

Article

Why Disability Studies Needs to Take Religion Seriously

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Abstract: Religion and theology are central ways that many people make sense of the world and their own place in that world. But the insights of critical studies of religion, or what is sometimes positioned as religious studies as opposed to theology, are scarce in disability literature. This article suggests some of the costs of this oversight and some of the benefits of including religion. First, this article discusses how some past scholarly engagements of disability and religion have misrepresented and denigrated Judaism. Second, it argues that Judaism paints different disabilities in quite different ways, and that we cannot coherently talk about “disability in Judaism” as if it is a single thing. Third, it discusses the medical model and the social model, and shows how one Jewish woman’s writing on pain complicates how we might think about these models. In this way, the article shows how religious studies can both help remedy past mistakes and bring new insights to disability studies.

Keywords: disability studies; pain; religious studies; Judaism

Disability studies needs more religion.¹ This is not an altar call, but rather a call for scholars of disability to pay attention to the intricacies of religious beliefs, practices, texts, and communities. Like other populations, disabled people are often religious: current figures say 80–85% of people with disabilities say faith is very important in their lives, a number roughly equal to non-disabled people (Ault Jones 2010; *Disabilities and Faith* 2016). In countless memoirs, people with disabilities discuss their comforts, struggles, and ongoing relationships with religion (for a diverse array of examples, see Sanford 2008; Cohen 2010; Coggins 2017), and even memoirists who reject religion feel the need to respond to theological interpretations of disability (Adams 2014; Linton 2007). Religion and theology are central ways that many people make sense of the world and their own place in that world. Religion also shapes cultural images of disability, even to the extent that we sometimes use theological language to talk about disability: in one explicit example, “pillow angel” became a term for children with developmental disabilities who are subjected to medical treatments to stop growth.² And yet very little critical disability studies or crip theory literature engages religion at all.

Christian theology and ethics, most visibly, have made headway into thinking about disability and religion. Theologians and ethicists write about how their communities should include people with physical or mental differences using religious texts and traditions as resources. But the insights of critical studies of religion, or what is sometimes positioned as religious studies as opposed to theology,

¹ In a forthcoming publication, I theorize why the growing field of disability studies largely neglects religion or treats it reductively. This is in part, I suggest, because of the ways “crip theory” has modeled itself on queer theory, a field that has also largely (though not completely) neglected religion and at worst been overtly hostile to religion. It is also in part because of the way intersectionality tends to neglect religion, an oversight which I suggest has to do with the Protestant-inflected legacy of thinking about religion.

² See, for example, the discussion in (Kafer 2013). I choose Kafer’s discussion as an example of the oversight of religious language and imagery in “pillow angel” discussions because of the author’s sophistication and erudition in so many other theoretical aspects. If an otherwise extremely astute analysis misses the religious meaning, it should be no surprise that many other scholarly works also do.

are scarce in disability literature. This article suggests some of the costs of this oversight and some of the benefits of including religion. First, this article discusses how some past scholarly engagements of disability and religion have misrepresented and denigrated Judaism. Second, it argues that Judaism paints different disabilities in quite different ways, and that we cannot coherently talk about “disability in Judaism” as if it is a single thing. Third, it discusses the medical model and the social model, and shows how one Jewish woman’s writing on pain complicates how we might think about these models. In this way, the article shows how religious studies can both help remedy past mistakes and bring new insights to disability studies.

Throughout, the article uses Judaism and the historical figure of Jessie Sampter, a disabled Zionist from the early twentieth century, as examples. Sampter had polio as a child and suffered from chronic pain, fatigue, scoliosis, and deformity of the hands and wrists, as well as what we would now call post-polio syndrome throughout her adult life. She wrote extensively, both privately and for publication, before and after she moved from the United States to Palestine in 1919. Throughout her adult life, she had a deep and complex relationship with Judaism. Why use a single person instead of many data points to support these three arguments? First, the deep theological considerations require context and investment to understand. Quantitative methods cannot access affect, nor embodied experience, nor religious reasoning. Concentrating on a single person allows the depth of focus to see the central place that religious reasoning and experience can have in making sense of disability. Second, disability studies has long recognized the importance of the memoir and the voice of disabled people, and so I present Sampter’s voice here directly.

1. Seeing Judaism, Avoiding Supersessionism

In general scholarly works on disability, religion rarely appears. In three of the most widely read disability studies readers, together comprising more than 1000 pages, there is no sustained discussion of religion.³ The entire run of the *Journal of Literary and Cultural Disability Studies* has only a single passing reference to religion, apart from the obligatory lists (“gender, race, religion,” etc.). And when religion appears in disability studies literature as something more than just part of a list, it tends to be cast in a negative light. “Religion” often becomes a monolith creating or upholding the idea of the “normal” that oppresses and excludes people with disabilities. The *Routledge Disability Studies Reader* for instance, stakes this claim with respect to work and employment: “People with mental health problems are at a particular disadvantage in some of these contexts [urban economies], whilst ritual, religion, and taboo continue to play a large part in constructions of normality and economic contributions” (Roulstone 2012). Elsewhere, in a discussion of “Judeo-Christian Beliefs” (itself a confused category) people with disabilities are described as “ostracized and stereotyped” and considered sinners or possessed by demons (Mackelprang and Salsgiver 1996, p. 8). Others generalize further: “Religion—over time and across societies—has been a particularly potent force in separating people as ‘abnormal,’” the *Handbook of Disability Studies* explains (Albrecht et al. 2001, p. 528). Religion, in this view, hurts people with disabilities.

But even in scholarship that seems otherwise sympathetic to religion, sometimes Judaism bears the brunt of the critique. The critique is, in part, warranted. The Hebrew Bible and rabbinic writings including the Talmud do sometimes single out persons who are deaf, unable to speak, or intellectually disabled and assign them lesser religious statuses. Some disability literature has painted religion in general, including Judaism, as harmful, perhaps because of textual traditions like these. For instance, one thesis proffered by *A History of Disability* is that “the Old Testament was shaped by religious

³ Just for a small sample, religion is overlooked in these introductory texts: Davis (2010), Goodley (2011), Titchkosky and Michalko (2009). Similarly, Oliver (1996) only mentions religion briefly, first in a mention of Mohammed Ali in which he experiences “religious bigotry” and his religion’s only mentioned characteristic is oppression of women (Oliver 1996, p. 16) and second when the author mocks at length a medical community’s attempt to cure spinal injuries using the stereotypes of “primitive” religion and failed prophecy (Oliver 1996, pp. 102–4).

prohibition” coupled with some social integration of disabled people. But, the book asks rhetorically, “Was this coherence not undone when the great disrupter of Jewish religion called Jesus of Nazareth appeared? He encountered many disabled people. This is, more over, one of the factors that give the gospels much of their tenderness. Without denying the global relationship between evil (and misfortune) and sin, Jesus quite decisively breaks the connection between disability and individual fault.” Later the author writes: “To me Jesus seems to be the wrecker of the prohibitions. But this is fraught with consequence, for the whole Jewish system was erected on it” (Stiker 1999, p. 33). Jesus invited to his banquet “the crippled, the blind, the lame,” but “the Judaism of the Old Testament, on the other hand, is dominated by ritual, cultic prohibition, while the theological currents that derive from it (Christianity and Islam) differ on this point, as on others.” (Stiker 1999, p. 25) These and other passages suggest that Judaism was backward, worse for people with disabilities, and less enlightened, but Jesus and Christianity came and improved on its strict and exclusionary legal nature.

To take another example, a recent article in a leading disability studies journal shows some of the ways that theological renderings of disability can denigrate Judaism. The article was chosen here not for its particular egregiousness but for its representative nature: it suggests that Judaism paints all disability as deserved or inherited through sin. This is mistaken on two counts: First, when scholars discuss religion more generally, they can take up viewpoints that border on supersessionism, in which Judaism represents the unenlightened and law-bound past and Christianity represents more enlightened and inclusive views. (Supersessionism is the theological view that Jesus Christ came and superseded Judaism and Jewish law). Second, as the next section discusses, Jewish law and Jewish texts approach different disabilities differently. There is no one unified category of people with disabilities; in fact some physical and mental differences, such as inability to walk or being hard of seeing, have no marginal status in halakhah or Jewish tradition.

The 2009 article in *Disability Studies Quarterly*, perhaps the foremost venue for the field, explored the relationship of “biblical and theological perspectives” and disability rights. Although the author acknowledges that religious traditions can be both beneficial and harmful for people with disabilities, the examples of harm almost all come from the “Old Testament,” which it conflates with Jewish tradition, and the redemptive examples come from the New Testament and Christian traditions. For example, the author explains: “Disability is attributed to God. The general view of the Old Testament writers is that God brings disability as punishment for transgressions for sin or as an expression of God’s wrath for people’s disobedience. It is seen as a curse and as a result of unbelief and ignorance”. The citation directly associates this negative view with Judaism: “Jewish Encyclopaedia, 1920; The Talmud of Jerusalem, 1956; and Encyclopaedia Judaica, 1972” (Otieno 2009). Later, it similarly assumes that Hebrew bible texts, in particular those that disparage physical difference, are located in Jewish tradition. The author explains: “The interpretation of this Leviticus text can be traced to the conflation between physical disability, perfection of the body, and moral impurity,” for which it cites “Encyclopaedia Judaica” as its sole source (Otieno 2009). There are plenty of Christian interpretations of this same Leviticus text, but the author cites none.

In both of these instances, the author has assumed that the “Old Testament” is Jewish, which is not only a mistake of nomenclature but also a curious assumption given that the Hebrew Bible is canonical for Christians too. In order to explain the “general view of the Old Testament writers,” the author cites Jewish materials from the late 4th to 5th century (the Palestinian or Jerusalem Talmud)—and then also two Jewish encyclopedias from the twentieth century. Even citing the Jerusalem Talmud, though it is from antiquity, makes the mistake of assuming that the “Old Testament” is Jewish. To make a rough analogy, citing the Jerusalem Talmud to explain part of the Hebrew Bible is very similar to citing the New Testament to explain it. Both the Talmud and the New Testament take the writings in the Hebrew Bible and build upon and interpret them, but neither is a clear and direct window back to the times when the books of the Hebrew Bible were composed and edited.

Christianity, on the other hand, becomes a place where an unenlightened set of Jewish texts can be made more inclusive. The article explains: “In general, the gospels show Jesus as sensitive and

caring to PWD [persons with disabilities]. They are the main focus of the healing ministry of Jesus (Mk 8: 22–26; 10: 46–52).” And later: “Apart from examining the image of God, the healing narratives in the Gospels also gives insight into viewing theology as liberative rather than discriminatory. Christ’s mission on earth, which is spelt out clearly in Matthew 11: 2–5 and Luke 4: 18–19 (also called the Nazareth Manifesto) supports a liberative theology” (Otieno 2009). This oversimplification of the Old Testament and the New Testament is hardly unique to this article. For example, one narrative theory of disability asserts: “In contradistinction to the advocacy of murder and ostracization of cripples in the Old Testament, the New Testament sets up its alternative value of acceptance and tolerance by curing cripples. Rather than barring the deformed or incapacitated from religious practice, Jesus Christ heals the infirm, deformed, and possessed and opens up the temples to them”. (Mitchell and Snyder 2000, p. 183). In this picture, Judaism is at best a proto-Christianity, waiting to be revised by the mercy of Jesus.

This issue with scholarly work that suggests a supersessionist view is not merely an issue of Christian apology. Otieno, for example, acknowledges Christian textual traditions that denigrate people who cannot see and people who cannot walk. Yet though such scholarship can acknowledge negatives in Christianity, it often does not acknowledge positives in Judaism. And although these works are scholarship rather than theology, it seems to have some of the pitfalls that Katherina von Kellenbach has described; she explains, some “Christian theology annexes Judaism as its prologue and renders Judaism outdated” (Von Kellenbach 1994, p. 51). It is, of course, tricky to work with texts like these that suggest supersessionism or anti-Judaism without replicating it. As Julia Watts Belser and Melanie S. Morrison explain: “Efforts to resist the oppression of people with disabilities by deemphasizing literal acts of healing tend to highlight Jesus’s structural critique against unjust institutions, often represented in the Gospels by the Jewish leaders. Yet that message of structural critique and social transformation can easily lead to anti-Jewish readings of the Gospel narratives” (Belser and Morrison 2011). Despite this, as they and other scholars have shown, it is possible to avoid the twin traps of ableism and anti-Judaism in scholarship as well as in the pulpit (Belser and Morrison 2011; Koosed and Schumm 2005; Salmon 2006).⁴

Supersessionist or anti-Jewish undercurrents like these do not stem from a lack of research on Judaism and disability. Sophisticated research has shown that Jewish textual traditions are neither ideal with respect to disabilities nor purely oppressive and discriminatory. And here this connects to the second main claim of this essay: representations of physical difference in Jewish textual traditions (as well as many other religious tradition) are complex, in part because there is no single unified category of “people with disabilities”.

2. Differentiating Disabilities

The life and writing of Jessie Sampter present one illustrative example of this complexity within Jewish religion and culture. She had chronic pain, post-polio syndrome, and could walk only short distances for most of her adult life. Although she did not explicitly mention biblical texts in many of her reflections, her ideas about her pain and chronic illness were deeply informed by her theology. “For forty-three years,” she wrote, “since I was twelve years old—I have been an invalid, or, rather, what is called a semi-invalid, half an invalid. For all that time the valid part of me has been striving desperately to be normal, to think, feel, and experience the ordinary human thing.” And yet she also decided that “the other half, the damaged half” was beautiful too. “The pain has been very sweet; it may have been hard to bear; death would at any time have been easier; but, having been borne, it is good to look back upon.” She concluded, “As I figure up the account, it seems to have been all valid. Every kind of life is life if one lives it” (Sampter n.d.d). Once she moved to Palestine, she would

⁴ Koosed and Schumm (2005), for instance, give both a deep reading of the New Testament text and a critique of its anti-Jewish uses.

mention her chronic pain and limited mobility in letters to her sister. She had “no strength for walking” so she couldn’t get stamps for her nephew, she wrote in 1921 (Sampter n.d.e). Later that year, she explained why she had not been into town, even though it was only a short distance: “Some day I’ll take a carriage. I have not been in town in months, not since my illness [severe weakness and fatigue]. I simply don’t walk here in the summer” (Sampter n.d.f). She lived with pain, muscle weakness, and fatigue as a matter of her daily life. Because of her commitment to Zionism and Judaism, she had moved to Palestine, where she had no family, even though her symptoms would be more disabling there than in the urban northeastern United States.

We would surely consider her disabled. However, when she took up an interest in deaf children’s education in Palestine, she expressed sympathy rather than solidarity. These children were marginalized, in her eyes, but she was not. This is not merely to say that they had it worse than she did (though they did, given widespread attitudes that deaf and deaf-mute children were also intellectually deficient), but that in her worldview there was a categorical difference between them and herself. Jewish traditions and Jewish law sometimes disparage and exclude deaf people, but these traditions and laws do not treat chronic pain and limited mobility in the same disparaging and exclusionary ways. The distance that Sampter saw between herself and deaf people was not merely arrogance, wishful thinking, or lack of solidarity; Jewish traditions, law, and cultures framed and portrayed mental and physical differences in significantly different ways.

To understand this point, we might begin with the observation, made by many disability theorists, that what counts as disabling differs with cultural and physical environment. For instance, Susan Wendell writes:

For example, I, who can walk about half a mile several times a week but not more, am not significantly disabled with respect to walking in my society, where most people are not expected to walk further than that in the course of their daily activities. But in some societies, in Eastern Africa, for example, where women normally walk several miles twice a day to obtain water for the household, I would be much more severely disabled. It is not just that I would be considered more disabled in those societies but that I would in fact need constant assistance to carry on the most basic life activities. (Wendell 1996, p. 14)

Some of the observation that Jewish law treats different disabilities differently can be attributed to the fact that what was disabling in the ancient near east is not identical to what is disabling today. But more: some of the embodied differences that would have been an impediment to “normal” life in the ancient near east are still not marginalized in Jewish law. Halakhah does not marginalize everyone we would consider disabled. Have epilepsy? Not an issue under Jewish law.⁵ Have mobility issues? Also not a halakhic problem. So someone like Jessie Sampter, who experienced disability in her daily life, experienced in Judaism a space where she was regarded as any nondisabled woman would be. That is to say, some Jewish communities may in practice discriminate against people in wheelchairs or with epilepsy, but strictly speaking, Jewish law does not.

This is not to say that Jewish texts or Jewish law is entirely inclusive; overall, Judaism has a complicated relationship to disability. On the one hand, people with disabilities appear, sometimes even as protagonists, in sacred texts and laws. At a basic level, people with disabilities count as people: the Hebrew Bible prohibits putting a stumbling block in front of the blind, for instance. What’s more, some of the main characters of the tradition have disabilities: Isaac the patriarch is blind, and Moses stutters. Persons with disabilities aren’t completely erased or seen primarily as objects of charity, as religious traditions are sometimes depicted. In his volume on disability and Jewish law, Tzvi Marx writes that “sensitivity to the disabled” is “at the heart of Jewish tradition” (Marx 2002).

⁵ In at least one case, a person’s epilepsy has served as a way for her to connect to Jewish tradition: See (Gerson 2013).

On the other hand, people with certain disabilities are assigned fewer religious responsibilities, and in Judaism, fewer responsibilities means, to oversimplify slightly, lower religious status. Women's exclusion from some commandments, for example, has proved a stumbling block to ordaining women as rabbis. The Hebrew Bible posits a physical ideal for the priesthood that excludes all sorts of bodily difference, as well as other textual traditions that sometimes disparage those who cannot hear, speak, or see (Abrams 1998; Olyan 2008; Raphael 2009). Rabbinic literature, especially the Talmud, can both objectify and disable the bodies it scrutinizes—and yet, its narratives also contain the seeds of self-critique (Belser 2011).

So what are we to make of these seemingly incompatible stances on disability?

One move must be to take a step back from disability as a singular category of analysis. Only attention to each form of physical or mental difference as lived and experienced, as I've suggested with regard to Jessie Sampter, can help us understand whether people with them were marginalized or disabled with respect to texts and rituals.

Take blindness for example. Even when this single disability is under consideration, the textual traditions can seem to be both inclusive and exclusive. *Baba Kamma*, a tractate from the Babylonian Talmud, seems to suggest that blind persons are exempted (or excluded) from performing religious commandments. But in typical Talmudic fashion, the section is in fact a discussion with opposing views, and the closing authoritative words are given to Rav Yosef, a revered sage who was blind: "Now that I have heard what Rabbi Hanina taught [I changed my mind about whether deaf men are exempted from commandments]. For Rabbi Hanina said: 'Greater is the one who is commanded and performs, than one who is not commanded and performs'" (BT *Baba Kamma* 87a, quoted in Abrams 1998, pp. 195–96). Rav Yosef decided that blind Jewish men should be obligated to the same halakhic standard as sighted Jewish men—a decision he made because it would bring him more religious standing! As Judith Abrams points out in her discussion of this text, "the Bavli [the Babylonian Talmud] here allows a blind person to speak for himself and express his desires, instead of simply being the subject of legislation" (Abrams 1998, p. 196).⁶

Related to these complex textual traditions about blindness, many of today's Jewish communities also have complicated stances toward the religious status of blindness. A recent religious ruling from the Conservative movement, for example, concluded by emphasizing inclusion and accommodation: "Jews who are blind should participate in synagogue rituals together with sighted Jews, all of whom are obligated to keep the Torah . . . Jews who are blind may: a. Lead the congregation in prayer; b. Receive an aliyah [ascending to the pulpit for a Torah reading] and chant the appropriate blessings; c. Chant haftarah [Hebrew Bible selection from the writings of the prophets]" (Nevins 2003). Yet at the same time, the conclusion went on to explain that blind Jews cannot fulfill the commandment to read from the Torah scroll on behalf of others because a braille Torah scroll cannot be a kosher scroll. Perhaps someday with advanced technologies, the ruling hoped, there would be a way for blind Jews to read the Hebrew on kosher scrolls. So blindness excludes a person from one particular commandment but not others.

A more straightforward example might be deafness. Jewish law seems to exclude deaf people from a larger number of rituals and religious requirements. A quick reading of rabbinic texts suggests that a deaf person who does not speak is in the same category as the mentally confused and the minor: they "lack understanding"—that is, that they are mentally disabled or ill. Because of this assumption, the textual traditions exclude deaf Jews who do not speak from many religious commandments. "Those who can neither hear nor speak, those who are mentally unsound, or those who are minors," the Talmud explains, "are exempt from all the commandments of Torah" (Babylonian Talmud Hagiga 2b).

⁶ I am indebted to Dale Spicer for his insight about this passage.

And yet, although it is clear that ancient texts excluded deaf Jews who did not speak from religious obligation,⁷ today the halakhic view is less simple. Because today we know that there is no reason to assume that deaf people who cannot speak have any mental disability, even communities committed to halakhah must reexamine their exclusion from religious obligation on those grounds. Many of these halakhic opinions also build on Deaf rights and developments in the status of sign language as a real language and not just an inferior second choice for people who do not hear. For example, the Conservative movement's committee on halakhah also recently unanimously approved a ruling that Deaf Jews are religiously equal to all other Jews: "1. Jews who are deaf are responsible for the mitzvot [religious commandments]. 2. Our communities, synagogues, schools, and camps must strive to be welcoming, accessible, and inclusive. 3. Sign language may be used in matters of personal status (weddings and divorce proceedings) . . . 4. Sign language may be used in liturgy" and rituals (Babylonian Talmud Hagiga 2b). Even with respect to deafness, then, Jewish texts, traditions, and communities can combine to be simultaneously inclusive and exclusive, and only attention to the particulars of the case of deafness (as opposed to disability in general) can offer a fuller understanding.

When Jessie Sampter got into "deaf-mute affairs," as she and her contemporaries called the project of creating Palestine's first school for the deaf, her voice was very different from how she described her own life. She sounded much more like a philanthropist conscious that she was helping out the marginalized and the lesser. In the early 1930s, she wrote a lengthy essay called "They Have Ears but They Hear Not," a reference to both Psalm 115 and Jeremiah 5:21. The piece reflected her theological understanding of deafness, with both the sense that deaf people were fully human and deserving of respect but also excluded and in need of saving:

I went with my friend the violinist to hear her make music at the school for deaf children. As I saw the miracle in their faces, my thoughts wandered back over the long and steep and rocky path that had led up to this miracle.

1916–18: Two children born deaf two years apart to a Jewish mother in Palestine who has had three normal ones. (Sampter n.d.c)

Next she typed, "Their defect is a memorial to war, terror and starvation," but then edited in her own handwriting to say: "They were born and conceived during war, terror and starvation." (Sampter n.d.c) Like God talking to Ezekiel, she rejected the initial narrative in which "the parents eat sour grapes and the children's teeth are set on edge." No, it was neither the children's fault nor their parents' position amidst suffering that caused their deafness. She also moved away from the language of "defect," though she would return to appeals to sympathy from her audience of potential philanthropists later in the essay.

Although Sampter did not have the language of "social construction" to describe gender or disability, her writing shows resonance with imagining disability socially (in addition to medically, as she certainly did): "If these children can attend school until the age of fourteen, with its preliminary vocational training," she explained of the deaf school's pupils, "they will then be equipped to enter the world of man as equals and as workers" (Sampter n.d.c). To Sampter, children who could lip-read and speak would not be disabled. They could work as other workers—an essential for the Zionist cause—and communicate fully. She wrote to her sister about the new school for the deaf, which she had been instrumental in creating (No Author 1932): "the school made an excellent impression. I'm most satisfied" (Sampter n.d.g).

As both this brief discussion of halakhah and of Jessie Sampter show, we cannot fully answer the question of how Judaism confronts disability as a category because Jewish traditions do not have a

⁷ Even this is not quite as simple as it first seems. As Bonnie Gracer explains in her analysis of the Mishnah, rabbinic literature makes distinctions between deaf people who speak, people who are born deaf, people who lose their ability to speak or hear later in life, people who cannot hear but use their hands to communicate, and others (Gracer 2011).

singular category of disability. Instead, we would do better to reform the question to ask how Jewish texts, traditions, and communities treat individual physical or mental difference.

3. Social Model, Medical Model, and/or Something Else?

Close attention to religion can also bring insight into debates about medical and social models of disability. Most critical disability scholars and crip theorists reject the medical model of disability, in which disability resides in the person's body, calls for diagnosis and treatment, and would ideally be eradicated. This model locates the burden on the individual, and it can deflect attention from larger social and structural problems and accommodations. Many of these scholars instead promote the social model of disability, in which disability is a social construction. In this view, environments are disabling, societies deem a physical body abnormal, and people and institutions marginalize. Instead of being an empirical biological fact, disability is a label and a situation created by human culture and the built environment.

This critique of the medical model is surely a valid one, but the medical model/social model divide can present problems when scholars try to understand a person with a disability (and even more so about historical people with disabilities). First, many people with disabilities see themselves through the medical model. If we want to understand their own self image and relationship to their bodies, we will need to understand their diagnoses, their interactions with doctors, and their own attempts at self-treatment, for example. This is not to endorse the medical model as the "right" way to understand their disabilities, but it is to make an effort to understand their embodied or mental differences as they themselves saw these differences. Second, the medical model deeply informs the social model. One of the primary discourses through which societies have created the social model is the discourse of medical research—however good or bad—and its production of expectations of how life should be. And lastly, a purely social model works less well to explain the experience of people with certain disabilities. Sampter's chronic pain provides one lens through which to see these issues.

No amount of change in Jessie Sampter's culture and environment could have created the situation where she felt normal and good in her body. Even if there were a bed in every room, and she had her own solar powered hover-car, she still would have felt pain and exhaustion. She may have felt it less often, and so this is not to say that we should dismiss accommodations in the case of people with chronic pain; to the contrary, accommodations are crucial. But when the social model seems to imply that if changing our social expectations and built environments sufficiently would cause all disability would go away, this is a mistaken view. As disability theorist Tobin Siebers writes, "Pain is not a friend to humanity. It is not a secret resource for political change. It is not a well of delight in the individual. Theories that encourage these interpretations are not only unrealistic about pain; they contribute to an ideology of ability that marginalizes people with disabilities" (Siebers 2001). The vast majority of people with chronic pain do want a cure for their pain; they do want treatment. They would like to have no chronic pain, and this is not because they have internalized the medical model or social pressures to be normal.

During her rehabilitation after polio, Sampter recalled trying to make sense of her pain. She did so in theological terms, even referring to herself as "the child Job." "I said to myself," she wrote, "I have suffered so much, I can endure all. If only instead of knowing life's misery, I myself could bear it! While one child suffers, while history records one injustice, the world is awry. I imagined myself a martyr, secretly bearing all the pains of mankind, and mankind rejoicing. If that were possible! Pain is an easier thing to bear than to accept" (Sampter n.d.b). She would continue to bear pain for the rest of her life, and she would also think a lot about what it meant and how to accept it.

Sampter rejected any theological accounts that explained suffering as a tool of punishment or a tool of ennoblement, and she also rejected the idea that her pain and disability made the rest of her life

pitiful.⁸ She wrote of herself as a young teen: “The child Job had something still to lose—o much still to lose. How lovely are the blossoming fruit trees in our garden, how the young grass starred with dandelions! There is that—and God” (Sampter n.d.b). Sampter still saw nature as a source of beauty and joy, and she had not given up on God. Though the family soon had to move out of the house she grew up in because of financial trouble, Jessie cultivated her love of plants and flowers throughout her life.

In more philosophical venues, she wrote: “He that understands it does not suffer it. He does not suffer. Life is joy.” (Sampter n.d.a) This unpublished essay called “Joy,” worked through the ideas of pleasure and pain and their relationships to a good human life. “Pleasure is good, no matter how insufficient and unsatisfactory. Pain is bad, no matter how instructive and interesting. Which does not mean that we are to go seeking pleasure and avoiding pain.—Nor the opposite. To do either is stupid.” So if pain is bad, why isn’t it simply to be avoided? Sampter explained, “Pain is an indicator, pain is direction. Pain is a mold, pain is that un-desire which gives desire shape. It is the lever of action, the springboard of desire.” She saw her pain as the “lever of action” that would help her direct her choices wisely and well. In letters to her sister, she discussed “enjoying” troubles, by which she meant gaining perspective (Sampter n.d.h), and being motivated by things “we don’t like.” (Sampter n.d.i). In doing so, she described her pain and disability as ways of experiencing and learning from experience in the world. Unlike Elaine Scarry’s account of pain, in which “even though [pain] occurs within oneself, it is at once identified as ‘not oneself,’ ‘not me,’ as something so alien that it must right now be gotten rid of” (Scarry 1985), Sampter sought to make sense of her body and her life *with* her pain. To use Scarry’s terms, pain was also part of the making of Sampter’s world, not just its unmaking. Either the medical model or the social model alone, then, is an uneasy fit for someone seeking to understand Sampter’s chronic pain.

In her discussion of pain, Sampter also touched on a perennial religious question: if God is good, why does the world have bad things like pain, disease, and suffering? Sampter posited that this problem of theodicy was entirely a human invention, and one that had merely been projected onto God. “Pain is not—to say the least—pleasant, but that is its virtue. The nature of pain is to be unpleasant, and our business is to dislike it, to cast it out. But we thought it was God’s business, and so we created the silly problem of evil and solved it with a thousand superstitions” (Sampter n.d.a). To understand Sampter’s embodied experience, the medical model does not suffice, but neither do most interpretations of the social model. Taking religion seriously, however, may help revise the social model or create a new model that can better understand Sampter and others like her.

As Sampter so astutely suggests, theology and theodicy are primary ways that many people make sense of pain. To overlook these interpretations in studies of pain-related disabilities leaves an impoverished understanding of the experiences of many people with these disabilities. This is not to suggest that religion is always good or ameliorative. It is not. Instead it is to suggest that when people say and act as if religion is central to how they understand their own bodies, it is incumbent upon scholars to study it closely as a source of meaning.

4. Conclusions

Disability studies, then, would benefit from integrating religious studies into its methodologies. The need for attention to religion in people with chronic pain is not just a theoretical need, nor is it just a historical one. Current studies show that assessing the spiritual or religious needs of patients is challenging for health professionals, and they do not feel they have adequate tools (Royal College of Nursing 2011).

Contemporary studies also suggest that religion plays a central role in how people both interpret and cope with chronic pain. For instance, the authors of one study noted the significant presence

⁸ For accounts of these familiar theological understandings of disability, see (Eiesland 1994).

what they called a “positive framing of pain”: “Through their faith or belief in a God, participants found strength to manage and cope with their pain” (Edwards et al. 2016, p. 296). They also noted that interpretations of chronic pain were specific to religions; that is, some religions facilitated certain interpretations where others did not. For example, “suffering in itself was regarded a necessary part of being a Christian and almost an expectation in this faith group” (Edwards et al. 2016, p. 296). Sampter, as a Jewish woman, did not frame her suffering as Jesus-like, as many Christians did, but she also did not dismiss theology as irrelevant for understanding why humans experienced pain: “I don’t look upon suffering as a problem,” she wrote to her sister in 1936. “The only problem is how to meet it.” (Sampter n.d.j). Other studies have noted how religious beliefs can provide answers to difficult existential questions and influence the cognitive appraisal of circumstances, making them feel less distressing, reducing anxiety, and increasing a person’s sense of control over them—findings that are obvious pertinent to those with chronic pain (Koenig 2012).

Both these contemporary sociological studies and historical sources such as Sampter’s writings emphasize that religion can be an integral part of meaning-making for people with disabilities. For devotees of the social model of disability, religious ideas, texts, communities, and practices must be considered part of the social discourses that construct the disabled body. For those using the medical model, religious ideas, texts, communities, and practices have real effects for mental and bodily status. And for those open to new models, religious studies offers a space from which we might begin to think about the meaning and experience of chronic pain as disability. That is to say, no matter where one stands with respect to disability studies, religious studies has new insight to bring.

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