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## Sleeping while disabled, disabled while sleeping



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### ABSTRACT

This essay considers areas in which the study of sleep and sleep disorders might profit from the perspective of disability studies, as practiced in the humanities and social sciences. This interdisciplinary perspective considers the social and cultural dimensions of bodily and mental states and conditions that a particular society deems “abnormal” or impaired, as well as the lived consequences of those determinations. Some sleep disorders are considered disabilities, but almost all disabilities entail some disruption from “normal” sleeping patterns—whether because of physical pain, exhaustion, and emotional stress of facing obstacles in work and other areas of waking life, or challenging sleeping environments in which many disabled people live. Despite these disruptions, finding adequate nighttime care is often difficult for people with disabilities, and consequently, night is often when social isolation and vulnerability are most profound. In addition, caretakers themselves often find their own sleep profoundly disrupted, whether this occurs in a family setting or an institutional space. Finally, the essay suggests that a disability studies perspective can help us to see that disordered sleep—whether primary or secondary to a disabling condition—can both impact and be shaped by social relationships.

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A 2014 article in America's finest news source, the *Onion*, raises the question: What would it mean to consider sleep a disability? Reporting on a strange “mass debilitation” that descends upon the entire population for a period of between 6 and 9 hours at night, the satirical paper forced readers who consider themselves nondisabled to confront the fact that virtually all of the phenomena they associate with disability—sensorimotor impairments, reductions and derangements of cognitive capacity, and inability to work or be productive in socially recognized ways—are in fact experiences common to everyone, every night (if we are lucky). As one terrified citizen put it, “It's horrifying to think we were all just sprawled on our backs, completely motionless for literally hours. We had no sense of sight or hearing, no idea what was going on around us.” This near-complete loss of sensory input and physical immobilization was accompanied by periodic hallucinatory episodes suggestive of a profound mental disability or posttraumatic episode: “At one point,” according to an interviewee, “my teeth just fell out. How am I supposed to move on after such a horrific vision?”<sup>1</sup> The comedy of the piece rests on its revelation of the strangeness of sleep: its weird inversion of just about everything we are taught to think about human virtues: we are no longer rational creatures who can navigate our bodies through time and space, weave our own desires and behaviors into patterns that are considered productive by our society, fend for ourselves, or care for others.

Even stranger, though, is that entering into and maintaining this state of near total physical and mental impairment is considered absolutely normal: it is only when we lose the ability to sleep, or when sleep fails to seize us completely or does so at the wrong time, that it counts as a disorder—an abnormality that may shade into disability. The Americans with Disabilities Act does not, obviously, treat sleep as a disabled state; however, its definition of disability as “a physical or mental impairment that substantially limits one or more major life activities” includes sleeping as one of the major life activities so impacted.<sup>2</sup> Inability to sleep, or sleeping in a disordered way, or having one's sleep disturbed by a non-sleep-related impairment or illness can lift the sleep/wake cycle into the realm of disability, whereas the arguably more profound experience of impairment—sleeping itself—is simply a basic body function, like eating, breathing, seeing, and hearing. In fact, chronic sleep disorders like primary insomnia, insufficient sleep syndrome, or sleep apnea may be the only kind of disorders or disabilities that result from not being impaired enough.

This essay considers the ways that sleep researchers and clinicians might benefit from the perspectives offered by disability studies, a field of inquiry developed in the humanities that explores the social and cultural dimensions of what particular societies choose to label as “normal” and “abnormal.”<sup>3</sup> At least in its first few decades of germination, disability studies scholarship stood in contrast to medical framings of human variations that are labeled as disordered or disabled. Those of us who are born missing a limb, for instance, do not necessarily have a “problem” that needs to be corrected

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medically; same with those of us born blind, or deaf, or cognitively impaired.<sup>4,5</sup> Such conditions can be seen as adding to human diversity and generating valuable perspectives on everything from art to science: watching sign-language poetry, even for someone who doesn't understand the language, is a thrilling and beautiful experience,<sup>6</sup> and a host of technologies, from voice recognition software to closed captioning on television benefits millions of users who fall outside of the category of disability for which such tools were originally intended.<sup>7,8</sup> This is not to say that disability is conceived as a wholly positive experience. Yet the pain and suffering associated with disability are often just as much a matter of social stigma born out of fear or pity for disabled people, who historically have been subjected to extreme forms of prejudicial treatment including employment discrimination, institutionalization, and even sterilization or euthanasia.<sup>9,10</sup> Medicine was and still often is complicit in such treatment: one only has to speak with loving parents of children with Down syndrome to understand how the medical profession often views such lives as somehow less valuable than "normal" ones, in some cases not even worth living.<sup>11</sup>

In recent years, disability studies scholars have come to recognize that rejecting the "medical model" of disability altogether, though, can be a trap. Some disabled people may lead long lives relatively free of the need for medical intervention; yet as a population, people with disabilities experience more medical fragility than others, and many disabilities entail heightened medical risks. At its core, though, disability studies relies on a "social" rather than a "medical" model of interpreting bodily and mental variation. It makes a cardinal distinction between "impairment," which is a biological condition, and "disability," which arises when that impairment meets a barrier imposed by society.<sup>12</sup> If you have 1 leg instead of 2, for instance, you are disabled only when there are no suitable prosthetic devices available, or no ramps for the wheelchair you must use, or you encounter an employer who says you need not apply because she assumes you lack stamina, and so on. In keeping with this movement away from a medical framing of disability, disability studies generates knowledge by listening to the perspectives of people with disabilities, through life writing, ethnography, artistic representation, and the like. As disability theorist Susan Wendell put it, "Knowing more about how people experience, live with, and think about their own impairments could contribute to an appreciation of disability as a valuable difference from the medical norms of body and mind."<sup>13</sup>

What does all this have to do with sleep? Sleep is one of the most relentlessly "normed" aspects of human life. The data collected on sleep—through the NSF's Sleep America poll, the American Time Use Survey, academic research detailed in this and numerous other professional journals, medical observation in clinics, information gleaned from apps, wearable devices, and even smart beds—all this is subject to intense professional and public scrutiny with the aim of defining, monitoring, and correcting irregularities, often through medical means. To fall outside the distribution of normal sleeping patterns usually does not mean that one is "disabled," but disordered sleepers experience many of the same kinds of stigmas and social obstacles that people with more recognized disabilities do. This is not simply a parallel, as "abnormal" sleep patterns intersect with issues of disability in numerous ways. A disability studies approach can not only highlight those areas of overlap but enlist the knowledge about sleep challenges from the perspective of people with disabilities, their families, and caregivers, in ways that might provide food for thought to sleep researchers, clinicians, and other health science professionals interested in sleep.

Many of the intersections between sleep and disability concern the issue of sleep duration. As research conducted by the editor of this journal reveals, people with cognitive, physical, and multiple impairments are at risk for either unusually long or unusually short durations of sleep. Such sleep disparities warrant hygienic interventions

among a population that has been little studied in sleep research.<sup>14</sup> Disability scholars and activists often refer to these and other temporal matters as part of "crip time"—the notion that people with disabilities often find themselves at odds with social expectations about how to manage time. For instance, students with learning disabilities may require more time to complete assignments; people with mobility impairments may take longer to get to and from work; people who communicate through assistive technologies often do so at a slower rate than those who speak; children with developmental or cognitive impairments are often said to be "slow" or "behind"; people with fibromyalgia, rheumatoid arthritis, migraine, lupus, and depression experience chronic fatigue that slows down the pace of many activities for prolonged and irregular periods. People with all sorts of disabilities speak about the simply exhausting nature of moving through a world in which they constantly have to navigate obstacles.<sup>15,16</sup> For instance, the exertions required for deaf people to communicate with hearing people all day, or for people of short stature to reach and climb toward objects designed for others contribute to a persistent disability-related fatigue that may explain some of the findings about sleep differentials. Facing barriers to inclusion in school, work, and public space on a daily basis adds to the sense of steady draining of energy. These are often the hardest dimensions of disability to accommodate or negotiate. Even when the impairment itself can be accommodated in work or housing or school, with say a ramp or an interpreter, the fatigue itself slips under the radar.

What is often most frustrating for many people who experience this disability-related fatigue is the skepticism that meets claims of the impairment. Writer and professor of composition Kristin Lindgren, who developed a chronic illness involving extreme fatigue that her doctors had trouble diagnosing, wrote of visiting a sleep specialist at her local university hospital, who only made her feel somehow judged for the condition. The specialist tried 2 sleep medications on her, but as Lindgren reports, she "told me that these medications always worked, and implied that their failure to work for me was somehow my fault. On my insurance forms she checked off 'adjustment disorder.'" Eventually, though, she was fortunate enough to visit an internist with an unusually collaborative and inquisitive manner: "I recognized some of the methods of literary criticism in her toolkit—close reading, attention to the seemingly marginal aspects of a story, careful construction of argument and counter-argument—and I could see that she was an astute listener and interpreter."<sup>17</sup> (She eventually diagnosed the fatigue as a symptom of cytomegalovirus—an incurable virus whose symptoms can be managed with various medications.) Lindgren's experience parallels quite closely that of writer Gayle Greene, whose book *Insomniac* details her frustration with having her own primary insomnia taken less than seriously by medical professionals, and the difficulties she had in adjusting her professional life to her struggles with sleep. As Greene tells it in a chapter called "Blame the Victim," professionals often told her that her problem was psychological, with an implication of moral failure for her inability to sleep well. This comports with a general attitude toward health as virtue: "Good sleepers often assume that they sleep well because they're doing something right. But if they're doing something right, this means that I or anyone who has a sleep problem must be doing something wrong."<sup>18</sup>

Disability, of course, is not one common experience, and people with different disabilities experience different temporal challenges associated with sleep. Physical pain associated with certain disabilities simply makes it difficult to sleep for prolonged periods. As Hannah-Rebecca Joy Guscoth writes in her blog, her bone condition, diaphyseal aclasis, or multiple exostoses, causes sharp pain when her body is at rest for any prolonged period: "I've learnt through the years that there is no comfortable standing, sitting or sleeping position for me. Eventually, they will all hurt. Sometimes it will take thirty minutes and sometimes it will take three. This leads to me being in pain in

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