle" blindness over madness. He had, after all, prepared for blindness. But he was not prepared for madness. However, he also says that prior to what he describes as the "medical verdict" of blindness, he seemed more ready to believe that the experiences he was having were the result of "madness." In his performance, he shares his familiarity with the language of mental illness. He even knew the symptoms, which for him appeared with the awareness that *something's not right*. After a while, he starts to manipulate his newly present sensibilities, orienting to them as a pleasurable distraction. But, for whom is madness, or blindness, a pleasurable distraction? From what perspective is such a statement based – the actual experience of living in and with the difference that disability makes, or what Hannah Arendt refers to as "the experience of the thinking ego" (1978, p. 33)?

As students, teachers, researchers, artists and activists in disability studies, we have a collective responsibility to recognize that we have inherited some of the established traditions of our community and culture from ableist assumptions about how people are supposed to look, think and feel. In our examinations of how disabled people have been constituted as a marginalized and excluded group, let us also ask what power and privileges the field of disability studies has gained as a result of its intimate relationship with psychiatric knowledge and practice. As things "stand," we are proceeding as though the experience of madness, while providing for new understandings and revaluations of disability, is best understood as a tool for pinpointing the reflective origins (Canguilhem, 1991) of normate able-bodied culture.

The use of the word "stand" is important, for it tells us something about how we have positioned ourselves, in an upright position, sanctioned and supported by the authority of a psychiatric worldview which treats our thoughts and ideas of the world as always potentially separable from the experiences the world gives us and the words we've used to make the world. Ahmed writes, "Bodies stand out when they are out of place" (Ahmed, 2007, p. 159). What, then, is providing for the persistent reappearance and disappearance of the language of mental illness in personal narratives of being given disability as a name? Does this apparent "disappearing act" point to a need to rethink my relation to this paper's question? Does it signal that the *real* issue in the call for more adequate representations of the lived experience of mental illness is a matter of proper placement? Is the body of knowledge that is represented in the

language of mental illness *out of place* in disability studies? How do these questions both reinforce and disrupt conventional understandings of disability?

### Making the Language of Mental Illness “Worldly”

The medical diagnosis provides a name that can direct people to the disability community, but there is a fundamental difference between residing in a community and being fluent in its culture. Medicalized and psychiatrized understandings of disability secure a position for disabled persons within the community, but they do so primarily from a nondisabled perspective, and within an institutional framework that has its historical origins in the devaluation of corporeal difference.

“Naming the figure of the normate is one conceptual strategy that will allow us to press our analysis beyond the simple dichotomies of male/female, white/black, straight/gay, or able-bodied/disabled so that we can examine the subtle interrelations among social identities that are anchored to physical differences” (Garland Thomson, 1997, p. 8).

In the above passage, Garland Thomson offers an interesting counter to McRuer (2006). Rather than treating our not having been named as a deficiency or a loss, perhaps we need to rethink our relations to being named and naming, and name the namer in an effort to make visible both theirs and our advantage. Such a move represents what Titchkosky (2008) has referred to as a “politics of wonder.” This offers a new perspective from which we can reflect on how we have been positioned without normate culture. Here, I use the word “without” in two ways: as an expression of being outside of normate culture, and as though we do not have our own normate culture, like a “dump” for whatever it is that normate culture is *not* (Titchkosky, 2008). No longer are we objects that have been named, left unnamed or treated as forgotten, but social beings who can name, and who have named our worlds in ways that resist any easy explanation, summary or diagram, using our first languages. As Freire (1983) tells us, our first languages are the languages we create in our initial encounters with the world we had yet to experience through the word, before we learned to separate our words from worlds and ourselves from both. My question brings me to why we need social theory and social theory that is grounded in a self-reflective, phenomenological approach. Thinking of mental illness as a name that can either be adequate or inadequate, right or wrong, and a claim whose legitimacy can be measured by its distance from dominant cultural conceptions of disability secures disabled people in preconceived notions of disability. It teaches us that the disability we live with is all in our heads. It teaches us that, as alluded to by Manning (2003), unless we claim disability as a name, unless we can qualify our claim, and unless we can relegate our experience of disability to one of disadvantage, we will never escape the question: are we just doing it to ourselves?

In *The History of Disability* (1999), Henri Jacques Stiker writes, “But the fear I fear is an ancestral one, for in the end it is the fear of fault. Somewhere in me there lies a culpability, and I am made to feel it acutely” (1999, p. 4). What do the questions, “Am I just doing it to myself?” or “Are we just doing it to ourselves?” speak to, politically? Are they just a representation of a delusional personal culpability, and the consequences of the dominance of the medical model? Could such questions also be read as the site of a struggle to negotiate the meaning of collective

responsibility in a world that values individualism? Rather than a symptom of the hegemony of medicalised thinking, could such questions be a space for re-politicization?

In *Responsibility and Judgment*, Hannah Arendt writes that collective responsibility is always political (2003, p. 149). However, Arendt says that there are two conditions which have to be present for collective responsibility:

“I must be held responsible for something I have not done, and the reason for my responsibility must be my membership in a group (a collective) which no voluntary act of mine can dissolve, that is, a membership which is utterly unlike a business partnership which I can dissolve at will” (Arendt, 2003, p. 149).

The culpability Stiker (1999) writes of, and the constant anxiety that finds form in the question, “Am I doing it to myself?” have been read as further proof of the existence of an individual, medicalised model of thinking. This model describes disability as a personal tragedy that is imposed on disabled people by able-bodied perspectives in neoliberal societies. These expressions, which tend to appear in the presence of a disjuncture (Pollner, 1975), could also be read as attempts to make sense of our membership in a group which as Arendt says, “no voluntary act can dissolve” (Arendt, 2003, p. 149). In recognizing that we have learned in Western culture to orient to the question, “Am I doing it to myself?” as a symptom of mental disorder, we can begin to trouble the usual ways we have of representing our sensibility of disability.

This question could also be read as an expression of a personal recognition of membership in a community, and of oneself as a participant in this community’s realization - an individual embodiment of collective responsibility. Answering the question, “Am I just doing this to myself?” in a definitive way separates disabled people from their capacity to participate in discussions about mental illness. It also reinforces the belief that as disabled rather than mentally ill people, or ordinary people who happen to have disabilities, they do not have the authority to comment. As Goffman says in *Asylums*,

“To have one’s behavior defined as involuntary, non-responsible, and non-culpable may be helpful in some cases, but this none the less involves a technical schema, not a social one, and ideally ought to disqualify the patient for any participation in the service relation even while qualifying him as an object of service” (1961, p. 364).

To re-turn to the question orienting this paper, perhaps what is at issue cannot be reduced to an observation that the disability community discriminates against psychiatric survivors, consumers, and mad people. Perhaps it is rather the systematic separation of disabled people from their capacity to speak back to the presence of the language of mental illness in their own lives, a process facilitated by psychiatric knowledge and practice. Do not worry. You are disabled, not crazy. The doctor tells Manning he is blind, and he can live with that. He can manage that. But madness, well, only the experts can manage *that*.

Reclamation stories provide a politically significant way to reunite disabled people with their capacity to speak back to language. This is because reclamation stories draw on a commonsense of the body to speak their relationships with the world. Such stories provide a clue

as to how we understand our positions in the world as given to us by the world. That each story reveals a perceived barrier, whether in the form of another language, “strange silhouettes of red” (Manning, 2003), or psychology textbooks (Titchkosky, 2003), tells the reader something about how this position is being negotiated by the one who recounts the story. That is, as a relationship to the limits our culture gives us knowledge of. For, as Hans-George Gadamer (1996) writes in *The Enigma of Health: The Art of Healing in a Scientific Age*, “... there are limits to what we can do, limits which are taught to us by illness and death” (p. ix).

Representations of mental illness thus teach us about how Western culture understands itself and recognizes and relates to its limits. As I have tried to show, the question, “Am I doing it to myself?” reflects the value of individualism in Western cultural knowledge. More importantly, it reveals its underlying anxiety: as long as we are doing it to ourselves, there is something we can do about it. At the very least, we can learn to control our environments and manage situations, mitigating the effects of stress. In this context, in the visibility of the assumption that we can do anything if we put our minds to it, there is a growing recognition that the definition of the problem and its solution are given to us by environments. What should be of concern to us is that in contemporary times these environments are becoming more and more institutionalized.

Titchkosky says, “The point is not that stories change, but that people change in the telling and retelling of stories” (2003, p. 36). Manning’s depiction represents a self-reflective relation to the cultural worlds he moves through. This, even as it represents culture’s demand to leave the difficulties that bind body-world-self behind and accept in their place a new name and with it a new life. In our day-to-day lives, we are often told that we have no time, or that there is no use and no point in asking what assumptions and inversions made this new life possible. We are encouraged to overcome difficulties and welcome the advances and improvements which will allow us to do so. Even if the new understandings they give us are the result of dissecting dead bodies, or walking around with our eyes shut. Manning explicitly names his name, giving it a life. He does so not once but twice: “Is this blindness or is it madness?” Given a choice between blindness and madness, Manning says he is relieved to be able to choose blindness, but only after this name has been conferred on him—only once madness is no longer a choice. The doctor tells him he is blind. The reality of the experience of madness disappears, and with that, sweet relief. The doctor’s diagnosis confirms it; whatever *it* is that is happening to him, he is not doing it to himself.

We in the disability community are not all the same and our lived experiences are irreducible. What unites the disability community is not our distance from the norm. It is rather what Michalko refers to as our shared “recognition that a life must be lived within the paradoxical awareness of the necessity and desire for life itself” (1998, p. 37). This recognition meets Arendt’s conditions for collective responsibility. In making us aware that we need and desire life, the paradoxical awareness that comes with being recognized as *something wrong* in need of diagnosis and discovery, or a problem in need of a solution, places us in a group which no voluntary act can dissolve. The assumption of formal equality within the movement is both problematic, and downright dangerous. Saying people who are experienced and experience themselves through the language of “mental illness” are invisible in disability studies communicates a sense that in the present moment *we are just a thought*. It suggests that our perspectives and personal experiences of issues of mental illness are lacking in reality. This way

of approaching how the field of disability studies represents issues of mental illness justifies, welcomes and encourages the demand to intervene and the authority of psychiatric knowledge. We therefore have to think about how we as disabled persons and disability studies scholars and activists are implicated in the reproduction of the authority of psychiatric knowledge. The present task concerns how together we can take collective responsibility for the way the disability studies community recognizes and responds to its relations with psychiatric knowledge.

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