About the Encyclopedia Covers: Visualizing Variation

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The five covers for the *Encyclopedia of Disability* represent a selection of artistic impressions across a range of cultures, time periods, and multiple disabilities. They also render some of the unique orbits for the complex relationships that disability experiences provoke. Each is purposively nontragic and discourages pathos or too easy sentiment. Instead, the covers emphasize the creative and self-inventive side of disability experience. All make disability a window onto diverse landscapes for the body different.

Taken collectively, they may even suggest an odd refuge in disability—the degree to which incapacities can be viewed as protecting us, and motivating creative agency, even as they may render us most vulnerable. Perhaps someone such as Frida Kahlo, who lived so intensely in her body, could identify the lure of incapacity to this extent. She wrote in her diaries:

> We take refuge in, we take flight into irrationality, magic, abnormality, in fear of the extraordinary beauty of truth of matter and dialectics, of whatever is healthy and strong—we like being sick to protect ourselves. Someone—something—always protects us from the truth—Our own ignorance and fear. (*The Diary* 1995:248–249)

Thought about in such a way, disability no longer means a condition, an incapacity, or lack that belongs to a body, but rather a product of the interactions between self, society, body, and the variety of interactions (from political economies to personal commitments) that they engender. Disabled bodies, then, are artifacts—found or experienced while saturated with the meaning of our own investments, concerns, hopes, and insignificance in the world.

That the relations precipitated by human differences so often become detrimental to people with disabilities, turning even families or institutions devoted to their care into warehouses or danger zones, does not lessen their significance. Analysis of disability from a social perspective reveals the extent to which cultures prove creative at inventing endless varieties of human diminishment. In response, one finds counter-creativity demanded of disabled people. Their own livelihood, and sometimes their very lives, can rely on an ability to subvert supernatural views held about their conditions, contest medical fascination with their corporeality as "specimens," or spend years finding the means to escape confinement from back wards, closets, and institutions. The art depicted on the covers of this five-volume set, then, present us with this multisided nature of disability experience. Each portrays individuals both marked as undeniably different and actively transforming of the social terms of their reception.

The bronze sculpture of the Nigerian King Oba (cover of Volume IV) speaks directly to this idea of disability as urgently necessary renegotiation of the terms by which the nondisabled may see us. The king stands between the dual supports of his personal assistants with his mudfish legs on full display to the viewer. Rather than a story of personal diminishment by paralysis, the king explains his condition, contrariwise, as a deepening of his power. Mudfish represented a revered species in Nigerian culture at the time of this event. A king who awakens to discover himself immobile—particularly when the appearance of physical or cognitive disability in a ruler results, by law, in exile or execution from his subjects—can avert certain catastrophe only by such inventive quick thinking. Instead of concealing

his paralysis, the king parades his body transformation before more lethal rumors can begin to circulate.

The Oba's explanation for his sudden mobility impairment draws directly upon insider understanding: Difference of form does not equate with absence of kingly capacity. Legs bow out and gradually modify into the heads and forelegs of the mudfish as the product of a powerful formulation of the meaning of body changes. The king tells his subjects that he can now pass between earthly and spiritual realms just as the mudfish navigate land and sea as half-reptile and half-fish. Circling the human figures, a series of four amphibian heads stare out as totemic sentries. The artist admires the flexibility of such an in-between space occupied by the Oba in his claimed role as a mediator now between human assistants and animal protectors.

Both Oba and artist participate in the recognition that variation exists across species and hence offers to us a rich array of explanations for the value of bodily configurations that might otherwise be cast out as undesirable. The sculpture posits continuity to natures, creatures, cohabitants, in a portrayal of paralysis: mudfish legs, human assistants with partially truncated torsos, pineapples, elephant trunk, snake, and swamp tangle. All life forms mesh in a symbiotic system of mutual belonging despite intense differences of capacity. Diversity teems across the bronze figure's vertical and horizontal axes. A celebration of varying capacities from human to animal culminates in the exhibition of Oba's bowing legs in order that variations across bodies in nature can provide context for a human body with paralyzed legs without a lessening of value.

The nineteenth-century Japanese triptych *Hua T'o Treating an Instance of Necrosis on the Arm of the Warrior Guan Yu* (cover of Volume III, 1853) by the famous printmaker Utagawa Kuniyoshi, depicts a historical event from fourteenth-century China. To the far left of the work we witness a surgeon, dwarfed in the presence of the massive body of Guan Yu, plying his trade in spite of the recreational distractions taking place around him. The physician, Hua T'o, meaning "miracle working doctor" (or "divine physician" based on the Japanese word *shenyi*), concentrates on a lesion eating away at the general's right arm. His localized treatment effort contrasts with the social frivolity portrayed in the rest of the painting. Medicine pursues its healing art as the world continues on indifferent to the work of bodily salvage. In this reading, we could situate ourselves as admirers of precise medical application as the "patient" stubbornly pursues other desires with a reckless lack of concern: Medicine works against time and gross inattention to attend to human vulnerability. We are situated as admirers of medical technique; the physician's perseverance is sustained in spite of activities that might prove distracting to the treatment effort.

Likewise, a viewer of the painting may also contemplate the work as a commentary on war. Bodies are wantonly exposed to violence and disability, disease, and death. Human wreckage is exposed as the primary product of militarized clashes between individuals, tribes, and nations. The painting depicts Guan Yu calmly receiving treatment following a battle wound caused by a poison arrow. The warrior ignores the cleaning of the wound down to the bone as an example of the power of the first administration of anesthetic. He has adopted an attitude that places his body as fully secondary to more immediate concerns, whether the task at hand is a battle or gamesmanship. In the unfinished disability play *The Deformed Transformed* (1822), the renowned Romantic poet Lord Byron, argued that masculine able-bodiedness seemed to require that men put their healthy bodies at risk of violation, as if they could not feel their lives as "real" enough without exposing themselves to the potential of disability. The thrill of physical threats pursued and then evaded. The painting of Hua T'o suggests a similar reading in that the development of necrosis suggests a near-gangrenous wound progressing to the point of a serious medical condition. A poor result might yield the loss of a limb or disuse of his arm because the general has refused to attend to the initial laceration in a timely manner. This patient inattention to the poisoning produces an even graver medical predicament. From this vantage point, a viewer might choose to indict the warrior's indifference to his own health concerns or grow further weary of war's destruction.

Alternatively, one may also glimpse a cultivated demeanor in Guan Yu's laissez-faire attitude toward medical attention. We might draw an interesting parallel to the experience of medicalization by disabled persons—particularly in the case of individuals who have spent significant time "under the knife." While medicine demands the full attention of the patient to participate in its own healing mission, those exposed to continuous medical care often refuse this singular attention paid to their bodies. Undergoing medical care requires a multitasking mission, or the rest of one's life comes to a full stop. In this view, we might think of medicine as the disruptive event against which the rest of one's life must be experienced. A certain capacity develops among disabled people to

handle their other "business" as the medical industry rages around them. In fact, there's a form of patient *cool* where one refuses to allow a medical event to eclipse the myriad other demands on one's life—such an attitude can be found on display in the Kuniyoshi print as the game of Go continues in the face of surgery. In fact, the medical activity is reduced to a mere third of the triptych while the game occupies the remainder of the artist's interest. The social interaction requires as much seriousness as the presence of necrosis itself.

Likewise, Tim Lowly's *Beacon (Bless the Bastard)* (cover of Volume V, 1991) emphasizes independent coexistence among bodies occupying shared space. Rocks, river, grass, and other earthly elements populate the scene with an adult care provider and a disabled child positioned a few feet away. The two female figures, out of doors and beyond the traditional confines of domesticity, do not show shame or efforts to hide from the world's discomfort with disability. The caregiver looks off in the distance responding to some unknown force with a stem wielded over her shoulder in the gesture of a blessing. Behind and below the caregiver, a child (the artist's daughter Temma) lies on a bright blue pallet that cushions her from the ground—the same ground on which her mother's bare feet are firmly planted. The disabled girl's body, illuminated in the landscape and sprawled beneath the sky, wears a one-piece playsuit with socks and shoes, carefully swaddled despite the apparent warmth of the day. The relationship between the two figures, emphasized by the colors in the child's garment and repeated in the mother's striped dress, openly proclaims their identification. This is Temma's consciously placed residence in the world; she might be lying there contemplating a future yet to be articulated by the adults around her. The daughter's figure, aimed like a magnetic compass arrow toward the bridge in the upper left canvas, serves as a beacon to the artist, and, in this landscape, literally could be cast in a red outfit as if a signal translated from one location to another. The way a painter selects and places a subject onto a canvas in a highly self-conscious act parallels how Temma's caregiver has consciously situated her in this setting. In other works, Temma lies near a muddy puddle, a pond, on a day bed, across a desert floor, near a wooded river stream; her figure a geographic nomad yet without apparent mobility. These portraits capture Temma's vantage point as contemplative of universes unrevealed in ordinary landscapes—and strangely altered by the insertion of a disabled body. The historical absence of disabled people in routine places makes every appearance potentially transgress audience expectations. Conversely, every insertion undermines the belief that there are some places disabled persons should not go.

Just below the bridge, a small group clusters around a makeshift stone altar and, in a rather ritualistic manner, evokes a history of atonement practices. These ritualistic acts often occur in response to a mystery disability seems to evoke. Why me? Or what did I do to deserve this fate? Or what does this difference mean for the community? Are we culpable in some way? Piled stones reference all the hard things humans negotiate, arrange, and work with, just as the allegorical landscape offers hugely divergent elements, from spongy riverbed to wooden platform, to inhabit. Each formation seems to be selected for its yielding principles. Fjords—irregular land and water masses—remind us of the nonstandard geometries of embodiment and mirror the daughter's figure akimbo on land. Bodies of water and of land encroach on and define each other—clearly etched by nonregimented and unpredictable shorelines. The work on the makeshift altar occurs while the determined "blessing" of the mother above also redoubles as a fending off of outside forces and even our gaze, as viewers prying into a private scene. As if we must first fathom the precision of the mother's expression and gesture in the foreground before gaining access to the proceedings beyond her, she stands as a cautious gatekeeper before the rest of the painting.

The subtitle, *Bless the Bastard,* refers not to the child but to the concept of flinging back insults with a shield of mercy. The artist explains the idea as a matter of how one might bless those who curse one with additional punch. The mother's determined motions, her turning outward and her gesture toward the past, and her daughter's resident outside location, present them as participants in a fully parallel existence. The story of disability unveils that even the most ordinary outing requires a variety of self-conscious placements and protective gestures.

Finally, a white building perched near the skyline in the upper-right-hand corner recalls, as well, the Olson house on the upper horizon of Andrew Wyeth's famous painting *Christina's World.* As in the Lowly work, the house in Wyeth's painting also makes a young disabled woman's predicament into an allegory. The disabled figure in each work lies in the foreground staring off into the distance—relatively immobile or alternatively mobile in body but imaginatively engaged in future prospects unknown to, and unimagined by, viewers. In *Beacon,* the far-off residence appears like a temple

amid a landscape that is filled with objects that catch a viewer's eye. Each item serves as a potential enhancement or barrier to navigation across it. Certainly, both disability paintings place a demand on the viewer to acknowledge these scenes as complete worlds. In them an ordinary morning scene, the forthrightly mundane world, is lent a hue of studied complexity toward a disability's self-conscious placement therein. *Beacon* offers Temma's figure as a guidepost rather than repulsion. The disability-wise gestures of the figures themselves are understood to occur in the face of a modern hyperrational clarity that would dispense with disability experience as some all-too-obvious tragedy. The paintings provide a lesson in how to live in the world with severe disability. Both ask us to reexamine this premise by requiring that we look closely enough to discern the disability coordinates of lives that might at first glance appear wasted.

Whereas Lowly and Wyeth represent intimate works about disability by nondisabled artists, Frida Kahlo's work supplies an example of artistic traditions spawned by disabled artists themselves (cover of Volume I). Responses to the disability context of Kahlo's work and life have ranged from incredulity to simple disability disavowal: "Frida Kahlo—she's a national treasure. How could she be a disabled woman?" Contrariwise, the complex disability perspectives that inform her subject matter and the terms of her artistic exploration can become so central that disability interests may overwhelm all else in her work. Certainly, few artists since the Middle Ages made the topic of personal suffering such a wellspring for creative figuration. For disability critics, one must note the inventiveness that informs Kahlo's access to artistic practices, from painting on canvasses suspended over her bed to laptop easels to the elaborate journal she kept detailing her pain, confinement, and multiple surgeries (including the amputation of her right leg in 1955). Such investments in the ability of art to provide her with immense joy "in spite of my long illness" led her to have her four-poster bed dismantled and reconstructed in the national museum of Mexico City. The unusual accommodation occurred on an evening prior to the one exhibition during her lifetime in her home country for the purpose of being able to view the exhibit herself in comfort.

Kahlo's life, whether conceived as utterly conditioned by disability or as having disability merely incidental to it, has served as the topic of children's books and films. Controversies rage over the terms and origins of her multiple impairments. Some have identified her disability as resulting from a bus accident when she was 16 years old in 1926; others with the effects of polio contracted at the age of 6; and still others, such as Philip Sandblom author of *Creativity and Disease* (1997), propose that she was born with the congenital condition of spina bifida, which she spent her life concealing. We may be discussing some combination of all of these events in one body as well. These discussions are as interesting for the fears and concerns interpreters express about the meanings of congenital (as opposed to acquired) disabilities for stories of artistic achievement. Acquired disability makes one a hapless victim of circumstances while congenital disability signifies a status as metaphysical pawn.

Nevertheless, the latter attribution of spina bifida as an initial source of her disabilities becomes most provocative given her preoccupation with the spinal column in her work. Her paintings commonly depict Mexico as an ionic column with wings. In addition, she also uses duality or twinning such as in her work, *The Two Fridas* (1939), where we see her heart beating and a circulatory system that feeds the nearby identical body image with which she clasps hands. The work depicted here, painted in 1946 amid a flurry of surgeries and hospital stays, *Arbol de la Esperanza Mantente Firme* (*Tree of Hope—Stand Firm!*), associates an ironic meaning to the figure holding a back brace in one half and wounds along the supine figure's spine in the other. The sense of strength that Kahlo must have felt in herself—particularly through her political commitments to Communist revolution—resound as both a plea (make me strong in the face of pain) and a command to others (stand firm in your political convictions). These words, *"arbol de la esperanza mantente firme,"* which one of her biographers, Hayden Herrera, identified as the lyrics to a song she knew, would also appear a year later in a diary entry celebrating the 30th anniversary of the Bolshevik revolution. For Kahlo, debilitating physical anguish could be offset to some degree with a merger of disability and political images in that both coexist without eclipsing the other: The most disabled also embody the fiercest commitments for social justice. The two often become a self-referencing system in the body of her works.

Compositionally, the contrasted backgrounds of night and day suggest a confluence of binary associations between light and dark, health and illness, passive hospital patient and active revolutionary. Yet the painting throws such easy oppositions into question

in that all coexist, and enlightenment may come from either source. The more medical image appears in the day where one might expect to find her more "public"—that is, less vulnerable—self. Thus, the work is an emblem of Kahlo's artistic *oeuvre* in that these versions of the self do not simply balance the subject but rather serve as wellsprings for creative vision in their own right. The pink brace grasped securely in the hands of the formally dressed figure who waves a small flag contrasts with the night and small moon on the right side of the canvas. The body of the fully draped figure situated at a perfect right angle to the reposed figure on the wheeled operating table function as two supports along the canvas's vertical and horizontal planes. The figure on the left displays open seeping wounds across a back that is exposed between pulled-apart sheets as if to unveil her body in a surgical cut-away.

Likewise, spinal lesions echo across both halves of the painting. They duplicate cracks and ridges that split dry earth across which the stretcher seems precariously perched. This yawning crevasse is exactly the same size as the wheeled bed. A surreal glittery ball stands for the sun, and her flowery headdress hovers suspended in this cosmic stratosphere. The velvet dress suggests a more formal version of the Aztec clothing that she wore throughout her adult life. It's also a chosen legacy rescued from a colonized past. Hence the more surreal aspect of this painting: The body left behind, ruptured, and lying across night and day is juxtaposed to the upright, dressed red figure who gazes at the viewer while holding the brace in full display. It also appears that the seated figure wears a similar corset-like apparatus beneath the dress because the bulbous endings appear around her chest and match the same design of the brace in her hands. In a *Time* magazine article of April 27, 1953, Kahlo insisted that "I never painted dreams. I painted my own reality" (p. 90). The painting may most of all render homage to her prosthetic back brace and her investments in it. Today, one can find the same pink back brace with personal decorations in a visit to her home, now a national museum. In either case, both portraits echo with Kahlo's disability markers that worked to flaunt, as opposed to mask them, from the viewer.

Kahlo's work has been often attributed to the influence of northern Dutch painters such as Pieter Brueghel the Elder, and particularly, Hieronymus Bosch (Jeroen Van Aken: 1450–1516). While Brueghel painted mimetic images of everyday northern peasant life, Bosch's impact on Kahlo is often identified through his portrayals of bizarre imaginings such as the events captured in his work *Extraction of the Stone of Madness (The Cure of Folly)* (ca. 1475) (cover of Volume II). Whereas Kahlo followed Vincent van Gogh in portraying her physicians in respectful portraits as a sign of appreciation, Bosch participates in a less reverent approach. In this painting, Bosch satirizes the medieval medical practice of removing stones from the head as a treatment for madness, traumatic brain injury, and insanity. In addition, the other two onlookers—a friar and a nun—represent alternative religious domains where madness was commonly addressed with alms and prayer. Thus, Bosch assembles the surgery's audience carefully in his effort to draw the three figures into the net of this parody—as if every charlatan, barber, and pious practitioner of his day comes together in this unholy gathering to witness someone else's suffering. Their own moral stature in the community depends on catering to those residing among the "less fortunate."

The subject of the surgery—a patient drawn in the guise of various "fools" of the day—undergoes a risky intervention. Hopes for release from such conditions as insanity resulted in a willingness to expose oneself to disastrous—and often life-threatening—efforts to alleviate symptoms. Similar practices for the treatment of mental illness were widespread in Bosch's day. Evidence also suggests that in spite of critiques such as this one, the practice continued into the Renaissance where similar procedures are documented as late as the sixteenth century. Like Kahlo, Bosch rarely ventured far from home, and his works include details of familiar scenes within a tightly circumscribed area. Yet, as in this work, Bosch's paintings place the rituals of life in question by unveiling the violence that often resides just beneath the surface. Consequently, *Extraction of the Stone of Madness* suggests that "deviant" behavior may be found on both sides of the treatment divide.

Bosch's painting, inspired by various folk tales and critiques of the physicians' guilds of his time, appears fairytale-like in its allegorical assemblage of medical and religious personnel. In each figure, the primary treatment tools come on display—from the barber's scalpel to the friar's chalice-like vessel to the nun who balances a book on her head. The physician applies his effort directly to the body, the male priest talks and gestures toward the patient during the ordeal as if performing an exorcism of demons, and the nun looks on in contemplation as if patiently awaiting inspiration

from the text above. Each intervention strategy seems poised to encourage equal levels of suspicion. Rather than a stone, the surgery results in the extraction of a flower from the man's head. This is a curious object in that the flower appears much more at home in the naturalistic setting while the human practitioners seem out of place. The town situated off in the distance further emphasizes their displacement. As one commentator puts it:

> Moreover, this work of art bears the inscription 'Master, take away the stone, my name is Lubbert Das." It is worth pointing out that Lubbert Das was a comical character that originates in the Dutch literature of that time. The stone is represented as a flower (tulip) on the head of the patient near the surgeon's knife, because of the similarity between the words tulip (*tulp*) and madness in Dutch. (Babiloni et al. 2003:1)

This direct parallel between organic life and insanity may suggest Bosch's effort to equate both objects with the forces of nature that ultimately evade human control.

While madness may be commonly represented as severe distraction from the applications of daily living, only the patient's gaze breaks the painting's plane as he looks out uncertainly toward the artist capturing the event and/or the hapless viewer consuming the event. His look of personal concern contrasts with the concentrated efforts of the others as they attend directly to the site of conflict—namely, his brain as resident location for the "disorder"—and thus the "patient's" objectification turns out to be at least threefold on behalf of the barber, artist, and viewer. We participate as consumers of the discomforting scene. Bosch captures the worst kind of medical theater, one that not only subjects one to painful procedures of dubious merit but also is witnessed by others to further deepen the stigma.

The painting also comments on a long-standing belief in medicine that the body functions as symptomatic surface for otherwise ephemeral "cognitive" phenomena (i.e., madness in this case). Without a tangible bodily location, medicine would prove at a loss as to how to proceed in its material correctives. The concept of a "stone" of madness then takes an abstract matter of behavior perceived as deviant and objectifies it in physical terms. Thus, various bodily zones get targeted as the seat/source of intangible phenomena. In the eugenics period (1840–1940), "idiocy" was theorized as a lack of control of the will, and "docile" bodies were targeted through physical exercises, concentration rituals (e.g., standing in one place for minutes at a time), and hygienic grooming practices—a presentable body represents a compliant citizen. In each instance, exerting force on the physical body provided a route through which to impose control over minds.

In sum, these artistic works demonstrate that disability is both a product of specific local contexts *and* shared, even global, disability perspectives. Africa, Japan, the United States, Mexico, and the Netherlands all contribute to a multinational mosaic of disability representation; in doing so, disability transcends geography, culture, and history in its situation as a metaphorical and pragmatic device of social meaning making. The question "What do we do with our disabled people?" resonates in most cultures and across historical moments. In the midst of its invocation as perpetual crisis, disability can expose ruses to the control and mastery of human variation, give expression to individual assertions of difference and group identity, portray indifference or excruciating investment in the denial of deviance, resignify incapacity into unexpected ability, or provide opportunities of interdependency among human vulnerabilities in search of mutual support. On each cover of Volumes I through V, disability serves as the medium through which artists—and, consequently, the viewers of their art—may ponder cultural responses to the persistence of human heterogeneity. Difference prompts myriad social schemes of suppression in futile efforts to contain variation within a narrower range of expression. Artists of disability are not in any way immune to the homogenizing projects of cultures, but their work gives us perspective on how we might improve the future by contemplating the limitations of tolerance in our past.

Further Readings

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