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Literature and Medicine, Volume 20, Number 2, Fall 2001, pp. 209-230 (Article)

Published by Johns Hopkins University Press

DOI: [10.1353/lm.2001.0019](https://doi.org/10.1353/lm.2001.0019)



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Breaking Down: A Phenomenology of Disability

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Experience anticipates a philosophy and philosophy is merely an elucidated experience.

—Maurice Merleau-Ponty, *Phenomenology of Perception*¹

Disability is not simply a physical affair for us; it is our ontology, a condition of our being in the world.

—Robert F. Murphy, *The Body Silent*²

In *Being and Time*, Martin Heidegger states that his purpose is to “raise anew *the question of the meaning of Being*.”³ In this essay, I hope to raise anew the question of the meaning of being *disabled* in order to describe the ways in which the experience of disability anticipates a philosophy, specifically the philosophy of phenomenology. In order to do so, I will look at three autobiographies that deal with the experience of disability caused by neurological damage. These three autobiographies—Oliver Sacks’s *A Leg to Stand On*, Nancy Mairs’s *Waist-High in the World*, and Jean-Dominique Bauby’s *The Diving Bell and the Butterfly*—are at once neurological and phenomenological case studies that seek to describe nothing less than the disabled body in the world.⁴ The body breaking down is the key to a crisis that then leads each author to raise anew the question of the meaning of being.

The three authors share the fact that they all have reached adulthood before disability sets in; thus, a before-and-after structure is established in each case. However, the etiology and prognosis of each case is quite different, and these differences, in turn, affect each individual’s situatedness in the world: Oliver Sacks describes a traumatic injury to his left leg and the lengthy recovery from that injury; Nancy Mairs describes the slow but gradual degeneration of bodily

ability that is characteristic of multiple sclerosis; and Jean-Dominique Bauby describes the sudden and catastrophic onset of extreme paralysis after a stroke, occurring with full alertness to his situation—a condition called, appropriately enough, locked-in syndrome. My three phenomenological and neurological cases are meant to reveal not a universal experience of being-disabled-in-the-world, but rather the particularity of such experiences, despite the reduction of such particularities under the universalizing sign of “disability.”

In his book, *The Body Silent*, Robert Murphy provides a personal account of his experience of disability as the result of a spinal tumor, as well as an ethnographic account of the culture of disability. Trained as an anthropologist, Murphy utilizes his skills at participant observation honed in the Amazon forest to describe the “impact of a quite remarkable illness upon my status as a member of society.”⁵ Murphy notes that, for the disabled, “not only are their bodies altered, but their ways of thinking about themselves and about the persons and objects of the external world have become profoundly transformed. They have experienced a revolution of consciousness. They have undergone a metamorphosis.”⁶ In this essay, I will first look at Heidegger’s discussion in *Being and Time* of the breakdown of instrumentality and then consider this notion in regard to the breakdown of the instrumentality of the body itself, with particular reference to Merleau-Ponty’s discussion of bodily motility in *Phenomenology of Perception*. I will then turn to my neurological and phenomenological cases in order to discuss the specific conditions in each: of breakdown and recovery in the case of Sacks; of breakdown as incremental and perhaps taken-for-granted in the case of Mairs; and of breakdown as catastrophic and integrally connected to suffering, solitude, and death in the case of Bauby. I will conclude with a discussion of the imperative, which all of these writers express, to describe in writing the experience of disability in particular and the experience of the body-in-the-world in general, and to show the ways in which disability defamiliarizes and denaturalizes not only the experience of the body-in-the-world but also the experience of language itself.

Breakdown

In the beginning is an interruption. Disease interrupts a life, and illness then means living with perpetual interruption.

—Arthur W. Frank, *The Wounded Storyteller*⁷

From Husserl forward, phenomenology has sought to return to the things themselves and, by doing so, to describe the structures of the life-world or, in Heidegger's terminology, "the worldhood of the world."⁸ According to Husserl, the world and the self as being-in-the-world are taken-for-granted and self-evident; this taken-for-granted condition Husserl identified as "the natural attitude."⁹ Only when the world's taken-for-granted and self-evident condition is interrupted can the world itself appear and be brought into question, that is, its appearance relies on its being brought into question. In an often-cited section in *Being and Time*, Heidegger describes this moment of the bringing into question of that which has been taken-for-granted with reference to the instrumentality of tools. Heidegger notes that tools—or "equipment"—possess a kind of being, which he calls "readiness-to-hand [*Zuhandenheit*]" (p. 98). Because of this readiness-to-hand character of tools, when we work with them, we are not concerned with the tools themselves, as entities "present at hand"; rather, we are concerned with the work produced, the "towards-which" of the tools. "If, then, we start with the Being of these [ready-to-hand] entities," Heidegger asks, "is there any avenue that will lead us to exhibiting the phenomenon of the world?" Is there, in other words, a means by which the world is revealed, disclosed, "lit up" (p. 102)?

According to Heidegger, the phenomenon of the world is exhibited when, in varying ways and on varying occasions, a tool presents itself not as ready-to-hand but as "unready-to-hand." That is to say, when the tool's instrumentality breaks down—when the tool becomes, in Heidegger's terminology, conspicuous, obtrusive, or obstinate rather than simply taken-for-granted or ready-to-hand—"[t]he environment announces itself afresh" (p. 105). As Drew Leder explains in his book *The Absent Body*, in certain instances the tool "stands forth as 'present-at-hand' because of a dysfunctional break in its employment."¹⁰ At the moment of breakdown, the "readiness-to-hand" of not only the tool but also the world is bracketed, and it becomes possible to disclose the world's presentness-at-hand, to light up "the worldly character of what is within-the-world."¹¹

Heidegger discusses breakdown as an interruption of the ready-to-hand character of entities such as tools, but I want to consider this notion of breakdown in relation to the instrumentality of the body itself. The body is an entity whose readiness-to-hand (readiness-to-body, perhaps) can also break down, and such a bodily breakdown also discloses or illuminates the worldhood of the world. Although Heidegger is undoubtedly, if implicitly, concerned with the body throughout *Being*

and Time (he speaks of, for example, “readiness-to-hand,” and his “towards-which” is plainly manifested through the body), he rarely explicitly speaks of the body. It is in the work of Merleau-Ponty that phenomenology is explicitly concerned with the body as the medium through which one is conscious of the world. According to Merleau-Ponty, “the world is not what I think, but what I live through,” and the body is the vehicle in which one lives through or inhabits the world (pp. xvi–xvii). Merleau-Ponty’s lived body, like the ready-to-hand tools in Heidegger’s formulation, is for the most part inconspicuous, unobtrusive, and nonobstinate. The body in its “non-thematic circumspective absorption” disappears and is absent from our experience.¹² Or, as Robert Murphy notes, “People in good health take their lot, and their bodies, for granted.”¹³

The body, like Heidegger’s tools, however, can become conspicuous, obstinate, and obtrusive; it can break down, either temporarily or more permanently, and in doing so it appears to us and becomes an object of our attention. In his “Afterword” to *A Leg to Stand On*, Oliver Sacks explains that all pathology “makes startlingly visible (sometimes terribly visible) what is normally hidden” (p. 202). In a sense, this state of breakdown is the condition for the possibility to perform a phenomenological reduction, to bracket the natural attitude (the taken-for-granted, nonthematized everyday world) and stand back from the world in order to view it differently, or perhaps to view it for the first time. In their attempts to describe in writing their own experience of bodily breakdown and being disabled in the world, Sacks, Mairs, and Bauby are all phenomenologists. I would like to turn now to their individual cases, though I hope to relate them to one another as well.

Breakdown and Recovery

I found the abyss [caused by “an injury with peculiar effects”] a horror, and recovery a wonder; and I have since had a deeper sense of the horror and wonder which lurk behind life and which are concealed, as it were, behind the usual surface of health.

—Oliver Sacks, *A Leg to Stand On* (P. ix)

While hiking alone in Norway more than twenty years prior to the writing of his narrative, Oliver Sacks has a bizarre encounter with a bull, which leads to an equally bizarre encounter with his own body. When he spots a bull on a Norwegian mountain, Sacks, in terror, hurtles himself down the mountain and away from the animal. He falls

and severely injures his left leg. Alone, miles from the nearest town or house, Sacks is certain he will die of exposure if he stays on the mountain for even one night. And so he fashions a splint out of his umbrella and begins to crawl, crablike, down the mountain. He is eventually—and rather miraculously—rescued at nightfall by two hunters, still far from his destination. As Sacks tells the reader, his rescue seems to be the end of the story. “And yet,” Sacks writes, “there was to be another story or, perhaps, another act in the same strange complex drama, which I found utterly surprising and unexpected at the time and almost beyond my comprehension or belief” (p. 22). This other story is a neurological and phenomenological story of “a fundamental disruption and dissolution of the leg, a disruption and dissolution at once physiological and existential” (p. 108). As Sacks soon discovers, his leg is neurologically damaged, and he is unable to recognize it as a part of his own body. Just as the English neurologist, Henry Head, had the nerves in his wrist severed in order to learn about neural damage, Sacks has the opportunity to explore neurological as well as phenomenological questions via his own body through his experience of agnosia—the inability to recognize familiar objects or stimuli.¹⁴ Sacks’s discussions of bodily alienation, the passivity of patienthood, and his eventual recovery and “restitution”¹⁵ to full “morality” are of considerable relevance to phenomenology, and it is to these that I will now turn.

Bodily alienation, or dissociation, is often a prominent aspect of the experience of neurological illness. Sacks describes, as will Mairs and Bauby, a kind of objectification of the body or, in Merleau-Ponty’s terminology, a shift from the “phenomenal body” to the “objective body” (p. 106). Sacks perceives his left leg as a silent and dead object and no longer part of his body. This perception affects not only the leg apart from the rest of his body but also his overall body-schema and his sense of *being* itself. Sacks writes:

What was now becoming frightfully, even luridly, clear was that whatever had happened was not just local, peripheral, superficial—the terrible silence, the forgetting, the inability to call or recall—*this* was radical, central, fundamental. What seemed, at first, to be no more than a local, peripheral breakage and breakdown now showed itself in a different, and quite terrible, light—as a breakdown of memory, of thinking, of will—*not just a lesion in my muscle, but a lesion in me.* (P. 46; emphasis in the original)

Sacks does not know his own leg; it is “utterly strange, not-mine, unfamiliar” (p. 51). It is not *his* leg but a “cylinder of chalk” (p. 51),

an object that is nonetheless attached to him and therefore disturbing to his body image. Sacks's description of his leg as a "cylinder of chalk" is reminiscent of Merleau-Ponty's discussion of agnosia and phantom limb syndrome in *Phenomenology of Perception*. According to Merleau-Ponty, agnosia and phantom limb syndrome are phenomena that force us to "find a means of linking the 'psychic' and the 'physiological,' the 'for-itself' and the 'in-itself,' to each other to form an articulate whole" (p. 77). The "for-itself" of Sacks's leg has been lost, compromising his being as being "for-itself." According to phenomenology beginning with Husserl, that which distinguishes the being of entities from conscious being is intentionality. Consciousness is defined as consciousness of something; consciousness is directed outward, forming an "intentional arc" surrounding the lived body in the world. In Sacks's case, this intentional arc is disturbed, and he must somehow recover what Merleau-Ponty calls an "organic thought through which the relation of the 'psychic' to the 'physiological' becomes conceivable" (p. 77).

Not only Sacks's experience of bodily alienation through the apparent loss of his leg but also the experience of passivity associated with patienthood "slackens the intentional threads," in Merleau-Ponty's terminology (p. xiii), that connect Sacks's body to the world and through which his body inhabits time and space. "I aim at and perceive a world," Merleau-Ponty writes, and it is this aiming, this intentionality, that is the "active meaning-giving operation which may be said to define consciousness" (pp. xvi and xi). The body is not *positioned* in the world like an object, but *situated* in the world, which, for Merleau-Ponty, implies a dynamic "attitude directed towards a certain existing or possible task" (p. 100). Although Husserl describes intentionality in terms of both active and passive genesis, Heidegger and Merleau-Ponty spotlight the active rather than the passive character of intentionality.¹⁶ Sacks, too, stresses that activity defines humanness, and he views the "abdication of activity," a consequence of patienthood, as a "moral" reduction of self:

There had been, for me—and perhaps there must be for all patients, for it is a condition of patienthood (though, one hopes, one which can be well- and not ill-handled)—two miseries, two afflictions, conjoined, yet distinct. One was the physical (and "physical-existential") disability—the organically determined erosion of being and space. The other was "moral"—not quite an adequate word—associated with the reduced stationless status of a patient, and, in particular, conflict with and surrender to "them"—"them" being the sur-

geon, the whole system, the institution—a conflict with hateful and even paranoid tones, which added to the severe, yet neutral, physical affliction a far less tolerable, because irresolvable, moral affliction. I had felt not only physically but morally prostrate—unable to stand up, stand morally before “them,” in particular, before the surgeon. (P. 129)

If *moral* is not quite an adequate word, then why does Sacks move so easily from the physical to the moral? In *The Body in the Mind*, Mark Johnson offers an explanation for such a slippage. He identifies what he calls “image schemata” as “recurring patterns without which our experience would be chaotic and incomprehensible.” According to Johnson, these image schemata emerge from human bodily movement and positions, and then “can be figuratively developed and extended as . . . structure[s] around which meaning is organized at more abstract levels of cognition.”¹⁷ Thus, for example, “uprightness” implies not only being vertical or erect but also having strength, competence, and thus morality, as it does in Sacks’s depiction of his loss of status as a patient in relation to those doctors with whom he once associated on an equal level.

Nancy Mairs, who has lived with multiple sclerosis for nearly thirty years, also describes this “moral” reduction brought on by patienthood and the need for constant care, as well as the perceived inability to give any care in return. This loss of the ability to physically act, Mairs explains, often leads to

the attitude that those of us who require care constitute an intolerable burden upon society, that we have nothing to offer to the human project, that we are, in fact, not worth taking care of. This implication breaks my heart. I am reduced to a vortex, sucking in the resources of all around me without replenishing them in kind. (P. 76)

Although illness and disability cause a shift in the character of one’s intentionality, they are not conditions in which there is simply a *lack* of intentionality. Rather, in illness and disability, active intentionality seems to shift to the background, to become the spatial and temporal horizon of one’s essentially passive being-in-the-world. I will return to the question of passivity and intentionality when I consider the case of Jean-Dominique Bauby, who, more than Sacks or even Mairs, experiences such extreme passivity that perhaps we can speak, as philosopher Emmanuel Levinas does, of something “beyond intentionality,”¹⁸ where

consciousness is not only outward-directed but also inward-directed. Nonetheless, Sacks's description of the experience of patienthood as a contraction of one's world and as a diminishment of one's intentional arc—as well as a diminishment of one's sense of oneself as a moral being—is critical to the understanding of disability as an experience that reveals the meaning of being-in-the-world.

From the moment Sacks begins his crablike motion down the mountain in Norway, his very humanness is compromised. He is no longer able to assume the taken-for-granted upright posture characteristic of humans. Sacks's morally compromised state continues as he assumes the role of patient and undergoes surgery and a lengthy rehabilitation. For a time at least, Sacks experiences the doctor-patient relationship from the patient's side of the binary, and this experience requires that he rethink his profession as a neurologist. As G. Thomas Couser notes, "Sacks believes his accident has put him literally in a position to correct the scotoma—blind spot—at the heart of neurology, its ignorance of the patient's experience, its willed and sometimes callous objectivity."¹⁹ But what is perhaps most important to Sacks's story, however, is that he recovers, and this recovery involves, ultimately, the ability to "stand up" both literally and figuratively, both physically and morally. His leg is restored to its full function and his status—that is, his human status and his neurologist's status—is restored as well. In a sense, then, Sacks returns to his rightful position (at least to him) in the doctor-patient binary.

Sacks's final chapter is entitled "Understanding," and the understanding at which he arrives is both neurological and phenomenological. In *Phenomenology of Perception*, Merleau-Ponty notes that "to understand is to experience the harmony between what we aim at and what is given, between the intention and the performance" (p. 144). It is the return of this harmony that begins Sacks's recovery and understanding. And for him, this harmony is found in the "musicality of motion," or what he calls his "kinetic melody" (p. 119). The body's modality toward the world, as I've said, is usually taken for granted. This means that one does not inhabit time and space in a self-conscious way; one's gestures toward the world—from simple to complex—are not "a collection of partial movements strung laboriously together," but rather are composed like a melody.²⁰ By listening to Mendelssohn's Violin Concerto, therefore, Sacks *remembers* "walking's natural, unconscious rhythm and melody" (p. 117). His successful treatment is not medical but musical. "I felt," Sacks writes, "in those first heavenly bars of music, as if the animating and creative principle of the whole world was revealed,

that life itself was music, or consubstantial with music; that our living moving flesh, itself, was 'solid' music—music made fleshy, substantial, corporeal" (p. 94). Sacks's disability—the loss of his "kinetic melody"—is thus temporary. But what if the loss itself—or the losing—characterizes one's being-in-the-world?

Breakdown As Taken for Granted

This is my perpetual view, from the height of an erect adult's waist. And the difference has consequences. This is a book about such consequences.

—Nancy Mairs, *Waist-High in the World* (P. 16)

Citing the anthropologist Victor Turner's work on liminality, Robert Murphy describes the long-term disabled, like Nancy Mairs and himself, as "neither sick nor well, neither dead nor fully alive, neither out of society nor wholly in it." According to Murphy, the disabled

are human beings but their bodies are warped or malfunctioning, leaving their full humanity in doubt. They are not ill, for illness is transitional to either death or recovery. Indeed, illness is a fine example of a nonreligious, nonceremonial liminal condition. The sick person lives in a state of social suspension until he or she gets better. The disabled spend a lifetime in a similar suspended state. They are neither fish nor fowl; they exist in partial isolation from society as undefined, ambiguous people. (P. 131)

Whereas recovery is an integral component to Sacks's "understanding," for Mairs understanding cannot come through actual recovery or even the hope for recovery; it can only come, paradoxically, through her experience of persistent, incremental loss of ability. Merleau-Ponty asserts that "consciousness is in the first place not a matter of 'I think that' but of 'I can'" (p. 137). But for Mairs (and for Bauby, as we shall see below), the very ability to say "I can" is suspended, called into question. The subject loses the ability to be able, and in this loss, consciousness reveals itself. In the attention Mairs must pay to every act, because even the "slightest gesture requires effort now," she is able to "focus on each moment without much regard for past mistakes or the future's threats or blandishments" (p. 37). The present presents itself and Mairs is able—indeed, must—give it her full "attention, resource-

fulness, and adaptability" (pp. 33–34). As she explains, "The body in trouble, becoming both a warier and a humbler creature, is more apt to experience herself all of a piece: a biochemical dynamo cranking out consciousness much as it generates platelets, feces, or reproductive cells to ensure the manufacture of new dynamos" (p. 42).

Thus, Mairs knows that she will never again hear the "kinetic melody" that gives Sacks such wonder; in fact, any movements she might make are precisely, in Merleau-Ponty's words, "a collection of partial movements strung laboriously together." Mairs leads a life "bound by permissions," in which her sense of self must constantly be revised and redefined in the face of ever-increasing bodily impairment (p. 17). "With degenerative conditions like mine," Mairs writes, "self-definition may have to be revised . . . again and again as new limitations develop" (p. 133). Mairs's body, therefore, can never disappear or be taken for granted; rather, it is perpetually a "body in trouble." How might being a body-in-trouble-in-the-world and spending the rest of one's life in a wheelchair—being waist-high-in-the-world, as Mairs says—afford one a different view of the natural attitude, the world the nondisabled take for granted? Furthermore, what happens when disruption becomes the norm; that is to say, what happens when breakdown—or breaking down—is that which is taken for granted?

Mairs's literal diminishment is an opportunity for her to perform a phenomenological reduction of sorts, to bracket the natural—and upright—attitude. "I am literally diminished by my disability," Mairs writes, "reduced to a height of about 4'8", consigned to gazing at navels (generally shrouded) other than my own. But diminution is not the whole of it. 'Waist-high' also resonates with 'knee-deep.' This is no piteously deprived state I'm in down here but a rich, complicated, and utterly absorbing process of immersion in whatever the world has to offer" (p. 18). Being both "waist-high" and "knee-deep" in the world affords her a different view of the world and of herself in the world. And although she requires constant attention and care in order simply to survive, she is not a patient in the same way as Sacks. Her immersion is not into the world of the hospital and convalescence home, as it is for Sacks, but into, as she says, the "wider world," which she moves through day after day, most often with great difficulty. Her wheelchair—"a compact electric model called a Quickie P100"—is not only an extension of her body or "a bodily auxiliary," as Merleau-Ponty calls a blind person's cane, but has become incorporated, made a part of her body—so much so that when the Quickie P100 breaks down, it is the breakdown not simply of an instrument employed by the body

but of Mairs's self itself. According to Mairs, "the wheelchair I experience is not 'out there' for me to observe, any more than the rest of my body, and I'm invariably shocked at the sight of myself hunched in its black framework of aluminum and plastic" (p. 46). In her *Quickie P100*, Mairs is at one and the same time positioned and situated in the world.

Mairs recognizes that the experience of a degenerative disease that begins in adulthood is different from the experience of disability caused by traumatic injury—as in Sacks's case, where one knows the worst from the outset and where improvement is a possibility—and is also different from the experience of congenital disability, where one has never known "another way of being" (p. 29). Despite her condition, Mairs persists "in feeling grateful both that I lived nearly thirty years in the oblivion of 'normalcy' and that I've had more than two decades to descend step by step (and then lurch by lurch) to the level where I live now" (p. 29). In this step-by-step descent, the only thing that becomes taken for granted in Mairs's world is breakdown itself, the body as a "set of problems" where "no accommodation is ever final" (p. 88). Merleau-Ponty describes the "world-structure" as the "core of consciousness" and as consisting of two stages—sedimentation and spontaneity. Mairs's disabled-body-in-the-world calls into question this formulation on both counts: for her, experience of the world is not spontaneous; nor does it ever become sedimented from one moment to the next. In her essay "The Body in Multiple Sclerosis," S. Kay Toombs, who like Mairs lives with MS, notes this paradox: "My body appears as Other-than-me in that it continually opposes and frustrates my intentions; yet I *am* my body for I cannot escape impaired embodiment."²¹

In many ways Toombs's paradox is applicable not only to those living with MS (most of whom are women), but, in a milder form, to the experience more generally of being female in the world. Many feminist philosophers have read Merleau-Ponty's lived-body-in-the-world as representing not a universal body but an "intrinsically masculine" body.²² In her well-known essay "Throwing Like a Girl," Iris Marion Young suggests "that the modalities of feminine bodily comportment, motility, and spatiality exhibit . . . tension between transcendence and immanence, between subjectivity and being a mere object."²³ Here Young describes Merleau-Ponty's two bodies—the "phenomenal" and the "objective"—and places the feminine body in the world as somewhere in between, or as occupying both positions at the same time. All the characteristics Young associates with feminine motility—"an *ambiguous transcendence*, an *inhibited intentionality*, and a *discontinuous unity*

with its surroundings"—could just as easily describe the disabled-body-in-the-world.²⁴ The disabled person, in other words, not only is made passive but is feminized as well. This is not to say that the experience of physical disability is *the same as* being female in the world; and I think Young is wrong to conflate the two as she does at the end of "Throwing Like a Girl."²⁵

Mairs herself admits that even if she were not disabled, she would be troubled by her body and the ways that it does or does not conform to the ideals of femininity, but it is her experience of disability that makes her conscious of the ways representations of femininity and able-bodiedness are normalized. Thus, Young's observations are quite relevant to the discussion of the disabled-body-in-the-world, if only because they highlight differences in comportment, motility, and spatiality; because, as Mairs knows and I am attempting to show, differences—and, in particular, "embodied differences," as Rosemarie Garland Thomson has called them—have consequences.²⁶

Breakdown As Catastrophic

I have indeed begun a new life, and that life is here, in this bed, that wheelchair, and those corridors. Nowhere else.

—Jean-Dominique Bauby, *The Diving Bell and the Butterfly* (P. 129)

In my discussions of *A Leg to Stand On* and *Waist-High in the World*, I have attempted to show the ways in which bodily breakdown affords the disabled person another view of the world and the self in the world. Like Sacks and Mairs, but even more so, Jean-Dominique Bauby undergoes such an extreme bodily breakdown that it leads him to question the meaning of being. In fact, Bauby's breakdown is so extreme—his paralysis so complete—that the objectification of his body is experienced neither as temporary, as in the case of Sacks, nor as incremental, as in the case of Mairs, but rather as permanent and total. Is Bauby's body, therefore, only an object for him? And, if so, where does his constituting consciousness reside? As Bauby notes, "something like a giant invisible diving bell holds my whole body prisoner" (p. 3). It is important to note that Bauby says this diving bell holds his *body*, not his *mind*, prisoner, implying that the diving bell does not signify a mind/body split so much as a phenomenal/objective body split: his phenomenal body is contained within an objective body (the diving bell) that then mediates his being-in-the-world. In his diving bell, Bauby

is submerged in the world but not of it. Merleau-Ponty explains that we must “avoid saying that our body is *in* space, or *in* time. It *inhabits* space and time” (p. 139). Bauby’s body, on the contrary, cannot be said to *inhabit* space and time, but is rather *in* space and *in* time like an object that lacks intentionality. Yet paradoxically, Bauby also cannot be said to entirely lack intentionality. Even contained within and by his diving bell, he nonetheless manages to direct himself outward toward the world. He is conscious of the world, or at least his immediate world of bed, wheelchair, and hospital corridors, and does succeed, as I will discuss later, in communicating with others, not only in his immediate environs of room and hospital but also in the wider world through what he calls, appropriately enough, his “samizdat bulletins” (p. 81). Bauby might be said to lack *active* intentionality, but nonetheless, he expresses intentionality that is animated if not by act, then at least by meaning. Bauby’s condition of utter passivity—his extreme suffering, his solitude, and his nearness to death²⁷—is, in a sense, a phenomenological reduction. Consciousness, for him, is not directed outward in a taken-for-granted manner, but is rather directed inward and back upon itself. Bauby not only has a different view of the world and his self in the world but is further afforded a different view of consciousness itself: for Bauby, consciousness itself is “lit up.”²⁸

With reference to Bauby’s work, I want to turn now briefly to Levinas’s assertion that while phenomenology defines consciousness as that which has intentionality—being as “for-itself,” not simply as an entity “in-itself,” as Sartre and Merleau-Ponty make the distinction—phenomenology must also attempt to describe that which is “beyond intentionality.”²⁹ Phenomenology has always spoken of something “beyond intentionality,” though Levinas is the first to use such terminology. In Husserl and Merleau-Ponty, for example, temporal and spatial horizons imply an infinite possibility of meanings for consciousness, only some of which are ever actualized. Nothing—not consciousness itself nor even an object in the world—is ever completely given. As Levinas says in a reading of Husserl, “The concept of consciousness includes more than the central sphere of awakened and active consciousness.”³⁰ And as Husserl himself notes, the transcendental character of consciousness implies

that an *actual* Object belonging to a world or, all the more so, a *world itself*, is an *infinite idea*, related to *infinities of harmoniously combinable experiences*—an *idea that is the correlate of the idea of a perfect experiential evidence*, a complete synthesis of possible experiences.³¹

Phenomenology is, first and foremost, a method that describes that which is given. But that which is given, that which is present, that which is being itself, is dependent upon that which is not given, absent, and nonbeing as the horizon of possibility of givenness, presence, and being. Those temporal and spatial horizons give form to that which is present to consciousness. Levinas's conception of the horizons of consciousness is of particular importance to my discussion of Bauby because Levinas locates that which is "beyond intentionality" in suffering and solitude, alterity and death.

Both Mairs and Sacks mention the solitude of the disabled-being-in-the-world. Sacks, for example, finds his enforced solitude unbearable. Still, for him this is only a temporary condition. Mairs also experiences the solitude that comes with not being able to move freely through the world and among able-bodied others, but even so, as I pointed out earlier, she makes many forays into the wider world where she still teaches and gives public readings of her work. Although both Sacks and Mairs experience what Sacks calls the "prisoner syndrome," neither must contend with anything like Bauby's diving bell. As Bauby notes, "In my contracted world, the hours drag on but the months flash by" (p. 101). His suffering and solitude are marked by what Levinas calls the "non-intentional," which is duration itself, a "pure passivity," a waiting that ends only in death (*Levinas Reader*, p. 80). Through this experience of duration, of pure passivity, according to Levinas, "one comes not into the world but into question" (*Levinas Reader*, p. 81). What comes into question is consciousness itself, or, in the words of Heidegger that began this essay, what comes into question is the meaning of being.

Furthermore, Levinas relates the experience of duration and pure passivity to the relationship of the self to the Other and the relationship of the self to death. According to Levinas, the Other is not an alter ego, someone whose experiences one can assimilate into one's own; rather, the Other "summons me, calls for me, begs for me, and in so doing recalls my responsibility, and calls me into question" (*Levinas Reader*, p. 83). The relationship with the Other that Levinas describes and employs as his ethical method is "the face-to-face with the Other, the encounter with a face that at once gives and conceals the Other."³² Moreover, for Levinas, speech is an essential aspect of this face-to-face relation. We do not have an understanding of another person prior to speech. According to Levinas, "The other is not first an object of understanding and then an interlocutor. The two relations are merged. In other words, addressing the other is inseparable from understanding the other."³³ Clearly

Bauby, confined to his diving bell and unable to speak, is in many ways unable to engage in the face-to-face encounter that Levinas says is as much about hearing and speech as about vision. This is not because he is unwilling to do so, but because others are unable to grasp the being within the body that does not move. His experience of solitude comes not only from his isolation in a hospital far from his Paris home but also from the fact that others cannot or are unwilling to recognize him within the stillness of his body. As Rosemarie Garland Thomson explains, the disabled body is often perceived as “a visual assault, a shocking spectacle to the normate eye”; thus, there is no ethical face-to-face encounter, but rather the disabled body is the object of the stare that “sculpts the disabled subject into a grotesque spectacle.”³⁴ The visual assault to the “normate eye” provokes the stare that closes off the avenues of hearing and speech between the nondisabled person who can only stare and the disabled person who can only be stared at.

Bauby is unaware of the extent of his own bodily transformation until he comes face-to-face with it, that is, until he comes face-to-face with himself transformed. One day when he is imagining a conversation with the large stained-glass image of the Empress Eugénie, wife of Napoléon III and the hospital’s patroness, “an unknown face interposed itself between us” (p. 24). He sees, reflected in the stained glass,

the head of a man who seemed to have emerged from a vat of formaldehyde. His mouth was twisted, his nose damaged, his hair tousled, his gaze full of fear. One eye was sewn shut,³⁵ the other goggled like the doomed eye of Cain. For a moment I stared at that dilated pupil, before I realized it was only mine. (P. 25)

In the mirror, Bauby encounters himself as a stranger; he is both self and stranger to himself, revealing what Levinas has called “that strangeness of self to self” (*Levinas Reader*, p. 163). It is in the pupil of his one open eye that he recognizes himself. This eye, with which he sees himself transformed and in which he recognizes himself, is the same eye whose blinks launch him out of his diving bell and into the world. Through the use of a special code that requires only that he blink this one open eye, Bauby is able to communicate with others.³⁶

When he discovers that the dilated pupil in the window is “only” himself, he recognizes as well what Levinas calls “the fundamental absurdity of being” (*Time*, pp. 50–51), and a “strange euphoria” comes over him:

Not only was I exiled, paralyzed, mute, half deaf, deprived of all pleasures, and reduced to the existence of a jellyfish, but I was also horrible to behold. There comes a time when the heaping up of calamities brings on uncontrollable nervous laughter—when, after a final blow from fate, we decide to treat it all as a joke. (P. 25)

The silent “gaze full of fear” is replaced by a “jovial cackling” that infects the other image in the glass, that of Empress Eugénie, or so Bauby imagines and describes it to his reader. His jovial cackling infects not only the image of the Empress but us, his readers, as well.

Bauby recognizes himself as a “visual assault, a shocking spectacle,” but this moment of recognition is also a moment in which he communicates—not through speech per se but through his imagination and his writing—with others—the dead Empress and his living readers—and laughs in the face of death. “What is important about the approach of death,” Levinas asserts, “is that at a certain moment we are no longer *able to be able*” (*Levinas Reader*, p. 42; emphasis in original). We are unable to seize or grasp death; we ourselves are seized. Bauby as disabled-being-in-the-world knows intimately the countless situations in which he is no longer able to be able. He might be said, then, to be residing in what Levinas calls “the empty interval” or “the meanwhile.” “In *dying*,” Levinas writes, “the horizon of the future is given, but the future as a promise of a new present is refused; one is in the interval, forever an interval” (*Levinas Reader*, p. 140; emphasis in original). And yet, Bauby writes, “not for a second does it occur to me that I may be dying” (p. 126).

Although his suffering and his solitude have brought him close to death, he nonetheless maintains hope, and this hope expresses itself in his all-consuming effort to communicate beyond his diving bell. Thus, Bauby’s samizdat bulletins are motivated, he tells us, in part to counteract the rumor, making its way through “the base camps of Parisian snobbery” and overheard by his friends at the Café de Flore, that he is a “complete vegetable” (p. 82). Bauby relishes relaying to his readers this unseemly tale of his own reduction to the bottom of the food chain: “Henceforth I belonged on a vegetable stall and not to the human race” (p. 82). How to respond to such gossip, how to recover his status as a member of the human race? Bauby decides, “I would have to rely on myself if I wanted to prove that my IQ was still higher than a turnip’s” (p. 82).

According to Levinas, “Prior to death there is always a last chance; this is what heroes seize, not death. The hero is the one who

always glimpses a last chance, the one who obstinately finds chances" (*Levinas Reader*, p. 42). And thus, to the last, Bauby is still searching for his own last chances, "keys for opening [his] diving bell" (pp. 131–132). The keys he imagines are not medical cures but metaphorical treatments, and are offered not as answers but as questions: "A subway line with no terminus? A currency strong enough to buy my freedom back? We must keep looking. I'll be off now" (p. 132). The subway line with no terminus is a new route, unexplored and even unimagined; the strong-enough currency is a new medium of exchange—a new language, a new form of address. Trapped in his diving bell, Bauby, paradoxically, is able to launch himself into the world through the medium of the book that we read. It is not precisely a face-to-face encounter, but the very fact of Bauby's book is, nevertheless, a representation of the ethical relation that Levinas calls for: "devoting-of-oneself-to-the-other" (*Entre*, p. xii). Bauby's responsibility for the Other is enacted in the writing of his book, which is, in Levinas's terms, "a vocation of an existing-for-the-other stronger than the threat of death" (*Entre*, p. xii). We, the readers of Bauby's book, are the Others with whom Bauby forms an ethical relation, despite his diving bell.³⁷ And, as he understands, through reading and our own imaginations, we can join him in his diving bell as it takes him—and us—"into unexplored territory" (p. 83).

Embodied Stories, Embodied Tellings

To be a consciousness or rather *to be an experience* is to hold inner communication with the world, the body and other people, to be with them instead of being beside them.

—Maurice Merleau-Ponty, *Phenomenology of Perception* (P. 96)

In conclusion, I want to touch on the relationship between writing bodily experience and phenomenology. I noted at the outset that Sacks, Mairs, and Bauby are all phenomenologists because they attempt to describe in writing their everyday experience of being disabled—the meanings of being disabled—in the world; and in so doing, they attempt to communicate about and through this experience to others. Although Terry Eagleton, for one, asserts that "language poses a severe problem" for Husserlian phenomenology because it conceives of meaning as "something which predates language,"³⁸ phenomenology (especially as elaborated by Heidegger and Merleau-Ponty) also establishes

intersubjectivity—being-in-relation—as a basic element of being in the world. In fact, a communicative structure undergirds phenomenology’s fundamental call for a “return to experience.”³⁹ The imperative to write—to translate one’s experience of embodiment into words, to offer oneself up to the world in words, which Levinas likens to prayer (*Levinas Reader*, p. 149)—is revealed most vividly in the case of Bauby, whose mode of communicating to the world outside his diving bell is so painstaking; his capacity to express himself is reduced to the blink of an eye. This becomes the means by which he writes *The Diving Bell and the Butterfly*; from blink to blink and letter to letter, words come from the void of his inert body. In Bauby’s case, the necessarily intersubjective nature of communication is revealed; he cannot speak or write, except of course to himself, without another person there to receive his words, to make his thoughts into words. His story—the story we read—is a story produced in a labor-intensive collaboration.

The “communication code” Bauby uses is actually quite simple. The letters of the alphabet are read out by a companion, not in their usual order, but in a special order based on the frequency of their use in everyday speech and writing. Bauby blinks his eye when his companion gets to the letter he is looking for, and the process is then repeated. In this process language itself is broken down; but in this case, it is broken down so that it may be built up again. This literal and figurative breakdown of communication gives us access, in a sense, to that which is taken for granted in the act of communication: by undoing the structure of language, it defamiliarizes language itself and makes the act of communication strange. Bauby, his interlocutors, and we readers are compelled to pay attention to “the material process of language itself.”⁴⁰ While it is true that we do not read the book in the same fashion as Bauby has composed it, we are made aware of the deliberate and precarious manner in which it has been composed. “Because of nervousness, impatience, or obtuseness, performances vary in handling of the code” (p. 20), Bauby notes of his particularly unusual situation; but of course all communicative performances—even those not requiring an unfamiliar code—vary as well. Both recognition and misrecognition are always at work in the performance of language, and thus meaning is always already deferred. The inevitability of meaning that is in excess of intended meaning is revealed when, in a visit with a friend, Bauby attempts to ask for his glasses (*lunettes*), and his companion asks what Bauby wants to do with the moon (*lune*). In this moment of slippage (not exactly a slip of the tongue), Bauby himself realizes that something ineffable emerges from the distance between

understanding and misunderstanding, between everyday language and poetic language, between asking for one's eyeglasses and asking for the moon.

Bauby dictates his book, letter by letter, to an "emissary" from his publisher, highlighting writing as an event, as Jameson has called it.⁴¹ In order for his words to have meaning, another person must comprehend them. This is not unique to Bauby; all stories need a listener or reader. What is remarkable about his particular situation is that he must compose his "bedridden travel notes" prior to the emissary's arrival, "learning his text by heart, paragraph by paragraph," in a prayerful manner, weeding out that which is extraneous to his story, and to his very being. Not surprisingly then, the resulting notes "are a distilled collection of stories patiently extracted from the void" (p. 131), as if consciousness itself has been concentrated.

While the diving bell represents Bauby's sense of himself as plunged into a void, like a diver separated from the elements of the sea, the butterfly, on the other hand, represents his capacity to imagine, to desire, and thus to travel from his void out into the world. The butterfly, a symbol of spiritual transformation, signifies the transformation that comes from Bauby's effort to bring his experiences to language and thus outside of and beyond himself into the world. The diving bell and the butterfly are both vehicles of Bauby's being-in-the-world. On occasion, as Bauby notes, "my diving bell becomes less oppressive, and my mind takes flight like a butterfly. There is so much to do. You can wander off in space or in time, set out for Tierra del Fuego or for King Midas's court" (p. 5). His wanderings through space and time—a mixture of memory, dreams, and imagination—are "fragile threads" ("intentional threads," as Merleau-Ponty would say [p. xiii]) linking Bauby "to the living world" (p. 104). And, although Bauby bemoans the fact that his "communication system disqualifies repartee" and that "this forced lack of humor [is] one of the great drawbacks of [his] condition," wit, a sense of enjoyment, and a refreshing unwillingness to reach for facile feel-good descriptions of his life are prominent features of his work.⁴² Bauby's wit is not lost to the void at all, but, like everything else he communicates, it is refined, so much so that he ironically chastises himself (with a wink to his readers) at the beginning of the book to carry on with his work and quit rambling, as if he were still capable of rambling. Locked-in syndrome allows Bauby a new perspective—again, the perspective of both the diving bell and the butterfly—on the world and the self-in-the-world, on life and death (on "life in death," as the subtitle of the Vintage edition suggests⁴³), and on that which can be described in language and that which cannot.

Mairs recognizes that living with MS is not only a diminishment, that through her writing she is capable of giving care to others. Commenting on all the tasks she can no longer do, Mairs admits any “act involving sharp instruments” is off limits. “But wait!” she writes. “One sharp instrument is left me: my tongue. (Here’s where metaphor comes in handy.) And my computer keyboard is . . . just waist high” (p. 63; ellipses in original). When a young woman recently diagnosed with MS calls Mairs from across the country, Mairs wonders what she is to do about and for this woman whom she does not even know. The answer, she quickly realizes, is to write a book that provides “the observations and responses of a single wayfarer who hopes, in sketching her own experiences, to make the terrain seem less alien, less perilous, and far more amusing than the myths and legends about it would suggest” (p. 6). Through her writing, Mairs, like Bauby, is able to devote herself to the Other; she is able to respond to the summons into an ethical relation with the Other, who is the woman recently diagnosed with MS, as well as the readers of her book.⁴⁴ Sharing Mairs’s philosophy, Arthur W. Frank notes that “as wounded, people may be cared for, but as storytellers, they care for others.”⁴⁵

Through the works of these three phenomenologists I have attempted to offer a phenomenology of disability. But it is not only the experience of being-disabled-in-the-world that Sacks, Mairs, and Bauby describe. The radical transformation of their beings-in-the-world—their experiences of breaking down—are the condition of the possibility “to seize the meaning of the world.”⁴⁶ Through their experiences of disability and through their compulsion to communicate those experiences to others, Sacks, Mairs, and Bauby reveal not only something about what it means to be disabled but also something about what it means, simply, to be.

NOTES

1. Maurice Merleau-Ponty, *Phenomenology of Perception*, trans. Colin Smith (London and New York: Routledge, 1962), 63. All references are to this edition and will be cited parenthetically in the text.

2. Robert Murphy, *The Body Silent* (New York: Henry Holt, 1987), 90.

3. Martin Heidegger, *Being and Time*, trans. John Macquarrie and Edward Robinson (San Francisco: HarperCollins, 1962), 1 (emphasis in original). All references are to this edition and will be cited parenthetically in the text.

4. Oliver Sacks, *A Leg to Stand On* (New York: HarperCollins, 1993); Nancy Mairs, *Waist-High in the World: A Life Among the Nondisabled* (Boston: Beacon, 1996); Jean-Dominique Bauby, *The Diving Bell and the Butterfly*, trans. Jeremy Leggatt (New

York: Knopf, 1997). All references are to these editions and will be cited parenthetically in the text.

5. Murphy, 4.
6. Murphy, 87.
7. Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: Univ. of Chicago Press, 1995), 56.
8. Heidegger, 91.
9. Edmund Husserl, *Cartesian Meditations: An Introduction to Phenomenology*, trans. Dorion Cairns (The Hague: Martinus Nijhoff, 1960), 18.
10. Drew Leder, *The Absent Body* (Chicago: Univ. of Chicago Press, 1990), 83.
11. Heidegger, 107. Terry Eagleton relates Heidegger's interest in the theoretical knowledge that emerges out of "practical social interests" with the Russian Formalists' understanding of art as defamiliarization: "when the hammer breaks," Eagleton writes of Heidegger's phenomenological theory, "its familiarity is stripped from it and it yields up to us its authentic being. A broken hammer is more of a hammer than an unbroken one." See *Literary Theory: An Introduction* (Minneapolis: Univ. of Minnesota Press, 1983), 64.
12. Heidegger, 107.
13. Murphy, 12. See also Victoria W. Leonard, "A Heideggerian Phenomenological Perspective on the Concept of Person," in Patricia Benner, ed., *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness* (Thousand Oaks, Calif.: Sage, 1994), 53; and S. Kay Toombs, "The Body in Multiple Sclerosis: A Patient's Perspective," in Drew Leder, ed., *The Body in Medical Thought and Practice* (Dordrecht: Kluwer Academic Publishers, 1992), 127.
14. See Henry Head, *Studies in Neurology: Vol. 1* (London: Hodder and Stoughton, 1920).
15. Arthur W. Frank describes "restitution stories" as those narratives that project a "future that will not be disrupted by illness"; see *The Wounded Storyteller*, 90. *A Leg to Stand On* is a restitution story according to this aspect of Frank's definition. But Frank also states that "the restitution story, precisely because it treats sickness as banal, displays a heroism in the face of bodily breakdown. But this heroism of the ill person is invariably tied to the more active heroism of the healer" (93). Sacks's own position as a patient who is also a doctor is interesting in this regard. Sacks does not treat his own sickness as banal, and he is possibly most frustrated by his having to assume the passive role of the patient rather than the active, heroic role of the healer.
16. Husserl, 77-79; on Heidegger and Merleau-Ponty, see David Carr, *Time, Narrative, and History* (Bloomington: Indiana Univ. Press, 1986), 111; Michael Hammond, Jane Howarth, and Russell Keat, *Understanding Phenomenology* (Oxford: Basil Blackwell, 1991), 83; Iris Marion Young, *Throwing Like a Girl and Other Essays in Feminist Philosophy and Social Theory* (Bloomington: Indiana Univ. Press, 1990), 148.
17. Mark Johnson, *The Body in the Mind: The Bodily Basis of Meaning, Imagination, and Reason* (Chicago: Univ. of Chicago Press, 1987), xix.
18. "Beyond Intentionality" is the title of an essay by Levinas, which provides an excellent introduction to his notion of the face-to-face relationship with the Other (a relationship that is beyond intentionality); see Alan Montefiore, ed., *Philosophy in France Today* (Cambridge: Cambridge Univ. Press, 1983), 100-115.
19. G. Thomas Couser, *Recovering Bodies: Illness, Disability, and Life Writing* (Madison: Univ. of Wisconsin Press, 1997), 188.
20. Merleau-Ponty, 105.
21. Toombs, 134.
22. Margrit Shildrick, *Leaky Bodies and Boundaries: Feminism, Postmodernism and (Bio)Ethics* (London and New York: Routledge, 1997), 14. See also Judith Butler, "Sexual Ideology and Phenomenological Description: A Feminist Critique of Merleau-Ponty's *Phenomenology of Perception*," in Jeffner Allen and Iris Marion Young, eds., *The*

Thinking Muse: Feminism and Modern French Philosophy (Bloomington: Indiana Univ. Press, 1989), 85–100; and Elizabeth Grosz, *Volatile Bodies: Toward a Corporeal Feminism* (Bloomington: Indiana Univ. Press, 1994).

23. Young, 144.

24. *Ibid.*, 147; emphasis in original.

25. *Ibid.*, 153.

26. Rosemarie Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia Univ. Press, 1997), 127.

27. Although Bauby does eventually die from his condition, I am not speaking here about his actual death, which, of course, he himself cannot experience and therefore cannot possibly communicate to us. The possibility of death informs his entire account, however, and it is this possibility, which he can neither take for granted nor ever really forget about, that marks the closeness of his encounter with death that I am describing.

28. Heidegger, 102.

29. Levinas, "Beyond Intentionality," 100–115.

30. Emmanuel Levinas, *The Levinas Reader*, ed. Seán Hand (Oxford: Blackwell, 1989), 13.

31. Husserl, 62; emphasis in original.

32. Emmanuel Levinas, *Time and the Other*, trans. Richard A. Cohen (Pittsburgh: Duquesne Univ. Press, 1987), 78–79.

33. Emmanuel Levinas, *Entre Nous: On Thinking-of-the-Other*, trans. Michael B. Smith and Barbara Harshav (New York: Columbia Univ. Press, 1998), 6.

34. Thomson, 26.

35. Bauby's right eye is sewn shut because his lid no longer closes and thus no longer protects his cornea from being overwhelmed by outside stimuli. When his right eye is being sewn shut by his doctor, he fears the doctor will get "carried away" and sew up his left eye as well, eliminating his "only link to the outside world, the only window to [his] cell, the one tiny opening of [his] diving bell" (53–54).

36. I will describe this technique in more detail below.

37. Thanks to Rita Charon for her insight on this crucial point.

38. Eagleton, 61.

39. Merleau-Ponty, 97.

40. Eagleton, 99.

41. Fredric Jameson, *The Prison-House of Language: A Critical Account of Structuralism and Russian Formalism* (Princeton: Princeton Univ. Press, 1972), 200. Levinas also speaks of "the event of language" (*Entre*, 6).

42. Jill Ker Conway emphasizes Bauby's ability to maintain a "strong sense of agency" in the tradition of St. Augustine, and a "drive to improve the moment" in the manner of Benjamin Franklin. See *When Memory Speaks: Reflections on Autobiography* (New York: Knopf, 1998). It seems to me, however, that Bauby is less concerned with agency and improvement than with maintaining the possibility of enjoyment of the world. Bauby's delight and emphatic need in forging "glorious substitute destinies" for himself seems very different from Augustine's and Franklin's forms of asceticism.

43. Jean-Dominique Bauby, *The Diving Bell and the Butterfly: A Memoir of Life in Death*, trans. Jeremy Leggatt (New York: Vintage, 1998).

44. Thanks to Rebecca Garden for pointing out that this is another example of a representation of the ethical relation that Levinas calls for.

45. Frank, xii.

46. Merleau-Ponty, xxi.